



THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

**Assessment and Diagnosis of Autism in Developing Countries:
The Indonesian Adaptation of Autism Detection in Early Childhood
(ADEC)**

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*A thesis submitted for the degree of Doctor of Philosophy at
The University of Queensland in 2015
School of Psychology*

Abstract

The most recent estimates of the prevalence rates of Autism Spectrum Disorder reveal that 1 in 68 children in the US are diagnosed with ASD. However, although the awareness of ASD has been increasing around the world, most studies of the prevalence rates and diagnosis of ASD originate in developed countries, and little is known about the situation in developing countries. Indonesia is the fourth most populated country in the world. However, as is the case in most developing countries, disability still receives limited attention from the Indonesian Government. In terms of ASD, there is no recent estimate of the prevalence rate of ASD in Indonesia following the estimates released 22 years ago which suggested that 1 in 833 children in Indonesia were being as diagnosed with ASD. Currently studies on ASD are still lacking and almost 500 cities and regencies in Indonesia are unable to identify and provide appropriate support services for people with ASD.

As a starting point to understanding the situation relating to ASD in developing countries, the first study in this thesis aimed to investigate the application of best practice guidelines in Indonesia. A survey was developed and undertaken with 67 practitioners with experience in assessing ASD. It was found that, similar to situations in developed countries, the three best practice components relating to ASD diagnosis were challenging to apply in the Indonesian context. Further, having more validated and culturally sensitive tools to assess ASD in Indonesian language was found to be one of the crucial needs of ASD specialists in Indonesia.

As a response to this finding, an Indonesian version of ADEC (ADEC-IND) was developed and evaluated for its psychometric properties and cultural appropriateness. The ADEC is an observation tool that has been shown to be effective in detecting ASD in children as young as 12 months. The tool has been validated within Australian and in Mexican children. In comparison to the gold standard measurement tools, the use of ADEC is more

affordable, less time consuming in administration, and does not require lengthy and expensive training for its use. Considering these benefits and as a response to the first study results, the second and third studies that comprise this thesis were conducted in order to translate and validate the use of ADEC within the Indonesian context.

The ADEC was translated into the Indonesian language and then pilot tested with eight Indonesian children ($M_{age} = 31.8$ months, $SD = 11.36$) in Brisbane and Melbourne. In the translation process, after being translated, the first Indonesian version of ADEC (ADEC-IND) was reviewed independently by two reviewers and a revised draft was made based on the reviewers' feedback. Subsequently, the revised draft was then pilot tested with each testing session videotaped and given an English subtitle. Each participant was tested using ADEC-IND and their parents interviewed using the ADI-R. All of the sessions were videotaped and given English subtitles. The study found that the revised and translated draft of ADEC-IND is ready for use in a large scale study, as the participants in the pilot study had no problem in understanding the instructions of ADEC-IND, and no difficulties were experienced with either the implementation or scoring.

Following the pilot testing and review, the revised version of ADEC-IND was tested with 82 children in Indonesia. The children were aged between 14 and 72 months ($M=45.23$ months, $SD=14.51$) who were classified within three diagnostic groups (typical developing children, children with ASD, and children with other disabilities). The participants were recruited from clinics and schools in five major cities in Indonesia (Jakarta, Bogor, Depok, Tangerang, and Bekasi). Similar to the pilot study, the children were assessed using the ADEC-IND and the parents were interviewed using the ADI-R. All sessions were videotaped. For investigating the inter-rater reliability, fifty videotaped sessions were given English subtitles and re-scored by a second assessor who was blind to the original scores, using the English version of the ADEC. The results showed that ADEC-IND possessed good

sensitivity (.92 to .96), good specificity (.85 to .92), and high inter-rater reliability ($r = .94$, $p < .001$). ADEC-IND also showed good concurrent validity and good agreement (82.92%) with the ADI-R in classifying children into ASD and non-ASD groups. The implications of these findings are discussed in relation to the assessment and diagnosis of ASD in Indonesia.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Papers submitted to peer-reviewed journals:

- Sidjaja, F. F., Newcombe, P. A., Irwanto., & Sofronoff, K. (2015). *Understanding Developing Countries' Challenges in Applying the Best Practice: The Diagnosis of Autism Spectrum Disorder in Urban Indonesia*. Manuscript submitted for publication to International Journal of Disability, Development and Education, 5 January 2015.
- Sidjaja, F. F., Newcombe, P. A., Irwanto., & Sofronoff, K. (2014). *Diagnosing Autism Spectrum Disorder in Developing Countries: The Validation of Autism Detection in Early Childhood-Indonesian Version (ADEC-IND)*. Manuscript submitted for publication to Research in Autism Spectrum Disorder, 21 October 2014.

Conference and other oral presentations:

- Sidjaja, F. F. (2014, July 18). *An Indonesian Cultural Adaptation of the Autism Detection in Early Childhood (ADEC)*. Paper presented at the 22nd International Congress of International Association for Cross-Cultural Psychology, Reims, France.
- Sidjaja, F. F. (2014, April 30). *The Autism Detection in Early Childhood Indonesian Version (ADEC-IND) Project: A cultural adaptation of a Western assessment tool to a developing non-Western country*. Paper presented at the Chonnam National University Colloquium, Chonnam, South-Korea.
- Sidjaja, F. F. (2013, December 6). *Assessment and Diagnosis of Autism Spectrum Disorder in Young Children: The needs and challenges of Indonesian Practitioners*. Paper presented at the Kyoto University School of Letter Workshop, Kyoto, Japan.
- Sidjaja, F. F. (2013, November 12). *Adapting the Autism Detection in Early Childhood – Indonesian Version (ADEC-IND)*. Paper presented at the School of Psychology, Postgraduate Seminar, University of Indonesia, Jakarta, Indonesia.
- Sidjaja, F. F. (2013, July 3). *Assessment and Diagnosis of Autism Spectrum Disorder in Young Children: The needs and challenges of Indonesian Practitioners*. Paper presented at the Australian Human Development Association 18th Biennial Conference, Gold Coast, Australia.

Publications included in this thesis

Sidjaja, F. F., Newcombe, P. A., Irwanto., & Sofronoff, K. (2015). *Understanding Developing Countries' Challenges in Applying the Best Practice: The Diagnosis of Autism Spectrum Disorder in Urban Indonesia*. Manuscript submitted for publication to International Journal of Disability, Development and Education, 5 January 2015. – incorporated as Chapter 3.

Contributor	Statement of contribution
Sidjaja, F. F.	Conception and design (80%) Development of questionnaire used in the study (100%) Recruited participants (90%) Data collection and analysis (100%) Wrote the paper (100%)
Sofonoff, K.	Conception and design (10%) Edited paper and provided feedback (50%)
Newcombe, P. A.	Conception and design (10%) Edited paper and provided feedback (50%)
Irwanto	Recruited participants (10%)

Sidjaja, F. F., Newcombe, P. A., Irwanto., & Sofronoff, K. (2014). *Diagnosing Autism Spectrum Disorder in Developing Countries: The Validation of Autism Detection in Early Childhood-Indonesian Version (ADEC-IND)*. Manuscript submitted for publication to Research in Autism Spectrum Disorder, 21 October 2014 – incorporated as Chapter 6.

Contributor	Statement of contribution
Sidjaja, F. F.	Conception and design (80%) Translation of measures used in the study (100%) Recruited participants (70%) Data collection and analysis (100%) Wrote the paper (100%)
Sofonoff, K.	Conception and design (10%) Edited paper and provided feedback (50%)
Newcombe, P. A.	Conception and design (10%) Edited paper and provided feedback (50%)
Irwanto	Recruited participants (30%)

Contributions by others to the thesis

Parts of Thesis	Contributors	Contributions
Whole thesis	Associate Professor Kate Sofronoff	<ul style="list-style-type: none"> • Conception and design of the research project • Feedback on manuscripts and the entire thesis
	Associate Professor. Peter Newcombe	
	John Schiller	Editorial assistance
Study 1	Professor Irwanto	Recruitment of participants
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	Cicilia Evi Yuwono	
	Herry Sentosa	
Study 2	Dr. Agnes Maria Sumargi	Reviewers of the translated measurement tool
	Dr. Augustian Sutrisno	
	Dr. Fransisca Maria Ivonne	
	Dr. Agnes Maria Sumargi	Research assistant
	Anthony Kusoy	Back-translator
Study 3	Professor Irwanto	Recruitment of participants
	Annisha Susilo	Research assistant and data collection coordinator
	Laila Ayu Karlina	Research assistant
	Morgan Nangoy	
	Ngadiman Djaja	Statistical support
	Karen O'Brian	Second assessor
	Fuye Ongko	Data collection support
	Vickie Januar	

This research program was partially funded by the Australian Award Scholarship and the Disability Studies Center, Faculty of Social Sciences, University of Indonesia (contract no 088/Puska-D/VIII/XI/2013) awarded to Fransisca Febriana Sidjaja.

Statement of parts of the thesis submitted to qualify for the award of another degree

None

Acknowledgments

My desire to do this PhD was firstly sparked in 2007, after I worked with my clients, a small group of parents of children with disabilities at a therapy centre in North Jakarta. Many times these parents talked to me in tears as they shared their struggles in raising their children who have disabilities with a limited funding and facilities. For two years, as I kept listening to their stories, I started to dream that someday all children with disabilities in Indonesia could receive supports, services and facilities as good as those in developed countries. In 2009, I shared my dream to my former lecturers (Assoc. Professor Peter Newcombe and Professor Irwanto) and to my pastor (DR. Drs. Yoas Tanugraha) who then motivated me to pursue a PhD degree in order to help people with disabilities in Indonesia. Encouraged by them, I decided to follow the passion in my heart to do this study, and when I dared myself to step in, doors of opportunities were widely opened– and I began my PhD journey.

Therefore, as a traditional African proverb says *‘It takes a whole village to raise a child’*, I would never been able to finish my PhD without guidance and supports from a whole village of people. First and foremost, my deepest gratitude goes to my three supervisors who have patiently guided me in accomplishing my study. **Professor Peter Newcombe** – *thank you for always believing in me and patiently guiding me through these years. You really have a teacher’s heart and in front of you I always feel that I am the smartest student who can do anything to change the world.* **Professor Irwanto** – *thank you for supporting me continuously. You have been my inspiration since my undergraduate year – I will follow your life example to dedicate my knowledge to those who are in needs.* **Associate Professor Kate Sofronoff** – *thank you for patiently supervising me and broadening my perspectives, especially in the area of Autism. I learned so many important lessons from your feedback throughout the journey. Thank you for helping me grow.*

Besides my supervisors, I would also like to acknowledge **Assoc. Professor Robyn Young**, for her ongoing supports and for giving me the permission to adapt the ADEC in my study; **Bu Winarini Wilman**, my former supervisor, for being my recommender; **dr. Felicia Kurniawan** and **Dr. Soegianto Ali** who supported me in the scholarship application; and **Bu Mayke Sugianto** who helped me in collecting data in the first and third study. My deep thanks also goes to **Agnes Sumargi**, my friend who have accompanied and supported me all the way through my PhD journey. For me, she has become a writing tutor, a tool reviewer, a proofreader, a research assistant, a housemate, a best friend, and a sister - *when I count my*

blessings, I count you triple! Moreover, I would also like to appreciate **Britta Wigginton**, who has helped me to improve my presentation skills through the years, and to **Ko Ngadiman Djaja and Christiany Suwartono** for kindly assisting me with the challenging statistical analyse – *Both of you are my statistic superheroes.*

My first study could not have been accomplished without the support of **Dr. Melly Budhiman**, Mbak ‘**Super Woman**’ **Josephine Ratna**, and **Joane McKenna-Kerr** who helped me in promoting my first study. My thanks also goes to **Yodi Iwan** who helped me to translate the questionnaire for my first study; as well as to **Cicilia Evi Yuwono, Kwe Janice**, and **Herry Sentosa** who have kindly assisted me in recruiting participants for my first study. My completion of the second study was fulfilled by the support of **Maria Fransisca Ivonne** and **Agustian Sutrisno** who reviewed the translated measures used in the study; **Nurul Fadhillah Praherso, Bunga Citra Pratiwi**, and **Intan KusumaWardhani**, my research assistants for the pilot study in Brisbane; **Benaiah Soenarto** who helped me in my pilot study at Melbourne; and **all the parents of children who participated in my pilot study**. The final study was the most challenging one, and I am highly indebted to my amazing research assistants; **Sasha Riyeni**, my recruitment coordinator who has endeavoured to lead the data collection in a very professional and amazingly organised way; **Laila Ayu Karlina**, my research assistant who has worked tremendously in contacting institutions and reminding parents about the testing schedules; and **Morgan Luke Nangoy** who helped me with the video recording and data management. I also give thanks to **Pak Widi** who drove through Jakarta’s horrible traffic to reach participants’ houses. I would also like to thank **Karen O’ Brian** for being a great research partner and friend, **Anthony Kusoy** for helping me with the back translation, and all of my **subtitlers team members (Monica, Viana, Dhea, Syiva, Karina, and Dhana)** who have provided excellent subtitles for the videos. I would also like to thank **Cici Lisa Tanugraha, Fuye Ongko, and Vickie Januar** for supporting the data collection, as well as to all of the **heads of institutions** who helped me in recruiting the participants and, most importantly, to all **participating parents and children**.

I would also like to give appreciation to **families of Mas Raja Juli Antoni, Mas Wahyu Prijonggo**, and **Bang Libertus Darus**, my housemates who have become my second families in Brisbane; my friends from **Philia and Hillsong Church**, especially to **Anna Farrel and ‘Cici’ Brodie Burger**, my caring Aussie sisters. I would also like to thank all of my friends who accompanied me in this PhD journey: **Anh Bui Hai Thiem and Jaimei Garcias, Mas Candra Samekto and Mbak Sari Candra, Damian and Josie Santomauro, Huma Bokhim, Mari Horiguchi, Monica Wirawan, Yoan Godzali, Evren Etel, Jason**

McIntyre, and all of **my friends at the office 303** (especially my night owl friends **Laura Ferris and Kelly Garner**). My deep appreciation also goes to **Jia Song**, my Korean friend like a sister who shares similar passion to help people with disability - *thank you for cheerleading me in my presentations and for being such a wonderful friend in my PhD journey*. I would also like to acknowledge **Alison Pike** who always made my day with her funny emails (and for helping me with the school administrative needs); **Astrid Sirowatka**, who always reminded me to go to the gym; **John Schiller** who helped me with the thesis proofreading; **Marian Butler**, my writing tutor who helped me in improving my writing skill; and the UQ safety bus drivers: **David, Darrel, and John** who always faithfully took me home safely from my late work. My deep gratitude goes to the **Australian Leadership Award Scholarship** for providing me with this opportunity to study in one of the best universities in the world and for equipping me with leadership programs to maximise my potential. I am also glad to be coached by **Juliet Hargreaves** and **Mal Lowther** in my leadership skills and wisdom.

I would also want to acknowledge all of my friends **at Brilliant Church** who have faithfully supported me in prayer and encouragement. My very special gratitude goes to my loving pastors, **Om and Tante Yoas Tanugraha** who always remind me to be a blessing for others. I would also like to appreciate my beloved team like a family at the Ministry of Children with Disabilities Kelapa Gading; **Weni, Budi and Yanti, Yenny, and Ko Andy, Deasy and Jeffry, Silva and Lukman, Kalina and Yosua, Gatot, Yohanes, and Irene** - thank you for our beautiful friendship and amazing teamwork throughout the years. My gratitude also goes to all my former clients at Smile Kids Parent Child Centre, especially to **Bu Novi and Pak Gui, Bu Lily and Pak Barnabas, Bu Lucy and Pak Andri** who have motivated and encouraged me all the ways; and to my friend like a brother **Felix Xia**, for always there to support me in fulfilling my passion.

Finally, I could never go this far without the love and support from my family. I am grateful for my loving **mother, father, and brother** who always encourage me and become a secure haven in difficult times. I am also showered with love and support from my aunties and uncles; **Ako Rita, Ako Mimi and Om Sugi, Mamani, Iie Esther and Om Iwan, Tante Hennie and Om George** – *yes, it does take a village to raise me!*

Above all, I would like to express my gratefulness to my **Heavenly Father** who have loved and blessed my life abundantly. His love and favour has enabled me to accomplish this PhD marathon, and by His grace, I am ready to embrace my next life journey to help children with disabilities in Indonesia.

Keywords

Autism spectrum disorder, assessment, diagnostic tools, developing countries, Indonesia, ADEC.

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 170106, Health, Clinical and Counselling Psychology, 60%

ANZSRC code: 170109 Personality, Abilities and Assessment, 40%

Fields of Research (FoR) Classification

FoR code: 1701, Psychology, 100%

Dedication

This dissertation work is dedicated to the memory of my beloved grandmother, Oma Suze de Wilde, with a hope that one day the application of scientific methodology and evidence based approaches in assessment and intervention could be applied throughout Indonesia and may help Indonesian children with disabilities to live their life to the fullest.

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List of Abbreviations

ASD	:	Autism Spectrum Disorder
ADOS	:	Autism Diagnostic Observation Schedule
ADOS-2	:	The Autism Diagnostic Observation Schedule, Second Edition
ADI-R	:	Autism Diagnostic Interview-Revised
ADEC	:	Autism Detection in Early Childhood
ADEC-SP	:	Autism Detection in Early Childhood – Spanish Version
ADEC-IND	:	Autism Detection in Early Childhood – Indonesian Version
CARS	:	Checklist for Autism Rating Scale
CHAT	:	Checklist for Autism in Toddlers
MCHAT	:	Modified Checklist for Autism in Toddlers
PDD	:	Pervasive Developmental Disorder
PDD-NOS	:	Pervasive Developmental Disorder Not Otherwise Specified
DSM IV	:	Diagnostic and Statistical Manual of Mental Disorders
ICD	:	International Classification of Disease
ToM	:	Theory of Mind
EF	:	Executive Function
WCC	:	Weak Central Coherence
GARS	:	Gilliam Autism Rating Scale
DISCO	:	Diagnostic Interview for Social and Communication Disorders
HIMPSI	:	Himpunan Psikologi Indonesia (Indonesian Psychological Association)
BISCUIT	:	The Baby and Infant Screen for Children with aUtIsm Traits

Chapter 1

Introduction

1.1. Background

A child diagnosed with ASD shows impairments in his or her social interaction skills, communication ability, and flexibility of thought or imagination (Wing & Gould, 1979). In terms of helping children with ASD, it is crucial to provide these children with effective and early intervention, as this can help minimize the expression of the more severe symptoms of ASD (Fenske, Zalenski, Krantz, & McClannahan, 1985). In developed countries, such as the UK, US, Canada, and Australia, governments actively provide early detection and intervention services. Funding for these services is also accessible for children who are diagnosed with ASD. For example, in Australia, each child has access for up to A\$12,000 in funding support (maximum of A\$6,000 per year) that can be used for intervention programs until his/her seventh birthday (Department of Social Services, 2014). In addition, the government provides proper facilities and services for children who are diagnosed with ASD in order to help them to maximize their developments. However, the situation is different for those who live in developing countries. Most families of children with ASD in developing countries experience shortages in services and programs, as government support, attention and funding, are very limited. For example, in India, the availability of ASD specialists is rare and services for people with ASD are limited (Daley, 2004).

In terms of diagnosing ASD, best practice guidelines aimed at providing health practitioners with the most recommended approaches to assess ASD have been published by developed countries. Guidelines from the US, UK, Canada, and Australia commonly suggest the diagnosis of ASD be conducted in multiple stages, within a multidisciplinary team, and using standardized tools. In terms of the use of standardized tools, the four guidelines recommend the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989) and

Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) as the gold standard tools for diagnosing ASD (Autism Services Coordinating Committee, 2003; Department of Developmental Services, 2002; Nachshen et al., 2008; National Initiative for Autism: Screening and Assessment, 2003). Studies, nevertheless, have suggested that the application of these guidelines, as well as the use of ADOS and ADI-R in developed countries, is challenging, as these tools are expensive, require extensive and expensive training, as well as considerable time to administer (Hering, 2005; Williams, Atkins, & Soles, 2009). This leads to the question of whether the guidelines are appropriate for application in developing countries.

Studies have found that parents of children in developing countries have encountered difficulties in accessing early detection and diagnoses for ASD, due to the high cost of health services, as well as limited access to the services (Daley, 2004; Hedley, Young, Juarez-Gallegos, & Marcin-Salazar, 2010; Samadi & McConkey, 2011; Seif Eldin et al., 2008). A lack of trained health practitioners and assessment tools in the local languages was also found to be constraints in India, Iran, Mexico and Saudi Arabia (Daley, 2004; Seif Eldin et al., 2008; Hedley et al., 2010; Samadi & McConkey, 2011). A similar situation is likely to occur in the fourth most populated country in the world, Indonesia, although there is a lack of empirical data to support this consensus.

Indonesia is a country with the largest number of islands in the world. It is located between the Indian and Pacific Oceans and has a total area of 1,811,569 square km. Indonesia is the sixteenth largest country in the world, with about 80% of its territory being covered by water. It comprises more than 17,500 islands, of which only 6,670 islands are inhabited (Mirpuri, Cooper, & Spilling, 2012). As illustrated in Figure 1.1, there are five main islands in Indonesia: Sumatra (#1 in Figure 1.1), Java (#2 in Figure 1.1), Kalimantan,

which shares the border with Malaysia (#3 in Figure 1.1), Sulawesi (#4 in Figure 1.1), and Irian Jaya, which is located in the west of the New Guinea island (#5 in Figure 1.1).



Figure 1.1. Map of Indonesia

According to the World Bank, Indonesian's population in 2013 was 249.9 million (World Bank, 2015), making it the fourth most populated country in the world after China, India, and the United States. The population of Indonesia comprises more than 300 ethnicities, with 250 different languages. Bahasa Indonesia is the national language, spoken by almost all Indonesians, in addition to their native languages ('*bahasa*' means language). The main ethnic groups in Indonesia are Javanese (40.6%), Sundanese (15%), Madurese (3.3%), and Minangkabau (2.7%). The Chinese Indonesians are a minority group who migrated from the Chinese Mainland to Indonesia in the late 19th century. The Indonesian people practice four main religions; Islam, Christianity, Hinduism, and Buddhism. Islam is the religion mostly practiced by Indonesians. In fact, Indonesia is known as the country with the largest Moslem population in the world. Approximately 57% of Indonesian people live in Java, one of the five main Islands, where the capital city, Jakarta, is located. In 2010, 9.6 million people lived in Jakarta, which functions as the centre of economic and political development (Mirpuri et al., 2012). Most health facilities are focused on the bigger cities, with the development of health industries showing wide differences between different parts

of Indonesia, as well as increasing differences in availability and accessibility between people on high and low incomes (Irwanto, 2014).

1.2. ASD in Indonesia

Based on a survey conducted by Badan Pusat Statistik (BPS: Statistics Indonesia), an Indonesian Government Institution, the total number of people with disabilities (including visual impairment, hearing impairment, mutism, physical disabilities, intellectual disability and multiple disabilities) in Indonesia was 2,126,785 in 2009 with 1,198, 185 of these residing in rural areas and 928,600 people in urban areas (Irwanto, Kasim, Fransiska, Lusli, & Siradj, 2010). This data, however, are considered biased, as Irwanto et al. (2010) argued that it indicates only the number of poor people with disabilities, and does not reflect the situation for the whole population. The percentage of people with disabilities in Indonesia is believed by Adioetomo, Mont, and Irwanto (2014) to be similar to that globally, approximately 11 – 15%. This means that there could be as many as 26 to 36 million people with disabilities in Indonesia.

Assessing the precise number of people diagnosed with ASD in Indonesia is challenging. The annual population survey conducted by the Indonesian Central Statistics Agency (BPS) included a category of those with mental disabilities, but did not specifically identify ASD. In 2009, the number of people in the mental disability category was 181,202 but again this number is considered to be an underestimate of the actual figure (Irwanto et al., 2010). The only published data specifically related to the prevalence of ASD are from a 1992 study which found that 1 in 833 Indonesian children were diagnosed with ASD (Wignyosumarto, Mukhlas, & Shirataki, 1992). Since then, no other studies have been conducted. Therefore, the precise current number of people with ASD in Indonesia remains unknown. However, using the prevalence rate from one of Indonesia's closest neighbours, Australia, where 0.5% of its people have been diagnosed with ASD (Australian Bureau of

Statistics, 2012), the number of Indonesian people with ASD could be estimated to be approximately 1,249,500.

In Indonesia, Government support and programs for people with disabilities are provided by the Indonesian Ministry of Social Affairs, Ministry of Health, and Ministry of Manpower and Transmigration (Adioetomo et al., 2014). Through these three ministries, several Government programs aim to support people with disabilities. They are the Social Assistance for Severely Disabled Persons, Social Assistance for Children Program, Social Health Insurance for Informal Workers, Subsidised Rice for the Poor, Family Hope Programme, and Health Insurance for the Community or JAMKESMAS (Adioetomo et al., 2014). The Social Assistance for Severely Disabled Person is a social security program aimed at providing funding for people with severe disabilities. Those who are eligible for support within this program are provided with direct grants of up to IDR 300,000 per month (approximately AU\$30). However, only approximately 19,500 out of potentially 7.2 million eligible recipients are covered by the program; therefore the program is considered to be ineffective (Adioetomo et al., 2014). In addition, the Government provides rehabilitation centres for people with visual or hearing impairments, mutism, physical disabilities, intellectual disability, and for those who have a disability associated with a chronic illness. There is also a rehabilitation institution for people who have diagnosed with a mental disorder such as schizophrenia (Irwanto et al., 2011). These rehabilitation institutions delivered training and day care services appropriate for their disabilities. All of these programs and centres, however, do not specifically cover people with ASD, and only since 2010 has the Indonesian Government started to give attention to people with ASD, despite ASD campaigns being prominent since 1990 (Budhiman, 2010).

In 1990, due to a lack of understanding about ASD, ineffective initiatives in dealing with ASD were common amongst Indonesian parents. At that time, ASD was perceived as a

contagious disease. Most parents felt embarrassed for having children with the disorder and tended to hide their children from the public. In addition, parents tended to use traditional and superstitious approaches to deal with symptoms of ASD, such as taking the children to shamans instead of to medical practitioners. The Government was not aware of the rise in the number of children with ASD and did not pay attention to their needs (Budhiman, 2010). In 1997, the Indonesian Autism Foundation (Yayasan Autisma Indonesia) was formed by a group of Indonesian medical practitioners and parents. Since then, the foundation has promoted ASD awareness among Indonesian people and advocated for parents who have children with ASD. The foundation has also endeavoured to unify centres and institutions that work with people with ASD. One of the foundation's famous events is the "Walk for Autism". It is an annual event held in Jakarta and aims to increase the awareness of ASD among the Indonesian community. During the event, the foundation invites all centers that work with people with ASD, as well as families who have children with ASD and other people who care about people with ASD, to walk together along Jakarta's main streets (Budhiman, 2010).

Since 2010, the Indonesian Government has increased its efforts to focus more attention on ASD, and provide support for services and programs for people with ASD, by providing therapy services for people from low socio-economic areas and allocating a budget to build Autism Centers that can be accessed freely. However, at the time of writing this thesis, none of the centres had been established. Currently most services for people with ASD are still provided by the private sector and are located in large cities (Budhiman, 2014; Kartika, 2013). These available services can only be afforded by people from middle to high income backgrounds, while those from low socio-economic areas can only go to mental health clinics provided by the government (Kartika & Ana, 2013) or to social institutions that provide low cost services (e.g., Rumah Autis; Fajri, 2013).

Melly Budhiman, one of the medical doctors who pioneered the establishment of the Indonesian Autism Foundation, stated that a lack of ASD specialist practitioners was one of the crucial issues limiting intervention in ASD cases in Indonesia (Budhiman, 2014). Currently there are only 132 registered centres for ASD available throughout Indonesia, located in 27 cities or sub-cities (Yayasan Autisme Indonesia, 2014) leaving 483 cities and sub-cities lacking any services for ASD. Data collected by a local Indonesian newspaper, Kompas, indicated that the lack of ASD specialists, as well as the lack of affordable and accessible programs, was the main constraint to delivering services for people with ASD in Indonesia (Fajri, 2013; Kartika & Ana, 2014).

In terms of assessment and diagnosis, a psychologist's best practice guideline for diagnosing ASD was published by Himpunan Psikologi Indonesia (Indonesian Psychological Association) in 2008. Based on these guidelines (HIMPSI, 2008), in order to conduct a diagnosis, Indonesian psychologists are advised to interview the parents and observe the child using a Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001) and a Checklist for Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, & Daly, 1980). Currently, the translated versions of the Checklist for Autism in Toddlers (CHAT; Baron-Cohen, 2000), M-CHAT and CARS are available in the Indonesian language. These tools have been accepted and are in use by Indonesian health practitioners, despite no empirical evidence for their validity in the Indonesian context.

Furthermore, evidence-based strategies for ASD are challenging to develop in Indonesia, since studies regarding the needs and challenges of ASD specialists in dealing with ASD cases are not yet available. Studies on the effectiveness of interventions provided in Indonesia are also not available and, to date, there are only a few peer reviewed journal articles relating to ASD in Indonesia, that have been published (e.g., Ginanjar, 2007; Supartini, 2009). More studies on ASD, specifically studies related to assessment practices

of ASD are urgently needed in Indonesia. Such information will help policy makers improve the assessment and services for people with ASD in Indonesia.

1.3. Aims of the Studies

The first study in this thesis was conducted to provide an understanding of the current assessment practices in Indonesia, as well as to investigate the needs and challenges of Indonesian health practitioners in assessing ASD. Based on studies from developed and developing countries, and also given that to date there are only a few translated measurement tools in Indonesia, it is expected that the practitioners will report difficulties in following the best practice guidelines, particularly in relation to the use of standardised tools. Having more validated tools in the Indonesian language, which is appropriate in the Indonesian context, is expected to be one of the needs identified in the study. The basis for this hypothesis is that the gold standard tools are not available in the Indonesian language; the tools are too expensive for Indonesian practitioners, and they would require lengthy as well costly training.

Compared with the gold standard tools and other measurement tools currently used, the Autism Detection in Early Childhood (ADEC; Young, 2008) offers a number of benefits, especially for practitioners who work in developing countries. First, the ADEC can be used to detect ASD at a very young age, even younger than the minimum age covered by the M-CHAT (16 months). Second, the ADEC is less expensive than ADI-R and ADOS. The flexibility in providing the test materials (e.g., toys) also enables testers to use cultural toys familiar to the child. Third, the testing time for the ADEC is shorter (15 to 30 minutes) compared to the gold standard tools (60 to 120 minutes). Fourth, the ADEC shows strong psychometric properties, as shown by its high sensitivity and specificity, as well as a high correlation with the ADI-R and ADOS (Young, 2007); and fifth, the results of a study undertaken in Mexico suggests that ADEC has less cultural bias and has the potential to be used in other cultural settings (Hedley et al., 2010).

Therefore, in consideration of advantages possessed by ADEC, the second and third studies in this current thesis were carried out in order to provide an Indonesian version of ADEC that is valid, affordable, and culturally appropriate in the Indonesian context. The second study involved the translation of ADEC and pilot study. The translation aimed to produce a draft of the Indonesian version of ADEC (ADEC-IND), while the pilot study served as a small scale research project which aimed to provide the necessary resources and materials needed for the large scale third study. The third and final study aimed to evaluate whether the ADEC-IND was valid and reliable as a diagnostic tool for use with Indonesian children. In this study, a sample of Indonesian children was tested using the ADEC-IND, in order to examine the tool's effectiveness in differentiating children with ASD from their peers who do not have the disorder.

1.4. Significance of the Studies

Based on the framework described above, the three studies covered in this thesis aimed to provide a practical solution that will potentially lead to an improvement in the quality of assessment and diagnosis of ASD in Indonesia. Such an outcome will make a potentially significant contribution to improving the welfare of people with ASD in Indonesia. To date, little information is available about the application of the developed countries' best practice guidelines for ASD in developing countries. Therefore, the data collected from the first study could serve as a starting point in helping to understand the applicability of best practice guidelines for ASD in developing countries. In addition, the findings from the first study could be used by policy makers in Indonesia. By understanding the needs and challenges encountered by ASD specialists, effective strategies on how to respond to their specific needs and challenges could potentially be addressed.

Considering that, to date, there has been no validation study in Indonesia on translated measurement tools for ASD, the second and third studies will serve as pioneering studies that

open the possibility for ASD specialists in Indonesia to have their first validated measurement tool that suits to Indonesia's condition. The ADEC's characteristics of being cost efficient, relatively easy to use, and the relatively short time needed for use set it aside from other tools. In addition, the results of second and third study may also assist ASD practitioners and specialists in working with children with ASD, as the ADEC can also be used in developing intervention programs (Hedley et al., 2010).

1.5. Overview of Thesis

This thesis is comprised of seven chapters. Chapter one introduces the ASD phenomena around the world. The issue relating to the importance of early detection is highlighted, followed by an outline of the efforts by developed countries to recommended ways to evaluate the disorder. Subsequently, and specifically in relation to the ASD issue, data about the conditions in developing countries are questioned, and a detailed description about the Indonesian context is provided, with a focus on the inadequate support services available for Indonesian people with ASD. Finally, the aims of each study in the current thesis are presented, in the context of their significance in responding to the needs of people with ASD in Indonesia.

Chapter 2 provides the reader with an understanding of ASD based on a review of current literature. In this chapter, the definition and characteristics of ASD, according to DSM IV-TR and DSM-5, are described, followed by a discussion of the changes in DSM-5 and how these changes might affect the diagnosis of ASD. The prevalence of ASD worldwide and three cognitive theories of ASD (theory of mind, executive dysfunction, and weak central coherence) are also outlined. A review of the three elements of best practice guidelines from the UK, US, Canada, and Australia is presented followed by a description and critique of six assessment tools recommended by the guidelines and most often used. Subsequently, current situations in developed and developing countries regarding the

application of the best practices are outlined, with a highlight of major challenges faced by practitioners in developing countries. In the final section of the chapter, a discussion of the crucial role of formal measurement tools to guide the diagnosis of ASD is outlined to highlight the framework used to guide the current research program.

Chapter 3 covers the first study by presenting the details of a survey disseminated to ASD specialists (n=67) in Indonesia. In this chapter, firstly, conditions regarding the diagnosis of ASD in developed countries and developing countries are introduced; four best practice guidelines published by four developed countries are presented, with three elements of best practices being highlighted. Then, a critical review of the application of the four guidelines is presented, leading to the research question concerning the applicability of the guidelines in developing countries, in particular, Indonesia. Subsequently, the study's methods, procedures, and results are presented, which found that the best practice guidelines were seldom practiced by ASD specialists in Indonesia. The findings suggest that one of the most urgent needs of the specialists is to have more validated tools made available in the Indonesian language. Finally, the limitations of the study and recommendations based on the findings of the first study are discussed.

Chapter 4 provides a detailed description of the ADEC. In this chapter, the rationale behind the ADEC's development is outlined. Robyn Young, the developer of ADEC, constructed 16 tasks in the ADEC that can be used to detect ASD in children from 12 months of age. The ADEC was developed on the basis that ASD characteristics should be able to be operationalised and observed in children younger than 36 months. Subsequently, the details of ADEC's administration, scoring, and interpretation are described. The psychometric properties of ADEC and ADEC-SP are then explored and finally the advantages of the ADEC are explained, with an emphasis on its potential for use as a detection tool in developing countries.

Chapter 5 outlines the translation process of the ADEC into the Indonesian language and the pilot study conducted in Australia. In the first section, the details of the translation process are described. In order to produce an Indonesian version of ADEC, the original version of ADEC was translated into the Indonesian language and then reviewed independently by two bilingual graduate students. The draft was then revised following a discussion between the translator and the two reviewers. The next section of the chapter describes the details of the pilot study where the revised version of the ADEC-IND draft was tested with eight Indonesian children in Australia. The children were recruited by a research assistant in order to maintain the assessor's objectiveness in diagnosing the children. All of the sessions were videotaped and given English subtitles. Finally, the findings and recommendations from the pilot study are presented. The pilot study successfully identified problems that might potentially emerge in the final study and, based on the data, practical suggestions are provided.

Chapter 6 covers the third study, which serves as the heart of the thesis. In the first section of the chapter, the needs of health practitioners in Indonesia to have more validated assessment tools are presented, followed by a brief description of the ADEC. The purpose of the study (to evaluate the effectiveness of ADEC-IND) is then outlined and details of the study's methods, procedures, and analysis are presented. The study involved 82 children classified in three groups (ASD, other disabilities, and typically developing). The children were tested using the ADEC-IND and their parents were interviewed using the ADI-R. All of the testing sessions was videotaped with 50 videos being given an English subtitle and rescored by a second English-speaking assessor. All of the recruitments and communications to the participants' parents were completed by research assistants in order to keep the assessor blind to the child's prior diagnosis. In addition, to provide the reader with information regarding cultural issues, the chapter also includes a section that explains the

problems encountered related to the Indonesian cultural context (e.g., challenges in recruiting participants due to the lack of familiarity of the Indonesian parents with clinical research).

The next section then outlines the study's results which found that the ADEC-IND was effective for use with Indonesian children. The ADEC-IND shows high sensitivity and specificity, as well as good validity and reliability. Finally, the findings are discussed, followed by an outline of recommendations, limitations, and conclusions of the study. The ADEC-IND is highly recommended for use by ASD specialists in Indonesia, in combination with the CARS.

Chapter 7 summarizes the main findings and limitations of each study, as well as identifies future research needs, along with providing practical recommendations that will help enable the ADEC-IND to be accepted and disseminated among Indonesian health practitioners. In the first part of the chapter, a table is presented to provide the reader with a quick overview of the three studies' aims, results, strengths and limitations. Next, the findings of each study are discussed and related to current literature. Finally, recommendations are presented, followed by a brief conclusion to close the thesis.

Chapter 2

Understanding and Diagnosing Autism Spectrum Disorder

The first three sections of the current chapter (2.1 to 2.3) aim to provide an understanding of the nature of ASD by outlining the characteristics, prevalence and causes of the disorder. Subsequently, specific issues regarding diagnosis of ASD are discussed in the final four sections (2.4 to 2.7) with the final section (2.7) discussing the theoretical framework that forms the basis of the research reported in this thesis.

2.1. Definition and Characteristics

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder that is characterized by impairments in social interaction, communication, and flexible behaviour (Baron-Cohen, 2000; Dumont-Mathieu & Fein, 2005; Hill and Frith, 2003). ASD was first recognized by Leo Kanner and Hans Asperger through their detailed observations of children and adolescents who showed impairments in social interaction ability (Venter, Lord & Schopler, 1992). Kanner found that the children he observed were unable to form effective contact with others. They were also impaired in their communication ability, and obsessively repeated the same activities and routines (Feinstein, 2010). The term 'Autism' is derived from the Greek word 'Autos' which means 'self'. It was firstly used by Bleuler in 1901 to describe a type of thinking in both children and adults, and it actually does not have any relationship to pathological or childhood disorder issues. Kanner then used the term to describe the disorder he discovered in his study (Feinstein, 2010). Similar to Kanner's observations, Asperger also observed children and adolescents who showed high levels of attraction to unusual things and routine tasks. Unlike Kanner, Hans Asperger observed speech ability but an inability to use it in an appropriate social context (Wing, 1997). The disorder reported by Kanner later became known as Autistic Disorder, while that reported by Asperger is known as Asperger's Disorder. Since then, numerous studies have been

conducted and currently many refer to ‘Autism Spectrum Disorder’ or ASD, where ‘Autistic Disorder’ is perceived as the more severe expression with Asperger’s Disorder seen as the higher functioning expression of the condition (Feinstein, 2010; Wolffe, 2004).

In the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition – Text Revised (DSM IV-TR; American Psychiatric Association, 2000), the term used for ASD was ‘Autistic Disorder’, and was categorized under the classification of Pervasive Developmental Disorders, together with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger’s Disorder, Rett syndrome, and Childhood Disintegrative Disorder (CDD) (American Psychiatric Association, 2000). Three core features of ASD, according to the DSM IV-TR and ICD-10, are: (1) qualitative impairments in social interaction ability; (2) qualitative impairments in communication ability; (3) restricted repertoire of interests, behaviour and activities (American Psychiatric Association, 2000; World Health Organization, 2007). These three core features are known as the triad of impairments (Wing, 1993) and, to be diagnosed with ASD, the symptoms are required to be present before 36 months of age (American Psychiatric Association, 2000; World Health Organization, 2007). The impairments in social interaction are shown in children’s inability in using non-verbal behaviour, such as eye contact or body language in social interactions. Children with ASD rarely develop meaningful peer relationships and have difficulties in expressing and sharing their feelings. The impairments in communication ability are shown in symptoms such as a delay in language development with no compensation through non-verbal language; inability to start a conversation; the use of stereotyped and repetitive language or idiosyncratic language; and a lack of imitative and imaginative play. The restricted repertoire of interests, behaviour and activities are seen in the children’s attraction to objects or parts of objects, stereotyped or repetitive movements, such as hand flapping or twisting, and inflexible adherence to routines (American Psychiatric Association, 2000; Charman, 2008).

In May 2013, the American Psychiatric Association published the DSM-5 (APA, 2013). In this latest version of DSM, several changes to the diagnostic criteria for ASD were made. First, while the DSM IV-TR classified ASD under the broader category of Pervasive Developmental Disorder, together with Asperger's Disorder, PDD-NOS, Rett syndrome, and Childhood Disintegrative Disorder, the new DSM-5 merges the three disorders (Autistic Disorder, Asperger's Disorder and PDD-NOS) under a new term 'Autism Spectrum Disorder', while Rett syndrome and Childhood Disintegrative Disorder have been removed. Second, DSM-5 has refined the three criteria of impairments listed in the DSM IV-TR into two: (1) persistent deficits in social communication and interactions; and (2) restricted, repetitive patterns of behaviour, interests, or activities. Third, in DSM-5, a new disorder termed 'Social (Pragmatic) Communication Disorder' (SCD: APA, 2013) was added. The disorder is characterised with deficits in the social use of verbal and non-verbal communication, but not accompanied with restricted, repetitive patterns of behaviour, interests or activities. According to APA (2013), the DSM IV-TR did not provide specific criteria for SCD which led people with the disorder to be diagnosed as having PDD-NOS, and receive improper treatment. Therefore, in the DSM-5, the disorder is outlined in detail in order to provide more accurate diagnosis and effective treatment (APA, 2013). Finally, while the diagnostic criteria of DSM IV-TR and ICD 10 indicate that the symptoms are required to be present before 36 months of age (APA, 2000), DSM-5 only indicates that the presence of the symptoms should be observed in the early development period, without specifically stating the exact time when the diagnosis can be conducted (APA, 2013). However, and although DSM-5 classification has only begun to be used and recognised, the DSM-5 criteria for diagnosing ASD is continually being evaluated as it has been found to under-diagnose individuals with PDD-NOS. For example, Mayes et al. (2013) found that DSM-5 failed to identify 16% of children with ASD who were previously diagnosed with DSM IV-TR

criteria, and 90% with PDD-NOS. These results are in line with the results of (to date) 11 other studies that have showed a median of 33% children with ASD who were not identified by the DSM-5 criteria (e.g., Frazier et al., 2012; Matson, Belva et al., 2012; Young & Rodi, 2013).

2.2. Prevalence of ASD

Numerous studies have shown that the prevalence and incidence of ASD has increased significantly in the past 40 years, although there continues to be great variability across countries. In 1966, the incidence of ASD in the UK was found to be 4.1 in 10,000 children (Baron-Cohen, Leslie, & Frith, 1985; Lotter, 1966), while in 2009 it had risen to 157 in 10,000 children (Baron-Cohen et al., 2009). In Canada, the prevalence rate in a 1988 study was found to be 10.1 per 10,000 (Bryson, Clark, & Smith, 1988), whereas in 2010 the prevalence rate of ASD had increased to 25.4 per 10,000 (Lazoff, Zhong, Piperni, & Fombonne, 2010). In Japan, the prevalence increased from 21.08 per 10,000 in 1996 to 37.5 per 10,000 children in 2005 (Honda, Shimizu, Misumi, Niimi, & Ohashi, 1996; Honda et al., 2005). In Australia, the prevalence rate was found to be 1 in 160 children Williams, MacDermott, Ridley, Glasson, & Wray, 2008). The highest incidence of ASD has been reported in the US, with 1 in 68 children being recently received a diagnosis of ASD (CDC, 2014); this compares with an incidence of 1 in 91 children in 2009.

In contrast to studies citing increasing numbers of ASD, a study conducted by Baxter et al. (2014) suggests that the number of ASD cases has remained steady over the past 20 years and that the global prevalence of ASD in 2010 represented no significant change compared with the incidence in 1990. This study conclusion also supports the claim of Saracino and Fombonne (2010) who have argued that there has been no significant increase in the number of ASD cases from 1966 to 2010. Saracino and Fombonne (2010) reviewed 61 prevalence studies across 18 countries from 1966 to 2010. They found that the increase in

the incidence of ASD was affected by five factors. First, the increase reflected changes in ASD's definition or diagnostic criteria over the years. Second, the increase reflected improvements in health services and accessibility for ASD evaluations. The improved health services enabled individuals who previously were not considered as having ASD to receive a second diagnosis by ASD specialists. For example, Bishop et al. (2008) found that 66% of adults who received an initial diagnosis of developmental language disorder were later diagnosed as having PDD, a mild form of ASD. Third, the prevalence rates were influenced by the methods used in identifying ASD cases. The highest rates were found in studies using population-based screening techniques, while the lowest rates were found in studies using administrative records (Saracino & Fombonne, 2010). Fourth, the increasing ASD prevalence rates were related to the increased awareness of parents, support services and new policies. Finally, the study also found that the improvement of a professional's ability in detecting ASD was positively correlated with the increase in incidence of ASD. Improved clinical skills helped clinicians to identify children with more varied symptoms at an earlier stage of development (Saracino & Fombonne, 2010).

2.3. Cognitive Theories of ASD

With respect to explain causes of ASD, from cognitive point of view, Theory of Mind, Weak Central Coherence, and Executive Dysfunction are the most well-known theoretical frameworks put forward to explain the possible origins and mechanisms underlying the disorder (Hill, 2004; Rajendran & Mitchell, 2007). The three theories are discussed briefly in the next paragraph followed by a brief discussion about biological approaches in explaining causes of ASD.

Theory of Mind (ToM) is the ability to understand one's own and other people's perspectives, sometimes referred to as 'mind reading' (Baron-Cohen, 2001). The ToM hypothesis stated that children with ASD had deficits in reading their own and other people's

thoughts and, as a consequence, they experienced difficulties in predicting other people's behaviours (Baron-Cohen, Leslie, & Frith, 1985). In practice, according to this theory, children with ASD will experience difficulties in responding to tasks that require their mind reading ability. Therefore, evaluating this ability in children (i.e. using pretend play) could be used in detecting early signs of ASD in children as studies showed children with ASD generally failed or showed lower performance in accomplishing tasks that require the ToM ability (Baron-Cohen, 1989; Baron-Cohen, 2001; Baron-Cohen, Jolliffe, Mortimore, & Robertson, 1997; Baron-Cohen, Leslie, & Frith, 1985; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001).

The central coherence is the ability to process information by drawing on varied information perceived from the environment, and constructing all the information in a higher-level contextual meaning (Frith & Happe, 1994). Studies suggest that due to their weak central coherence, people with ASD are able to perceive a stimulus in a detailed and local way that is different from their typical developing peers (Rajendran & Mitchell, 2007; Shah & Frith, 1983; Shah & Frith, 1993). Based on the weak central coherence theory, superior performance in accomplishing tasks that require ability to distinguish minor parts of objects from major parts could be an indicator of ASD. One of the tests that measure this ability is the Children's Embedded Figures Test (CEFT; Witkin, Oltman, Raskin, & Karp, 1971). In the test, children were asked to place the cut-out target shapes or point to the target figure they had chosen.

Executive Function is an umbrella term used to describe functions that are needed to solve problems such as planning, working memory, impulse control, behavioural inhibition, shifting attention, initiation, monitoring of action, decision-making, judgement, self-perception, set maintenance, organized search, flexibility of thought and action, and the ability to spontaneously generate new responses (Hill, 2004; Rajendran & Mitchell, 2007).

The Executive Dysfunction hypothesis suggests that the impaired abilities in people with ASD are the result of problems or dysfunctions in their Executive Function (EF) ability (Hughes, Russell, & Robbins, 1994; Ozonoff & Jensen, 1999). Similar with ToM and weak central coherence, impairment in Executive Function area such as difficulties in joint attention, focusing attention on instruction, and in planning or organising, could be used to detect early signs of ASD in children.

Besides cognitive studies on causes of ASD, currently ASD is understood to be a group of highly heterogeneous neurodevelopmental disorders with complex genetic and epigenetic underpinnings, and efforts to investigate the biological bases of ASD are continually growing. One of the biological mechanisms underlying ASD is in the issue of sensory abnormalities (Leekam, Nieto, Libby, Wing, & Gould, 2007). As mentioned earlier, the DSM-5 (APA, 2013) includes sensory problems as one of ASD symptoms. These sensory problems are indicated by; (1) hyper or hypo reactivity to sensory input or; (2) unusual interest in sensory aspects of the environment. For example, children with ASD could show unusual reactions to certain types of sounds, textures. They also could smell or touch objects excessively or become highly fascinated with lights or movement (APA, 2013).

2.4. Diagnosing ASD: Best Practice Guidelines

Currently there is no medical test for diagnosing ASD despite ongoing research efforts. Assessment and diagnosis are based on the evaluation of behaviour in order to detect the symptoms of ASD using behavioural assessment tools (Jones & Lord, 2013). In the past, the symptoms of ASD could only be detected in children aged 4 or 5 years (Charman, 2008). However, it is now possible to conduct screening for early detection of ASD as early as 12 months of age (Young, 2007).

The escalation in the prevalence of ASD, together with the plethora of screening and diagnostic tools, have raised the awareness of practitioners in providing better assessment and

diagnostic standards in order to give more adequate explanations about a child's condition. Among the efforts, initiatives have come from developed countries such as the United States, Australia, Canada and the United Kingdom, to provide best practice guidelines for clinicians and practitioners (Autism Services Coordinating Committee, 2003; Department of Developmental Services, 2002; National Initiative for Autism: Screening and Assessment, 2003; Nachshen et al., 2008). The guidelines from these four countries are alike in terms of suggesting three key elements in assessing and diagnosing ASD: be conducted within a multilevel system, by a multidisciplinary team, and using standardised assessment tools.

2.4.1. Multilevel Assessment of ASD

Conducting the assessment of ASD in a multistage system is the first element suggested by the best practice guidelines from the US, UK, Canada, and Australia (Autism Services Coordinating Committee, 2003; National Initiative for Autism: Screening and Assessment, 2003; Department of Developmental Services, 2002; Nachshen et al., 2008). The US guideline divides the assessment into four stages: (1) developmental surveillance; (2) screening; (3) diagnostic evaluation; and (4) assessment for intervention plan (Department of Developmental Services, 2002). The UK guideline suggests three stages: (1) general developmental assessment; (2) multi-agency assessment; and (3) tertiary assessment (National Initiative for Autism: Screening and Assessment, 2003). Similar to the UK guidelines, the Canada guideline also suggests three stages: (1) developmental surveillance; (2) screening; and (3) assessment and diagnosis (Nachshen et al., 2008). Only Australia has suggested two levels of assessment which consists of: (1) screening, and (2) assessment (Autism Services Coordinating Committee, 2003). Table 2.1 listed the details of stages suggested by each of the guidelines.

Table 2.1
Details of Assessment Stages Recommended by Four Best Practice Guidelines

Countries	Stages	Characteristics
US	Developmental surveillance	Aims to search for clinical signs (red flags) by assessing the degree of language development, the presence of specific gestures, ability in following nonverbal communication by 12 months, and the presence of skills appropriate in certain ages. Children who hardly show those skills should be referred for further evaluation.
	Screening	Aims to screen for ASD within the primary care practice. In this stage, the general developmental tools should be used. Providers may use different tools based upon their training, expertise, and scope of practice.
	Diagnostic evaluation	Aims to diagnose a child by collecting information through interview, observation, and testing. It is recommended to be conducted by an interdisciplinary team and includes components as follows: <ol style="list-style-type: none"> a. Review of background information b. Caregiver Interview c. Comprehensive Medical Evaluation d. Direct Behaviour Observation e. Cognitive Assessment f. Measures of Adaptive Functioning
	Assessment for intervention plan	Aims to assess the strengths and weaknesses of a child with ASD in order to produce treatment planning and intervention based on the child's personal profile. Domains assessed are as follows: <ol style="list-style-type: none"> a. Communication (speech and language) b. Motor Skills and Sensory Processing c. Behavioral Functioning d. Adaptive Functioning e. Family Functioning and Coping Resources.
UK	General developmental assessment	Aims to identify any possible developmental problems in children. It comprises clear identification of concerns, developmental history, full examination, and appropriate further test. However, this level does not require ASD tests to be conducted.
	Multi-agency assessment	Aims to diagnose of possible ASD and provide a baseline profile for the child and family. It is recommended to be conducted by a multi-disciplinary team with a maximum duration of 17 weeks.
	Tertiary assessment	This stage is needed when the multi-agency assessment needs second opinion and further advices in dealing with challenging cases.

(Table continued overpage)

Canada	Developmental surveillance	Aims to detect any developmental problems in young children. It can be conducted at any possible child health evaluation.
	Screening	Aims to evaluate young children with a high risk of having ASD. The Canada guideline does not recommended the first level screening that targets all children as suggested by US guideline but suggests the second level of screening that targets high risk population.
	Assessment and diagnosis	Aims to assess and diagnose children by a multidisciplinary team and using at least one standardised measurement tool (gold standard tool in combination with clinical judgment is recommended). Components suggested to be included in the diagnosis process are as follows: <ol style="list-style-type: none"> a. a full medical examination b. psychological or psychiatric consultation c. audiology consultation d. speech-language pathology assessment e. occupational therapy evaluation
Australia	Screening	Conducted when a child's development is concerned. Screening could be made by local doctor (GP or pediatrician), children's service team, community health centre, Specialist early intervention agency, maternal and child health service.
	Assessment	Aims to diagnose the referred child. The assessment could be arranged either by an assessment team or personally coordinated by family of the evaluated child. Suggested components of the assessment process are as follows : <ol style="list-style-type: none"> a. Paediatric Medical Assessment b. Communication Assessment c. Cognitive Assessment d. Audiological Assessment e. Sensory Integrative Assessment f. Psychosocial Assessment g. Behavioral Observations h. Child Psychiatric Consultation i. The use of rating scales (such as CARS) j. Multidisciplinary Case Conference.

Conducting detailed assessment using standardised tools and involving ASD specialists is costly; therefore having surveillance and screening stages could save costs, as practitioners at the surveillance and screening stages are usually those who work as general practitioners. Each multistage system offers their own guidelines and has their own strengths. The Australian multistage system appears to be the least complex, as it comprises

only two stages (screening and assessment). However, a model of Australian developmental surveillance using the Social Attention and Communication Study (SACS; Barbaro & Dissanayake, 2010) checklist has been developed and ongoing studies in order to provide evidence on its effectiveness were conducted (Barbaro & Dissanayake, 2013). The US guideline includes the assessment for intervention planning as its fourth stage, which is not formally included in other guidelines. The UK guideline includes a ‘tertiary assessment’ stage that is needed when the second stage team encounter difficult cases or conditions that would benefit from a second opinion. As showed in Table 2.1., the tertiary assessment involves more professionals with specific expertise or speciality in ASD. The Canadian guideline offers a very detailed screening stage, as it includes developmental surveillance, first level screening, and second level screening. However, one of the limitations of a multilevel system is that it demands parents go through a longer waiting time in order to receive their child’s final diagnosis, potentially leading to increasing stress. More details about the limitations of this multilevel system are discussed in Section 2.5.1.

2.4.2. Multidisciplinary

The second element suggested by the four best practice guidelines is that the assessment of ASD needs to be carried out by a coordinated multidisciplinary team that communicates with each other before conducting a diagnosis, or during the assessment process (Autism Services Coordinating Committee, 2003; Department of Developmental Services, 2002; National Initiative for Autism: Screening and Assessment, 2003; Nachshen et al., 2008). Five professions are suggested for inclusion by each of the four guidelines: (1) Occupational therapist; (2) Paediatrician; (3) Psychiatrist; (4) Psychologist; and (5) Speech pathologist or therapist. All of the guidelines highlight the importance of communication and coordination among members of the multidisciplinary team. Table 2.2 listed the types of professions suggested by each of the guidelines.

Table 2.2
List of Professionals Involved in the Assessment Process Recommended by the Best Practice Guidelines

Stages		Professionals			
		UK	US	Canada	Australia
Developmental Surveillance	Not applicable		paediatricians family physicians	physicians public health nurses other professionals in regular contact with children (e.g. day care workers, early childhood educators)	Not applicable
Screening	Not listed		<p>Birth to age five paediatricians family physicians social workers audiologists speech and language pathologists occupational therapists physical therapists nurses hospitals / attending physicians early intervention specialists</p> <p>Age six and older physicians school psychologists private practitioners</p>	physicians public health nurses nurse practitioners psychologists	local doctor (GP or paediatrician) children's service team community health centre specialist early intervention agency maternal and child health service.

(Table continued overpage)

Table 2.1

List of Professionals involved in the Assessment Process Recommended by the Best Practice Guidelines (continued)

Stages	Professionals			
	UK	US	Canada	Australia
Assessment	<p>Stage 2 educational and/or clinical psychologist specialist teacher, or early years professional speech and language therapist paediatrician, child and adolescent psychiatrist child and adolescent learning disability consultant occupational therapist physiotherapist dietician and nutritionist ASD family support worker administrator.</p> <p>Stage 3 neurodevelopmental paediatrician and/or child psychiatrist with specific expertise in ASD specialist psychologist (educational/ clinical) specialist speech and language therapist specialist teacher specialist occupational therapist and physiotherapist child psychotherapist art, drama, music therapist specialist social worker specialist</p>	<p>Birth to age five physicians paediatric nurse medical social worker qualified health professionals with expertise in the area of ASD</p> <p>Age six and older^a clinicians experienced and trained in ASD cases</p>	behavioural specialists / early interventionists dieticians educational Specialists neurologists nurse practitioners occupational therapists paediatricians psychiatrists psychologists social workers speech Pathologists	paediatrician speech pathologist psychologist audiologist occupational therapist

Note. ^aThe US guideline does not specifically mentioned the types of professionals, however the assessment is suggested to cover areas of medical, psychological, communication, social competence, social functioning, restricted patterns of behaviour, interests and activities, family functioning, academic, and neuropsychological.

The UK guideline recommends that practitioners who provide assessment and diagnosis of ASD should undergo regular ASD specific training, while the US guideline specifically suggests that professionals who assess ASD cases need to meet the following requirements: (1) have qualifications from a California State Licensure; (2) have had supervision and training in ASD; (3) have been supervised in a graduate training program for ASD within a clinic or treatment centre; and (4) have had clinical experience in dealing with ASD cases. The specific qualification of a California State license has been required since the guideline was published in California, however this license is likely to be different in other states.

2.4.3. Standardised Measurement Tools

The third element suggested by the guidelines is the use of standardised tools in assessing ASD. For the screening and surveillance stage, the UK guideline (National Initiative for Autism: Screening and Assessment, 2003) suggests the use of Parents Evaluation of Developmental Status (PEDS; Glascoe, Maclean, & Stone, 1991), CHAT (Baron-Cohen et al., 2000), Social Communication Questionnaire (SCQ; Rutter et al., 2002), Childhood Asperger's Syndrome Test (CAST; Scott et al., 2002), and Pervasive Developmental Disorder Screening Test (PDDST; Siegel, 1998), while for further assessments (stages two and three), the ADOS and ADI-R are recommended.

Similar to the UK guideline, the US guideline (Department of Developmental Services, 2002) suggests the use of the M-CHAT and the second version of Pervasive Developmental Disorder Screening Test (PDDST-II; Siegel, 2004) for screening purposes. In the diagnostic stage for children aged to five years, the US guideline suggest the use of the ADI-R and the Parent Interviews for Autism (PIA; Stone & Hogan, 1993) for interviewing caregivers, and recommends the ADOS-G (Lord, 1993), the Behavior Observation Schedule (BOS; Freeman, Ritvo, Guthrie, Schroth & Ball, 1978), the Ethological Observation Schedule

(ETHOS; Siegel, 1991), and the CARS (Schopler et al., 1980), for observing the child. In relation to the diagnostic stage, the guideline also suggests the evaluation of the child's cognitive and adaptive ability using the Bayley Scales of Infant Development-II (Bayley II; Bayley, 1993), the Wechsler Preschool and Primary Scale of Intelligence (WPPSI; Wechsler, 1967), Stanford-Binet Intelligence Scale: Fourth Edition (SB4; Thorndike, Hagen, & Sattler, 1986b), or the Mullen Scales of Early Learning (MSEL; Mullen, 1995). In addition, the Vineland Adaptive Behaviour Scales (VABS; Sparrow, Balla, & Chicchetti, 1984), Scales of Independent Behaviour-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996), and Vineland Social-Emotional Early Childhood Scales (Vineland SEEC; Sparrow, Balla, & Chicchetti, 1998), have been suggested for evaluating the adaptive functioning skill of the child. Within the fourth stage (assessment for intervention planning), the US guideline recommends the child be evaluated in the areas of communication, motor skills, sensory processing, behavioural functioning, adaptive functioning, family functioning, and family coping resources. For each area, the guideline lists its recommended measurement tools. For example, the ADOS-G is recommended for assessing the child's communication ability, while the Peabody Developmental Motor Scales (PDMS; Folio & Fewell, 1983) is suggested for measuring the child's motor skills.

Similar to the UK and US guidelines, the CHAT is one of the tools suggested in the screening stage by the Canadian guideline (Nachshen et al., 2008). Other screening tools identified are the Autism Behaviour Checklist (ABC; Krug, Arick, & Almond, 1980), GARS, ESAT, M-CHAT, PDDST-II, Screening Tool for Autism in Two-Year-Olds (STAT; Stone, Coonrod, & Ousley, 2000), and Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999). In addition, the ADI-R, ADOS, and CARS are suggested for use within the stage of assessment and diagnosis. Specifically, the ADI-R and ADOS are recommended as the gold standard. In terms of ADOS, the newest version of

ADOS is The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012), and is recommended to be used replacing the ADOS and ADOS-G.

In contrast, the Australian guideline does not mention any specific tools for the screening stage. However, for the assessment stage, the use of the CARS, Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1995), ABC, and Psycho Educational Profile (PEP-R; Schopler, Reichler, Bashford, Lansing, & Marcus, 1990), are recommended. Within the diagnostic stage, similar to other guidelines, the Australian guideline suggests the evaluation of communication, cognitive, auditory, sensory integrative and psychosocial aspects of the child. Table 2.3 provides summary of the four best practice guidelines.

2.5. Formal Measurement Tools Commonly Used in Screening and Diagnosing ASD

The availability of diagnostic and measurement tools for assessing ASD is important, since the tools help practitioners to make an early detection and diagnosis (Leekam, Libby, Wing, Gould, & Taylor, 2002). All tools suggested by the four guidelines were developed based on the criteria of DSM-IV TR, although currently the DSM-5 has been published and is suggested by the American Psychological Association (2013) as a substitute for DSM IV-TR. Esler (2013) confirmed that most of the screening and diagnostic tools available in the market were developed based on the criteria of DSM IV-TR. In the following sections, the two screening and four diagnostic tools that are listed in the best practice guidelines are briefly discussed. These six measurement tools were chosen on the basis of their wide investigative properties and high use in clinical practice. The ADOS and ADI-R have been widely studied and have been recommended as the gold standard assessment tools by the US, UK, Canada, and Australia's guidelines. The CHAT and GARS are screening tools that are widely used in identifying ASD, whilst the DISCO and CARS are widely used for diagnosing ASD.

Table 2.3

Comparison of the Four Developed Countries' Best Practice Guidelines for Assessing ASD

Components	United Kingdom	Canada	United States	Australia
Multidisciplinary				
Audiologist	-	X	X	X
Behavioural Specialists	-	X	X	-
Dieticians / Nutritionist	X	X	-	-
Educational Specialists	X	X	X	-
Family Support Worker	X	-	-	-
Neurologists	-	X	X	-
Nurse Practitioners	-	X	-	-
Occupational Therapists	X	X	X	X
Physiotherapy	X	-	-	-
Paediatricians	X	X	X	X
Psychiatrists	X	X	X	X
Psychologists	X	X	X	X
Social Workers	-	X	X	-
Speech Pathologists/Therapist	X	X	X	X
Other Physicians	-	-	X	-
Multistage				
Developmental Surveillance	-	X	X	-
Screening	X	X	X	X
Assessment and Diagnosis	X	X	X	X
Standardised tools				
Screening tools				
Modified Checklist for Autism in Toddlers (M-CHAT)	-	X	-	-
Checklist for Autism in Toddlers (CHAT)	X	X	X	-
Denver Developmental Screening Test (DDST)	-	X	X	-
Screening Tool for Autism in Toddlers and Young Children (STAT)	-	X	-	-
Social Communication Questionnaire (SCQ) ^a	X	-	-	-
Parents' Evaluation of Developmental Status (PEDS)	X	-	-	-
Childhood Asperger's Syndrome Test (CAST)	X	-	-	-
Pervasive Developmental Disorder Screening Test (PDDST)	X	-	-	-
Gilliam Autism Rating Scale (GARS)	-	X	X	-
Assessment and Diagnostic tools				
Autism Diagnostic Interview – Revised (ADI-R)	X	X	X	-
Diagnostic Interview for Social and Communication Disorders (DISCO)	X	-	-	-
Childhood Autism Rating Scale (CARS)	X	X	X	X
Autism Diagnostic Observation Schedule (ADOS)	X	X	X	-
Autism Behaviour Checklist (ABC)	-	-	-	X
Psychoeducational Profile – Revised (PEP-R)	-	-	-	X

Note. All data for best practice guidelines have been sourced from: (i) the United Kingdom: National Initiative for Autism: Screening and Assessment (2003); (ii) Canada: Nachshen et al (2008); (iii) the United States: Department of Developmental Services (2002); (iv) Australia: Autism Services Coordinating Committee (2003).

^aPreviously known as Autism Screening Questionnaire (ASQ)

2.5.1. Checklist for Autism in Toddlers (CHAT)

The Checklist for Autism in Toddlers (CHAT) is a screening tool developed to detect ASD features in children 18 months of age and who are at risk for ASD (Baron-Cohen et al., 2000). It is based on the assumption that children at 18 month of age have abilities in joint attention and pretend play. A lack of these abilities may suggest the diagnosis of ASD (Allison et al., 2008; Baron-Cohen et al., 2000). The original version of CHAT consisted of two sections; Section A comprising nine questions for parents, and Section B comprising five points of observation of the child completed by clinicians (Baron-Cohen et al., 2000).

The CHAT has excellent specificity but low sensitivity (Baron-Cohen et al., 2000, p.11). Specificity refers to the possibility of a child being screened negative while truly not having that condition (i.e., true negative rate), whereas sensitivity refers to the possibility of a child being screened positive and in reality, having that condition (i.e, true positive rate). The CHAT's normed data are based on 16,235 children who were screened at 18, 20, and 42 months of age. All of the children were born in the South Thames region of the UK. Detailed information regarding the participating children's social economic background is not provided (Baron-Cohen et al., 1996). The CHAT, however, is not recommended as a diagnostic tool because it shows a high false negative (Baron-Cohen et al., 2000, p.11).

Other versions of the CHAT are the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001), and the Quantitative CHAT (Q-CHAT; Allison et al., 2008). The Q-CHAT is a screening tool that is appropriate for children aged 18 to 24 months of age, and contains 25 items to be answered by parents. Further studies are required to confirm whether the Q-CHAT possesses better psychometric properties when compared to M-CHAT and CHAT (Allison et al., 2008).

The M-CHAT is a screening tool for children who are at risk of having ASD and PDD-NOS. It consists of 23 items that are expanded from the first section of the CHAT. M-

CHAT is appropriate for use with children aged between 16 to 30 months (Dumont-Mathieu & Fein, 2005; Robbins et al., 2001). Several studies have found the M-CHAT to be more sensitive than the CHAT (e.g. Matson & Sipes, 2010), and useful in distinguishing children at high risk of ASD from children with global developmental delays and developmental language disorders (Ventola et al., 2006). The specificity of the tool is relatively high but the sensitivity in the general population remains unknown (Allison et al., 2008; Robins et al., 2001). Normed data were obtained from 1,293 children who were referred for early interventions. Most of the participating children came from Connecticut in the US (Robins et al., 2001). Both the CHAT and M-CHAT do not require specific training for administration (Baron-Cohen et al., 2000; Robins et al., 2001).

The newest version of M-CHAT, the Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F; Robins, Casagrande, Barton, Chi-Ming, Dumont-Mathieu, & Fein, 2014) has recently been published. The M-CHAT-R/F has excluded three items from the previous version, reorganized the sequence of the remaining 20 items, and simplified the language used in the test. The tool was validated with 15,612 children (*Mean* = 20.95 months, *SD*=3.30 months, age range = 16 – 30.95 months) from a low risk population in Atlanta city, USA. The study found the internal consistency of the tool to be adequate (Cronbach's $\alpha = 0.79$). Children who were screened positively with the M-CHAT-R/F were 114 times more likely to receive an ASD diagnosis than children who were screened negatively (Robins et al., 2014).

The M-CHAT has been translated into 22 languages. However, not all of these translated versions have been validated (Robins & Fein, 2011). A recent study conducted by Scarpa et al. (2013) found that M-CHAT had low internal consistency when it was used within a sample of mothers with a low education background or from ethnic minority groups. Therefore, further validation and adaptation studies of the translated versions of M-CHAT are

required, as Scarpa et al. (2013) have argued that M-CHAT tends to show less accuracy amongst children from low economic backgrounds and live in rural areas. Investigating the appropriateness of this tool is urgent, as Robins (2011) suggested that the M-CHAT is currently widely used for ASD screening by most practitioners in many countries in the world (e.g. China; Sun et al., 2013a). In Indonesia, the CHAT is recommended by the Indonesian Psychological Association for use in assessing ASD, in addition to CARS (HIMPSI, 2008). The Indonesian version of M-CHAT is available from the Official M-CHAT Website (http://www2.gsu.edu/~psydlr/Site/Official_M-CHAT_Website.html). However, a validation study of the Indonesian version of M-CHAT is still needed in order to evaluate the validity and reliability of the tool when used in the Indonesian population.

2.5.2. Gilliam Autism Rating Scale-Second Edition (GARS-2)

The Gilliam Autism Rating Scale-Second Edition (GARS-2; Gilliam, 2006) is a screening tool for children and adults with ASD from 3 to 22 years (Montgomery et al., 2008; South et al., 2002). It is a behaviour checklist completed by parents, teachers or professionals, to identify children and adults with ASD. It is aimed to be used as a supplementary tool together with other assessment tools and information, in order to fully undertake the diagnosis of ASD.

The GARS-2 consists of three components: (1) subscale and composite scores from the behaviour checklist; (2) parent or caregiver interviews; and (3) key questions. The subscales are adopted from DSM IV-TR diagnostic criteria for ASD and aim to assess the person in the areas of stereotyped behaviour, communication, and social interaction. The total score derived from the subscales generates an ASD index that represents the severity of the disorder. Those who receive 69 or less in their scores would be categorised as ‘unlikely’ to receive ASD diagnosis, while those with scores of 70 to 84 would be classified as ‘possibly’ diagnosed with ASD, and those who receive 85 or higher scores are placed in the

category of 'very likely' diagnosed with ASD. The parent or caregiver interview consists of closed questions (yes/no responses) regarding the first three years of the person's life, while the key questions component is a set of open-ended questions about the person's medical history, behaviour, ASD symptoms, and parental concerns.

The GARS-2 shows good psychometric properties, reflected in high internal consistency, test-retest reliability and high validity. Normed data for GARS-2 were collected from 1,107 children and young adults aged 3 to 22 who were diagnosed by professionals as having ASD. All the participants resided in the US. Despite the large size of the sample, more detail about the characteristics of the participants are regarded is needed, as the manual does not specifically describe the sample's criteria (e.g. whether the participants had a history of language delay). The tool is relatively easy to use for either assessing or developing intervention plans, although training is recommended for the rater (Montgomery et al., 2008). Although GARS-2 was regarded as being suitable for assessing children and young adults aged between 3 to 22 years, Montgomery et al. (2008) suggested its use be limited to those younger than 15 years as only 9% of the sample was aged between 16 and 22 years. Moreover, one of the test's protocols mentioned that when the child's data cannot be completed by one rater, another rater is allowed to complete the form. According to Montgomery et al. (2008), this procedure of having two potential raters to gather one child's information, needs to be reviewed considering that it has not been psychometrically evaluated.

The latest version of GARS is the Gilliam Autism Rating Scale, third edition (GARS-3; Gilliam, 2013). However, no psychometric studies related to the tool are presently available. Brief reference to the tool exists on online purchase websites (e.g. Pearson, ACER), where high reliability and validity were reported, as well as excellent sensitivity and specificity. In addition, the website mentioned that the items in GARS-3 were developed

based on the criteria of DSM-5 (e.g. <https://www.pearsonclinical.com.au/products/view/524>).

The sources of the information, however, could not be found on the websites.

2.5.3. The Autism Diagnostic Interview-Revised (ADI-R)

The Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le, 1994) is a diagnostic tool for children and adults who are at risk of receiving a diagnosis of a Pervasive Developmental Disorder (Lord & Corsello, 2005). It is a semi-structured interview conducted by a clinician to collect information from the child's primary caregiver, on aspects of a child's behaviour (Matson & Sipes, 2010). It consists of 93 questions that are based on DSM-IV TR diagnostic criteria. The questions cover three main areas: (1) qualitative or reciprocal social interactions; (2) communication and language; and (3) restricted and repetitive, stereotyped interests and behaviour (Chawarska, Klin, Paul, & Volkmar, 2007; Lord et al., 1993). The ADI-R is an updated version of The Autism Diagnostic Interview (ADI; Couteur et al., 1989). The ADI-R was found to be a more reliable instrument for preschool aged children when compared to the original ADI (Cox et al., 1999; Lord et al., 1993).

The ADI-R does not provide norms or scales. However, numerous studies have showed the effectiveness of ADI-R in differentiating children with ASD from their peers without ASD. For example, a study among 94 preschool children found good inter-rater reliability (kappa agreement between .62 and .89; Lord et al., 1993). Cicchetti, Lord, Koenig, Klin, and Volkmar (2007) found that the ADI-R showed an excellent level of agreement (94% – 96%) across all items in evaluating a child. A longitudinal study using the ADI-R with 50 children showed that the instrument demonstrated a high specificity in diagnosing children at 20 months of age (Cox et al., 1999). However the tool is not recommended for use as a diagnostic tool for children below two years of age, because of its low ability in identifying ASD within this age range (Cox et al., 1999). Most of the psychometric studies

of ADI-R were conducted in the US and UK (e.g. Cicchetti et al., 2006). The ADI-R is recognised as one of the gold standard assessment tools that provides accurate diagnosis, despite its lengthy administration time and high cost. Translated versions of ADI-R are available (e.g. Chinese Version of ADI-R; Sun et al., 2013a).

2.5.4. The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) is a play-based diagnostic assessment specifically developed as an extension of the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989), the Pre Linguistic-Autism Diagnostic Observation Schedule (PL-ADOS; DiLavore et al., 1995) and the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000). The ADOS is recommended as one of the gold standard measurement tools for diagnosing ASD (Kanne, Randolph, & Farmer, 2008).

The original ADOS was a highly sensitive instrument that could be used to assess ASD in children from two years of age to adults (DiLavore et al, 1989; Lord et al., 2000; Lord & Corsello, 2005). It was developed based on the DSM IV-TR criteria and covers the areas of communication, social reciprocal interaction, play, stereotyped behaviour, and restricted interests. The ADOS was originally designed for children who had already developed fluent phrase speech, whereas the PL-ADOS was developed for preschool children who showed poor speech ability (DiLavore et al, 1995; Lord et al., 2000; Lord & Corsello, 2005). Both instruments were combined into the ADOS-G, with an additional two modules (Lord et al., 2000). In the ADOS-2, a new module specifically for Toddlers was added. The diagnostic algorithms used in Modules 1 to 3 were updated and minor changes to the administration instructions and test protocols have also been made (Lord, Rutter, DiLavore, Risi, Gotham, & Bishop, 2012). The psychometric data of ADOS-2 are based on a sample of

children residing mostly in the US, with 80% of participants being Caucasian children (McCrimmon & Rostad, 2014).

The ADOS-2 consists of five modules with selection based on the child's expressive language level, chronological age, abilities and interests. The first module is designed for children aged 31 months or older, and who have not produced two words of speech. The second module is appropriate for children who have used phrase speech but who have not spoken fluently. The third module is for those who are able to speak fluently and play appropriately with an action-figure toy. The fourth module is designed for adolescents and adults who are able to communicate fluently, while the new toddler module is appropriate for children aged between 12 and 30 months and who have not been able to produce phrases in their speech.

2.5.5 Diagnostic Interview for Social and Communication Disorders (DISCO)

The Diagnostic Interview for Social and Communication Disorders (DISCO: Wing, Leekam, Libby, Gould, & Larcombe, 2002) is a diagnostic tool designed for people with a high risk of ASD and is suitable for use at all age levels. The main objective of the DISCO is to obtain information related to the broad autistic spectrum condition. The information is used to create a picture of the level of development, disability, and specific needs of an individual (Lord & Corsello, 2005). DISCO systematically records a wide range of behaviour and developmental skills needed by clinicians to make a diagnosis and recommendation relating to ASD. In addition, it has been used as a research tool (Wing et al., 2002). DISCO is a standardized, semi-structured interview. Each component reflects a specific example of behaviour seen in the spectrum of ASD, from mild to severe conditions. DISCO is based on the DSM IV-TR and ICD-10 diagnostic systems (Leekam et al., 2002; Leekam et al, 2007). DISCO has also been found to be effective in identifying patterns of sensory abnormalities in children with ASD. A study by Leekam et al (2007) found that

more than 90% of children with ASD had sensory abnormalities that could affect single or multiple sensory domains. Sensory domains can be divided into proximal (e.g. touch, taste, smell), auditory and visual domains. An example of sensory abnormalities in the auditory area is when a child's auditory condition is very sensitive and easily distressed by sounds that do not affect others. In the visual area, a child's sensory ability is suspected to be abnormal if he or she is extremely and unusually excited by bright lights. In proximal area, a sensory abnormality can be suspected when a child unusually tends to explore objects or people by smelling them. Leekam et al. (2007) found that items in the DISCO investigated abnormalities in these three sensory areas and therefore the tool could be used to investigate any sensory abnormalities in children.

The psychometric properties of DISCO 9 and DISCO 10 have been examined using samples of participants from the UK and Sweden (Leekam, Libby, Wing, Gould, & Taylor, 2002; Nygren, Hagberg, Billstedt, Skoglund, Gillberg, & Johansson, 2009). A study involving 115 Dutch children aged 34 to 137 months indicated that the latest version of DISCO (DISCO 11; Maljaars, Noens, Scholte, & Berckelaer-Onnes, 2012) possessed high sensitivity, moderate specificity, and sufficient validity with ADOS and SCQ (Maljaars et al., 2012).

However, the tool has a limitation in terms of its extensive administration time (120 – 180 minutes; McClintock & Fraser, 2011). Nevertheless, currently the DISCO is the only tool that has been found to be in line with the DSM-5 criteria (Carrington et al., 2014; Kent et al., 2013).

2.5.6. Checklist for Autism Rating Scale (CARS)

The CARS is a behaviour rating scale that is used to diagnose ASD in children from two years old. It consists of 15 scales that measure a child's capability in areas such as human relationships, imitation, affect, use of body movement, relation to non-human objects,

reaction to environmental changes, sensory responsiveness, anxiety reaction, verbal and nonverbal communication, activity level, and intellectual functioning. Each scale is scored from 1 to 4 indicating normal to severely abnormal behaviour. Children who receive a total score of 30 or above are classified as having ASD (Schopler et al., 1980).

Breidboard and Croudace (2013) investigated empirical reports of the use of the CARS from 1980 to 2012 and found that the tool possessed good internal consistency and inter-rater reliability over time. In terms of validity, a study by Ventola et al. (2006) found high diagnostic agreement with the gold standard tool, ADOS-G, but lower agreement with the ADI-R. To date, the CARS has been widely studied and used for diagnosing ASD (Breidbord & Croudace, 2013). It has been translated to other languages, including Portuguese (CARS-BR; Pereira, Riesgo, & Wagner, 2008) and Japanese (CARS-TV; Kurita, Miyake & Katsuno, 1989). A Chinese version of CARS was investigated in four studies (e.g. Sun et al, 2013a). However, since these studies are only available in Chinese, psychometric data are difficult to interpret. The CARS is also available in Indonesian language and has been used previously in a prevalence study reported by Wignyosumarto, Mukhlas, and Shirataki (1992). The tool has also been recommended by The Indonesian Psychological Association to be used by Indonesian practitioners for assessing and diagnosing ASD (HIMPSI, 2007) although, to date, there has been no published validation of the CARS with an Indonesian sample.

The latest version of CARS is the Checklist for Autism Rating Scale – Second Edition (CARS2; Schopler, Van Bourgondien, Wellman & Love, 2010). This newer version can be used to diagnose ASD in individuals with high functioning ASD, as well as those with high IQ scores, fluent verbal skills, or for those with more profound social and behavioural deficits. The CARS2 consists of four parts: (1) Standard Version Rating Booklet (CARS2-ST) that can be used for assessing children younger than 6 years old, children with

communication difficulties, or children with below average IQ; (2) High-Functioning Version Rating Booklet (CARS2-HF) that is appropriate to use for assessing children aged 6 and older, individuals with fluent verbal ability, and for those with IQ above 80; (3) Questionnaire for Parents or Caregivers (CARS2-QPC) which is a scale developed only for collecting information that can be used with the CARS2-ST and CARS2-HF (Schopler et al., 2010). The psychometric properties of CARS and CARS2 have been evaluated with children and adults residing in the North Carolina, USA. In terms of psychometric properties, similar to GARS-2, more empirical studies on the validation and reliability of this latest version of CARS are still required (Nannan, 2012).

2.6. Current Practice of Diagnosing ASD in Developed and Developing Countries

As discussed in Section 2.4, developed countries such as UK, US, Canada and Australia have published best practice guidelines that can be used by health practitioners for diagnosing and developing intervention for ASD. Such detailed guidelines are rarely available in developing countries (e.g. China; Sun et al., 2013a). This section outlines the conditions in developed and developing countries regarding the assessment and diagnosis of ASD. Three developed countries' detailed situations are discussed (US, UK, Canada) followed by a section about the conditions in some developing countries (China, India, and Indonesia). These three developing countries are considered to be appropriate examples, as they are categorised as the three most populated developing countries in the world. India has similar features to Indonesia in terms of its high practice in cultural approaches and religion.

2.6.1. Developed Countries' situations

Studies suggest that health practitioners and ASD specialists in the UK, US, and Canada have encountered difficulties in putting into practice the principles relating to ASD diagnosis in their guidelines. A study conducted in the US compared the assessment procedures among three community settings (public schools, California Regional Centres,

and a mental health clinic) and found that, in terms of determining whether a child had ASD, disagreement across the three types of institutions was high at 55%. This disagreement was seen to be a consequence of practitioners involved in the study not applying best practice guidelines in conducting the diagnosis. The use of gold standard tools (ADOS and ADI-R) was high only at the mental health clinic (96% and 60% respectively). At the California Regional Centres, the ADOS was used only in 25% of cases, while the ADI-R was used in 8% of cases. None of these tools were used in the public schools assessments. The high price of the tools, as well as lengthy duration and high cost of training, were considered to be the reasons behind their low use (Williams et al., 2009). This study supports the findings from an earlier study by Hering (2005) that disseminated a self-developed questionnaire to 59 California licensed psychologists in order to understand the ASD assessment procedures. The study found that 59% of respondents indicated that they never or only occasionally used the ADOS, whereas 71% never or occasionally used the ADI-R. In addition, the CARS was found to be the most common tool used in diagnosing ASD among participants (53%; Hering, 2005).

Somewhat similar conditions were found in Canada. In a study that evaluated the assessment procedures of Canadian health practitioners, a survey was disseminated to 126 health practitioners in Ontario province (Berenstein, 2012). It was found that less than 50% of participants used standardised tools for screening and diagnosing ASD. Another study in Canada was conducted by Siklos and Kerns (2007) who aimed to understand the diagnostic experiences of 56 Canadian parents who sought ASD diagnosis for their children. Using a combination of formal and self-developed questionnaires, the study found that long waiting lists to meet ASD specialists meant that, on average, parents needed to wait for two years eight months ($SD = 2$ years 6 months; range = 0 – 10 years 6 months) to receive their child's diagnosis. Specifically, the parents needed to meet four clinicians before obtaining the

diagnosis, with 41% seeing more than five professionals, and 5% needing to see more than ten professionals. Such circumstances were perceived as being highly stressful for these parents (Siklos & Kerns, 2007).

The lack of use of standardised measurement tools and lengthy delays in receiving a diagnosis of ASD were also found in the UK. McClure et al. (2011) found that a skills training program for a local assessment team in using the gold standard tools was effective in increasing the practitioners' skills in diagnosing ASD cases. The training was conducted in response to reports of the lengthy waiting time encountered by parents in order to receive an ASD diagnosis for their children. Delays in receiving a diagnosis reflect the low level of availability of ASD specialists. The long delays were occurring at the stage when the high risk children were being referred to a multidisciplinary team that specialised in diagnosing ASD.

The lengthy waiting time encountered by the parents is an ongoing problem. In 2013, Connolly and Gersch conducted a support group program for a small group of parents who experienced extensive waiting times to receive their children's diagnoses. The support program was effective in reducing parent's stress and frustration (Connolly & Gersch, 2013). In a study conducted by Harthorn, Alateeqi, Graham, & O'Hare et al. (2014), it was found that training in the use of standardised measurement tools significantly increased the use of formal tools from 15% to 45%. The most commonly used tool by the practitioners was GARS considering that the tool could be completed by parents, carers, and school staff, independently. The use of ADI-R, and DISCO was rare, due to the lengthy time required for their administration, while ADOS was only used if there were uncertainties in the diagnosis of a child.

At the time of writing this review, studies relating to ASD assessment practices by Australian health practitioners could not be found. Nonetheless, studies from the US, UK,

and Canada have confirmed that the application of best practice guidelines is challenging, even in the countries where the guidelines were originally developed. These situations raise questions about whether the development of the guidelines was accompanied by pilot studies, since no pilot studies were reported to have been undertaken in the process of generating the guidelines. Pilot studies would have provided the developers of the guidelines with information about possible challenges that would be encountered by practitioners in implementing the principles covered in the guidelines.

2.6.2. Developing Countries and ASD assessment

Similar to developed countries, shortages in the number of ASD specialists and in the use of standardised measurement tools are considered to be main challenges encountered by health practitioners in developing countries. The situation in developing countries, however, can be less conducive to positive change than in developed countries, since government attention, funding, and supports, are still very limited (WHO, 2011). Social pressure, stigmatisation, and cultural influence, are common issues that have to be taken into account in developing countries. For example, in India, parents prefer to take their children to be evaluated using spiritual or alternative approaches, while in Saudi Arabia, China, and India, parents tend to delay meeting ASD practitioners in order to avoid the social stigma of having a child diagnosed with ASD (Divan et al., 2012, Seif Eldin et al., 2008, Sun et al., 2013a).

A study from the most populated country in the world, China, found that Chinese parents seek diagnosis of ASD from children's hospitals, psychiatric hospitals, neurological hospitals, paediatricians or rehabilitation centres, with most parents preferring to seek diagnosis from children hospitals and paediatricians (Sun et al., 2013a). The problem of accurate assessment and diagnosis is compounded, as the knowledge and skills relating to ASD are varied among practitioners across different areas in China. Some areas have well-recognised specialists in ASD (such as the Neurological and Mental Illness Prevention

Hospital; Sun et al., 2013b), and some areas require more training workshops in order to enhance the health practitioners' skills and knowledge in diagnosing ASD (such as practitioners in Wuxi city; Sun et al., 2013c).

A similar situation exists in India. In a study by Divan et al. (2012), 10 parents of children with ASD who lived in a small city at Goa, Western India, were interviewed in order to understand their challenges and needs. Besides the parents, the study also interviewed 4 Indian government officials from the Department of Social Welfare and Education, 6 general practitioners, and 26 teachers. In order to receive a diagnosis for their child, most of the parents needed to travel outside of Goa to larger cities due to lack of ASD specialists in Goa. Parents usually sought opinions from more than one health practitioner because they did not feel satisfied with the evaluations given. In addition, most health practitioners in the study did not feel confident about their skills for giving a diagnosis of ASD and were therefore reluctant to give a diagnosis. This result is in line with the report by Daley (2004), where a survey was disseminated to 56 psychiatrists, 51 psychologists, 21 neurologists and 21 paediatricians. The survey aimed to understand practitioners' approaches in assessing ASD, as well as their experience in dealing with ASD cases. It was found that most practitioners needed to update their knowledge about ASD, as most responses showed that their understanding about the disorder was outdated. For example, most of the practitioners believed that ASD was usually associated with children from high social-economic backgrounds. Most of them also believed that ASD originated from a cold and distant parenting style (Daley, 2004). The study, however, did not evaluate the use of measurement tools by practitioners in diagnosing ASD. A more recent article by Rudra, Banerjee, Singhal, Barua, Mukerji, and Chakrabarti (2014) identified a crucial need to adapt and validate measurement tools for diagnosing ASD for people in India and other South Asia countries,

since most tools used in developed countries for screening and diagnosing ASD, have not been adapted into local languages and contexts.

The lack of validated and adapted measurement tools related to ASD is reported to be a major challenge in developing countries. Two validation studies confirmed the availability of five diagnostic tools for ASD. First, Russell et al. (2010) validated the Indian version of CARS. Second, Rudra et al. (2014) produced the Indian validated version of four tools for screening and diagnosing ASD. The four tools were the Social Communication Disorder Checklist, Autism Spectrum Quotient, SCQ, and ADOS. In China, a literature review by Sun et al (2013a) found that currently eight screening and two diagnostic tools (CARS and ADI-R) are available in the Chinese language and have been validated with Chinese samples. In practice, the CARS is the tool most widely used by Chinese practitioners in the assessment process, while ADI-R is less preferred due to the time required for its application (Sun et al., 2013a). However, although these tools are available, Sun et al (2013a) argued that there is a crucial need to introduce these tools to ASD specialists and health practitioners, as the majority of practitioners in China prefer to use clinical judgement rather than standardised measurement tools, for the diagnosis of ASD.

Following China and India, Indonesia is known as the third most populated developing country in the world. Using the ASD prevalence from Australia (Australian Bureau of Statistics, 2014), the estimated number of people diagnosed with ASD in Indonesia would be approximately 1,249,500. However, when compared with China and India, there are very few specific studies about ASD in Indonesia. In terms of measurement tools for ASD, although some have been translated into the Indonesian language (e.g. CHAT and CARS), no validation studies on these translated tools are available. This situation indicates an urgent need to have more ASD diagnostic tools in the Indonesian language and for these tools to be empirically tested and validated with an Indonesian sample.

Besides China, India and Indonesia, studies from other developing countries such as Mexico, Iran and Saudi Arabia also support the notion of the need for more ASD specialists and adapted assessment tools in developing countries (Hedley et al., 2010; Samadi & McConkey, 2011; Seif Eldin et al., 2008). Apparently, both developed and developing countries are dealing with somewhat similar challenges regarding the use of formal assessment tools in assessing ASD. Nevertheless, in developed countries many standardised measurement tools are already available, but practitioners still need to be encouraged and trained in the use of these tools in diagnosing ASD. On the other hand, in developing countries it is the lack of availability of translated and validated measurement tools that is considered to be the main factor underlying their low use. Therefore, studies on measurement tool validation and related training to equip those using the tools, are needed in order to provide more standardised tools for practitioners in developing countries.

2.7. Theoretical Framework

In clinical practice, specifically in diagnosing behavioural, social and emotional problems, most clinicians conduct diagnosis using both nomothetic and idiographic approaches (Merrell, 2008). These two approaches were coined by Wilhelm Windelband in 1894 in order to highlight the two polarised methods during the time when statistical methods started to be increasingly used in acquiring scientific knowledge. In a nomothetic approach, scientific laws are generated by finding similarities among phenomena, while in the idiographic approach, knowledge is acquired by identifying the uniqueness of each phenomena (Merrell, 2008). Using a nomothetic approach in diagnosis implies that clinicians need to know the position of the tested individual among his or her peers. This can only be accomplished by using formal measurement tools that can be used to compare the score obtained from normed data. On the other hand, using an idiographic approach suggests that clinicians need to understand the individual's condition and environment, knowing that each

case is unique and has its own characteristics. Therefore, the first approach requires the availability of formal measurement tools while the second approach requires a more clinical judgment (Merrell, 2008).

The three studies conducted in the present research were guided by the assumption that using standardised measurement tools is important in order to provide a clinician with empirical information that can be later used in conducting diagnosis. In other words, in diagnosing ASD, clinical judgements should be guided, accompanied, and supported by data acquired from empirically based measurement tools, and should not be based purely on a clinician's intuition. This thesis places a high value on formal measurement tools, considering their significant role in producing valid and accurate diagnoses. Accurate diagnosis is essential in developing effective intervention plans for the child. However, in developing countries, the provision of formal measurement tools that have been empirically adapted and validated using local samples is challenging. As discussed in Section 2.6.2, clinical judgements seem to be the approach used by developing countries' practitioners in diagnosing ASD (Sun et al., 2013a). Without the intention of underestimating other approaches in assessing and treating ASD cases, the current thesis holds the premise that the use of empirical based measurement tools is essential in order to provide accurate and accountable ASD diagnoses. It is within this context that the three studies reported in this thesis were conducted.

Chapter 3

Understanding Developing Countries' Challenges in Applying the Best Practice:

The Diagnosis of Autism Spectrum Disorder in Urban Indonesia

This chapter consists entirely and solely of a paper submitted to the International Journal of Disability, Development and Education.

Abstract

The best practice guidelines for assessing and diagnosing Autism Spectrum Disorder (ASD) in developed countries present a challenge for health practitioners in developing countries where services are very limited. As a starting point to understand these challenges in assessing ASD, the present study investigated the needs and practices of urban Indonesian practitioners in their assessment of young children with ASD. A questionnaire was developed and distributed to 67 Indonesian health practitioners who reported that they assessed at least one case of ASD a month. Using descriptive statistics, it was found that best practice components were not easily applied in Indonesia. The use of a multistage system and a multidisciplinary approach remains a challenge. Furthermore, most practitioners endorsed the need for validated tools in Indonesian language and training in assessing ASD. This is the first study to evaluate the diagnostic processes, needs and challenges of Indonesian practitioners in diagnosing ASD.

Keywords: Autism Spectrum Disorder, Indonesia, best practice, assessment, developing country, health practitioners, diagnosis, assessment tools

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that occurs in every part of the world (Saracino, Noseworthy, Steiman, Reisinger, & Fombonne, 2010; Sun & Allison, 2010). In developed countries such as Australia, the prevalence rate was found to be 1 in 160 in children aged 6 to 12 years (MacDermott, Williams, Ridley, Glasson, & Wray, 2007) while in the United States it was found to be 1 in 68 (CDC, 2014). In developing countries, a study from China found that 1 in 909 children aged 2 to 6 years was diagnosed with ASD (Zhang & Ji, 2005) and in Iran, the prevalence rate was found to be 1 in 159 children aged 5 years (Samadi & McConkey, 2011). However, and although ASD is prevalent around the world, its existence in developing countries receives little attention and fewer ASD studies from developing countries are available (Al-Salehi, Al-Hifthy, & Ghaziuddin 2009; WHO & World Bank, 2011). Studies have found that services, facilities, and programs for people with ASD in most developing countries are problematic. In India, for example, most of the assessment and therapy centres are available only in large cities and consequently, people living in rural areas are required to travel to reach the services (Daley, 2004). Other studies from India, Iran, Mexico and Saudi Arabia also showed that diagnoses and assessments for ASD cases were difficult to conduct because of a lack of trained practitioners and culturally appropriate assessment tools (Daley, 2004; Seif Eldin et al., 2008; Hedley et al., 2010; Samadi & McConkey, 2011).

While conditions in developing countries are found to be less advantageous for people with ASD, initiatives have emerged to provide best practice guidelines in order to deliver information, recommendations, and guidelines for professionals and policy makers about current best practice in identifying, assessing, diagnosing, and intervening in ASD cases (National Initiative for Autism: Screening and Assessment, 2003; Department of Developmental Services, 2002; Nachshen et al., 2008). Developed countries such as the United Kingdom, Canada, the

United States and Australia have established ASD best practice guidelines that can be used by practitioners as the gold standard in assessing and intervening in ASD cases (Autism Services Coordinating Committee, 2003; National Initiative for Autism: Screening and Assessment, 2003; Department of Developmental Services, 2002; Nachshen et al., 2008). Table 1 provides a comparison of the best practice guidelines from these countries.

While more detailed investigations are needed, current studies from the United States, Canada, and the United Kingdom found that these best practice guidelines are often difficult to apply in a real setting due to time constraints, lack of training, and high cost of the measurement tools (Berenstein, 2012; Hering, 2005; McClure, Mackay, Mamdani, & Mccaughey, 2010; Siklos & Kerns, 2007; Williams, Atkins, & Soles, 2009). With respect to a multistage and multidisciplinary approach in Canada, parents have to wait, on average, almost three years to receive their child's diagnosis (Siklos & Kerns, 2007). Similarly, in England, parents can face a long wait when ASD specialists are not available in their area (McClure et al., 2010). Those studies, however, were conducted in developed countries where facilities, services, programs, and government supports in disabilities are better than in developing countries (WHO & World Bank, 2011). For example, in terms of service delivery, a study by WHO found that 76% to 85% people with mental health problem in developing countries, received no treatment. This percentage is lower compared to condition in developed countries where 35% to 50% of people with serious mental disorders unable to receive treatment (WHO & World Bank, 2011).

Amongst the very few studies from developing countries, only a limited number are available from the fourth most populated country in the world, Indonesia. In 1992, it was found that 1 in 833 children born between 1984 and 1991 in Indonesia had a diagnosis of ASD (Wignyosumarto, Mukhlas, & Shirataki, 1992). To date, there is no further prevalence data. It

Table 1

Comparison of the Four Developed Countries' Best Practice Guidelines for Assessing Autism

Components	United Kingdom	Canada	United States	Australia
Multidisciplinary				
Audiologist	-	X	X	X
Behavioural Specialists	-	X	X	-
Dieticians / Nutritionist	X	X	-	-
Educational Specialists	X	X	X	-
Family Support Worker	X	-	-	-
Neurologists	-	X	X	-
Nurse Practitioners	-	X	-	-
Occupational Therapists	X	X	X	X
Physiotherapy	X	-	-	-
Paediatricians	X	X	X	X
Psychiatrists	X	X	X	X
Psychologists	X	X	X	X
Social Workers	-	X	X	-
Speech Pathologists/Therapist	X	X	X	X
Other physicians	-	-	X	-
Multistage				
Developmental Surveillance	-	X	X	-
Screening	X	X	X	X
Assessment and Diagnosis	X	X	X	X
Standardised tools				
Screening tools				
Modified Checklist for Autism in Toddlers (M-CHAT)	-	X	-	-
Checklist for Autism in Toddlers (CHAT)	X	X	X	-
Denver Developmental Screening Test (DDST)	-	X	X	-
Screening Tool for Autism in Toddlers and Young Children (STAT)	-	X	-	-
Social Communication Questionnaire (SCQ) ^a	X	-	-	-
Parents' Evaluation of Developmental Status (PEDS)	X	-	-	-
Childhood Asperger's Syndrome Test (CAST)	X	-	-	-
Pervasive Developmental Disorder Screening Test (PDDST)	X	-	-	-
Gilliam Autism Rating Scale (GARS)	-	X	X	-
Assessment and Diagnostic tools				
Autism Diagnostic Interview – Revised (ADI-R)	X	X	X	-
Diagnostic Interview for Social and Communication Disorders (DISCO)	X	-	-	-
Childhood Autism Rating Scale (CARS)	X	X	X	X
Autism Diagnostic Observation Schedule (ADOS)	X	X	X	-
Autism Behaviour Checklist (ABC)	-	-	-	X
Psychoeducational Profile – Revised (PEP-R)	-	-	-	X

Note. All data for best practice guidelines has been sourced from: (i) the United Kingdom: National Initiative for Autism: Screening and Assessment (2003); (ii) Canada: Nachshen et al (2008); (iii) the United States: Department of Developmental Services (2002); (iv) Australia: Autism Services Coordinating Committee (2003).

^aPreviously known as Autism Screening Questionnaire (ASQ)

has also been reported that most Indonesian people with disabilities (including ASD), particularly those who live in rural areas, are not able to afford appropriate services (Adioetomo, Mont, & Irwanto, 2014). A lack of specialists and practitioners in ASD as well as the limited number of ASD centres has become a crucial issue for parents. Currently there are only 132 registered centres for ASD available in Indonesia, located in 27 cities and sub-cities (Yayasan Autisma Indonesia, 2014) leaving 483 cities and sub-cities still unable to provide localized services. The registered centres are mostly private or funded by non-government organizations, such as religious or social institutions and no government funding is available for children diagnosed with ASD. Indonesia's situation is likely to be reflected in many low-income countries where less than 1% of health budgets are spent on mental health care and, as a result, most mental health care services rely more on private and non-government sectors (WHO & World Bank, 2011).

Therefore, the current study aims to investigate the approach to ASD assessment and diagnosis in Indonesia. Understanding the approach of Indonesian practitioners serves as a starting point to comprehend the experiences in developing countries where services, facilities, and government support for ASD are very limited.

Method

Participants

A total of 120 people participated in the study. Ninety-one participants took the survey online with 29 participants completing a printed version. The inclusion criteria were practitioners (a) with a professional background either as psychologist, medical doctor, or therapist; (b) worked in Indonesia; and (c) diagnosed at least one case of ASD per month, at the

time the survey was disseminated. Fifty-three participants were excluded for not fulfilling the criteria leaving a sample of $N = 67$. Most participants were female ($n = 57$, 85%) and the age range was 26 to 74 years ($M = 38.29$ years, $SD = 10.60$). A majority of the participants ($n = 52$, 78%) worked as psychologists with 11.9% ($n = 8$) as psychiatrists. Almost all participants worked in Java Island ($n = 61$, 81.33%). The length of time the participants had been working with ASD cases ranged from 1 to 36 years ($M = 6.85$ years, $SD = 6.70$). The number of ASD cases received in a month by practitioners ranged from 1 to 160 cases ($Mdn = 2$, $IQR = 1 - 5$). Approximately one-half of participants ($n = 37$, 56.7%) received training in assessing ASD cases, either from their clinical practices as a part of their educational qualification or from seminars and workshops. Participant demographic details are listed in Table 2.

Table 2
Participants' Demographic Details

Characteristics	<i>N</i>	%
Gender		
Male	10	14.9
Female	57	85.1
Age (<i>M, SD</i>)	38.24	(10.61)
Years in practice (<i>M, SD</i>)	9.18	(7.81)
Years in diagnosing autism	6.85	(6.70)
Professional background		
Psychologist	52	77.6
Psychiatrist	8	11.9
General Practitioner	4	6
Paediatrician	2	3
Therapist	1	1.5
Working area ^a		
Java	61	81
Sumatra	9	12
Kalimantan	2	3
Sulawesi	2	3
East Indonesia	2	3

Note. ^aTwo participants worked in more than one area

Recruitment of Participants. Practitioners were recruited from a popular social networking website (Facebook), mailing lists of Indonesian community organizations (Indonesian Psychological Association, Atmajaya Medical Faculty, and University of Queensland Indonesian Student Association), emails to ASD practitioners, and by word of mouth. Invitations to participate were also sent via letters to 90 therapy centres in Jakarta, Indonesia. Eligible practitioners were invited to participate in the survey by using the survey link and were also informed that a printed version could be posted.

Research assistants attended two professional events in Indonesia to recruit health professionals (the Clinical Psychologist National Scientific Gathering and 2nd National Congress of Indonesian Children and Teenagers Mental Health Association). The total number of participants approached by personal email, mail, and word of mouth was approximately 300.

Procedures

Measures. The survey aimed to evaluate how assessment and diagnostic processes were conducted by Indonesian practitioners, as well as to understand the needs and challenges faced in dealing with ASD cases. The questionnaire consisted of 51 items, which were divided into seven sections, and included a variety of open-ended, closed, and Likert-type scale responses. The online survey could be accessed by clicking a url link provided in the invitation that would direct the participant to the survey page website. An information page was provided as the first page of the website and described the aim of the study, inclusion criteria, risk, data confidentiality, security, and ethics approval details.

Survey Development. The survey was developed following a literature review of ASD best practice in four developed countries (the United Kingdom, the United States, Canada, and Australia). The English version of the survey was reviewed by two experts in the field of ASD

and child development who provided feedback on the form and content. This version was translated by the bilingual first author into Bahasa Indonesian Language, and converted into an online version using the survey software, Qualtrics. A bilingual Indonesian graduate student then reviewed the online Indonesian version. In parallel with the language review, four Indonesian practitioners completed the pilot survey independently. The four practitioners were asked to provide feedback about the questions in the survey. They suggested minor revisions in terminology and questions and this informed the final version of the survey. A summary of the survey questions is provided in Table 3.

Analysis

The statistical analyses were performed using the Statistical Package for the Social Sciences version 20 (SPSS version 20; IBM, 2011). Analyses were first run to describe the data and then to describe the trends resulting from each item. Nominal data were described with frequencies while central tendencies were identified using means and variability with standard deviations. Chi-square analyses were used to explore relationships between training and the use of standardized tools. Not all participants responded to all questions however no participants were excluded from analyses due to missing data considering the small sample size. Overall, the percentages of missing data on individual items ranged from 0 to 18%. Each item was analysed independently and where percentages are noted, those relate to the percentages of valid responses for that question.

Results

Current trends in assessing ASD cases in Indonesia

The average number of meetings reported by participants to conduct a diagnosis was 2.69 ($SD = 1.36$) with an average of 1.89 hours ($SD=1.01$) for each meeting. Due to an unequal

Table 3
Indonesian Autism Practitioners Survey's Summary of Content

Sections	Themes	Questions		
		Type	N of Questions	Example
A	Participant's demographic and practice information.	Close ended	11	What is your gender? <input type="checkbox"/> Male <input type="checkbox"/> Female
B	The assessment and diagnosis procedure	A combination of close, open-ended, and multiple-choices.	Four groups of questions about interviews, observations, referrals, and assessment result delivery	In assessing children suspected as having autism; A. On average, you usually need _____ meeting(s) where each meeting takes _____ hour(s) before you make a diagnosis.
C	Type of interventions recommended	A combination of close, open-ended, multiple-choice, and Likert scale.	7	Do you regularly communicate with parents and professionals (therapist / teacher / etc) who involve in the intervention? <input type="checkbox"/> Yes, always <input type="checkbox"/> Sometimes <input type="checkbox"/> No, why not? _____
D	Needs and challenges encountered in working with autism cases	A combination of multiple-choice and ranking	8	What are the challenges you usually encounter in assessing children with autism? (you can tick more than one option) <input type="checkbox"/> My skill is not sufficient in assessing autism cases. <input type="checkbox"/> I am not familiar with assessment tools provided <input type="checkbox"/> It is difficult to find standardized instruments in Indonesian language <input type="checkbox"/> The time provided to assess autism cases is insufficient <input type="checkbox"/> The fee for assessing autism cases is insufficient <input type="checkbox"/> Other (please specify)_____
E	Degree of importance in working with autism cases	7-point Likert scale from 1=Not at all important to 7=Extremely important	6	Availability of professional training in assessing children with autism.
F	Degree of satisfaction in working with autism cases.	5-point Likert scale from 1=not at all to 5=extremely	6	To what extent are you satisfied with the training provided for professionals to assess autism cases?
G	Expectation in working with autism cases.	Open-ended	9	What would you expect to see in terms of the professional training for assessing autism (e.g., availability of specific professional training in assessing children with autism)?

of psychologists (52) and non-psychologists (15) diagnosing ASD, 15 psychologists were randomly selected into a subset group and the time spent on an individual diagnosis was compared using independent-samples t-test. Results showed that there was a significant difference between psychologists and non-psychologists in the duration of time taken to conduct diagnosis, $t(27) = 5.54$, $p < .001$, two-tailed. Further, Cohen's effect size value ($d = 2.58$) suggested high practical significance.

Participants from the subset of psychologist group ($M = 1.97$ hours, $SD = 0.04$) spent significantly longer in diagnosing ASD cases compared to those from the non-psychologist group ($M = 1.07$ hours, $SD = 0.49$). For the main psychologist group, 2.14 hours on average ($SD = 0.99$) was spent on diagnosing ASD cases. Moreover, a Mann-Whitney test indicated that duration of diagnosis was greater for the psychologist group ($Mdn = 2$) than for the non-psychologist group ($Mdn = 1$), $U = 17$, $p = .003$, $r = 1.07$

The number of ASD cases received by participants in a month positively correlated with participants' age ($r = .51$, $p < .05$) and the number of years in dealing with ASD cases ($r = .65$, $p < .05$). No significant relationship was found between training received by participants and the number of ASD cases received each month.

Referral to other practitioners. For those who responded to this item ($N=62$), 56 (90%) reported referring the children to other practitioners (outside of their own discipline) either before or after conducting the diagnosis while six participants (10%) responded that they conducted the diagnoses by themselves because of these following reasons; unavailability of other ASD specialists in the area ($n=1$); confident with their own diagnoses and thought that a

referral was unnecessary (n=2); children had been assessed by other practitioners (n=2); only if the parents of the child permitted the referral (n=1).

For those who referred the children to other practitioners (n=56), only three said they did not communicate with the other practitioners. Using email, letter, phone, short text message, or direct meeting, 53 participants gave information to the other practitioners about the child's working diagnosis, assessment results, and further assessments needed. Details of referrals made by participants are provided in Table 4.

Standardized tools. Forty-nine of 56 participants (86%) agreed on the importance of measurement tools in assessing ASD, but only seven (13%) were satisfied with the measurement tools currently available in Indonesia. Thirty-three of 63 respondents reported using standardised tools in diagnosing ASD. Of the 33 participants who used standardised tools, 22 (66%) reported using the tools listed in best practice guidelines. None of the practitioners used the ADOS or ADI-R, which are recommended by the United States, Canada, and the United Kingdom as gold standard assessment tools in assessing ASD cases. The standardized tools used by the participants are listed in Tables 5.

Table 4

Referrals made by Indonesian Health Practitioners in Assessing Autism Cases

Referral	<i>N</i>	<i>%</i>
Not referring	6	10
Referring	56	90
Before conducting diagnosis		
Communicate with the referred practitioners	23	
Not communicate with the referred practitioners	3	
After conducting diagnosis		
Communicate with the referred practitioners	30	
Not communicate with the referred practitioners	0	
Total	62	100

Of 33 participants who responded using standardised tools, 14 (42%) indicated using the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision (DSM-IV-TR; American Psychiatric Association, 2000) accompanied by other tools in diagnosing while three (9%) used it as a stand-alone. One participant who worked as psychiatrist used DSM-III (American Psychiatric Association, 1980) alone and 15 (27 %) had developed their own observation tools.

Eighteen of 30 participants who did not use standardised tools responded to the question about why they did not use them. Ten indicated that they did not use standardised tools because they had difficulties in finding them as they are not available in Indonesian language. Four indicated that the DSM was sufficient and therefore they did not need to use standardised tools for diagnosing. Two used their own developed checklist while another two indicated that they had received no training on how to use standardised tools for diagnosing ASD.

Training. From those who responded to receiving training, two participants received training in general knowledge about ASD, three received training about early detection of ASD, and five received training concerning the diagnosis of ASD. Two participants received training about ASD therapies, four received training on how to use DSM and ICD to diagnose ASD, and two received training about screening tools for ASD.

Fifty-two of 56 respondents (93%) agreed that professional training in assessing ASD was important but only 12 of 55 (22%) were satisfied with the professional training currently available in Indonesia. There was no significant relationship between training and the use of standardized tools, $\chi^2(1, n=63) = 0.19, p = .66$.

Table 5
Use of Standardised Tools Reported by Indonesian Health Practitioners

Category	<i>N</i>	<i>%</i>
Not using standardized tools	30	48
Using standardized tools		
Level 1 Best Practice		
Checklist for Autism in Toddlers (CHAT) ^a or Modified Checklist for Autism in Toddlers (MCHAT) ^b	4	
Autism Behaviour Checklist (ABC) ^c	1	
Gilliam Autism Rating Scale (GARS) ^d	1	
Denver Developmental Screening Test (DDST) ^e	1	7
Level 2 Best Practice		
Childhood Autism Rating Scale (CARS) ^f		11
Level 1 and 2 Best Practice		
Denver Developmental Screening Test (DDST), Checklist for Autism in Toddlers (CHAT), Childhood Autism Rating Scale (CARS)	1	
Gilliam Autism Rating Scale (GARS), Checklist for Autism in Toddlers (CHAT), Childhood Autism Rating Scale (CARS)	1	
Autism Screening Questionnaire (ASQ) ^g , Denver Developmental Screening Test (DDST), Childhood Autism Rating Scale (CARS)	1	
Modified Checklist for Autism in Toddlers (MCHAT), Childhood Autism Rating Scale (CARS)	1	4
Not listed in Best Practice Guideline	11	33
Total	63	100

Note. ^aBaron-Cohen(2000). ^bDumont-Mathieu & Fein (2005). ^cKrug, Arick, Almond (1980) ^dGilliam (1995). ^eFrankenburg & Dodds (1967). ^fSchopler, Reichler, DeVellis, & Daly (1980). ^gBerument, Rutter, Lord, Pickles, & Bailey (1999).

Indonesian practitioners' needs and challenges

Of 55 participants, more than 50% indicated their preference to have more professional training in assessing ASD cases, more assessment tools provided in Indonesian language and more training in using assessment tools. Moreover, of 56 respondents, 30 (54%) agreed that difficulty in finding assessment tools in Indonesian language was the main challenge they experienced in assessing ASD cases. The complete list of practitioners' needs and challenges are presented in Table 6.

Table 6

Needs and Challenges of Indonesian Health Practitioners in Assessing Autism Cases

	<i>N</i>	<i>%</i>
<i>Needs (N = 56)</i>		
More professional training in assessing autism	48	87
More assessment tools in Indonesian language	42	76
More training in using assessment tools	39	71
Increasing the assessment's time	13	24
Increasing the assessment fee	12	22
<i>Challenges (N = 55)</i>		
Difficult to find standardized tools in Indonesian language	30	54
Lack of time in assessment	20	36
Feeling insufficient in assessing autism cases	16	29
Uncooperative parents	11	20
Lack of assessment fee	9	16
Unfamiliar with the provided tools	4	7

Note. Participants were allowed to select more than one

Discussion

The present study aimed to investigate the application of best practice guidelines in urban areas of Indonesia by understanding the current trend of assessment practices used by Indonesian practitioners as well as their needs and challenges. This is the first study to evaluate the diagnostic processes, needs and challenges of Indonesian practitioners. The results of this study provide insights with respect to the situation in Indonesia where services and facilities for ASD are still very limited.

The best practice from the United Kingdom, the United States, Canada, and Australia suggested that assessment should be conducted within a multidisciplinary team, using a

minimum of one formal standardized assessment tool and involving at least two stages (screening and assessment; Autism Services Coordinating Committee, 2003; Department of Developmental Services, 2002; National Initiative for Autism: Screening and Assessment, 2003; Nachshen et al., 2008). The present study found that none of these three elements were fully applied by the participants in this survey.

Firstly, in terms of a multidisciplinary approach, the present study suggests that Indonesian practitioners are not practicing this component of best practice (Autism Services Coordinating Committee, 2003; National Initiative for Autism: Screening and Assessment, 2003; Department of Developmental Services, 2002; Nachshen et al., 2008). Among Indonesian practitioners, different disciplines did refer to one another either before or after conducting the diagnosis. However, this was neither carried out in a coordinated way nor accompanied by regular and organized communication as suggested by the best practice guidelines. A likely explanation is that when the current study was conducted, there was no formal system in Indonesia established to manage the multidisciplinary practice of health practitioners in diagnosing ASD and although the Indonesian best practice guideline for assessing ASD suggested that practitioners make a referral to other practitioners, the guideline does not clearly explain how that communication between those practitioners should be conducted. This result, however, is similar to Canada and the United Kingdom. A Canadian study found that 75% of cases of ASD were assessed using a single disciplinary approach (Siklos & Kerns, 2007) while other studies have found that a lack of trained specialists in assessing ASD was considered to be the barrier in applying the multidisciplinary approach in Canada (Berenstein, 2012) and the United Kingdom (McClure et al., 2010).

Secondly, in terms of the use of standardized tools, the current study found that some participants used the CARS, which is suggested by Australian best practice guidelines but

none used ADOS or ADI-R, which are suggested by the United Kingdom, Canada, and the United States as gold standard assessment tools. This is likely because the ADOS and ADI-R are not available in Indonesian language and have not been validated with Indonesian children. However, even in the United Kingdom, Canada, and the United States, the use of standardised tools was rare due to unfamiliarity with the tools and a lack of awareness of best practice (Berenstein, 2012; Hering, 2005; McClure et al., 2010; Williams et al., 2009). Furthermore, it was found that the high cost of training and materials as well as the extensive length of the assessment were considered the main reasons for the low use of ADOS and ADI-R (Hering, 2005; Williams et al., 2009).

Thirdly, in terms of applying a multistage system, the present study did not address questions related to multistage system as currently there is no formal screening process that occurs in Indonesia. In the United Kingdom, for example, this brief screen would occur in a routine visit to a general practitioner. The formal regulation published by the Indonesian Health Department requires patients to follow three stages of assessment (general practitioners, specialists, and sub-specialists). Referrals to specialists and sub-specialist practitioners can be made by firstly meeting general practitioners. This regulation, however, is compulsory only for those who use public or private medical insurance. Moreover, the rules mentioned that in terms of emergency situations, natural disasters, special health problems and geographical consideration, the referral system can be disregarded (Indonesian Health Ministry, 2012). In real practice, most patients in Indonesia rarely follow the system and therefore directly meet specialists or sub-specialist medical practitioners for diagnosis (Kancee, 2009). Therefore, the component of best practice (multistage assessment) generally does not occur. This could mean that very early diagnosis is less likely since a parent would need to be aware that there was a problem in order to seek specialist help.

Besides the application of the best practice guidelines, the present study found that having more validated assessment tools in Indonesian language and more professional training in assessing ASD cases were two major needs indicated by most practitioners. The difficulty in locating diagnostic tools in Indonesian language is one of the main reasons indicated by practitioners who did not use these tools and although a majority perceived professional training and assessment tools as important, very few were satisfied with training and tools currently available. This situation is consistent with conditions reported in ASD studies in developing countries such as India, Iran, Mexico, and Pakistan (Daley, 2004; Seif Eldin et al., 2008; Hedley et al., 2010; Samadi & McConkey, 2011).

Furthermore, it is apparent in this study that most of the assessment tools used and listed as standardised tools by participants are only available in English language and have not been validated with an Indonesian sample. It seems that in Indonesia's situation where the availability of validated tools for diagnosing ASD is rare, the practitioners were constrained to use any assessment tools they could afford. This situation, however, is understandable as the Indonesian government provides very limited support and funding for research in the disability area (Irwanto et al., 2010). Studies from developing countries such as Mexico and Iran also confirmed that the availability of validated assessment tools in local language was still rare (Hedley et al., 2010; Samadi & McConkey, 2011).

Additionally, in terms of training, as with many other countries in the world, there is no national accreditation for practitioners to diagnose ASD in Indonesia and there are no formal regulations or guidelines published by the Indonesian Ministry of Health about the eligibility of practitioners who can assess and diagnose ASD cases. However, the present study found that about half of participants received training in ASD either during their clinical practices as part of their educational qualifications or from seminars and workshops. It is important that practitioners equip and then continue to update themselves and that

academic institutions ensure their graduates have the necessary skills and knowledge of ASD. Although the current study also found that there was no difference between trained and untrained practitioners in the number of cases received each month, the number of cases was positively related to age and years of experience of the practitioners. Indonesian parents prefer to have their children diagnosed by older and more experienced practitioners. It might be that older and more experienced practitioners are perceived as having higher skills in assessing ASD, perhaps only because of their age, despite their training background. The current study also found that training has no significant relationship to the use of standardized tools within the assessment procedure which possibly indicates that either the training did not suggest the use of standardised tools in assessing ASD or those practitioners had difficulty in finding the standardised tools suggested by the training.

Conclusions, Recommendations, and Limitations

The present study found that Indonesian practitioners did not apply the three internationally recognized best practice components in the assessment and diagnosis of ASD cases. The use of multistage and multidisciplinary approaches is problematic as Indonesia's health care system is not supportive of this approach. However the use of standardised tools remains challenging as most of the tools suggested are not available in Indonesian language. Furthermore, and importantly, most practitioners endorsed a need for validated tools in Indonesian language and training in assessing ASD.

Providing culturally validated standardized tools in Indonesian language – not merely translating the English version into local language – is fundamental in order to increase the quality of ASD assessment and diagnosis in Indonesia. The translation of any developed country's approach, assessment tools, and guidelines needs to be accompanied by cultural adaptation to the context of developing countries (Daley, 2004; Daley & Sigman, 2002; Samadi & McConkey, 2011). The affordability of the tool is also in need of serious

consideration since the price of the gold standard tools (ADOS and ADI-R) is too expensive for Indonesian practitioners. Therefore, as a response to the finding in the current study, there is an urgent need to culturally validate an Indonesian version of a cost-effective, easy-to-use screening instrument for ASD in young children. Ongoing evaluation of the effectiveness and quality of services provided in Indonesia is also recommended as a basis to gradually improve the current condition. These evaluations might be coordinated by the Indonesian Psychological Association in partnership with the Indonesian Medical Association. Moreover, providing ASD assessment training as part of the curriculum for medical and clinical psychology students as well as to investigate the trainings currently available are also suggested in order to equip future practitioners who will work with ASD cases.

The situation in Indonesia is surprisingly similar to that in many developed countries where the application of best practice is still difficult. The present study suggests that current best practice guidelines need to be re-evaluated in terms of their feasibility and applicability considering that studies from the United States, the United Kingdom, and Canada have also shown how challenging it is to apply best practice standards (Berenstein, 2012; Hering, 2005; McClure et al., 2010; Pearson, 2008; Siklos & Kerns, 2007; Williams et al., 2009).

The current study has a number of limitations that should be considered when evaluating the findings. First, the study consisted of a relatively small sample size. It should be considered, however, that currently, there is no data about the number of Indonesian health practitioners specialized in ASD, which makes it difficult to know whether the number of participants recruited in the present study adequately represents the number of Indonesian practitioners specialized in ASD. Nevertheless, the demographic data showed that the number of ASD cases received by the practitioners each month ranged from 1 to 160 and the number of years in dealing with ASD varied from 1 to 36 years, which means that the present

study included practitioners with a wide range of experience. Moreover, most of the participants (81%) worked in Java, Indonesian's main island where ASD centres are mostly located (Yayasan Autisma Indonesia, 2014). As a response to this limitation, establishing a regularly updated database system of ASD practitioners is highly recommended in order to provide information about the availability of ASD specialists that can be used for further research in Indonesia. This can be arranged through the cooperation of Indonesian Psychological Association, Indonesian Medical Doctor Association, and Therapist Associations.

Second, the current study did not remove any cases with missing data and used pairwise deletion for the analysis to safeguard against low statistical power. One possible explanation regarding the missing data is that the questionnaire was too long and required too much time to complete. In order to avoid substantial missing data, it is suggested that further research use questionnaires with a reduced number of questions and limit the time to a maximum 10 to 15 minutes to complete.

Third, the present study is limited in explaining the reasons behind challenges in applying the best practice guideline and more in-depth qualitative data are needed. Therefore, further research using in-depth interviews or focus group discussions is recommended to enrich the data about Indonesia's practitioners' current situation.

Regardless of these limitations, the present study may reflect the situation of assessment and diagnosis of ASD in urban Indonesia and thus serves as a starting point in understanding conditions in developing countries. This is the first study that has aimed to understand the application of best practice in ASD assessment in a developing country. The findings in this study have filled a gap in our knowledge about Indonesian current situation in the assessment and diagnosis of ASD.

Chapter 4

Autism Detection in Early Childhood (ADEC)

The survey of Indonesian practitioners covered in Chapter 3 found that one of the urgent and crucial needs of Indonesian health practitioners is to have more validated tools in the Indonesian language to aid in the assessment and diagnosis of ASD. Currently, the availability of standardised tools is still lacking, as those available in the Indonesian language have not been validated within an Indonesian sample.

Currently the combination of the Autism Diagnostic Interview-Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) and Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989) have been suggested as the gold standard for assessing and diagnosing ASD cases (de Bildt et al., 2004; Reaven et al., 2008). However, as discussed earlier, the use of ADOS and ADI-R in Indonesia is regarded as being inappropriate -- firstly because they do not exist in the Indonesian language, and secondly, because other studies have shown that, even in developed countries such as the US, UK, and Canada, the use of these tools is very challenging due to time constraints and the high costs associated with their use (Hering, 2005; Williams et al., 2009). There is a need for alternative standardized and validated tools that can be used in developing countries.

Among the measurement tools currently available, Autism Detection in Early Childhood (ADEC; Young, 2007) has been found to be an assessment tool that offers many benefits. The ADEC is an interactive observation tool that can be used to detect ASD in children as young as 12 months (Young, 2007). It consists of 16 tasks delivered in a child-friendly approach. The ADEC possesses positive qualities that make it appropriate for use in developing countries (Hedley et al., 2010; Nah et al., 2014). When compared with other assessment tools such as the ADOS and ADI-R, which require extensive training and are expensive, the ADEC requires less training and is more affordable. Furthermore, studies have

shown that the ADEC has excellent psychometric properties and correlates positively with the ADI-R and ADOS (Nah et al., 2014; Young, 2007). This good correlation between ADEC and gold standard tools makes the ADEC more preferable to be selected in the current research program over other screening tools such as the M-CHAT and GARS. Studies on the M-CHAT regarding its correlations with the ADOS and ADI-R have not yet been conducted while a study by Mazefsky and Oswald (2006) found low correlation between GARS with the ADOS-G and ADI-R. Moreover, Hedley et al. (2010) have argued that the ADEC could be used in developing countries given that they found it to be appropriate for Mexican children. The ADEC may therefore be potentially suitable for use in Indonesia, however, this assumption still requires further evidence, based on empirical work in an Indonesian context.

This chapter provides a detailed and comprehensive description of ADEC. In the first section, the rationale behind the development of ADEC is discussed, followed by a description of ADEC's administration, scoring, and interpretation. Subsequently the psychometric properties of ADEC, and the Spanish version of ADEC (ADEC-SP; Hedley et al., 2010), are presented. Finally, the perceived advantages of ADEC are discussed.

4.1. Rationale behind the Development of ADEC

The ADEC was developed taking a behavioural theoretical approach that is underscored by the principle of objective measurement (Young, 2007). The principle emphasizes that covert behaviours need to be operationalised into observed behaviours in order to be objectively evaluated.

To date, DSM IV-TR and ICD 10 are the most commonly used standardised criteria for diagnosing ASD. DSM IV-TR and ICD 10 list three domains of ASD symptoms: (1) impairment in social interaction; (2) impairment in communication; (3) restricted interests and or repetitive behaviour (APA, 2000; WHO, 2010). Most of the tools currently available for assessing ASD have also been based on DSM IV-TR and ICD 10 criteria. However,

Young et al. (2003) have argued that the criteria used by DSM IV-TR and ICD 10 are difficult to apply to children younger than 36 months, as most of the observed behaviours indicated within the criteria are rarely found in children younger than 36 months. For example, it is difficult to measure a child's ability to form peer relationships, as not every child develops this ability when they are younger than 36 months, although some children as young as 18 months have been recorded as having this ability (Schneider, 2000). Similarly, studies have found that repetitive behaviour in children does not appear until they are aged about three years (Lord, 1995). As a consequence, current diagnostic tools which were developed using these criteria are limited to the diagnosis of ASD in older children (Corsello, Akshoomoff, & Stahmer, 2013). This has prevented many parents from accessing a diagnosis of ASD for their young children (McClure, Mackay, Hamdani, & NcCaughey, 2010; Siklos, Kimberly, & Kerns, 2005). As a result of delayed diagnosis, children with suspected ASD are often unable to receive early intervention treatment which might make a significant difference to their lives and the lives of their family members (Fenske et al., 1985; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014).

The ADEC was developed based on the notion that the characteristics of ASD could be observed in children younger than 3 years (Young, 2007). This can be accomplished by observing the existence of the core deficit-linked behaviours. The core deficit behaviours refer to behaviours that emerge at a very young age as a result of neurological disturbance in children with ASD (Young, Brewer, & Pattison, 2003). In a study by Young, Brewer, and Pattison (2003), parents of 97 children with ASD were asked to indicate the early signs of ASD that first caused them to have concerns about their child's development. The parents were also asked to list the specific ages of their children when they first recognised these early symptoms. Based on the parents' responses, the study identified three domains of core deficit-linked behaviours as follows: (1) disturbances in interacting with others and with

objects; (2) stereotyped, repetitive movements; and (3) bizarre responses to environmental stimuli. Table 4.1 lists the specific behavioural tendencies within each domain.

The 16 tasks in the ADEC are as follows: (1) response to name; (2) Imitation (drum hands on box); (3) Stereotypical behaviour (upset when line of blocks disturbed); (4) Gaze

Table 4.1.
Three Main Domains of Core Deficit-linked Behaviours

Domains	Behavioural tendencies reported by parents
Disturbances in interacting with others and with objects	<ol style="list-style-type: none"> 1. lack of orienting to name 2. deficits in social referencing and sharing attention 3. poor eye gaze behaviour 4. deficits in functional play 5. deficits in pretend play 6. poor imitation of movements 7. poor reciprocity of smiles 8. lack of anticipation of other's social approaches 9. lack of nestling behaviour 10. rare use of gestures
Stereotyped, repetitive movements	<ol style="list-style-type: none"> 1. arranging objects in a line 2. hand-flapping 3. toe-walking 4. finger-flicking 5. rocking 6. other behaviours
Bizarre responses to environmental stimuli	<ol style="list-style-type: none"> 1. covering ears in response to sounds 2. smelling objects or people 3. mouthing objects

Note. Source: Young (2007). Autism Detection in Early Childhood (ADEC) Manual

switching; (5) Eye contact in a game of peek-a-boo (engagement); (6) Functional play (toy phone); (7) Pretend play (pretend phone); (8) Reciprocity of smile; (9) Response to everyday sounds; (10) Gaze monitoring (following point / pointing); (11) Responds to a verbal command; (12) Demonstrates use of words; (13) Anticipatory posture (for being picked up);

(14) Nestling into caregiver; (15) Wave good bye; and (16) Switch from task to task. All of the tasks were developed based on the behavioural tendencies covered in the three domains (Young, 2007). For example, the response to name task (#1 in the manual) was based on the behavioural tendency of a 'lack of orienting in name' while the imitation task (#2 in the manual) was based on the behavioural tendency of 'poor imitation movement'.

Moreover, the sixteen items in the ADEC can be related to impairment in the Theory of Mind and Executive Function abilities as well as sensory abnormalities experienced by people with ASD. The theory of mind ability can be found in tasks that require children's ability to understand social cues and tester's non-verbal expression. These tasks are: imitation (#2), gaze switching (#4), eye contact in a game peek-a-boo (#5), reciprocity of smile (#8), gaze monitoring (#10), anticipatory posture (#13), and waving good bye (#15); The executive function abilities can be found in those tasks that require flexibility, planning and organizing, response to instructions, reasoning, and problem solving. The ADEC tasks that are considered to relate to Executive Function include: response to name (#1), stereotypical behaviour (#3), functional and pretend play (#6 and #7), responds to a verbal command (#11), demonstrates use of words (#12), nestling into caregiver (#15), switch from task to task (#16). Additionally, abnormalities in sensory processing can be seen in stereotypical behaviour (#3), functional play (#6) and the response to everyday sound task (#9).

All of the behavioural tendencies are consistent with the DSM IV-TR criteria for ASD and are consistent with earlier reported findings based with a sample of young children (Baird et al., 2000; Baron-Cohen et al., 1996; Gilberg, 1989; Maestro et al., 2001). For example, the ADEC tasks include gaze switching (#4 in the manual) and pretend play (#7). The gaze switching ability was studied by Charman et al. (1997) who found that early signs of ASD could be evaluated in children as young as 12 months of age by evaluating the child's ability

The ADEC manual is divided into four chapters: Chapter 1, the introductory chapter, that explains the rationale of the ADEC; Chapter 2, the core deficit-linked behaviours covered in the ADEC; Chapter 3, the psychometric data of the ADEC; and Chapter 4, the details of ADEC administration, tasks, and scoring. The manual also contains two case studies and a training DVD. The ADEC training DVD contains a detailed explanation about the ADEC and two simulation videos on how it should be administered while details about scoring are provided in the manual.

Chapter 4 of the ADEC manual also contains the details of the ADEC's administration, scoring, and score interpretation of the 16 tasks that need to be administered to the child (Young, 2007). For the purpose of test administration, the tester provides the materials for the testing and prepares the testing room. Detailed guidelines about the types of toys and materials that are allowed in the test are listed within the manual, as well as the required setting for the testing room. In general, the tester is allowed to use any toys or materials that function in a similar way to those listed in the manual. For example, in the 'pretend play' task (#7 in the manual), the tester selects a piece of foam, holds it to his or her ear and pretends to use it as a telephone. For the foam, the tester is allowed to use any type of block or foam, as long as the block or foam is rectangular in shape.

In relation to 'responding to everyday sounds' task (#9 in the manual), the tester is required to play a CD that contains everyday sounds such as the sounds of a blender, vacuum cleaner, or someone coughing. The CD is provided by the publisher but can be replaced by similar sounds from other resources. In administering ADEC, the tester uses a page of ADEC's scoring form to record the child's responses (Young, 2007). Administration of the test takes, on average, 15 to 30 minutes. All 16 tasks are delivered to the child with the tester free to determine task order. A brief adaptation period (two to three minutes) is also included to build rapport and allow the child time to feel relaxed.

Each task is scored according to the child's responses. A score of zero (0) is recorded when the child responds appropriately, two (2) if the response is not appropriate, and one (1) if the response is not adequate to be scored as either zero or two. For example, in the 'imitation' task (#2 in the manual), the tester gains the child's attention and says, "Do this" while drumming on the top of a box for five seconds. The tester repeats the instruction three times with a five second pause between each trial. A score of zero (appropriate response) is given when the child responds by drumming on the box with both hands within at least one trial. A score of one is given either when the child makes a clear attempt to imitate but is impeded by a lack of motor coordination, or when any spontaneous imitation occurs during testing. A score of two (inappropriate response) is given when the child does not imitate the gesture in any of the three trials (Young, 2007).

4.3. Psychometric Properties of ADEC and ADEC-SP

The ADEC possesses strong psychometric properties. It has good internal consistency (Cronbach $\alpha = .94$), test-retest reliability ($r = .83$) and inter-rater reliability (intra-class correlation, ICC = .83; Young et al., 2007). The ADEC also shows high concurrent validity with the CHAT ($r = .74$) and moderate concurrent validity with the CARS ($r = .57$) (Young, 2007). Correlation between the ADEC total scores and the scores for ADI-R was found to be moderate ($r = .48$; Young, 2007), while the kappa agreement between the ADEC and ADOS was also found to be moderate ($k = .66$; Nah et al., 2014). The ADEC also showed a positive correlation with the ADOS-2 subscales ($r = .60 - .98$; Hedley et al., 2015). The ADEC showed its highest sensitivity (90%) and specificity (93%) within a sample of children aged 14 to 36 months (Hedley et al., 2010; Young, 2007). In a more recent study it was also found that the ADEC showed high sensitivity (93 - 94%) and moderate specificity (62-64%; Hedley et al., 2015).

The ADEC has also shown its applicability in different cultural and language settings. In line with the original ADEC, a Spanish version of ADEC (ADEC-SP; Hedley et al., 2010) also has good psychometric properties. Based on a study that involved 115 Mexican children aged 15 to 73 months, ADEC-SP was found to be valid and reliable in discriminating children with ASD from those without ASD. The ADEC-SP had good internal consistency (Cronbach $\alpha = .73$) and high inter-rater reliability ($r = .96$ for sample 1 and $.81$ for sample 2). It also showed moderate concurrent validity with ADI-R (Cohen's kappa = $.66$ for sample 1 and $.71$ for sample 2; Hedley et al., 2010). A recent study by Nah et al. (2014) also found that, in line with the CARS, the ADEC is effective when used as a screening tool to predict long-term outcomes in children with ASD. The study found that the ADEC total score had good predictive accuracy for both two and six year follow-up assessments.

4.4. The Advantages of the ADEC

In addition to having strong psychometric properties, ADEC offers other advantages that potentially make it more appropriate for use by health practitioners in developing countries. First, ADEC is more affordable than the gold standard assessment tools suggested by the four developed countries' best practice guidelines. The complete package of the ADOS-2 is available at AUD\$3,195 and the ADI-R costs AUD\$414.95 (Australian Council for Educational Research, 2012). A package of the ADEC consisting of manual and scoring sheets (10 pieces per package) costs AUD\$242.89 (Australian Council for Educational Research, 2012). Buying the testing toys or materials is not compulsory, as a tester is permitted to provide toys and materials for administration (Hedley et al., 2010; Young, 2007).

Second, while the ADOS-2 and ADI-R require costly and extensive training (AUD\$1,700 and AUD\$1,650, respectively), (Australian Council of Educational Research, 2012), ADEC provides more opportunities for health practitioners, especially those who are located in rural areas where access and funding for training is limited -- the ADEC manual is

equipped with a training DVD. The ADEC is less time consuming to deliver than the ADOS and ADI-R. While the administration of the ADOS requires 45 minutes and ADI- R is 120 minutes (Nah et al., 2014), the average time required to administer ADEC ranges from 15 to 30 minutes.

Third, ADEC is not limited to the diagnosis of ASD in children, but can also be used to design intervention programs (Hedley et al., 2010). Behaviour which is found to be absent or an inappropriate response in the test can later be included as targeted behaviours within an intervention. For example, if a child responds inappropriately to the 'joint attention' task, the tester can then recommend intervention programs that aim to increase the child's joint attention skill.

Fourth, ADEC is also considered to be more culture free than the gold standard assessment tools as most behaviours tested in the ADEC are non-verbal and the tester is allowed to provide toys or materials that are familiar within the child's cultural context (Hedley et al., 2010). For example, in the 'gaze switching' task (# 10), in order to elicit the child's excited behaviour, the tester needs to place a toy in front of the child. For this task, the ADEC manual recommends the use of toys such as the Wiggly Giggly Ball or Jack in the Box (Young, 2007). However, for testers who are located in areas or countries where these toys are rarely available, any cultural toy that can elicit the child's excitement behaviour is allowed. For example, for Indonesian children who live in rural areas, a traditional wooden toy called '*kereketan bambu*' (shown in Figure 4.2) can be used, as it produces a loud sound that can elicit excitement behaviour from the child.

Fifth, a study in Mexico suggested that the ADEC-SP can be used for level 2 assessments in Mexico, in locations where the availability of trained health practitioners for diagnosing ASD is insufficient (Hedley et al., 2010). The purpose of the level 2 assessment

is to evaluate children who have been identified as at-risk for developmental disabilities, as well as to separate children with ASD from those with other disabilities (Filipek et al., 1999).



Figure 4.2. Kereketan Bambu

The suggested use of ADEC-SP for the level 2 assessment opens up the possibility of using the ADEC in other developing countries that also experience shortages in accommodating the needs of specialists, services, programs and funding in the ASD area, such as in Indonesia. However, as previously mentioned evaluation is needed to ensure that an Indonesian version of ADEC will be valid and appropriate within the country's culture and circumstances. This is crucial when considering that, although Indonesia is similar to Mexico in terms of being developing countries, the two countries differ in terms of culture, languages, and ethnicities.

In conclusion, the ADEC was developed based on the principle that ASD can be detected earlier by observing the core deficit-linked behaviours in young children. This principle is drawn from the theoretical perspective of behaviourism that operates within a context of objective measurement. Although more studies on the effectiveness of ADEC are needed, current studies have found the ADEC to be an effective screening and assessment tool for ASD. ADEC offers good psychometric properties and was found to be more affordable, required less training and less time to administer when compared to the gold standard assessment tools. Initial testing of ADEC in a developing non-English speaking

country (Mexico) has shown that its psychometric properties hold and can assist in developing an intervention plan. These benefits suggest that the ADEC may be considered as an appropriate tool for use by ASD specialists in Indonesia where funding, resources and government support for ASD are still very limited. Therefore, in order to respond to the needs of ASD specialists in Indonesia of having more assessment tools for diagnosing ASD, the ADEC was translated into Indonesian language and pilot-tested with eight Indonesian children in Brisbane and Melbourne. Subsequently, following the translation and pilot study, the ADEC-IND was tested with a sample of 82 Indonesian children in five cities in Indonesia. The details of the translation process and the pilot study are covered in Chapter 5, while the main study is detailed in Chapter 6.

Chapter 5

The Translation of the ADEC and Pilot Study

This chapter describes the process of producing the Indonesian version of the ADEC. This includes translating the ADEC into the Bahasa Indonesian language and a pilot study with eight Indonesian children living in Australia. The first part of this chapter covers the translation process of the ADEC, while the details of the pilot study are outlined in the second part. The translation and adaptation of the ADEC into an Indonesian language version follows the guidelines within the International Test Commission Guidelines for Translating and Adapting Tests (International Test Commission, 2005).

5.1. The Translation of the ADEC

Initially, Chapter 4 of the ADEC manual (pages 24–28) and the case studies section (pages 44–45) as well as the ADEC scoring form (a one page form separated from the manual) were translated by a bilingual Indonesian clinical psychologist (PhD candidate FS: referred to as ‘translator’ within this section). Specifically, the fourth chapter consists of the details relating to test materials, testing rooms, scoring guide and interpretation, suggested testing sequence, adaptation period, and 16 ADEC tasks and scoring.

Next, this translated first draft was independently reviewed by two Indonesian bilingual researchers. The first reviewer had a master’s degree in Linguistics and the second had a master’s degree in Developmental Psychology. A meeting involving the reviewers and the translator was then held to discuss the reviewers' comments and feedback. In order to preserve the original meaning of the English version, amendments to terms used in the translated version were suggested by the reviewers, based on the use of *The Great Dictionary of the Indonesian Language of the Language Center* (Departemen Pendidikan Nasional, 2008). For example, the term ‘arch back’ (#14 in the manual) was difficult to translate, as there is no specific term or phrase for this in the Indonesian language. In the discussion, the

reviewers and the translator agreed on the use of the Indonesian terms '*menegangkan punggung*' as they were regarded as adequately representing the term 'arch back'. In English, this term is literally translated as 'back stretching'.

The reviewers also suggested amendments in the structure of some sentences in order to translate the original version, following the correct Indonesian language structure (grammar). This ensured that the translated sentences were arranged with an appropriate Indonesian structure. After the discussion, the first draft of the ADEC-IND was revised and a second draft was produced. The second draft was tested in the pilot study. The second draft was also back translated back into English by a bilingual Indonesian tutor who had a master's degree in Psychology.

5.2. The Pilot Study of the ADEC-IND

The pilot study aimed to ensure that the ADEC-IND draft conveyed the same content and meaning as the original version, so that the same behaviours could be evaluated. It was also planned to identify any logistical problems and determine whether other resources, such as additional staff, funds or tools, would be required for the larger scale study.

5.2.1. Participants

This pilot study obtained approval no. 2012000726 from the human ethics committee of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. The participants were eight Indonesian children aged between 15 and 54 months ($M = 31.8$ months, $SD = 11.36$). Table 5.1 lists the details of the children who participated in the pilot study. The recruitment of the children was undertaken by a research assistant and details of their autism diagnosis were not revealed to the assessor. The participants were selected based on the use of an Indonesian student mailing list and by verbal recommendations. Parents who were interested in participation in the study were contacted by the research assistant who then gave a detailed explanation to parents about the

study. Parents who agreed to participate were then asked to sign an informed consent form and complete a one-page questionnaire about their child's demographic details and developmental history. The research assistant then classified the participants based on information provided by the parents, either through the use of a questionnaire or by direct communication using email or phone.

As indicated in Table 5.1, only one participant had a previous diagnosis of ASD while the other seven were classified as typically developing children. Initially, the recruitment was not successful in finding any young Indonesian children diagnosed with ASD in Brisbane. However, through word-of-mouth, the research assistant became aware of an Indonesian couple who had a child diagnosed with ASD who was located in Melbourne. The research assistant then contacted the parents of the child and asked them to participate in the study. In order to avoid any potential bias in the tests, the research assistant recruited a further two participants in Melbourne to ensure that the assessor was not aware of which recruit was specifically diagnosed with ASD.

Table 5.1
Details of Pilot Study Participants

Participants	Gender	Age (months)	Condition prior to testing	ADEC-IND Scores	Testing location
1	Female	31	TD	9	Brisbane
2	Female	15	TD	8	Brisbane
3	Male	36	TD	7	Brisbane
4	Female	32	TD	8	Brisbane
5	Male	30	TD	8	Brisbane
6	Male	22	TD	7	Melbourne
7	Female	35	TD	5	Melbourne
8	Male	54	ASD	17	Melbourne

5.2.2. Procedures

In the pilot study, each participant was tested using the ADEC-IND and the parents were interviewed using the ADI-R. The assessor conducted both the child's assessment and the interview of the parent. The testing sessions were videotaped by the research assistant and the interviews were audio-recorded. Each participant's video was then given English subtitles using the Window Movie Maker software, by two bilingual Indonesian undergraduate students working independently. The subtitled videos were reviewed by the translator and a senior clinical psychologist to ensure that the ADEC-IND was administered correctly.

A one-page report was also distributed to each participant approximately one month after the testing. The report contained a summary of information about the child's testing result. The report did not specifically report whether the child was diagnosed as having ASD or not having ASD, but only indicated any symptoms of ASD identified in the assessment.

5.2.3. Results

The pilot study aimed to test the translated version of the ADEC as well as to identify any possible obstacles, before undertaking a further study with a large scale sample. The pilot study found that no further revision was needed of the second draft of the ADEC-IND. In relation to the preparation for the main study, the pilot study provided an understanding of the process of recruiting and scheduling the participants, administering the participants using the ADEC-IND, managing and analysing the data, and delivering the reports to the parents. In terms of the ADEC-IND administration, the current study also aimed to ensure that the language used in the instruction was clearly understood by the participants.

5.2.3.1. The final Indonesian version of ADEC

In terms of evaluating the translated version of the ADEC, the present pilot study suggested that the ADEC-IND required no further amendments, as the instructions, scoring

guides, and scoring form, were found to be satisfactory. The instructions were easily understood by the children and no difficulties were experienced with the scoring. Therefore, the ADEC-IND draft was considered to be ready for use in the larger scale study to be conducted in Indonesia. Table 5.2 shows the results of the comparison of the original English version of ADEC, the final Indonesian version, and the English back translation.

Some differences between the original and the back-translation versions were identified. Most of the differences reflected that some of the original terms needed to be translated into different terms in the Indonesian language, in order to make them more contextually appropriate. The following differences were identified between the original and back-translation versions: (1) In the response to name task (#1 in the manual), the term ‘emphatically’ is translated into the Indonesian language as ‘ramah’, which can be translated as ‘cordially’, ‘kindly’, or ‘friendly’, given that in the Indonesian language the term ‘emphatically’ is inappropriate for use in a context of interacting with a child; (2) In the stereotypical behaviour task (#3), the term ‘disturbed’ is translated into the term ‘diubah’ (which means ‘changed’ in English), because in the Indonesian language the term ‘disturbed’ is not a term commonly used in a context of ‘disorganizing a toy’. Therefore, the term ‘diubah’ is used as it is considered to be more contextually appropriate in the Indonesian language; (3) In ‘the pretend play task’ (#7), the term ‘imaginary’ has the same meaning as ‘khayalan’ in Indonesian (meaning ‘pretend’ in English); (4) In the reciprocity to smile task (#8), the term ‘immediate’ can be translated into ‘dengan segera’ (meaning ‘immediately’ in English); however, the terms are not structurally appropriate when placed in a sentence. Therefore, the term ‘spontan’ (meaning ‘spontaneous’ in English) is used in order to describe the concept of ‘immediate’, considering that the term ‘spontan’ does not change the meaning of the term ‘immediate’ and is suitable for use in a sentence; (5) In the response of everyday sounds task (#9), the term ‘everyday sounds’ can be literally translated into Indonesian as

Table 5.2
The Comparison of ADEC's Original Version, ADEC-IND, and ADEC-IND's Back-translation

Item	English	Indonesian	Back translation	
1	Task	Response to name	Respon terhadap nama	Response towards name
	Information	Child turns to look at tester's face when his/her name is called	Anak menoleh ke arah wajah pemeriksa saat nama anak dipanggil.	Child turns his/her head to look at the tester's face when the child's name is called.
	Materials	None. Child must be free from distractions and not interacting with the caregiver.	Tidak ada. Anak harus bebas dari segala gangguan dan tidak sedang berinteraksi dengan pengasuh.	None. Child needs to be free from distractions and must not be interacting with the caregiver
	Procedure	Tester positions self in relation to the child so that the child must turn their head 90 degrees in order to look at tester.	Pemeriksa memposisikan diri sedemikian rupa sehingga anak harus memutar kepalanya 90 derajat agar dapat melihat pemeriksa.	Tester positions himself/herself in such a way that a child needs to turn his/her head 90 degrees to be able to have a look at the tester.
		Tester calls child's name clearly and emphatically, pausing for 5 seconds in between name-calls, until child turns to look or until a maximum number of 5 calls is reached.	Pemeriksa memanggil nama anak dengan jelas dan ramah, memberi jeda selama 5 detik setelah panggilan nama tersebut, sampai anak menoleh untuk melihat atau sampai maksimum 5 kali panggilan.	Tester calls the child's name clearly and cordially / kindly / friendly, giving 5 seconds pause after calling the name, until the child turns to look or until 5 maximum calls.
	Trials	Maximum of 5 (activity ceases once head turn in response to name is achieved), with 5 second pause between trials.	Maksimal 5 kali (kegiatan dihentikan saat anak menoleh untuk merespon panggilan), dengan 5 detik jeda antar panggilan nama.	Maximum 5 times (activity ends when child turns to respond to the call), with 5 seconds pause between name calls.
	Response time	5 seconds (i.e. the length of the pause between trials)	5 detik (yaitu: jarak waktu dari jeda antar percobaan)	5 seconds (that is: time period from pause between trials)

(Table continued overpage)

2	Task	Imitation (drum hands on box)	Meniru (menabuh kotak)	Imitating (beating / banging / drumming the box)
	Information	The wall, floor or furniture can be substituted if convenient. The intention is that the child copies physical gestures demonstrated by tester.	Kotak dapat diganti dengan tembok, lantai atau perabot jika diperlukan. Tujuan yang ingin dicapai adalah agar anak meniru gerak yang didemonstrasikan oleh pemeriksa.	Box can be substituted with wall, floor, or furniture if needed. The aim is to have the child imitate the physical movement demonstrated by the tester.
	Materials	the box in which the ADEC items are stored	Kotak tempat menyimpan material ADEC-IND.	Storage box for ADEC-IND material.
	Procedure	place box in between tester and child on the floor. Tester gets child's attention and says "Do this" while drumming on the top of the box with their hands for 5 seconds. No other verbal instruction or direction is given, and words relating to the target action must not be used, eg. "drum".	Tempatkan kotak di lantai, posisikan di antara pemeriksa dan anak. Pemeriksa menarik perhatian anak dan mengatakan, 'Lakukan ini' sambil menabuh bagian atas kotak dengan kedua tangan selama 5 detik. Tidak ada instruksi verbal atau arahan lain yang diberikan, dan kata-kata yang berhubungan dengan perilaku target tidak boleh digunakan, misalnya: 'tabuh'.	Place box on the floor, position it between the tester and child. Tester draws the child's attention and says 'Do this' while beating / banging / drumming the top side of the box with both hands for 5 seconds. No other verbal instruction or guidance should be provided, and words related to the target behavior should not be used (for example, "beat/ bang / drum").
	Trials	3, with a 5-second pause between trials.	3 kali, dengan 5 detik jeda antar percobaan	3 times, with 5 seconds pause between trials
	Response time	5-seconds (i.e. the pause between trials).	5 detik (yaitu : lama jeda antar percobaan)	5 seconds (that is: period of pause between trials)
3	Task	Stereotypical Behaviour (upset when line of blocks disturbed)	Perilaku stereotipi (kesal saat deretan balok diubah)	Stereotypical behaviour (upset when line of blocks is changed)
	Information	Child becomes upset when the tester disturbs a line of blocks.	Anak menjadi kesal saat pemeriksa mengacaukan deretan balok.	Child becomes upset when the tester messes up a line of blocks.

(Table continued overpage)

	Materials	plastic blocks, such as the Stack and Nest Cubes	Balok-balok plastik, seperti the Stack and Nest Cubes.	Plastic blocks, such as the Stack and Nest Cubes
	Procedure	Tester takes blocks and arranges them in a line on floor/table in front of the child, also in reach of the child. Having lined them up, the tester then destroys the alignment by pushing the blocks in a variety of directions, out of the line.	Pemeriksa mengambil dan menderetkan sejumlah balok di atas lantai atau meja di depan anak, dalam posisi yang dapat dijangkaunya. Setelah selesai menderetkan, pemeriksa kemudian mengacaukan deretan balok dengan cara menggeser balok-balok tersebut ke berbagai arah, sehingga keluar dari deretan.	Tester takes out blocks and puts them in a set row on the floor or table in front of a child, in a position that can be reached. Next, tester will then mess up the line of blocks by moving them in random directions until they are no longer set neatly in a row.
	Trials	3, with a 5-second pause between trials (cease this item if the child is upset).	3 kali, dengan 5 detik jeda antar percobaan (hentikan tugas ini bila anak kecewa)	3 times, with 5 seconds pause between trials (end this task if child is upset)
	Response time	5 seconds (i.e. the 5 second pause between trials).	5 detik (yaitu: lama jeda antar percobaan)	5 seconds (that is: length of pause between trials)
4	Task	Gaze switching	Mengalihkan pandangan	Diverting/switching gaze/view
	Information	child shows an attempt to engage the caregiver's and/or tester's attention to object/event	Anak mencoba menarik perhatian pengasuh dan / atau pemeriksa untuk melihat ke arah benda atau kejadian.	Child tries to draw attention from the caregiver and/or the tester to look at an object or event.
	Materials	A toy, which elicits a startle response or surprises the child, such as Jack in the Box, or the Wiggly Giggly Ball.	Sebuah mainan, yang membuat anak heran atau terkejut, semacam Jack in the Box, atau the Wiggly Giggly Ball.	A toy that may surprise the child or left him/her wondering, like a Jack in the Box or the Wiggly Giggly Ball.
	Procedure	A toy is placed in front of the child who is positioned so that he/she can see tester and caregiver only by a significant turn of head (90 degrees). Tester activates toy.	Sebuah mainan ditempatkan di depan anak, anak ditempatkan pada posisi dimana ia perlu memutar kepalanya (90 derajat) untuk melihat pemeriksa dan pengasuh. Pemeriksa kemudian menyalakan mainan.	A toy is placed in front of the child, child is positioned in such a way that he/she needs to turn his/her head (90 degrees) to see the tester and caregiver. Tester then activates the toy

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		(Remind caregiver not to point to toy, vocalise, or in any way try to direct child's attention to the toy.)	(Ingatkan pengasuh untuk tidak menunjuk mainan, bersuara, atau dengan cara apapun mencoba untuk mengarahkan perhatian anak ke mainan).	(Remind caregiver to not point at the toy, make a noise, or draw the child's attention to the toy in any way).
	Trials	1	1 kali	1 time
	Response time	10 seconds: the 5 seconds in which the toy is active, and the 5 seconds following the cessation of the toy's movement	10 detik : 5 detik saat mainan menyala dan 5 detik berikutnya setelah mainan berhenti bergerak.	10 seconds : 5 seconds when the toy is activated and the next 5 seconds after the toy stops
5	Task	Eye contact in a game of Peek-a-boo (engagement)	Kontak mata dalam permainan cilukba (keterlibatan)	Eye contact in peek-a-boo (involvement)
	Information	child looks into tester's eyes during a game of peek-a-boo	Anak menatap mata pemeriksa selama bermain cilukba.	Child looks at the eye of the tester when playing peek-a-boo.
	Materials	Face flannel	Kain flanel	Flannel sheet.
	Procedure	Tester engages in a game of peek-a-boo. Five trials in which tester holds cloth in front of their face and pops out from behind it. There is a 3-second pause between trials during which tester's face is hidden by the cloth.	Pemeriksa mengajak anak bermain cilukba. 5 kali percobaan. Pemeriksa memegang kain di depan wajahnya dan tiba-tiba memunculkan wajah dari balik kain. Terdapat waktu jeda 3 detik antar percobaan yaitu selama wajah pemeriksa disembunyikan di balik kain.	Tester asks child to play peek-a-boo. 5 trials. Tester holds the sheet in front of his/her face and suddenly reveals his/her face from behind the sheet. There is a 3 seconds pause between trials that is during the period when the tester hides his/her face behind the sheet.
	Trials	5	5 kali	5 times
	Response time	-	-	-

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6	Task	Functional play (toy telephone)	Permainan fungsional (telepon mainan)	Functional play (toy telephone)
	Information	Play using toy as the way it is intended.	Memainkan mainan sesuai fungsinya.	Playing a toy according to its function
	Materials	Toy telephone shaped like a car, with wheels	Telepon mainan yang menyerupai mobil, memiliki roda.	Toy telephone that looks like a car, has wheels.
	Procedure	Toy telephone-car is presented to child for a 60 second period.	Telepon-mobil mainan diperlihatkan kepada anak selama 60 detik.	Toy telephone-car is shown to the child for 60 seconds.
	Trials	1	1 kali.	1 time.
	Response time	60 seconds (the time in which the child is allowed to play with the toy).	60 detik (waktu dimana anak dibiarkan bermain dengan mainan)	60 seconds (period when child is left to play with toy)
7	Task	Pretend play (pretend phone)	Permainan pura-pura (telepon khayalan)	Pretend play (imaginary phone)
	Information	Child uses an object as if it is another object, or attributes properties to an object that it does not have.	Anak menggunakan obyek seolah-olah sebagai benda yang lain, atau memberikan sifat atau fungsi terhadap suatu benda yang sebenarnya tidak memiliki sifat atau fungsi tersebut.	Child uses object as if it is another thing, or assigns attribute or function to an object that in reality is not possessed by the object.
	Materials	rectangular piece of yellow foam, or block	Busa berwarna kuning yang berbentuk persegi panjang, atau balok	A rectangular or a block of yellow foam.
	Procedure	Tester picks up the piece of foam and holds it horizontally to their ear. Says in animated tone, "Hello (pause). Oh, you'd like to speak to _____? Here he/she is", passes the piece of foam to child as if it is the telephone receiver. Says: "Here, _____, it's for you. Have a talk on the phone."	Pemeriksa mengambil busa dan memegangnya secara horisontal di telinga. Ucapkan dengan nada yang ceria, 'Halo (jeda). Oh, kamu ingin bicara dengan _____? Ini dia', memberikan busa tersebut pada anak seolah-olah gagang telepon. Katakan, 'Ini, _____, ini untuk kamu. Ayo bicara di telepon.'	Tester takes the foam and holds in horizontally near the ear. Say cheerfully the following, "Hello (pause). Oh, you want to talk to _____? Here he/she is!", then give the foam to the child as if it's a phone handle. Say, "Here, _____, this is for you. Come speak on the phone".

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	Trials	1	1 kali.	1 time.
	Response time	5 seconds	5 detik	5 seconds
8	Task	Reciprocity of a smile	Membalas senyuman	Responding to smiles
	Information	Child responds to the smile of the tester or caregiver by smiling in return.	Anak merespon senyuman pemeriksa atau pengasuh dengan cara membalas senyuman.	Child responds to a smile given by tester or caregiver by smiling back.
	Materials	None	Tidak ada	None
	Procedure	Tester positions self facing the child. Tester obtains the child's attention by calling his/her name or any other verbal means, then smiles enthusiastically at the child, tester may ask the child to smile or talk to the child, saying "_____ are you going to smile at me? ...Come on, give us a smile" in a warm encouraging manner.	Pemeriksa memposisikan diri berhadapan muka dengan anak. Pemeriksa menarik perhatian anak dengan cara memanggil nama anak atau dengan kata-kata lain, kemudian tersenyum antusias pada anak. Pemeriksa dapat meminta anak untuk tersenyum atau berkata pada anak, '_____ apakah kamu akan tersenyum padaku? ...Ayo, tersenyumlah.', dengan sikap yang mendorong dan hangat.	Tester positions himself/herself facing towards the child. The tester then draws attention to the child by calling the child's name or with other words, and then enthusiastically smiles to the child. The tester can ask the child to smile or say "_____ will you smile for me? Come on, smile." with a warm and encouraging demeanor.
	Trials	5 with 5 second pause between trials	5 kali, dengan 5 detik jeda antar percobaan.	5 times, with 5 seconds pause between trials
	Response time	Immediate response is scored	Berikan skor terhadap respon yang dilakukan secara spontan.	Give a score for spontaneous behaviour
9	Task	Response to everyday sounds	Menunjukkan respon terhadap suara yang biasa didengar	Responding to familiar voice
	Information	Child demonstrates an unusually adverse reaction to familiar household sounds.	Anak memperlihatkan reaksi terganggu saat mendengar suara-suara yang biasa didengar di rumah.	Child displays disturbed behaviour when hearing familiar voices usually heard at home.

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Materials	CD player, ADEC Stimulus Materials CD of sounds.	CD player, CD berisi suara-suara dari Perangkat ADEC-IND.	CD player, CD containing voices from ADEC-IND instrument.
Procedure	First check with caregiver whether any of the 5 sounds (a baby crying, a vacuum cleaner, loud bang, blender and a person coughing) are likely to really upset the child. If so, this sound is not played and a score of 2 is awarded.	Sebelumnya pemeriksa menanyakan kepada pengasuh apakah kelima suara (tangisan bayi, suara penyedot debu, suara keras, blender dan suara orang batuk) biasanya membuat anak sangat terganggu atau kesal. Jika benar demikian, suara tersebut tidak diputar dan berikan skor 2.	Initially, tester asks the caregiver if the five voices (a baby's cry, vacuum cleaner noise, loud voice, blender and coughing sound) usually make the child very upset or annoyed. If so, such voice is not played and given a score 2.
	CD player plays range of everyday, household sounds	CD player memperdengarkan suara-suara yang biasa didengar sehari-hari di rumah.	The CD player plays voices that are usually heard at home
Trials	1	1 kali	1 time
Response time	5 seconds	5 detik	5 seconds
10 Task	Gaze monitoring (following point / pointing)	Menatap untuk memantau (melihat ke arah yang ditunjuk / menunjuk)	Gazing to monitor (looking to see a pointed direction/pointing)
Information	Either (a) child follows tester's point or gaze by turning their head to look in the same direction in which the tester is looking or (b) child imitates pointing behaviour or shows spontaneous use of pointing behaviour.	Kedua hal ini ditunjukkan: (a) anak mengikuti atau menatap sesuatu yang ditunjuk oleh pemeriksa dengan cara menolehkan kepalanya untuk melihat ke arah yang sama yang sedang dilihat oleh pemeriksa atau (b) anak meniru perilaku menunjuk atau secara spontan memperlihatkan perilaku menunjuk.	These two things are shown by: (a) child follows or looks at something pointed at by the tester by turning his/her head to look at the same direction the tester is currently looking at or (b) child imitates pointing behaviour or spontaneously displays pointing behaviour.
Materials	None	tidak ada	None

(Table continued overpage)

	Procedure	Position child so that a head turn of 90 degrees is required to look at his/her caregiver. Using an excited, animated tone, the tester points and looks across the room and says, 'Oh look ____, is that your mummy (daddy) over there? Is that mummy?' or can you show me '.....' or where is '.....?' (tester points to something in the room)	Posisikan anak sedemikian rupa sehingga anak perlu menoleh 90 derajat untuk dapat melihat pengasuhnya. Dengan nada yang bersemangat dan riang, pemeriksa menunjuk dan melihat ke seberang ruangan dan berkata, 'Wah lihat ____, apakah yang di sana itu ibu(ayah)? Apakah itu ibu?' atau coba perlihatkan '.....' atau 'dimana?' (pemeriksa menunjuk ke suatu benda dalam ruangan).	Position the child in such a way that requires the child to turn 90 degrees to be able to look at the caregiver. With a happy and enthusiastic tone, tester points and looks at the other side of the room and says "Wow, look ____, is that mum(dad?) Is that mum?" or try to show '.....' or 'where is?' (tester points at an object in the room).
	Trials	1	1 kali	1 time
	Response time	5 seconds	5 detik	5 seconds
11	Task	Responds to verbal command	Mengikuti perintah lisan	Following verbal command
	Information	child responds to caregiver's verbal command.	Anak mengikuti perintah lisan dari pengasuhnya pemeriksa.	Child follows verbal command from the caregiver/tester
	Materials	None	Tidak ada	None
	Procedure	Ask caregiver whether the child responds to any verbal commands, such as 'come here' or 'clap hands.' If the response is 'no', a score of 2 is awarded. If the response is 'yes', ask the caregiver to identify one verbal command that the child can respond to. Then ask caregiver to demonstrate by using the command, without any accompanying gestures. Say to caregiver, 'Can you demonstrate how ____ responds to that command?	Tanyakan pengasuh apakah anak biasa mengikuti perintah lisan, misalnya 'ayo kemari' atau 'tepuk tangan'. Kalau 'tidak', berikan skor 2. Bila 'ya', minta pengasuh untuk mengidentifikasi satu perintah verbal yang dapat dilakukan anak. Kemudian mintalah pengasuh untuk menggunakan perintah tersebut, tanpa disertai gerakan tubuh. Katakan pada pengasuh, "Dapatkan anda memperlihatkan bagaimana ____ berespon terhadap perintah itu?"	Ask the caregiver if the child is used to follow verbal command, such as 'come here', or 'clap your hands'. If 'not', give a score of '2'. If 'yes' ask the caregiver to identify one verbal command that the child can do. Afterwards, ask the caregiver to make the command without any body movement without giving any physical movements / cues. Tell the caregiver, "Can you show how ____ responds to that command?"

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	First, get ____'s attention. Then, give the command but don't use any gestures, just the verbal command."	Pertama, coba tarik perhatian ____ . Kemudian berikan perintah tersebut, namun jangan menggunakan gerakan tubuh apapun, hanya perintah lisan."	First, draw ____'s attention. Then, give the command but do not use any body movements at all, only verbal command".
	If child has clearly responded to a number of commands prior to this, there is no need to get the parent/care-giver involved.	Pemeriksa tidak perlu melibatkan pengasuh jika anak dapat secara jelas meresponi sejumlah perintah.	Tester may not involve the caregiver if child can clearly respond to a number of commands.
Trials	1	1 kali	1 time
Response time	-	-	-
12 Task Information	Demonstrates use of words -	Mendemonstrasikan penggunaan kata -	Demonstrating use of words -
Materials	None	Tidak ada	None
Procedure	If the child has not used any words during the testing period, ask the caregiver whether the child uses any words, such as 'no' or 'mummy' but not made-up words. If the response is 'no', a score of 2 is awarded. If the response is 'yes', ask the caregiver to give examples of the words the child can use. Then ask caregiver to try to elicit a word or words from the child, but ask them not to get the child to copy (i.e., do not say, 'Can you say mummy'" but rather, 'Who's this?'	Bila anak tidak mengucapkan kata apapun selama tes berlangsung, tanyakan kepada pengasuh apakah anak mengucapkan kata-kata seperti 'tidak' atau 'mama' namun bukan kata-kata buatannya sendiri. Jika jawaban pengasuh adalah 'tidak', berikan skor 2. Jika 'ya', tanyakan pengasuh untuk memberi contoh kata apa yang anak dapat ucapkan. Kemudian minta pengasuh untuk mencoba mendorong anak menyebutkan satu kata atau lebih, namun jangan sampai anak meniru kata tersebut. (yaitu: jangan katakan, 'bisakah kamu bilang "mama" namun lebih baik tanyakan, 'siapa ini?')	If child does not say any word during the test, ask the caregiver if the child says words like 'yes' or 'mama' but not made-up words. If the caregiver says 'no', give a score of 2. If 'yes', ask caregiver to give an example of words that can be said by the child. Then, ask the caregiver to encourage the child to say one or more words, but don't ask the child to imitate the word (that is: do not say, 'can you say "mama"?' but rather ask "who is this?").

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	Trials	1	1 kali	1 time
	Response time	-	-	-
13	Task Information	Anticipatory posture for being picked up Child assumes appropriate posture (raising arms and/or elbows making armpit/s available) when caregiver approaches them to lift them up.	Postur siap (untuk digendong) Anak menunjukkan postur siap (mengangkat dan menaikkan kedua lengannya dan / atau sikunya sehingga ketiaknya tampak terbuka) ketika pemeriksa mendekati untuk menggendong anak.	Ready posture (to be picked up) Child shows ready posture (lifts and raises both arms and/or elbow so the armpits are clearly seen or seen to be open/seen clearly) when tester moves in close to pick the child up.
	Materials	None	Tidak ada	None
	Procedure	Ask caregiver to approach child as if they are about to pick him/her up but to pause before doing so, to see whether the child responds. Caregiver stands in front of child who is seated on floor. Caregiver bends towards the child and stretches arms toward the child's armpits (if no response from child initially, caregiver may clap hands to get child's attention)	Minta pengasuh untuk mendekati anak dan berbuat seolah-olah ingin menggendong anak namun berhenti sejenak sebelum melakukan hal tersebut, untuk melihat apakah anak memberi respon. Pengasuh berdiri di depan anak yang diposisikan duduk di lantai. Pengasuh membungkuk ke arah anak dan membentangkan kedua lengannya ke arah ketiak anak (bila anak tidak segera merespon, pengasuh dapat bertepuk tangan untuk menarik perhatian anak).	Ask caregiver to get close to the child and do as if the child will be picked up but pause a bit before doing it, to see if the child responds. Caregiver stands in front of the child positioned to be sitting on the floor. Caregiver bends to the direction of the child and spreads / Expands his/her hands to the child's armpits (if the child does not immediately respond, caregiver can clap to draw the child's attention).
	Trials	1	1 kali	1 time
	Response time	-	-	-

(Table continued overpage)

14	Task	Nestling into caregiver	Mendekapkan diri pada pengasuh	Hugging / cuddling / snuggling the caregiver
	Information	Child nestles into caregiver's body when held/picked up.	Anak mendekap pengasuh saat digendong / diangkat.	Child hugs / cuddles/ snuggles to the caregiver while being held/lifted up.
	Materials	None	tidak ada	None
	Procedure	This item may be conducted/ observed at the start of the session, if the caregiver is holding the child as the tester enters the room, or at any point during the testing session when the caregiver is holding the child.	Tugas ini dapat diberikan / diamati di awal sesi pemeriksaan, bila pengasuh sedang memegang anak saat pemeriksa memasuki ruangan, atau kapan saja selama sesi pemeriksaan ketika pengasuh sedang memegang anak.	This task can be given / observed in the beginning of the testing session, when the caregiver is holding the child when the tester enters the room, or at any time during the testing session when the caregiver is holding the child.
	Trials	1	1 kali	1 time
	Response time	5 seconds	5 detik	5 seconds
15	Task	Use of gestures (wave goodbye)	Menggunakan gerakan tubuh (melambaikan tangan saat berpisah)	Using body movement (waving goodbye when parting)
	Information	Child spontaneously (without prompting) waves goodbye	Anak secara spontan (tanpa diarahkan) melambaikan tangan saat akan berpisah.	Child spontaneously (without being directed) waves goodbye when parting.
	Materials	The box full of the ADEC materials, packed up ready to go	kotak penuh perlengkapan ADEC-IND yang sudah diringkas siap untuk dibawa	Box full of ADEC-IND tools / materials that is packed and ready to be taken away
	Procedure	Say to caregiver: 'I want to see if ____ waves goodbye to me without being prompted.	Katakan pada pengasuh,'saya ingin melihat apakah ____ melambaikan tangan pada saya saat berpisah tanpa diarahkan.	Say to the caregiver 'I want to see if ____ waves his/her hand to me when we part without being directed.

(Table continued overpage)

	I'll pretend to leave but don't wave to me or try to get ____ to wave.'	Saya akan berpura-pura pergi tapi jangan melambaikan tangan pada saya atau meminta _____ melambaikan tangan.'	I will pretend to go away but don't wave at me or ask ____ to wave his/her hand'.
	Tester returns all materials into box, says goodbye to caregiver and to child, and walks towards door.	Pemeriksa mengembalikan semua perlengkapan ke dalam kotak, mengucapkan salam perpisahan kepada pengasuh dan anak, dan kemudian melangkah menuju pintu.	Tester returns all the tools equipment/ materials into the box, says goodbye to the caregiver and the child, and then walks towards the door.
	Tester then pauses to look back and say 'bye-bye ____' and tester may wave goodbye to the child	Pemeriksa kemudian berhenti untuk menengok ke belakang dan berkata 'da da ____' dan pemeriksa dapat melambaikan tangan kepada anak.	Tester then stops to look back and says 'bye bye ____' and tester can wave his/her hand to the child.
Trials	1	1 kali	1 time
Response time	5 seconds	5 detik	5 seconds
16 Task	Ability to switch from task to task	Kemampuan berpindah tugas	Ability to switch tasks
Information	Child is <i>happy</i> to follow testing procedure and change tasks as the testing demands.	Anak dengan senang mengikuti prosedur pemeriksaan dan berpindah tugas sesuai tuntutan pemeriksaan.	Child gladly follows testing procedure and switches tasks according to testing demands.
Materials	-	-	-
Procedure	This ability should be observed throughout the testing procedure.	Kemampuan ini harus terlihat selama prosedur pemeriksaan berlangsung	This ability should be seen / observable during the testing procedure.
Trials	-	-	-
Response time	-	-	-

‘suara sehari-hari’; however, within an Indonesian context, the terms ‘suara sehari-hari’ are inappropriate for use in this context when compared to the phrase ‘suara yang biasa didengar’ (meaning ‘familiar sounds’ in English). In addition, the terms ‘unusually adverse reaction’ are difficult to translate directly into Indonesian, as the translation of ‘adverse’ into Indonesian is ‘merugikan’ (meaning ‘harm’ in English) and does not represent the concept of ‘adverse’. Therefore, the term ‘terganggu’ (meaning ‘disturbed’) is used because it is considered to reflect the term ‘unusually adverse’; (6) In ‘the gaze monitoring task’ (#10), the term ‘either’ needs to be translated into ‘these two things are shown by’, to make the sentence clearer. In addition, in reference to the same task, the term ‘to’ needs to be added between ‘gaze’ and ‘monitor’, to make the terms clearer in an Indonesian context; (7) In reference to the ‘anticipatory posture task’ (#13), the term ‘siap’ (meaning ‘ready’ in English) is used to represent the concept of ‘anticipatory’, as the term is not available in the Indonesian language; (8) In ‘the nestling into caregiver task’ (#14), the Indonesian term for ‘nestle’ is ‘mendekapkan diri’; this term can be translated into English as ‘cuddle’ and ‘snuggle’. However, the term ‘hug’ is used by the back-translator instead of ‘nestle’; (9) In the use of ‘gestures task’ (#15), the term ‘gesture’ is translated into ‘bahasa tubuh’ (meaning ‘body movement’ in English), while the term ‘when parting’ needs to be added for clarity, because there is no direct translation available for ‘goodbye’ in the Indonesian language. The term ‘wave goodbye’ in this task was translated into ‘melambaikan tangan’ (meaning ‘wave hand’ in English).

5.2.3.2. Recommendations for the Main Study

In reference to exploring the study procedures and investigating any problems that might occur, the following recommendations were made, based on the findings of the pilot study. First, the pilot study suggested that the role of the research assistant was important, as that person would be communicating and scheduling the participants as well as ensuring that

the assessor remained blind to the children's previous diagnoses. Based on the pilot study, it was decided to increase the number of research assistants from one to three, to cover the range of tasks and geographical locations within Java, Indonesia. Two research assistants would focus on the recruitment and scheduling tasks, while the third research assistant would take responsibility for the technical issues, such as video recording and managing the video files.

Second, the pilot study also provided information about the length of time that was needed to be spent with each participant. It was decided to allocate two hours of testing time for each participant, as the ADEC-IND would take a maximum of 30 minutes, with the time for the ADI-R to be administered ranging from between 45 and 90 minutes. Another 15 minutes was allocated for the rapport building, briefing, and debriefing sessions at the beginning and end of testing, respectively.

Third, in order to keep the assessor blind to the participants' previous diagnoses or conditions, the pilot study suggested that the research assistant should inform the parents and highlight the importance of not revealing any information about their child's condition to the assessor before, during, and after the testing. In the pilot study, although the requirement for keeping the children's diagnoses was mentioned in the information letter, one parent unintentionally revealed his child's previous condition. Therefore, in the main study, the research assistant needed to constantly remind the parents about not revealing any previous diagnostic information to the assessor.

In conclusion, as well as confirming that the second draft of the ADEC-IND was suitable for use in the large scale study, the pilot study effectively highlighted issues that might potentially occur in the main study and helped identify practical solutions. Finally, the insights provided in the pilot study were crucial in helping prepare for successful data

collection over a four month period in the main study that involved 90 participants from five cities in Indonesia.

Chapter 6

Diagnosing Autism Spectrum Disorder in Developing Countries:

The Validation of Autism Detection in Early Childhood-Indonesian Version

(ADEC-IND)

This chapter consists entirely and solely of a paper submitted on 21 October 2014 to the Journal of Research in Autism Spectrum Disorder.

Abstract

A central component in the diagnosis of autism is having validated tools and this is an urgent need encountered by health practitioners in developing countries. The current study aimed to evaluate whether the Indonesian version of Autism Detection in Early Childhood (ADEC-IND) was valid and reliable in distinguishing between children with Autism Spectrum Disorder (ASD), and those who do not have ASD within a sample of Indonesian children. A total of 82 children aged 14 to 72 months ($M=45.23$ months, $SD=14.51$) with a range of diagnoses were assessed using the ADEC-IND. The ADEC-IND showed good sensitivity (.92 to .96) and good specificity (.85 to .92) in the current sample. Inter-rater reliability was high at $r = .94$, $p < .001$ and concurrent validity, using the Cohen's kappa agreement between the ADEC-IND and the Autism Diagnostic Interview-Revised (ADI-R) diagnoses, was moderate at .64. The ADEC-IND is recommended as a potential tool to assist in diagnosing ASD in Indonesia. Cultural issues and challenges in validating the ADEC-IND are discussed and suggestions for further research are highlighted.

Key words: assessment measures in autism; cultural validation

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social interaction and communication, and restricted and repetitive behaviours (Baron-Cohen, 2000; Dumont-Mathieu & Fein, 2005; Hill & Frith, 2003). Currently, although there is increasing attention being given to ASD in developed countries, there is still a lack of services for people with ASD in developing countries and more studies are crucially needed (Baxter et al., 2014; Saracino, Noseworthy, Steiman, Reisinger, & Fombonne, 2010). Seif Eldin et al. (2008) and Saracino et al. (2010) have found that most people with ASD in developing countries encounter numerous obstacles to receiving services while in developed countries, at least some services for ASD are provided and funded by governments (Saracino et al., 2010). For example, in Australia each child until his or her seventh birthday has access to funding of up to AUD\$12,000 (maximum of AUD\$6,000 per year) that can be used for intervention programs (Department of Social Services, 2014), while in Canada, children under the age of six have access to funding of CAD\$22,000 (Ministry of Children and Family Development, 2014). In addition to funding for assessment and intervention, governments in developed countries support research on ASD, training for the specialists, as well as initiatives to establish best practice guidelines, in particular to search for the most effective methods and measurement tools to assess and diagnose children with ASD (Autism Services Coordinating Committee, 2003; Department of Developmental Services, 2002; Nachshen et al., 2008; National Initiative for Autism: Screening and Assessment, 2003). In contrast, developing countries, such as China, India and Iran, strive to have trained ASD specialists and validated assessment tools (Daley, 2004; Samadi & McConkey, 2011; Sun et al., 2013).

Problematic conditions also occur in Indonesia, the fourth most populated country in the world where government provision for people with ASD is limited. In 1992, the prevalence of ASD in Indonesia was found to be 1 in 833 children (Wignyosumarto, Mukhlas,

& Shirataki, 1992) but since that time prevalence data have not been updated and few studies on ASD in Indonesia exist. People with ASD and other disabilities in Indonesia encounter numerous obstacles in accessing services and programs as most centres for assessment and therapy are provided by private sector practitioners and are only affordable for people from middle and high economic backgrounds (Irwanto, Kasim, Fransiska, Lusli, & Siradj, 2010; Yayasan Autisma Indonesia, 2013).

In terms of assessing ASD, the best practice guidelines from four developed countries (USA, UK, Canada, and Australia) suggested the use of multilevel assessment system. For example, the Canadian guideline suggested the assessment of ASD to be conducted in three stages as follows; (1) The first level assessment is the developmental surveillance that is conducted at any possible health evaluation of young children; (2) the second level is the screening stage where evaluation for children with at risk of having ASD is conducted; (3) the third level is the assessment and diagnosis stage that specifically aims to diagnose the child as having or not having ASD. Different tools are recommended for use within each level. For example, the M-CHAT is suggested for use in the screening level while the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989) and Autism Diagnostic Interview-Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) are suggested for use at the third level.

Moreover, regarding the ASD evaluation in Indonesia, Sidjaja et al. (2015) conducted a study to investigate the needs and challenges of Indonesian practitioners in diagnosing ASD. The study involved the survey of 67 health practitioners (medical doctors, psychologists, and therapists) who assessed at least one ASD case in a month. Most participants worked in Java Island where most ASD centres are located in Indonesia. The number of ASD cases seen per month ranged from 1 to 160 cases while the participants' length of experience in dealing with ASD varied from 1 to 36 years. In assessing ASD, the study found that none of the three

components of the best practice guidelines from developed countries could be applied. Firstly, in terms of conducting multi-staged assessment, the study found that there was no formal screening protocol in place for ASD and the health system in Indonesia allowed patients to visit specialists directly without referral. Secondly, the suggestion that ASD be diagnosed within a coordinated multidisciplinary team is not possible since such teams do not exist in Indonesia. All practitioners, however, reported that they made referrals to practitioners in other disciplines for assessment either before or after conducting their own diagnosis. Thirdly, the study revealed that no practitioners reported the use of the gold standard tools. The use of standardised tools was limited to the Checklist for Autism Rating Scale (CARS; Schopler et al., 1980). Having more validated tools, especially observation tools, that can be used to assess ASD as well as having more training on how to assess and intervene in ASD cases was reported to be urgently needed by Indonesian practitioners.

The use of the ADOS and ADI-R in Indonesia remains a great challenge as these tools are not available in Indonesian language, are extremely expensive, and require extensive training. Studies have shown that even in developed countries such as the United States, the United Kingdom, and Canada, the ADI-R and ADOS were rarely used by the health practitioners because of the high cost and long administration time (Berenstein, 2012; Hering, 2005; McClure, Mackay, Mamdani, & Mccaughey, 2010; Williams, Atkins, & Soles, 2009). A Chinese version of the ADI-R was found not to be efficient due to time constraints (Sun et al., 2013). Developing countries such as Indonesia need a diagnostic tool that requires less time, is affordable, and is less difficult to train.

Amongst the current measurement tools, the Autism Detection in Early Childhood (ADEC; Young, 2007) has been found to be a good assessment tool that offers many benefits. The ADEC is an interactive observation tool that is used to detect ASD in children as young as 12 months (Young, 2007). Hedley, Young, Juarez-Gallegos, & Marcin-Salazar (2010)

found that the Spanish version of the ADEC (ADEC-SP; Hedley et al., 2010) was an appropriate screening tool for children with ASD in Mexico where the number of trained ASD practitioners was still limited. It may be then that the ADEC could be a valid assessment tool in other developing countries, such as Indonesia. Compared to other assessment tools such as the ADOS or the ADI-R, the ADEC requires less training and is more affordable because it allows the user to provide their own toys and testing materials as well as to include any culturally appropriate toys and objects. The ADEC is also relatively easy to comprehend through a manual that guides practitioners in conducting an assessment and is relatively quick to use and score compared to the ADOS and ADI-R that require extensive and expensive training. Behaviours observed in the ADEC can also be used to describe areas of impairment that can be useful in developing an intervention program.

Besides ADEC, the Baby and Infant Screen for Children with aUtism Traits (BISCUIT; Matson, Boisjoli, & Wilkins, 2007) and the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001) could also serve as alternatives to be used in Indonesia. The BISCUIT is an assessment battery suitable for toddlers aged 17 to 37 months and assesses symptoms of ASD, as well as comorbid psychopathology and problem behaviours that accompany the disorder (Matson et al., 2007). It is a caregiver-based assessment comprising three components: the first assesses ASD symptoms; the second evaluates comorbidity; and the third examines challenging behaviours common in children with ASD (Matson, Boisjoli, Rojahn, & Hess, 2009; Matson, Fodstad, & Mahan, 2009). The M-CHAT is a screening tool developed to detect ASD in children aged 16 to 30 months (Dumont-Mathieu & Fein, 2005). It consists of 23 items based on parent reports. The M-CHAT has been translated into 22 languages, including Indonesian, although not all translated versions have been validated (Robins & Fein, 2011).

Compared to the ADEC, the BISCUIT offers a broader range of assessment areas (comorbidity and challenging behaviours), and the M-CHAT has demonstrated effectiveness in a multinational populations. However, in the current study, the ADEC was chosen on the basis of its strong correlations with the gold standard measurement tools (ADI-R, ADOS, and ADOS-T; Hedley et al., 2015; Nah et al., 2014; Young, 2007) noting that these comparisons have not been investigated for the BISCUIT and M-CHAT. Moreover, in terms of the age range covered by the tool, the ADEC covers a younger age range than the BISCUIT and M-CHAT: the ADEC is effective for children from 12 to 36 months while the age range covered by the BISCUIT and the M-CHAT are 17 to 37 months and 16 to 30 months, respectively. Therefore, based on these advantages, the ADEC was chosen to be adapted for use in this research program with children in Indonesia.

The present research is a response to the expressed needs of ASD specialists in Indonesia to have a validated tool to assist in the diagnosis of ASD. In acknowledging that the ADEC would be effective as an observation tool together with the CARS, the current study aimed to determine whether an Indonesian translated version of the ADEC (ADEC-IND) was valid and reliable in distinguishing between children with ASD and those who do not have ASD, within a sample of Indonesian children.

2. Method

2.1. Participants

This study was approved by the human ethics committee of the University of Queensland (#2012000726) in accordance with the National Health and Medical Research Council's guidelines. The participants were 82 Indonesian children aged 14 to 72 months ($M=45.32$ months, $SD=14.51$) recruited from schools, therapy centres, and parent support group communities in five cities in Indonesia. Two-thirds of the participants were male ($n = 55, 67\%$).

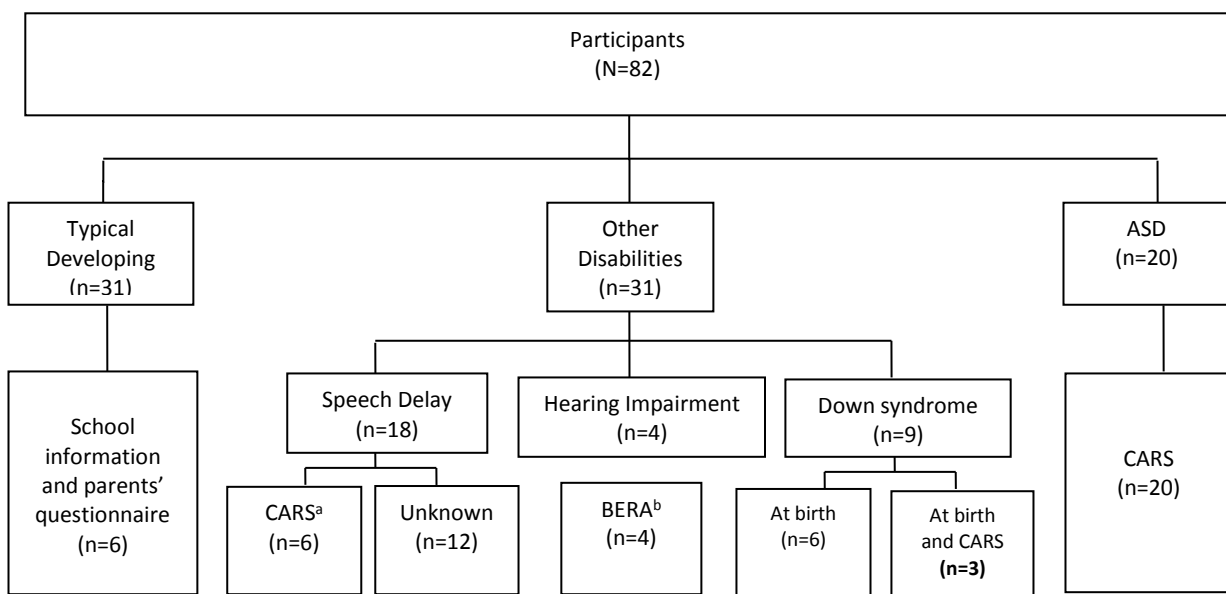
Children were classified into one of the following groups: (1) Typically developing (n=31, 18 males); (2) Other disabilities (n=31, 23 males); (3) ASD (n=20, 14 males).

Participants in the typically developing group were assigned based on information gathered from parents including the child's health history and parental concerns. For those who were recruited from schools, school records were also used to confirm the child's status.

Children in the "Other disabilities" group included those who were previously diagnosed with speech delay (n=18, 22%), hearing impairment (n=4, 5%), and Down syndrome (n=9, 11%). From the 31 participants in this group, six children with speech delay and three children with Down syndrome had also been assessed using the CARS. All of the participants with hearing impairment received their diagnoses from audiologists using the Brainstem Evoked Response Audiometry test (BERA; Jewett & Williston, 1971).

Information about the assessment procedures and tools used with other participants was not available.

Figure 1
Participants' Sources of Diagnoses



Note. ^aSchopler, Reichler, DeVellis, & Daly (1980). ^bJewett & Williston, 1971

The ASD group (n= 20) included participants diagnosed with ASD or Pervasive Developmental Disorder – Not otherwise specified (PDD-NOS) by Indonesian health practitioners. All of the participants in the ASD group were previously diagnosed using the CARS and DSM-IV TR. Details about sources of diagnoses of each group are presented in *2.1.1. Exclusion of Participants*

Of 115 individuals who agreed to participate in the study, 33 were excluded, leaving 82 participants for the final sample. The 33 participants were excluded for a variety of reasons including not finishing the assessment, a lack of clarity of diagnosis by practitioners, diagnoses not consistent with the CARS cut-off scores, and the child's previous diagnosis or condition being revealed to the assessor during the testing.

2.2. Testing materials

2.2.1. The Autism Detection in Early Childhood (ADEC)

The ADEC is an observation tool that was found to be effective in detecting ASD in children aged 12 to 36 months (Young, 2007). The behaviours identified in the ADEC are consistent with DSM IV-TR criteria for Autistic Disorder (Young, 2007) and are evaluated through 16 different tasks given to the child in a child-friendly situation in order to observe their behaviour. The 16 tasks cover behaviours as follow: (1) response to name; (2) imitation; (3) ritual play; (4) joint attention; (5) eye contact; (6) functional play; (7) pretend play; (8) reciprocity of smile; (9) reaction to common sounds; (10) gaze monitoring; (11) response to verbal instructions; (12) delayed language; (13) anticipation of social advances; (14) nestling to caregivers; (15) use of gestures and; (16) impairment in task switching (Hedley et al., 2010; Young, 2007). For each task, a score of zero (0) is given if the observed child is showing an appropriate or typical response, two (2) if the response is not appropriate, and one (1) if the response is not adequate to be scored either zero or two. For example, in response to name task, the tester calls the child's name for a maximum of five

trials and with a five second pause between calls. Score zero (appropriate response) is given when the child responds by turning his or her head to face the tester, looks at tester's face and makes eye contact on the first or second calling. Score one is given when the child turns his or her head on third, fourth, or fifth calling; or spontaneously turns his or her head at other times during the testing. Score two (inappropriate response) is given when the child does not turn head at all, either on any of the five trials or throughout testing. Furthermore, score one should also be given when the child shows spontaneous behaviour in all ADEC items when the targeted behaviours are not presented during item administration.

The ADEC has been reported to be a valid and reliable assessment tool. It has good internal consistency (Cronbach $\alpha = .94$), test-retest reliability ($r = .83$) and inter-rater reliability (intra-class correlation, ICC = .83; Young et al., 2007). Within a sample of children aged 14 to 36 months, the ADEC showed high sensitivity (90%) and specificity (93%; Young et al., 2007). Studies by Nah, Young, & Brewer (2014) and Young (2007) have shown that the ADEC correlates positively with the ADI-R and ADOS. The tool also showed good convergent validity when scores were correlated with the Checklist for Autism in Toddlers (CHAT; Baron-Cohen, 2000) and CARS scores (Young, 2007). A study in Mexico with two sample groups of participants found that the Spanish version of the ADEC (ADEC-SP) had good sensitivity (from .79 to .94) and specificity (from .88 to 1.00). The ADEC-SP also showed good concurrent validity compared with the ADI-R (Cohen's kappa = .66 for sample 1 and .71 for sample 2), inter-rater reliability ($r = .96$ for sample 1 and .81 for sample 2), and internal consistency (Cronbach $\alpha = .73$; Hedley et al., 2010). A recent study also found that the ADEC is effective to be used as a screening tool to predict long term outcomes in children with ASD (Nah et al., 2014). The study found that the ADEC total score demonstrated good predictive accuracy in both two and six years follow up assessment.

The ADEC package consists of a manual, scoring form, and a DVD showing two examples of the ADEC's administration by the author. The ADEC manual contains detailed descriptions and instructions as well as the scoring guidelines for each task. Compared to other standardized tools that require buying all of the toys and objects needed for administration, the ADEC allows the users to provide their own toys and testing materials (Hedley et al., 2010; Young, 2007). The price of the ADEC manual (includes the DVD) and scoring sheets (10 pieces) is AUD\$242.89 (Australian Council for Educational Research, 2012).

The average time of testing is 15 to 30 minutes. In some cases, it can be administered in less than 15 minutes. There is no strict regulation in terms of the testing order. Adaptation time, as mentioned in the ADEC manual, is compulsory in order to make the child feel comfortable. A DVD containing everyday sounds is also included in the package. The sounds need to be played in one of the tasks. In the current study, the first author used a smart phone to play the sounds.

2.2.2. The Autism Diagnostic Interview-Revised (ADI-R)

The ADI-R is a diagnostic tool for children and adults who are considered to be at risk to receive a diagnosis of an ASD (Lord & Corsello, 2005). It is a semi-structured interview conducted by a clinician to collect information about a child's behaviour from the child's primary caregiver (Matson & Sipes, 2010). It consists of 93 questions that are based on DSM-IV TR diagnostic criteria. The questions cover three main areas: (1) qualitative or reciprocal social interaction; (2) communication and language; and (3) restricted and repetitive, stereotyped interests and behaviours (Chawarska et al., 2007; Lord, Storoschuk, Rutter, & Pickles, 1993).

The ADI-R is a recent version of the Autism Diagnostic Interview (ADI: Le Couteur et al, 1989) and has been found to be a reliable instrument for preschool age children (Cox et

al., 1999; Lord et al., 1993). However, a longitudinal study using the ADI-R with 50 children showed that the instrument demonstrated high specificity but low sensitivity in diagnosing children at 20 months of age (Cox et al., 1999). It was recommended that the ADI-R not be used as a diagnostic tool for children below two years of age because of its low sensitivity (Cox et al., 1999). Furthermore, the administration of the ADI-R requires extensive time (one to two hours). The price of an ADI-R kit that includes the manual, 10 interview booklets, and 12 scoring forms is AUD\$414.95, while the training package that includes training program on DVD, guidebook, interview booklets, and scoring forms costs AUD\$1,699.99 (Australian Council for Educational Research, 2012).

2.3. Procedures

2.3.1. The ADEC and ADI-R training

The first author was trained in using the ADEC and ADI-R by a senior clinical psychologist using the test manual, case studies, training videos, and simulations. The training was completed in a month for the ADEC and two months for the ADI-R.

The ADEC training was conducted by the fourth author who is a child clinical psychologist. In the training, the manual of the ADEC was explained and the procedure of ADEC testing was described by the fourth author to the first author. Afterward, the first author read carefully the manual, testing instruction and watched the entire training video included in the ADEC manual. Nine children were tested using the ADEC-IND under supervision of the fourth author. Feedback and corrections were given along the training process.

The ADI-R training was delivered by the fourth author to the first author. During the training, the first author watched the training program on DVD and read carefully the guidebook with behaviour coding instructions. Examples of cases provided in the guidebook

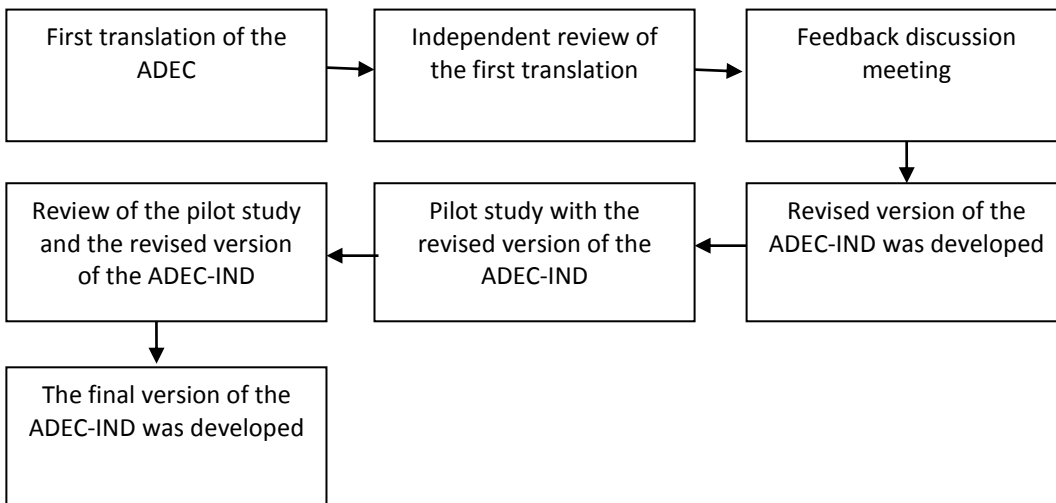
were studied carefully by the first author and afterward the first author was given another interview examples and simulations guided by the fourth author. Afterward, using the ADI-R, the first author then interviewed 9 caregivers. Questions, feedback and corrections about the first author's performance in using the ADI-R were given along the training.

2.3.2. Translating the ADEC

A bilingual Indonesian clinical psychologist translated the ADEC scoring form and the fourth chapter of the ADEC manual that consists of: (1) details about test materials and testing room; (2) administration; (3) scoring guide; (4) suggested sequence for testing; (5) adaptation period task; (6) operationalization and scoring of 16 ADEC items; and (7) three case studies from the original language (English) into Indonesian following the International Test Commission Guidelines for Translating and Adapting Tests (International Test Commission, 2005). An Indonesian bilingual researcher who has a master's degree in Linguistics and an Indonesian bilingual researcher who has a master's degree in Developmental Psychology reviewed the first translated version independently. Feedback and comments about the translation were then discussed and necessary revisions made.

The first translated version was pilot tested with eight Indonesian children aged 12 to 72 months with a range of conditions (6 typically developing children, 1 child with speech delay, and 1 child diagnosed with ASD). In the pilot study, the parents were also interviewed using the ADI-R. A research assistant was appointed to ensure that the assessor was blind to the children's conditions. Each assessment was videotaped and given English subtitles by two bilingual psychology students using the Windows Movie Maker Software. A senior clinical psychologist reviewed the subtitled videos to ensure there were no misinterpretations in administering the test in Indonesian. Figure 2 describes the schematic procedure of the ADEC-IND translation process.

Figure 2
Procedures of the ADEC-IND Translation



2.3.3. Recruitment of Participants

Participants were recruited from schools, therapy centres, and parent support group communities in Indonesia. Invitations to participate in the study were also advertised through community mailing lists and popular social networking websites (Facebook and Path). It was indicated in the advertisement that each participant would receive a toy, a certificate of appreciation, and a one-page report describing the test results.

Recruitment also occurred through institutions, such as schools and therapy centers. After the heads of institutions confirmed their willingness to help in recruitment, they were linked to research assistants. Of 75 institutions and communities located in Jakarta, Bogor, Depok, Tangerang, and Bekasi (five major cities in the area of Jakarta and West Java) that were approached, 21 therapy clinics, seven schools, and an online support group for parents of children with ASD agreed to assist with the recruitment and subsequently invited parents of eligible children to participate. Participating institutions included those run by private sectors and social foundations. Private institutions in the recruited area are generally attended by families from middle to high socio-economic backgrounds while the social foundations are mostly attended by those from lower socio-economic backgrounds.

The detailed process of recruitment through institutions is presented in Figure 3. After the heads of institutions agreed to help with recruitment, research assistants offered them three alternatives in recruiting participants (see Figure 3). Each potential participant received an invitation kit containing an information sheet, informed consent, flyer, and research assistants' name cards. Parents who expressed their interest to participate in the study were then contacted by the research assistants and informed about the process of assessment. Parents were also asked to complete a questionnaire related to their child's previous diagnoses or conditions. The questionnaires were sent either through e-mail or handed out through the institutions. In order to keep the assessor blind to participants' previous diagnoses, no contact was made with the parents before the testing. The research assistants also managed contact with the heads of institutions

2.3.4. Testing participants with the ADEC-IND

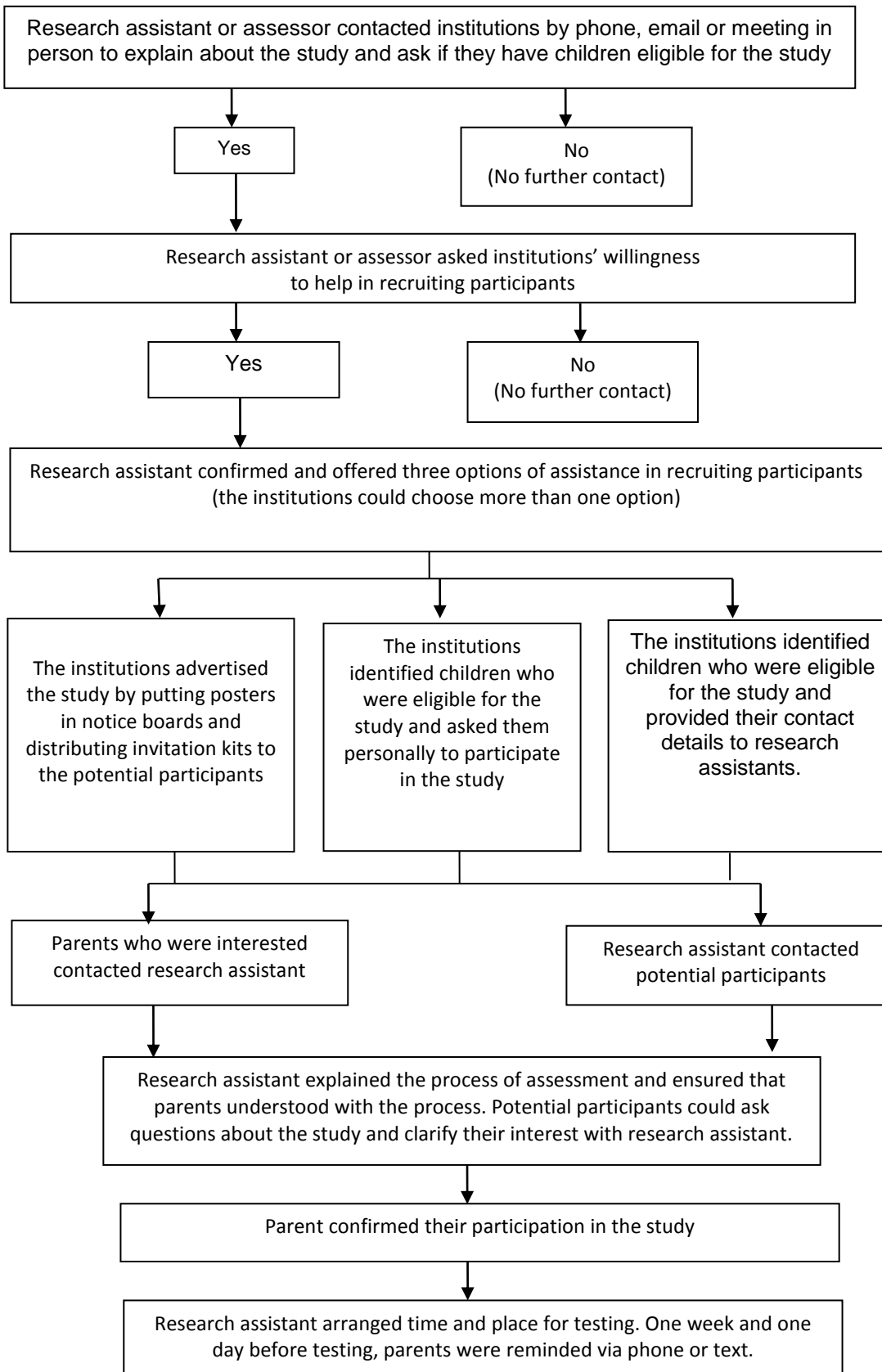
2.3.4.1. Scheduling

Parents who confirmed their participation in the study were scheduled by research assistants to have their child assessed. Testing was located either at institutions where participants were recruited or at participants' homes. Research assistants also reminded participants about the schedule of assessment one week and one day before the testing by calling or sending short text messages. On average, two to three children were tested in a day.

2.3.4.2. Briefing and rapport building

During testing, the assessor was accompanied by at least one research assistant who briefed the parents and managed video recording. Research assistants initially met the parents, explained the aim of the study, collected or requested that parents sign an informed

Figure 3
Recruitment of Participants through Institutions



consent. Parents were also reminded not to reveal prior diagnoses of their child to the assessor during or after testing. After the briefing, the assessor met the parents and the child. Culturally, for those who were tested at the participants' houses, parents often served snacks and drinks as an act of courtesy.

2.3.4.3. Testing

The participating child was assessed using the ADEC-IND and then the parents were interviewed using the ADI-R. The child assessment and parent interview were videotaped and audio recorded. The average time of the ADEC-IND testing was 15.94 minutes ($SD=3.71$) while the ADI-R lasted on average 57.16 minutes ($SD=18.29$). After testing, the assessor gave a small toy and a certificate of appreciation to the child and debriefed the parent. Certificates of appreciation were also provided for the heads of institutions at the completion of data collection.

2.3.5. Video subtitling

Research assistants screened all participants' videos and chose 50 videos with high-quality shooting angle and sound to be subtitled. In order to help the second assessor to understand the conversation during the test, using the Windows Movie Maker software (Microsoft, 2014), each videotaped session was given English subtitles by two Indonesian undergraduate students and six graduates in psychology who were fluent in English.

2.3.6. Report distribution

A one-page report about the child's test result was provided to participating parents. Participants' reports were completed and distributed seven months after the testing. In order to maintain good relationships with the parents and institutions, during the waiting period, research assistants informed participants about the progress of the study with emails and letters. Reports were distributed via post or email. For participants who were recruited from institutions, the report was distributed through the heads of institutions in a sealed envelope.

The reports consisted of a brief description of the child's responses to the task assigned during the ADEC testing and a conclusion derived from the parent's interview using the ADI-R. No diagnoses were indicated in the reports, it was explained earlier to the parents that the ADEC had not been validated with a sample of Indonesian children. Nonetheless, autistic and non-autistic symptoms observed in the testing were reported to parents. Parents who received reports describing the symptoms that were different from the child's previous diagnosis were asked to rely on the diagnoses received previously from practitioners.

3. Analysis and Results

The aim of the statistical analysis was to investigate the psychometric properties of the ADEC-IND. The psychometric properties examined were the predictive ability, inter-rater reliability, internal consistency, concurrent validity, and diagnostic discrimination.

For the Indonesian practitioner diagnosed groupings, Levene's test showed that the assumption of homogeneity of variance among the three groups was not violated. A one-way between-subjects ANOVA revealed a significant difference in the ages of the children in these previously diagnosed groups, $F(2,79) = 3.20$, $p = .04$. A post hoc comparison (LSD) indicated that the typical developing children ($M\ age = 40.29$ month, $SD = 15.43$) were significantly younger than the children in ASD diagnoses ($M\ age = 49.60$ months, $SD = 14.51$) and Other Disabilities ($M\ age = 47.35$ months, $SD = 12.69$) groups, which did not differ.

3.1. Predictive ability

The predictive ability of the ADEC-IND was evaluated in order to understand how strongly the ADEC-IND total score could predict the child's diagnosis. An initial logistic regression evaluated how well the ADEC-IND total score predicted the diagnosis from the ADI-R, and the second evaluated the capacity of the ADEC-IND total score to predict the diagnoses obtained from the Indonesian practitioners.

Firstly, the child's age and the ADEC-IND total score were entered in a model as predictors and the ADI-R diagnoses (coded as 0 for children without ASD and 1 for children with ASD) were entered as the outcome variable. The full model containing all predictors was statistically significant, $\chi^2(2, N = 82) = 54.58, p < .001$. This indicates that the model was able to discriminate between participants who were diagnosed with and without ASD. The model as a whole explained between 48.6% (Cox & Snell R^2) and 69.3% (Nagelkerke R^2) of the variance in diagnosis, and correctly classified 85% of cases. As seen in Table 1, only the ADEC-IND total scores made a unique statistically significant contribution to the model, while age did not contribute significantly in predicting the ADI-R diagnoses. The ADEC-IND total scores showed an odds ratio of 1.48, indicating that participants who had high ADEC-IND total scores were over 1.48 times more likely to be diagnosed as having ASD than those who did not have high ADEC-IND total scores, controlling for other factors in the model.

Secondly, the child's age and the ADEC-IND total score were entered in a model as independent variables (predictors) and the previous diagnoses (coded as 0 for participants without ASD and 1 for those with ASD diagnosis) were entered as a dependent variable. The results showed that the full model was statistically significant, $\chi^2(2, N = 82) = 53.03, p < .001$, and explained between 47.6% (Cox & Snell R^2) and 71% (Nagelkerke R^2) of the variance in diagnosis, and correctly classified 90% of cases. This indicates that the model was able to discriminate between participants who were diagnosed with and without ASD. Similar to results using the ADI-R diagnoses, the ADEC-IND total scores contributed significantly in predicting the diagnoses conducted by Indonesian practitioners while age did not. Moreover, the ADEC-IND total scores showed an odds ratio of 1.53, indicating that participants with high ADEC-IND total scores were over 1.53 times more likely to be

diagnosed as having ASD than those without high ADEC-IND total scores, controlling for other factors in the model.

Table 1

Logistic Regression of Predictors of the ADEC-IND Total Score and Participants' Age on the Diagnoses of ASD using the ADI-R and Diagnoses of ASD conducted by Indonesian Practitioners

	<i>B</i>	<i>S.E.</i>	<i>Wald</i>	<i>df</i>	<i>p</i>	<i>Odds Ratio</i>	<i>95.0% C.I. for Odds Ratio</i>	
							<i>Lower</i>	<i>Upper</i>
ADI-R diagnoses								
ADEC-IND Total Score	.39	.09	17.86	1	<.01	1.48	1.23	1.77
Age	.06	.03	3.74	1	.05	1.07	.99	1.14
Constant	-8.89	2.52	12.50	1	<.01	.00		
Indonesian Practitioners								
ADECTOT	.43	.11	15.02	1	<.01	1.53	1.23	1.89
AGE	.07	.04	3.52	1	.06	1.08	.98	1.16
Constant	-10.34	3.07	11.33	1	<.01	.00		

3.2. Internal Consistency

To measure the internal consistency of the ADEC-IND, a Cronbach alpha test was used.

The current study found that the ADEC-IND showed a good internal consistency, with a Cronbach alpha coefficient of .87.

3.3. Inter-rater Reliability

Fifty out of 115 videos were given English subtitles and rescored by a second assessor using the English version of the ADEC scoring guide. This person was blind to the original scores and the previous diagnoses of participants. The inter-rater reliability was assessed using Pearson's correlation and Cohen's kappa agreement between the ADEC-IND and the original version of ADEC. There was a strong positive correlation between ADEC-IND's total scores and ADEC's total scores, $r = .94$, $n = 50$, $p < .001$, indicating that high total scores on the ADEC-IND were associated with high levels on the original ADEC total scores.

Secondly, the agreement of diagnoses between the ADEC-IND and original ADEC was calculated using Cohen's kappa agreement. A cut off score of 11 was used in order to distinguish the ASD and non-ASD group (Young, 2007). Participants with a total score of 11 or above were classified into the ASD group while those with total scores below 11 were classified as non-ASD. The Cohen's kappa coefficient was found to be high at .76.

3.4. Concurrent Validity

To demonstrate concurrent validity, the ADEC-IND was compared with the measure considered a gold standard measure in ASD assessment, the ADI-R, and also with the measurement tool suggested by the Indonesian best practice guideline, CARS. Firstly, the relationships among the ADEC-IND total scores, ADI-R total scores, and CARS total scores were measured using Pearson's correlation. Secondly, using Cohen's Kappa agreement, the diagnoses conducted using the ADEC-IND total scores were compared with the ADI-R diagnoses and the diagnoses previously received by participants.

The ADEC-IND was found to have good validity as shown by the high correlation between the ADEC-IND total scores with the ADI-R total score, the moderate correlation between the ADEC-IND's total scores and the Indonesian practitioners' total scores, the moderate Cohen's kappa agreement between the ADEC-IND and the ADI-R diagnoses, and the moderate Cohen's Kappa agreement between the ADEC-IND diagnoses and the Indonesian practitioners' diagnoses.

3.4.1. Correlation among the total scores of ADEC-IND, ADI-R, and CARS

The total scores of ADEC-IND and ADI-R were found to be highly correlated at $r = .79, p < .001$. The ADEC-IND total score was also found to be significantly correlated with all ADI-R sub-scales, $r_s > .52, p_s < .001$. Moreover, the CARS showed significant correlation with ADEC-IND, $r = .64, p < .001$, as well as with the ADI-R, $r = .57, p < .001$. As there were age differences between the groups, correlations among the ADEC-IND total

scores, ADI-R total scores, and CARS total scores were rerun with age partialled out. Compared to Pearson correlations, a higher partial correlation was found between the ADEC-IND and ADI-R, $r = .81$, $p < .001$, while the CARS showed a similar correlation with the ADEC-IND, $r = .68$, $p < .001$, but higher correlation with the ADI-R, $r = .71$, $p < .001$. These results indicated that the ADEC-IND correlated strongly and positively with both the ADI-R and the CARS.

3.4.2. Diagnostic agreement

As above, the ADEC-IND diagnoses used a cut off score of 11 to classify participants into non-ASD and ASD groups. The same coding was also used for the ADI-R and Indonesian practitioners' diagnoses (0 for non-ASD and 1 for ASD).

3.4.2.1. Agreement between ADEC-IND and ADI-R diagnoses

Cohen's Kappa agreement between the diagnoses using the ADEC-IND and the ADI-R diagnoses was found to be significant, although moderate at $.64$, $p < .001$. The overall similar classification was 68 out of 82 (82.92%) with mis-classifications on the ADEC-IND for one of the 24 children with ASD (into non-ASD group) and 13 of the 58 non-ASD children (into ASD group).

3.4.2.1. Agreement between ADEC-IND and Indonesian practitioners diagnoses

Cohen's Kappa agreement between the ADEC-IND diagnoses and the diagnoses conducted by Indonesian practitioners was also found to be moderate, $.58$, $p < .001$ with the overall similar classification at 66 out of 82 (80.48%). All participants previously diagnosed as having ASD ($n=20$) by Indonesian practitioners were similarly classified into the ASD group with the ADEC-IND. Forty-six participants (74%) who were previously diagnosed as not having ASD were also correctly classified into non-ASD group using the ADEC-IND. Sixteen participants (26%) who were previously diagnosed as not having ASD were incorrectly classified into the ASD group by the ADEC-IND. These sixteen children included

two typically developing children and 14 participants with speech delay. Details about misdiagnosed participants are presented in Table 2.

Table 2
Descriptive Statistics of Misdiagnosed Participants

	Misdiagnosis		
	ADI-R		Indonesian practitioners
	ASD into non ASD (n=1)	Non ASD into ASD (n=13)	Non ASD into ASD (n=16)
Mage (SDage)	66	40.54 (15.89)	40.56 (13.95)
Age range	0	21 - 72	21 - 72
ADEC-IND scores	6	14.38 (3.28)	14.69 (3.19)
Range of ADEC-IND scores	0	11 - 20	11 - 20
ADI-R scores	29	12.77 (9.24)	19.25 (15.34)
Range of ADI-R scores	0	0 - 26	0 - 49

3.4.2.1. Agreement between ADI-R and Indonesian practitioners diagnoses

Cohen's Kappa agreement between the diagnoses of ADI-R and Indonesian practitioners was found to be high at .75, $p < .001$ with 74 out of 82 (90.24%) being similarly classified. Of 58 participants who were diagnosed with non ASD by ADI-R, two participants (3.44%) were misclassified into ASD group by Indonesian practitioners. However, six of 24 participants (24%) who received ASD diagnoses using the ADI-R were misdiagnosed as not having ASD by Indonesian practitioners. Moreover, all 31 participants in the typical developing group who were classified using parent's questionnaire were 100% consistently classified as not having ASD by the ADI-R.

3.5. Diagnostic Discrimination

The optimal cut off score of the ADEC-IND was determined using the receiver operating characteristic analysis (ROC) with agreed diagnoses (diagnoses conducted by Indonesian practitioners that were confirmed by the ADI-R) as the gold standard. Only diagnoses that were confirmed by both ADI-R and Indonesian practitioners were included leaving the sample with 76 participants (i.e., for 6 participants, the diagnoses of the practitioners did not concur with that of the ADI-R). As seen in Figure 4 and Table 2, the optimal cut off score for the ADEC-IND was found to be between 10.5 and 12.5. This result

confirmed the use of 11 as recommended by the original ADEC (Young, 2007). Using a cut off of 11, sensitivity and specificity were both found to be high at 95.83% and 84.61%, respectively. Specifically, sensitivity with a 95 % CI ranged from .87 to 1.03 while the specificity with a 95 % CI ranged from .74 to .94. These results indicate that the ADEC-IND is able to correctly categorize 95 out of 100 children with ASD into the ASD group and it is also able to correctly classify 84 out of 100 children without ASD into the non-ASD group. The cut-off score also corresponds with a positive predictive value of 74.19% and negative predictive value of 97.77%. That is, the possibility of someone actually having the ASD condition after being diagnosed as having ASD with the ADEC-IND is 74.19%. On the other hand, there is a 97.77% chance that someone will actually not have ASD after being classified as not having ASD by the ADEC-IND test. The area under curve was .96, indicating an excellent correlation between sensitivity and specificity.

The original ADEC sensitivity and specificity were found to be highest in the age group of 12 to 36 months (Young, 2007). However, in the present study, the ROC analysis was not repeated with this age group, as there were only two participants diagnosed with ASD within this age grouping.

Figure 4
Sensitivity and Specificity of ADEC-IND

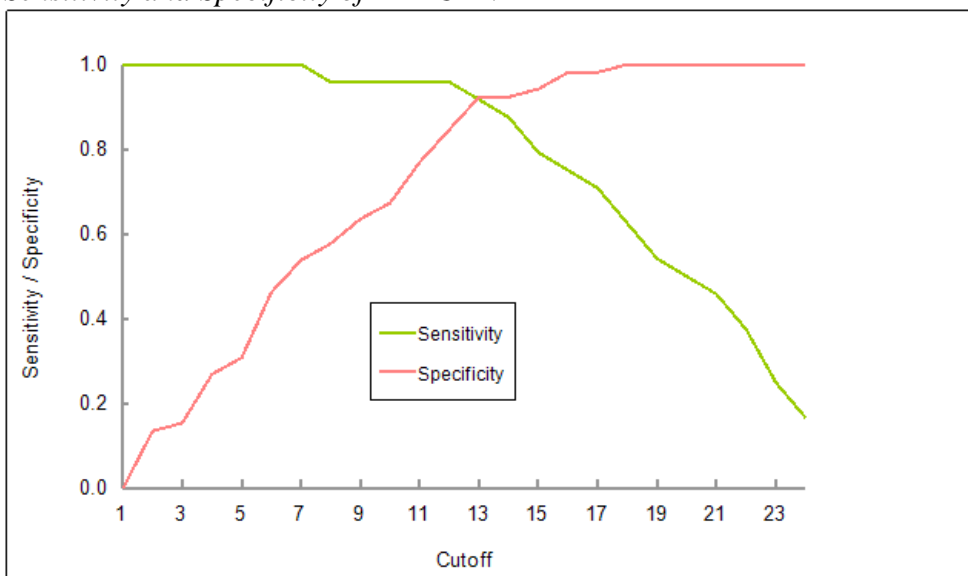


Table 3
Sensitivity and Specificity for Different ADEC-IND Cut Offs

Cut off	Sensitivity	Specificity
-1.00	1.00	.00
.50	1.00	.14
1.50	1.00	.15
2.50	1.00	.27
3.50	1.00	.31
4.50	1.00	.46
5.50	1.00	.54
6.50	.96	.58
7.50	.96	.64
8.50	.96	.67
9.50	.96	.77
10.50	.96	.85
11.50	.92	.92
12.50	.88	.92
13.50	.79	.94
14.50	.75	.98
15.50	.71	.98
16.50	.63	1.00
17.50	.54	1.00
18.50	.50	1.00
19.50	.46	1.00
21.50	.38	1.00
23.50	.25	1.00
24.50	.17	1.00
25.50	.04	1.00
27.00	0.00	1.00

3.6. Cultural issues in the administration of the ADEC-IND

As well as evaluating the psychometric properties of the ADEC-IND, the study also examined cultural issues that emerged in administering the ADEC-IND. In the present study, the fifteenth item of the ADEC-IND was found to be potentially problematic in Indonesian culture. The item aims to measure the child's ability in using gesture. In the task, after the assessor packed all of the toys into a box, the assessor pretended to leave the room with hands waving to the child. While the appropriate response that is expected from the child is to wave back to the assessor, some children in the present study responded by kissing the back of the assessor's right hand using forehead or tip of nose. This gesture is known as '*salim*' and is

commonly practised in Indonesia as a polite way of expressing farewell to older people.

Therefore, as the hand kissing behaviour as an expression of farewell in Indonesian culture, a zero score (i.e., appropriate response) was given by the assessor to those participants who responded using this gesture.

3.7. Responses on ADEC-IND items by participants with hearing impairment

In testing the children with hearing impairment (n=4), research assistants needed to ask parents to remove any hearing aid worn by the child as the aids would prevent the assessor being blind to the diagnoses. All of the participants with hearing impairment received a score of 0 for item 4 (gaze switching), 10 (gaze monitoring), 13 (anticipatory posture), 14 (nestling into caregiver), and 16 (ability to switch from task to task). In responding to items that required hearing ability (i.e. response to name, response to everyday sounds, responds to verbal command) some participants showed appropriate responses. For item 1, two of four participants turned their heads and made eye contact after the assessor called their names. Similarly, for item 9 (response to everyday sound), one participant scored 0 as within 5 seconds after the sounds were played, the child made an eye contact to the tester. None of the hearing-impaired participants responded appropriately to item 11 (following verbal instruction) although for some children, all instructions were given by looking directly at them. Their responses, however, were considered as unintentional because based on the assessor's observation, they tended to look at the testers and their caregivers frequently during the testing. However, the assessor decided not to modify the scoring for participants with hearing impairment considering the small number of participants.

3.8. Cultural issues in recruitment, scheduling, and working with the institutions

There were some challenges related to cultural context and Indonesian situation encountered in the recruitment process, scheduling the parents as well as working with the institutions in Indonesia. Challenges in recruitment included the complex bureaucracy of the

institutions, difficulties in engaging with the representatives, and the fear from the institutions that parents would react negatively if they knew that the topic of research was ASD. Some therapy centres refused to help because they were concerned that the result of the testing would be different from the clinic's previous results. Moreover, the term "testing tool" ("*alat tes*" in Indonesian language) used in the advertisement for this study was negatively interpreted by some parents who thought that their children would be examined using a device (the testing tools) that could harm children's physical health. Almost all participants asked for clarification from the research assistants about the process of assessment, particularly the meaning of "testing tools". Research assistants explained to parents that the study did not involve a device that could physically harm the children.

4. Discussion

The current study aimed to evaluate whether the Indonesian version of the ADEC would be effective in differentiating children with and without ASD within an Indonesian sample. It was conducted as a response to the urgent need of ASD specialists in Indonesia to have more validated tools in detecting ASD (Sidjaja et al., 2015). This is the first study to evaluate the validation of an assessment tool for ASD in Indonesia. Two major findings of this study will be highlighted in the current section followed by the practical implication and the limitations of the study.

Firstly and consistent with the evaluation of the Spanish version of the ADEC (Hedley et al., 2010), the current study found that the ADEC-IND is valid and reliable in differentiating children with and without ASD within a sample of Indonesian children. The ADEC-IND has sound psychometric properties, which are shown by high sensitivity and high specificity as well as good predictive ability, internal consistency, inter-rater reliability, and concurrent validity. The cut-off score of 11 was found to be the optimal cut-off score for the ADEC-IND as it corresponded to optimal sensitivity and specificity. This finding is

consistent with the original ADEC recommendation to use a cut off between 11 and 13 in differentiating between the ASD and non-ASD group (Young, 2007). The cut-off score was also found to be the optimal score of the Spanish version of ADEC (Hedley et al., 2010). Therefore, considering that the ADEC-IND shared a similar cut-off score with the original ADEC, amendments in the ADEC-IND total score categorization are suggested as not necessary.

Secondly, the present study also found a cultural issue in one of the ADEC-IND items where participants' responses were a reflection of Indonesian culture. In the item where children are expected to wave back to the assessor, some participants responded by kissing assessor's hand using their forehead or tip of nose. Cultural difference is an issue that needs to be considered in adapting a test or assessment tools. As indicated in the guideline of test adaptation, in adapting a measurement tool, it is important to be culturally sensitive with factors related to stimulus materials, administration procedures, and responses as this possibly affects the test scores' validity (Foxcroft, 2011; Hambleton, 2005; International Test Commission, 2005). The validation study of ADEC-SP (Hedley et al., 2010), however, did not report any cultural issues that affected validity but it is highly recommended that hand kissing behaviour within the ADEC-IND scoring guide is considered as an appropriate response because the gesture refers to a farewell expression in Indonesian context.

The current study was conducted as a response to the expressed need of Indonesian practitioners to have more validated assessment tools for diagnosing ASD (Sidjaja et al., 2015). Currently, the CARS is recommended by Indonesian best practice guidelines as a gold standard tool to be used in Indonesia (Himpunan Psikologi Indonesia, 2008). The CARS was found to be one of the most common standardized tools used by Indonesian practitioners beside the CHAT or M-CHAT, however to date there is no validated observation tool provided in Indonesian language that can be used by Indonesian practitioners to assist in the

diagnosis of ASD (Sidjaja et al., 2015). Therefore, using the ADEC-IND as an observation tool together with the CARS is recommended as worthwhile for Indonesian practitioners as the present study showed that the ADEC-IND possessed good psychometric properties and was strongly correlated with one of the gold standard tools, the ADI-R. Moreover, considering Indonesia's current circumstances where government support and funding in the disability area is still very limited, the ADEC-IND is considered to be more appropriate than either the ADOS or ADI-R as it is less expensive, less time consuming, and requires less extensive training while still holding strong psychometric properties.

The current study has limitations and future research is needed. It should be taken into consideration, however, that in terms of clinical research, developing countries such as Indonesia encounter more challenges compared to developed countries as facilities, supports, systems, and funding from Government in ASD research is extremely limited. Therefore, without any intention to reduce the quality of the research, limitations in the present study need to be evaluated with an understanding of the developing countries' situations. First, regarding the classification of participants, all of the children in the ASD group and some children in the Other Disabilities group were classified using the Indonesian version of CARS that is suggested by the Indonesian Psychological Association to be used in assessing ASD cases (Himpunan Psikologi Indonesia, 2008). Although the CARS has been used from 1992 in Indonesia (Wignyosumarto et al., 1992), to date there has been no validation study of the Indonesian version of CARS. The current study found that although some inconsistencies between diagnoses of Indonesian practitioners and the ADI-R occurred, the correlation between CARS and ADI-R was found to still be adequate. Therefore, further research on the Indonesian version of the CARS validity and reliability is recommended to ensure the psychometric properties of the tool.

Second, in the current study, participants in other disabilities group were classified using Indonesian practitioners' diagnoses. However, not all participants in this group could provide detailed information and formal report about the assessment procedures and tools used previously by the practitioners. As a recommendation for further study, it is suggested to have detailed report on how the assessment procedures and tools used in diagnosing participants by the practitioners.

Third, the current study is limited in conducting developmental assessment to participants within typical developing group. Typical developing participants were confirmed only a short questionnaire completed by parents. Within the questionnaire, parents were asked to provide information about their child's previous diagnoses and general health conditions. All participants in the typical developing group who were classified by the questionnaire were confirmed by the ADI-R as not having ASD. For further studies, assessing typical developing participants with developmental assessment tools is recommended in order to increase the validity in classifying the typical developing children as well as to provide data about their developmental level.

Fourth, the current study is limited in evaluating the optimal cut-off score for children younger than 36 months. Further research involving more Indonesian children within the age range of 12 to 36 months is needed in order to investigate the optimal cut-off of the ADEC-IND in this age group, considering that the sensitivity and specificity of the original ADEC and ADEC-SP were found to be highest with participants from 12 to 36 months (Hedley et al., 2010; Young, 2007).

Fifth, the current study is limited as the same assessor administered both the ADEC-IND and ADI-R. In order to reduce bias in testing by the same assessor, the ADEC needs to be assessed before the ADI-R. This ideal condition, however, is difficult to apply in some testing situations (e.g. the child slept when the assessor came, the child needed to eat).

Therefore, if in further studies a different assessor could not be provided, the assessor needs to ensure that the ADEC is tested prior to the ADI-R.

Sixth, Indonesia itself is a multi-ethnic country and not all ethnicities were represented in the current study. Therefore, it is suggested to recruit participants from all ethnic groups in Indonesia in order to generalize the findings to a wider area of Indonesia. Finally, the assessment of ADI-R and ADEC-IND in the current study was conducted by the same person as providing more than one assessor who is trained in using the ADI-R and/or the ADEC-IND was beyond the scope of the project. Therefore, if feasible, future research should have multiple assessors trained in ADI-R and ADEC-IND in order to increase the objectivity of the assessment and to minimize subjective bias.

In addition to the limitations in methodology, having a larger sample size in the current study would have improved the ability to generalize the findings. The capacity to include more participants was affected by challenges in recruitment as participating in research is not common in Indonesian society. Research assistants needed to encourage and convince institutions and parents of participants about the importance of the study in order to recruit participants. Nevertheless, this number (N=82) is consistent with other adaptation studies in the ASD area (e.g., Hedley et al., 2010; Inada et al., 2011; Jackson et al., 2013). For future research, the challenge of recruiting participants in Indonesia could be minimized by establishing a forum or community for parents or institutions in order to connect them with researchers. Through the forum, parents could be offered access to the latest ASD and disability research findings that could be presented in an easy to comprehend and appropriate way for parents.

5. Conclusions

In conclusion, the present study found that the Indonesian version of the ADEC was valid and reliable in discriminating participants with ASD from those without ASD in a

sample of Indonesian children aged 14 to 72 months. Only one item in the ADEC-IND is suggested to be modified in order to make the tool more culturally sensitive for the Indonesian population. Moreover, the ADEC-IND was found to have sound psychometric properties and be suitable for use in developing countries such as Indonesia. Finally, and following the Spanish version of ADEC that was recommended to be used as a diagnostic tool in Mexico (Hedley et al., 2010), the present study suggests that the ADEC-IND could be used together with the CARS to move closer to an Indonesian gold standard tool for diagnosing ASD. This is the first study aimed to validate a detection tool for ASD in the Indonesian context.

Acknowledgements

This study was partially funded by the Australian Award Scholarship and the Disability Studies Center, Faculty of Social Sciences, University of Indonesia under contract 088/Puska-D/VIII/XI/2013 awarded to Fransisca Febriana Sidjaja.

Chapter 7

General Discussion

Receiving good quality health care is one of the basic rights of children covered in the United Nations Convention on the Rights of the Child (UN General Assembly, 1989). Every child in the world has the right to have access to good facilities, services and treatment, to maximize their life span. For a child with ASD, this principle can be implemented by providing early detection. Early detection of ASD is useful if it is followed by appropriate intervention for the child, while for the family, early detection could reduce family stress by providing family support and education (Cox et al., 1999). However, in developing countries such as Indonesia, the application of the basic right of early detection for children with ASD is still problematic. Currently, the prevalence of children with ASD in Indonesia remains unknown, and health services for children with ASD are located only within big cities such as Jakarta, the capital city of Indonesia. Compared to developed countries where ASD services and facilities are systemised, funded, and supported by governments, children with ASD's basic right to have proper early diagnosis and intervention is still neglected by the governments in most developing countries. Therefore, motivated by the fundamental principle of the importance in providing appropriate health care for children, the three studies in the current thesis were conducted.

The results of the first study can be summarised within the context of two main issues. First, it was found that the principles based on the best practice guidelines from developed countries are not applied in Indonesia. The use of multidisciplinary and multilevel approaches are challenging in the Indonesian context, since Indonesia's health care system does not usually involve the two approaches (multidisciplinary and multilevel), while the use of formal diagnostic tools is lacking due to scarcity of validated measurement tools in Indonesia. Second, having more validated tools, as well as being equipped through more

professional training for assessing ASD, are the two most urgent needs indicated by Indonesian ASD specialists. These results provide an insight into the feasibility of adopting the developed countries' best practice guidelines in developing countries. The study also served as an initial study which described the needs and challenges of ASD specialists in Indonesia. From this study, specific data about ASD specialists' circumstances in Indonesia has been collected and can be used to develop effective strategies to improve the quality of ASD assessments in this fourth most populated country in the world. These findings relating specifically to Indonesia, however, are not surprising, as studies relating to developed countries have reported obstacles in following best practices, even in the countries where the guidelines were originally developed (e.g. Berenstein, 2012). In terms of the first study's results, although the principles of the best practice guidelines need to be revised in order to make them more applicable, the findings of the current thesis strongly supports the third element of the guidelines, this being the use of standardised tools in diagnosing ASD. As discussed by Merrel (2008), in acquiring information about whether a child meets criteria for a behavioural or social emotional disorder, a clinician needs to combine idiographic and nomothetic approaches. In making a diagnosis, clinical judgement is an application of the use of an idiographic approach that perceives each case as being unique, while the use of standardised tools to enable an understanding to be achieved of the child's position in a population is a form of a nomothetic approach where the child is seen as a part of a population. A good clinician should use the information received from the use of formal measurement tools (i.e., a nomothetic approach) to guide his or her clinical judgement (i.e., an idiographic approach). Therefore, in terms of diagnosing ASD, standardised tools help a clinician to categorise the evaluated child into an ASD or non ASD group, and subsequently, his or her clinical judgement can be used to describe the child in a unique way. This is why in a clinical perspective, although two children may receive similar scores which categorise

them into the same diagnostic group, they cannot be described as being equal to each other as each child possesses unique characteristic that differentiate them from each other (e.g. differences in the child's cognitive abilities, family environment, or personality). At this point, the clinicians need to use their clinical judgement to describe each ASD case in a specific and unique way. The second and third studies were undertaken based on the results of the first study, being guided by the principle of the use of information from formal measurement tools in diagnosing ASD cases. Both studies were conducted in order to provide a validated assessment tool for Indonesian practitioners. The ADEC was chosen for adaptation, based on its features and appropriateness for use in developing countries such as Indonesia.

The second study in the thesis involved the translation of ADEC and the pilot study. This study aimed to trial an Indonesian-adapted version of the ADEC that could then be tested in the third study, as well as to identify any future potential challenges that could possibly be encountered in the final study. These two aims were fulfilled. In terms of the translation process, after being reviewed independently by two bilingual graduate students, the final draft of the ADEC-IND was completed. With regards to the pilot project, the findings identified three needs that should be addressed in preparing a large scale study: (1) the need to recruit another research assistant to oversee technical issues; (2) the need to allocate two hours of testing time for each participant and parent; and (3) the need to frequently remind the parents to not reveal their child's diagnosis to the researcher.

In the second study, the main challenge encountered in the translation process was finding appropriate and equivalent words or terms in the Indonesian language that accurately represented the original meaning. This challenge is supported by the comments of Foxcroft (2011), who argued that finding equivalent translated terms or words which are able to represent the precise meaning of original terms, is one of the challenges usually found in the

translation process. The challenge in finding culturally appropriate terms can potentially affect the validity and reliability of the adapted tool. Therefore, in terms of using measurement tools developed from different cultures, this difference should be considered and acknowledged. A decision to use any measurement tools from developed Western countries without considering the tools' appropriateness within the population in which the tool will be used, can potentially lead to diagnostic inaccuracies. A sample explanation of this issue would be the well-known screening tool, M-CHAT. Although the screening tool has been translated into 22 languages, including Indonesian, not all of the translated versions have been fully validated (Robins & Fein, 2011). Some of the validated versions are the Japanese version (Inada et al., 2011), Arabic version (Seif Eldin et al., 2008), and Sri Lankan version (Perera, Wijewardena, & Aluthwelage, 2009). The current translated Indonesian version of the M-CHAT has been recommended for use (HIMPSI, 2008), despite issues of cultural differences that might potentially affect the validity of the tool when used in the Indonesian culture. Although the Indonesian version of M-CHAT may not carry any problematic cultural issues, it was found that the accuracy was low when it was used in a population of rural people with low economic backgrounds (Scarpa et al., 2013).

Therefore, based on the principle that the diagnosis of ASD needs to be conducted using standardised tools, the final study of this thesis aimed to provide a standardised tool that had been validated with a sample of Indonesian children. There were two major findings in the results of the third study. First, in terms of psychometric properties, the study found that ADEC-IND possessed excellent sensitivity and specificity, and had high reliability as well as validity. The level of agreement between ADEC-IND and the gold standard tool, ADI-R, was found to be moderate. Second, in terms of cultural appropriateness, it was found that only one item (item #14) in ADEC-IND needed to be modified in order to make it more culturally appropriate, with the remaining 15 items were found to be appropriate for use in the

Indonesian context. In terms of psychometric properties, the results were in line with a study by Hedley et al. (2010) who found a Spanish version of ADEC (ADEC-SP) also possessed good psychometric properties which made it effective for assessing ASD in Mexican children. No item modification of the Spanish version was reported

7.1. Contributions and Practical Implications

The results of the three studies undertaken in this research program collectively make a number of important contributions and suggest a number of practical implications for the diagnosis and assessment of ASD in young children in Indonesia. First, this research has contributed in providing information about the needs and challenges of ASD specialists in developing countries such as Indonesia, and could therefore serve as a starting point to provide a better understanding of developing countries' conditions. This information has considerable relevance for use by decision makers at the Ministry of Health Republic of Indonesia, the Indonesian Psychology Association, and the Indonesian Medical Association. For example, as well as having more validated tools for assessing ASD, it was found that additional training is needed for ASD specialists in Indonesia. In response to this need, the Ministry of Health might consider allocating funds to provide funded training for ASD specialists, especially for those who work in rural areas. The training could be held in Jakarta or in other large cities in Indonesia. It could be facilitated by the Indonesian Psychological Association in cooperation with the Indonesian Medical Association. Funding from the Health Ministry would be needed to support the training expenses, as well as the accommodation and transportation needed to be able to bring practitioners from rural areas to attend the training sessions.

The results of the present research also established that the ADEC-IND is a valid and reliable measure for use with Indonesian children. This is the first study focused on an examination of the validity of an assessment tool for diagnosing ASD in Indonesia. It

provided evidence for the successful validation of a measurement tool that can be used by ASD specialists in Indonesia. Based on this finding, effective strategic plans need to be developed to introduce and disseminate the ADEC-IND to ASD specialists in Indonesia. After acquiring permission from the ADEC's publisher to use the ADEC-IND, training for trainers on how to use the tool should be conducted. This can be arranged by inviting the developer of ADEC (Young, 2007) to provide training on how to administer ADEC in Indonesia. The initial training could serve as a pilot project before conducting training on a large scale. The training could be first conducted in Jakarta to involve ASD specialists and then larger scale training could be delivered to ASD specialists and health practitioners throughout Indonesia. All of the proposed training would need to be evaluated to ensure that the ADEC-IND was delivered in a culturally sensitive and appropriate way.

Considering that this research has shown the ADEC-IND holds strong psychometric properties, it provides evidence that the adoption of the ADEC-IND as one of Indonesia's good practice assessment tools should be considered for the future. As reported in the third study, the ADEC-IND possesses excellent sensitivity and specificity, high internal consistency, and high inter-rater reliability. The tool's price is lower than the gold standard tools, yet it showed good correlation with the ADI-R. Furthermore, when compared to ADOS and ADI-R, the ADEC-IND does not require extensive and expensive training, which makes it easier for training health practitioners across Indonesia. This feature fulfils the need of Indonesian ASD specialists, as the first study in this thesis found that most of the specialists expected to have more diagnostic tools for which training and costing are not prohibitive. In addition, the flexibility that allows testers to use culturally appropriate materials is another significant issue that highlights the appropriateness of ADEC-IND in a country such as Indonesia with more than 300 ethnic groups. For adoption, however, more research into the psychometric properties of the ADEC-IND is warranted in order to strengthen the current

findings. To then facilitate the widespread adoption of ADEC-IND, the recommendation is that the ADEC-IND becomes Indonesia's gold standard tool for diagnosing ASD which, together with CARS, could be communicated to the Indonesian Psychological Association, Indonesian Medical Association, and Indonesian Health Department.

ADEC-IND can also be used to improve ASD research. To date, it has been difficult to conduct any studies on ASD in Indonesia as there has been no validated measurement tool for potential use for categorising participants into ASD and non-ASD groups. Based on the results of the third study, researchers would now be able to classify participants into ASD and non-ASD categories using ADEC-IND, and also investigate ASD issues in Indonesia using an Indonesian sample. For example, investigating the effectiveness of interventions through measuring the quality of therapies and approaches commonly used to treat ASD is one of the most urgent needed studies. This issue is important, considering that currently the behaviour therapy applied for children with ASD in Indonesia is not conducted within the context of formal certified training. However, this does not mean that the types of interventions in Indonesia are not effective. Studies on the effectiveness of any intervention approaches will provide useful information that could be used by decision makers (e.g. Indonesian Psychology Association or Ministry of Health) in developing evidenced-based intervention guidelines that can be used by parents of children with ASD. Therefore, the introduction of the tool to academics and researchers, as well as practitioners, should be considered, as using ADEC-IND for research purposes could enrich the quality and quantity of ASD-related studies in Indonesia.

7.2. Strengths of the Studies

The research output reported in this thesis has a number of strengths, as well as limitations, that need to be recognized. First, this research serves as pioneering studies that can be used to provide evidence for ASD assessment and diagnosis within the Indonesian

context. In aiming to understand the application of best practice guidelines in developing countries, data from the first study could serve as a basis for beginning to understand other developing countries' situations in term of assessing and diagnosing ASD. Specifically, this is the first study aimed at comprehending the needs and challenges of ASD specialists in Indonesia. The second and third studies served to provide the first validation of an ASD assessment tool in an Indonesia context. Although CARS and M-CHAT are available in the Indonesian language, to date there has been no validation or adaptation study on the assessment tools used for diagnosing ASD in Indonesia.

Second, the three studies provide practical support for ASD specialists in Indonesia. By adapting ADEC into an Indonesian context, this thesis has addressed one of the crucial needs of ASD specialists of having more validated tools in the Indonesian language. The results of the current research have provided Indonesia with the first validated instrument that can be used for ASD diagnostic and research purposes.

Third, in contrast to the Mexican study (Hedley et al., 2010), participants in the ASD group in the third study in this thesis were all classified using CARS. In the Mexican study, 15 of 19 participants in the ASD group were grouped using the CARS, while four participants' diagnoses remained unknown. The third study in this thesis was an advance in classifying participants in the ASD group when compared with the Mexican study. Having all participants in the ASD group classified using CARS gives more confidence in the validity of the translated ADEC.

7.3. Limitations and Recommendations for Future Studies

The current thesis research is not without its limitations. Difficulty in finding and recruiting participants was a common problem encountered across all three studies. In the first study, a total of 300 health practitioners were approached to participate. However, only 120 participated in the survey and of these, 53 were excluded for not fitting the inclusion

criteria. Therefore, the first study's final sample is small ($n=67$). Nonetheless, the sample is considered to be representative, considering that the number of ASD cases received by the health practitioner participants per month ranged from 1 to 160 cases, while the participants' years of experience in dealing with ASD cases ranged from 1 to 36 years. For the benefit of future research, it is recommended that an autism practitioner's database be developed to assist researchers or other parties in recruiting participants.

In the second study, the research team was unsuccessful in finding more Indonesian children with ASD or other disabilities in Australia. This reduced the participants' variety of conditions in the pilot group. Of the eight child participants, only one had a previous diagnosis of ASD, while the others were all typically developing children. Therefore, the development of a social network for Indonesian parents of children with disabilities who live in Australia could be very helpful. Such a network would benefit researchers and parents, as the network would provide the opportunity for parents to share supportive information relating to their children's conditions during their time in Australia. Similar to the first and second studies, in the third study the research assistants encountered challenges in recruiting children with ASD in the 'less than 36 months' age group. This could mean that there were not many children under 36 months receiving ASD diagnoses, since conducting diagnosis for children in this age range can be very challenging without access to appropriate assessment tools. Past studies have found that the sensitivity and specificity ratings of ADEC are highest within samples of children aged less than 36 months (Hedley et al., 2010; Young, 2007). In the present study there were only two participating children classified with ASD aged less than 36 months. The challenge in finding appropriate participants impeded the study's scope in finding the maximum cut-off score of ADEC-IND. Therefore, for future research, it is recommended to extend the recruitment area to other cities in Indonesia in order to find more participants with ASD who are less than 36 months of age.

Most participants in the three studies were located in an urban area. In the first study, only two out of 67 participants worked in rural areas of Indonesia, with the highest number of participants working on Java Island, an area where most economic and health sectors are centralised. The study encountered difficulties in approaching and recruiting ASD specialists in rural areas, as there is no specific database containing contact information that can be accessed. In the second study, all of the participants were recruited from two large cities in Australia (Brisbane and Melbourne) while in the third study, all of the participants were located within five major cities in Java, Indonesia. Considering this limitation, further research is recommended to validate the ADEC-IND with a sample of children from rural areas of Indonesia. Moreover, if possible, future research should include more people with diverse ethnic backgrounds. There are approximately 300 ethnicities in Indonesia and the third study's sample did not cover all of these ethnic groups. Having data from rural areas and across the different ethnic groups will assist in supporting the wider acceptance of the ADEC-IND across Indonesia.

These above two limitations could limit the generalisability of the research findings. However, samples used in past ADEC and ADEC-SP validation studies were also recruited from urban areas in Australia ($N=269$; Young, 2007) and Mexico ($N=115$; Hedley et al, 2010), reflecting that the recruitment of children with disabilities from rural areas presents greater challenges.

Another limitation of this thesis is specifically related to the restricted range of tools for diagnosing ASD in Indonesia. In the third study, participants with ASD were categorised into different groups based on previous diagnoses by Indonesian practitioners using CARS. In the statistical analysis, agreement between the diagnoses based on the use of ADEC-IND and CARS was found to be moderate. However, although CARS has been available since 1992 (Wignyosumaryo et al., 1992), to date there is no evidence regarding its validation with an

Indonesian sample. CARS has been commonly and widely employed in Indonesia without empirical support for its use. Nevertheless, in the third study the Indonesian version of CARS was found to be moderately correlated with the gold standard tool, ADI-R. For future research it is highly recommended that an empirical study be conducted to examine the validity of the Indonesian version of CARS within a sample of Indonesian children, as having more validated tools for diagnosing ASD is urgently needed by Indonesian practitioners. In addition, the provision of more validated tools would increase opportunities for the conduct of studies in the area of ASD in Indonesia, as researchers would be able to use the tools to classify the participants into ASD and non-ASD groups.

7.4. Conclusions

In conclusion, this thesis provides strong evidence for the psychometric properties of an Indonesian adapted-version of ADEC, this being ADEC-IND. As a response to the survey of Indonesian practitioners, evidence that the ADEC-IND was effective to be used in diagnosing ASD within Indonesian children sample was gathered. Together, these results support the uptake of ADEC-IND for use in diagnosing and assessing ASD with Indonesian children. Further, following these positive findings, training on how to use ADEC is highly recommended, firstly in the Jakarta area, and then subsequently throughout Indonesia. Finally, considering that the gold standard tools suggested by developed countries' best practice guidelines are not directly applicable in Indonesia, this thesis recommends the use of ADEC-IND, accompanied with the CARS, to be the best practice tools for diagnosing ASD in Indonesia.

The goal of having a reliable and valid, as well as culturally appropriate and sensitive instrument for diagnosing ASD in young children in Indonesia has been achieved. The goal remains for the adoption of this instrument to provide early interventions for young children diagnosed with ASD in Indonesia.

References

- Adioetomo, S. M., Mont, D., & Irwanto. (2014). *Persons with Disabilities in Indonesia: Empirical Facts and Implications for Social Protection Policies*. Jakarta, Indonesia : Demographic Institute, Faculty of Economics, University of Indonesia/Tim Nasional Percepatan Penanggulangan Kemiskinan (TNP2K).
- Allison, C., Baron-cohen, S., Wheelwright, S., Charman, T., Richler, J., Pasco, G., & Brayne, C. (2008). The Q-CHAT (quantitative CHecklist for autism in toddlers): A normally distributed quantitative measure of autistic traits at 18-24 months of age: Preliminary report. *Journal of Autism and Developmental Disorders*, 38(8), 1414-1414-25. doi:10.1007/s10803-007-0509-7
- Al-Salehi, S. M., Al-Hifthy, E. H., & Ghaziuddin, M. (2009). Autism in Saudi Arabia: Presentation, clinical correlates and comorbidity. *Transcultural Psychiatry*, 46(2), 340-347. doi: 10.1177/1363461509105823
- Amaral, D. G. (2011). The promise and the pitfalls of autism research: An introductory note for new autism researchers. *Brain Research*, 1380(Journal Article), 3-9. doi: 10.1016/j.brainres.2010.11.077
- American Psychiatric Association (1980). *Diagnostic and statistical manual of mental disorders* (3th ed.). Washington, DC: Author
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., Text Revision). Washington, DC: Author
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C: American Psychiatric Association.
- Anderson, S. W., Damasio, H., Jones, R. D., & Tranel, D. (1991). Wisconsin Card Sorting Test Performance as a Measure of Frontal Lobe Damage. *Journal of Clinical and Experimental Neuropsychology*, 13(6), 909-922. doi: 10.1080/01688639108405107

- Australian Bureau of Statistics (2014, 3 June 2014). *Prevalence of Autism. 4428.0 - Autism in Australia, 2012* Retrieved 18 February 2015, from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Feature%20s32012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=>
- Australian Council for Educational Research. (2012). *Clinical assessment and resources 2012 – 2013*. Retrieved from the World Wide Web 7 August 2014
http://www.acer.edu.au/files/Psych_Cat_V7-web.pdf
- Autism Association of Western Australia. (2011, 8 September 2011). *Autism : New research findings*. Asia Pacific Autism Conference. Retrieved 24 February 2015 from http://www.autism.org.au/sites/autismorgau/assets/public/File/Media_Centre/apac11_media_release_september_8_2011.pdf
- Autism Services Coordinating Committee (2003). *Assessment guidelines and protocol for the identification of autism spectrum disorders*. Victoria: Autism Victoria. Retrieved from <http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/assessment-protocol.pdf>
- Barbaro, J., & Dissanayake C. (2010). Prospective identification of Autism Spectrum Disorders in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study (SACS). *Journal of Developmental and Behavioral Pediatrics*, 31, 376-385.
- Barbaro, J., & Dissanayake, C. (2013). Early markers of Autism Spectrum Disorders in infants and toddlers prospectively identified in the Social Attention and Communication Study (SACS). *Autism: International Journal of Research and Practice*, 17, 64-86.

- Baron-Cohen, S. (1989). The Autistic Child's Theory of Mind: a Case of Specific Developmental Delay. *Journal of Child Psychology and Psychiatry*, 30(2), 285-297. doi: 10.1111/j.1469-7610.1989.tb00241.x
- Baron-Cohen, S. (2000). The early identification of autism: The Checklist for Autism in Toddlers (CHAT). *Journal of the Royal Society of Medicine*, 93, 521-525. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1298126/pdf/11064690.pdf>
- Baron-Cohen, S. (2001). theory of mind in normal development and autism. *Prisme*, 34, 174-183
- Baron-Cohen, S., Jolliffe, T., Mortimore, C., & Robertson, M. (1997). Another Advanced Test of Theory of Mind: Evidence from Very High Functioning Adults with Autism or Asperger Syndrome. *Journal of Child Psychology and Psychiatry*, 38(7), 813-822. doi: 10.1111/j.1469-7610.1997.tb01599.x
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "Theory of mind?". *Cognition*, 21(1), 37-46. doi: 10.1016/0010-0277(85)90022-8
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. [10.1192/bjp.bp.108.059345]. *The British Journal of Psychiatry*, 194(6), 500-509.
- Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y., & Plumb, I. (2001). The "Reading the Mind in the Eyes" Test Revised Version: A Study with Normal Adults, and Adults with Asperger Syndrome or High-functioning Autism. *Journal of Child Psychology and Psychiatry*, 42(2), 241-251. doi: 10.1111/1469-7610.00715
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2014). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine, FirstView*, 1-13. doi: doi:10.1017/S003329171400172X

- Bayley, N. (1993). *Bayley scales of infant and development-second edition*. San Antonio, TX: The Psychological Corporation.
- Berenstein, A. N. (2012). *Predictors of screening and referral practices for autism among Canadian family physicians* (Doctoral dissertation, University of Windsor). Retrieved from <http://search.proquest.com/docview/1015338989?accountid=14723>
- Berument, S. K., Rutter, M., Lord, C., Pickles, A., & Bailey, A. (1999). Autism screening questionnaire: Diagnostic validity. *British Journal of Psychiatry*, 175, 444-451.
- Bishop, D. V., Whitehouse, A. J., Watt, H. J., & Line, E. A. (2008). Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder. *Developmental Medicine and Child Neurology*, 50, 341-345.
- Bowler, D. M. (1992). "Theory of mind" in Asperger's syndrome. *Journal of child psychology and psychiatry, and allied disciplines*, 33(5), 877-893.
- Breidbord, J., & Croudace, T. (2013). Reliability Generalization for Childhood Autism Rating Scale. *Journal of Autism and Developmental Disorders*, 43(12), 2855-2865. doi: 10.1007/s10803-013-1832-9
- Brereton, A. V., Tonge, B. J., Mackinnon, A. J., & Einfeld, S. L. (2002). Screening young people for autism with the developmental behaviour checklist. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(11), 1369-1375. doi:10.1097/00004583-200211000-00019
- Bryson, S. E., Clark, B. S., & Smith, I. M. (1988). First report of a Canadian epidemiological study of autistic syndromes. *Journal of Child Psychology and Psychiatry*, 29(4), 433-445. doi: 10.1111/j.1469-7610.1988.tb00735.x
- Budhiman, M. (2014). *Review masalah autisme di Indonesia [Reviewing autism problems in Indonesia]*. Indonesian Autism Foundation. Jakarta, Indonesia.

- Carrington, S. J., Kent, R. G., Maljaars, J., Le Couteur, A., Gould, J., Wing, L., . . . Leekam, S. R. (2014). DSM-5 Autism Spectrum Disorder: In search of essential behaviours for diagnosis. *Research in Autism Spectrum Disorders*, 8(6), 701-715. doi: <http://dx.doi.org/10.1016/j.rasd.2014.03.017>
- CDC. (2014). *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010*. (28 March 2014). Morbidity and Mortality Weekly Report Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm>.
- Charman, T. (2008). Autism spectrum disorders. *Psychiatry*, 7(8), 331-334. doi: 10.1016/j.mppsy.2008.05.015
- Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism spectrum disorder in the second year: stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry*, 48(2), 128-138. doi: 10.1111/j.1469-7610.2006.01685.x
- Cicchetti, D., Lord, C., Koenig, K., Klin, A., & Volkmar, F. (2008). Reliability of the ADI-R: Multiple Examiners Evaluate a Single Case. *Journal of Autism and Developmental Disorders*, 38(4), 764-770. doi: 10.1007/s10803-007-0448-3
- Connolly, M., & Gersch, I. (2013). A support group for parents of children on a waiting list for an assessment for autism spectrum disorder. *Educational Psychology in Practice*, 29(3), 293-308. doi: 10.1080/02667363.2013.841128
- Corsello, C. M., Akshoomoff, N., & Stahmer, A. C. (2013). Diagnosis of autism spectrum disorders in 2-year-olds: A study of community practice. *Journal of Child Psychology and Psychiatry*, 54(2), 178-185. doi: 10.1111/j.1469-7610.2012.02607.x
- Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., . . . (1999). Autism spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R

diagnosis. *Journal of Child Psychology and Psychiatry*, 40(5), 719-719-732.

doi:10.1111/1469-7610.00488

Daley, C., & Sigman, D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists and pediatricians. *Journal of Autism and Developmental Disorders*, 32(1), 13 - 23. doi: 10.1023/A:1017947922349

Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social Science & Medicine*, 58(7), 1323-1335. doi: 10.1016/S0277-9536(03)00330-7

de Bildt, A., Sytema, S., Ketelaars, C., Kraijer, D., Mulder, E., Volkmar, F., et al. (2004). Interrelationship between Autism Diagnostic Observation Schedule-Generic (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) classification in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders*, 34, 129–137. doi: 10.1007/s10803-009-0749-9

Departemen Pendidikan Nasional [National Department of Education]. (2008). *Kamus Besar Bahasa Indonesia [The Great Dictionary of the Indonesian Language of the Language Center]*. Jakarta : Pusat Bahasa

Department of Developmental Services (2002). *Autistic spectrum disorders: Best practice guidelines for screening, diagnosis and assessment*. Sacramento Ca: California Department of Developmental Services. Retrieved from http://www.dds.ca.gov/Autism/docs/ASD_Best_Practice2002.pdf

Department of Social Services (2014). *Helping children with autism*. Retrieved from the World Wide Web 7 August 2014 <http://www.dss.gov.au/our->

[responsibilities/disability-and-carers/program-services/for-people-with-disability/helping-children-with-autism](#)

- Dilavore, P. C., Lord, C., & Rutter, M. (1995). The Pre-Linguistic Autism Diagnostic Observation Schedule. *Journal of Autism and Developmental Disorders*, 25(4), 355-379.
- Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. *Autism Research*, 5(3), 190-200. doi: 10.1002/aur.1225
- Dumont-Mathieu, T., & Fein, D. (2005). Screening for autism in young children: The Modified Checklist for Autism in Toddlers (M-CHAT) and other measures. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(3), 253-262. doi:10.1002/mrdd.20072
- Einfeld, S., & Tonge, B. (1995). The Developmental Behavior Checklist: The development and validation of an instrument to assess behavioral and emotional disturbance in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders*, 25(2), 81-104. doi: 10.1007/bf02178498
- Feinstein, A. (2010). *A history of autism: conversations with the pioneers*. Chichester, West Sussex, U.K: Wiley-Blackwell.
- Fenske, E.C., Zalenski, S., Krantz, P.J. & McClannahan, L.E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis and Intervention in Developmental Disabilities*, 5, 49-58.
- Filipek, P., Accardo, P., Baranek, G., Cook, E., Jr., Dawson, G., Gordon, B., . . . Volkmar, F. (1999). The Screening and Diagnosis of Autistic Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 29(6), 439-484. doi: 10.1023/a:1021943802493

- Folio, M. R., & Fewell, R. R. (1983). *Peabody Developmental Motor Scales and activity cards*. Austin, TX: PRO-ED.
- Foxcroft, C. D. (2011). Ethical issues related to psychological testing in Africa: What I have learned (so far). *Online Readings in Psychology and Culture*, 2(2). doi: 10.9707/2307-0919.1022
- Frankenburg, W. K., & Dodds, J. B. (1967). The Denver Developmental Screening Test. *The Journal of Pediatrics*, 71(2), 181-191. doi: 10.1016/S0022-3476(67)80070-2
- Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., et al. (2012). Validation of proposed DSM-5 criteria for autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51, 28–40.
- Freeman, B. J., Ritvo, E. R., Guthrie, D., Schroth, P. & Ball, J. (1978). The Behavior Observation Scale for Autism: Initial methodology, data analysis, and preliminary findings on 89 children. *Journal of the American Academy of Child Psychiatry*, 17, 576-588.
- Frith, U., & Happé, F. (1994). Autism: beyond "theory of mind". *Cognition*, 50(1-3), 115-132. doi: 10.1016/0010-0277(94)90024-8
- Gilliam, J. (2006). *GARS-2: Gilliam Autism Rating Scale—Second Edition*. Austin, TX: PRO-ED
- Gilliam, James E. (2014). *GARS-3: Gilliam Autism Rating Scale, Third Edition, Examiner's Manual*. Austin, TX: PRO-ED.
- Gilliam, J. E. (1995). *Gilliam Autism Rating Scale*. Austin, TX: Pro-Ed.
- Ginanjar, A. S. (2007). Memahami spektrum autistik secara holistik [Understanding autism spectrum holistically]. *Makara*, 11(2), 87-99.
- Glascoe F. P. MacLean, W. E. and Stone W. L. (1991). The importance of parents' concerns about their child's behavior, *Clinical Pediatrics*, 30, pp.8-11.

- Hambleton, R. K. (2005). Issues, designs, and technical guidelines for adapting tests into multiple languages and cultures. In R. K. Hambleton, P. F. Merenda & C. D. Spielberger (Eds.), *Adapting Educational and Psychological Tests for Cross-Cultural Assessment* (pp. 3-38). Mahwah, New Jersey: LEA.
- Happé, F., Booth, R., Charlton, R., & Hughes, C. (2006). Executive function deficits in autism spectrum disorders and attention-deficit/hyperactivity disorder: Examining profiles across domains and ages. *Brain and Cognition*, *61*(1), 25-39. doi: 10.1016/j.bandc.2006.03.004
- Hathorn, C., Alateeqi, N., Graham, C., & O'Hare, A. (2014). Impact of adherence to best practice guidelines on the diagnostic and assessment services for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *44*(8), 1859-1866. doi: 10.1007/s10803-014-2057-2
- Hedley, D., Nevill, R. E., Monroy-Moreno, Y., Fields, N., Wilkins, J., Butter, E., & Mulick, J. A. (2015). Efficacy of the ADEC in identifying autism spectrum disorder in clinically referred toddlers in the US. *Journal of Autism and Developmental Disorders*, *45*(8), 2337-2348. doi:10.1007/s10803-015-2398-5
- Hedley, D., Young, R. L., Juarez-Gallegos, M. A., & Marcin-Salazar, C. (2010). Cross-cultural evaluation of the Autism Detection in Early Childhood (ADEC) in Mexico. *Autism*, *14*(2), 93-112. doi:10.1177/1362361309347676
- Hering, M. (2005). *A survey of psychologists' diagnostic practices in the assessment of children with autistic disorder* (Doctoral dissertation, Pepperdine University). Retrieved from <http://search.proquest.com/docview/305347938?accountid=14723>
- Hill, E. L. (2004). Executive dysfunction in autism. *Trends in Cognitive Sciences*, *8*(1), 26-32. doi: 10.1016/j.tics.2003.11.003

- Hill, E. L., & Frith, U. (2003). Understanding autism: Insights from mind and brain. *Philosophical Transactions: Biological Sciences*, 358(1430), 281-289.
doi:10.1098/rstb.2002.1209
- Himpunan Psikologi Indonesia (HIMPSI). (2008). *Panduan pemeriksaan dan diagnosa [The assessment and diagnosis guideline]*. Jakarta : HIMPSI Jaya.
- Honda, H., Shimizu, Y., & Rutter, M. (2005). No effect of MMR withdrawal on the incidence of autism: a total population study. *Journal of Child Psychology and Psychiatry*, 46(6), 572-579. doi: 10.1111/j.1469-7610.2005.01425.x
- Honda, H., Shimizu, Y., Misumi, K., Niimi, M., & Ohashi, Y. (1996). Cumulative incidence and prevalence of childhood autism in children in Japan. [10.1192/bjp.169.2.228]. *The British Journal of Psychiatry*, 169(2), 228-235.
- Hughes, C., Russell, J., & Robbins, T. W. (1994). Evidence for executive dysfunction in autism. *Neuropsychologia*, 32(4), 477-492. doi: 10.1016/0028-3932(94)90092-2
- IBM Corp. (2011). *IBM SPSS Statistics for Windows, Version 20.0*. Armonk, NY: IBM Corp.
- Inada, N., Koyama, T., Inokuchi, E., Kuroda, M., & Kamio, Y. (2011). Reliability and validity of the Japanese version of the Modified Checklist for autism in toddlers (M-CHAT). *Research in Autism Spectrum Disorders*, 5(1), 330-336. doi: 10.1016/j.rasd.2010.04.016
- Indonesian Health Ministry (2012). *Peraturan Menteri Kesehatan Republik Indonesia* [Republic of Indonesia health ministry regulation]. Retrieved May, 10, 2013, from http://www.depkes.go.id/downloads/PERATURAN_MENTERI_KESEHATAN_JUKNIS_JAMPERSAL.pdf
- International Test Commission (2005). *International guidelines on test adaptation*. Retrieved from the World Wide Web 1 August 2014 [http:// www.intestcom.org](http://www.intestcom.org)

- Irwanto, I., Kasim, E. R., Fransiska, A., Lusli, M., & Siradj, O. (2010). *The situation of people with disability in Indonesia: a desk review*. Jakarta: Centre for disability studies University of Indonesia.
- Irwanto. (2014). Hak atas kesehatan dan perlindungan sosial (Jaminan kesehatan) bagi difabel di Indonesia: Kajian kritis [medical and social protection rights for difable people in Indonesia: Critical analysis]. *Difabel*, 2(2).
- Jackson, L. S., Little, S. G., & Akin-Little, A. (2013). The Spanish adaptation of the Gilliam Autism Rating Scale-2: Translation and psychometric analysis. *Research in Autism Spectrum Disorders*, 7(9), 1160-1167. doi: <http://dx.doi.org/10.1016/j.rasd.2013.06.005>
- Jewett, D. L., & Williston, J. S. (1971). Auditory-evoked far field averages from the scalp of humans. *Brain*, (94), 681 – 696.
- Jolliffe, T., & Baron-Cohen, S. (1999). The Strange Stories Test: A Replication with High-Functioning Adults with Autism or Asperger Syndrome. *Journal of Autism and Developmental Disorders*, 29(5), 395-406. doi: 10.1023/a:1023082928366
- Jones, R. M., & Lord, C. (2013). Diagnosing autism in neurobiological research studies. *Behavioural Brain Research*, 251(0), 113-124. doi: <http://dx.doi.org/10.1016/j.bbr.2012.10.037>
- Kancee, A. (2009, December 21). Dokter umum jadi motor, pasien tak boleh langsung ke spesialis [General practioners should be the initiator, patients must not directly visit specialists]. *Radar Lampung*. Retrieved from <http://radarlampung.co.id/read/radar/berita-foto/25301-dokter-umum-jadi-motor-pasien-tak-boleh-langsung-ke-spesialis?tmpl=component&print=1&layout=default&page=>

- Kanne S. M., Randolph J. K., Farmer J. E. (2008). Diagnostic and assessment findings: A bridge to academic planning for children with autism spectrum disorders. *Neuropsychology Review*, 18(4), 367-384.
- Kartika, U., & Anna, L. K. (2014, 2 April 2014). Penanganan autisme belum bisa dilakukan di puskesmas [Autism treatment still cannot be conducted at government community health clinics], *Kompas Online*. Retrieved from <http://pilkada.kompas.com/jatim/read/2014/04/02/1320308/Penanganan.Autisme.Belum.Bisa.Dilakukan.di.Puskesmas>
- Kent, R. G., J. Carrington, S., Le Couteur, A., Gould, J., Wing, L., Maljaars, J., . . . R. Leekam, S. (2013). Diagnosing Autism Spectrum Disorder: who will get a DSM-5 diagnosis? *Journal of Child Psychology and Psychiatry*, 54(11), 1242-1250. doi: 10.1111/jcpp.12085
- Kim, Y. S., Leventhal, B. L., Koh, Y.-J., Fombonne, E., Laska, E., Lim, E.-C., . . . Grinker, R. R. (2011). Prevalence of Autism Spectrum Disorders in a Total Population Sample. *Am J Psychiatry*, 170(6). doi: 10.1176/appi.ajp.2011.10101532
- Koegel, L. K., Koegel, R. L., Ashbaugh, K., & Bradshaw, J. (2014). The importance of early identification and intervention for children with or at risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, 16(1), 50-56. doi: 10.3109/17549507.2013.861511
- Krug, D. A., Arick, J. R., & Almond, P. G. (1980). Behavior checklist for identifying severely handicapped individuals with high levels of autistic behavior. *Journal of Child Psychology and Psychiatry*, 21, 221-229. doi: 10.1111/j.1469-7610.1980.tb01797.x

- Kurita H, Miyake Y, Katsuno K. (1989) Reliability and validity of the Childhood Autism Rating Scale - Tokyo version (CARS-TV). *Journal of Autism and Developmental Disorders*, 19: 389-96.
- Lazoff, T., Zhong, L., Piperni, T., & Fombonne, E. (2010). Prevalence of pervasive developmental disorders among children at the English Montreal School Board. *Canadian journal of psychiatry. Revue canadienne de psychiatrie*, 55(11), 715-720.
- Le Couteur, A., Rutter, M., Lord, C., Rios, P., Robertson, S., Holdgrafer, M., & McLennan, J. (1989). Autism diagnostic interview: A standardized investigator-based instrument. *Journal of Autism and Developmental Disorders*, 19(3), 363-387. doi: 10.1007/bf02212936
- Leekam, S. R., Libby, S. J., Wing, L., Gould, J., & Taylor, C. (2002). The Diagnostic Interview for Social and Communication Disorders: algorithms for ICD-10 childhood autism and Wing and Gould autistic spectrum disorder. *Journal of Child Psychology and Psychiatry*, 43(3), 327-342. doi: 10.1111/1469-7610.00024
- Leekam, S. R., Nieto, C., Libby, S. J., Wing, L., & Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. *Journal of Autism and Developmental Disorders*, 37(5), 894-894-910. doi:10.1007/s10803-006-0218-7
- Li, Nannan. (2012). *Preliminary validation of the Childhood Autism Rating Scale - Second Edition Questionnaire For Parents Or Caregivers (CARS2-QPC) And The Gilliam Autism Rating Scale (GARS-2) with A Chinese-speaking population*. Eastern Kentucky University: Online Theses and Dissertations. Paper 69. Retrieved from <http://encompass.eku.edu/cgi/viewcontent.cgi?article=1068&context=etd>
- Lord, C., & Corsello, C. (2005). Diagnostic instruments in autism spectrum disorders. In F.R. Volkmar, R. Paul, A. Klin, & D.J. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed, pp. 730–771). New York: Wiley

- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The Autism Diagnostic Observation Schedule-Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, *30*(3), 205-223.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorder*, *24*(5), 659-685. doi:10.1007/BF02172145
- Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). Autism diagnostic observation schedule: A standardized observation of communicative and social behavior. *Journal of Autism and Developmental Disorders*, *19*(2), 185-212. doi: 10.1007/bf02211841
- Lord, C., Storoschuk, S., Rutter, M., & Pickles, A. (1993). Using the ADI—R to diagnose autism in preschool children. *Infant Mental Health Journal*, *14*(3), 234-234-252. doi:10.1002/1097-0355(199323)14:3<234::AID-IMHJ2280140308>3.0.CO;2-F
- Lord, C., Rutter, M., DiLavore, P.C., Risi, S., Gotham, K., & Bishop, S.L. (2012). *Autism Diagnostic Observation Schedule, Second Edition (ADOS -2) Manual (Part 1) : Modules 1- 4*, Torrance, CA : Western Psychological Services.
- Lotter, V. (1966). Epidemiology of autistic conditions in young children. *Social psychiatry*, *1*(3), 124-135. doi: 10.1007/bf00584048
- MacDermott, S., Williams, K., Ridley, G., Glasson, E. & Wray, J. (2008). The prevalence of autism in Australia. Can it be established from existing data? *Journal of Paediatrics and Child Health*, *44*(9), 504-510. doi: 10.1111/j.1440-1754.2008.01331.x
- Maljaars, J., Noens, I., Scholte, E., & van Berckelaer-Onnes, I. (2012). Evaluation of the criterion and convergent validity of the Diagnostic Interview for Social and

Communication Disorders in young and low-functioning children. *Autism*, 16(5), 487-497. doi: 10.1177/1362361311402857

- Matson, J. L., Belva, B. C., Horovitz, M., Kozlowski, A. M., & Bamburg, J. W. (2012). Comparing symptoms of autism in a developmentally disabled adult population using the current DSM-IV-TR diagnostic criteria and the proposed DSM-5 diagnostic criteria. *Journal of Developmental and Physical Disabilities*, 24, 403–414.
- Matson, J. L., Boisjoli, J. A., & Wilkins, J. (2007). *Baby and Infant Screen for Children with aUtism Traits (BISCUIT)*. Baton Rouge, La. Disability Consultants, LLC.
- Matson, J. L., Boisjoli, J., Rojahn, J., & Hess, J. (2009). A factor analysis of challenging behaviors assessed with the Baby and Infant Screen for Children with aUtism Traits (BISCUIT-Part 3). *Research in Autism Spectrum Disorders*, 3(3), 714-722. doi: <http://dx.doi.org/10.1016/j.rasd.2009.01.008>
- Matson, J. L., Fodstad, J. C., & Mahan, S. (2009). Cutoffs, norms, and patterns of comorbid difficulties in children with developmental disabilities on the Baby and Infant Screen for Children with aUtism Traits (BISCUIT-Part 2). *Research in Developmental Disabilities*, 30(6), 1221-1228. doi: <http://dx.doi.org/10.1016/j.ridd.2009.04.004>
- Matson, J., & Sipes, M. (2010). Methods of Early Diagnosis and Tracking for Autism and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS). *Journal of Developmental and Physical Disabilities*, 22(4), 343-358. doi: 10.1007/s10882-009-9184-2
- Mayes, S. D., Calhoun, S. L., Murray, M. J., Pearl, A., Black, A., & Tierney, C. D. (2014). Final DSM-5 under-identifies mild Autism Spectrum Disorder: Agreement between the DSM-5, CARS, CASD, and clinical diagnoses. *Research in Autism Spectrum Disorders*, 8(2), 68-73. doi: <http://dx.doi.org/10.1016/j.rasd.2013.11.002>

- McClintock, J. M., & Fraser, J. (2011). *Diagnostic instruments for autism spectrum disorder : A brief review NZ*: Retrieved from http://www.health.govt.nz/system/files/documents/publications/asd_instruments_report.pdf.
- McClure, I., Mackay, T., Mamdani, H., & Mccaughey, R. (2010). A comparison of a specialist autism spectrum disorder assessment team with local assessment teams. *Autism, 14*(6), 589-603. doi: 10.1177/1362361310373369
- McCrimmon, A., & Rostad, K. (2014). Test Review: Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) Manual (Part II): Toddler Module. *Journal of Psychoeducational Assessment, 32*(1), 88-92. doi: 10.1177/0734282913490916
- Merrell, K. W. (2008). *Behavioral, social, and emotional assessment of children and adolescents*. New York: Lawrence Erlbaum Associates.
- Ministry of Children and Family Development (2014). *Autism funding programs. The Government of British Columbia*. Retrieved from the World Wide Web 09 March 2014 http://www.mcf.gov.bc.ca/autism/funding_programs.htm.
- Mirpuri, G., Cooper, R., & Spilling, M. (2012). *Indonesia*. Tarrytown, NY: Marshall Cavendish.
- World Bank (2015). *Indonesia* Retrieved 18 February 2015, 2015, from <http://data.worldbank.org/country/indonesia>
- Montgomery, J. M., Newton, B., & Smith, C. (2008). Test Review: Gilliam, J. (2006). GARS-2: Gilliam Autism Rating Scale—Second Edition. Austin, TX: PRO-ED. *Journal of Psychoeducational Assessment, 26*(4), 395-401. doi: 10.1177/0734282908317116
- Mullen, E. M. (1995). *Mullen Scales of Early Learning : AGS Edition*. Circle Pines, MN: American Guidance Service.
- Nachshen, J., Garcin, N., Moxness, K., Tremblay, Y., Hutchinson, P., Lachance, A., . . . Ruttle, P.L. (2008). *Screening, assessment, and diagnosis of autism spectrum*

disorders in young children: Canadian best practice guidelines. Miriam Foundation, Montreal, Quebec.

Nah, Y.-H., Young, R., & Brewer, N. (2014). Using the Autism Detection in Early Childhood (ADEC) and Childhood Autism Rating Scales (CARS) to predict long term outcomes in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(9), 2301-2310. doi: 10.1007/s10803-014-2102-1

National Initiative for Autism: Screening and Assessment. (2003). *National autism plan for children (NAPC): Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorders*. London: National Autistic Society.

Nygren, G., Hagberg, B., Billstedt, E., Skoglund, A., Gillberg, C., & Johansson, M. (2009). The Swedish version of the Diagnostic Interview for Social and Communication Disorders (DISCO-10). Psychometric properties. *Journal of Autism and Developmental Disorders*, 39, 730-741.

Ozonoff, S., & Jensen, J. (1999). Brief Report: Specific Executive Function Profiles in Three Neurodevelopmental Disorders. *Journal of Autism and Developmental Disorders*, 29(2), 171-177. doi: 10.1023/a:1023052913110

Pearson, L. M. (2008). *A survey of Pennsylvania school psychologists' training, knowledge and evaluation practice for assessing and diagnosing autism spectrum disorders* (Doctoral dissertation, Philadelphia College of Osteopathic Medicine). Retrieved from http://digitalcommons.pcom.edu/cgi/viewcontent.cgi?article=1111&context=psychology_dissertations

- Peduli autisma kalangan menengah bawah [Care for people with autism from low economic background], *Kompas Online*. Retrieved from <http://pilkada.kompas.com/jatim/read/2013/12/18/1811205/Peduli.Autisma.Kalangan.Menengah.Bawah>
- Pereira, A., Riesgo, R. S., & Wagner, M. B. (2008). Childhood autism: translation and validation of the Childhood Autism Rating Scale for use in Brazil. *Jornal de Pediatria*, 0(0). doi: 10.2223/jped.1828
- Perera, H., Wijewardena, K., & Aluthwelage, R. (2009). Screening of 18–24-Month-Old Children for Autism in a Semi-Urban Community in Sri Lanka. *Journal of Tropical Pediatrics*, 55(6):402-5.
- Perner, J. & Wimmer, H. (1985). "John thinks that Mary thinks that...": Attribution of second-order beliefs by 5- to 10-year old children. *Journal of Experimental Child Psychology*, 39, 437-471.
- Premack, D., & Woodruff, G. (1978). Does the chimpanzee have a theory of mind? *Behavioral and Brain Sciences*, 1(4), 515-526.
- Rajendran, G., & Mitchell, P. (2007). Cognitive theories of autism. *Developmental Review*, 27(2), 224-260. doi: 10.1016/j.dr.2007.02.001
- Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F). *Pediatrics*, 133(1), 37-45. doi: 10.1542/peds.2013-1813
- Robins, D., & Fein, D. (2011). Modified Checklist for Autism in Toddlers (M-CHAT) also CHAT. In J. Kreutzer, J. DeLuca & B. Caplan (Eds.), *Encyclopedia of Clinical Neuropsychology* (pp. 1647-1650): Springer New York.

- Robins, D., Fein, D., Barton, M., & Green, J. (2001). The Modified Checklist for Autism in Toddlers: An Initial Study Investigating the Early Detection of Autism and Pervasive Developmental Disorders. *Journal of Autism and Developmental Disorders*, 31(2), 131-144. doi: 10.1023/a:1010738829569
- Rudra, A., Banerjee, S., Singhal, N., Barua, M., Mukerji, S., & Chakrabarti, B. (2014). Translation and Usability of Autism Screening and Diagnostic Tools for Autism Spectrum Conditions in India. *Autism Research*, 7(5), 598-607. doi: 10.1002/aur.1404
- Russell, P., Daniel, A., Russell, S., Mammen, P., Abel, J., Raj, L., . . . Thomas, N. (2010). Diagnostic accuracy, reliability and validity of Childhood Autism Rating Scale in India. *World Journal of Pediatrics*, 6(2), 141-147. doi: 10.1007/s12519-010-0029-y
- Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism Diagnostic Interview-Revised*. Los Angeles: Western Psychological Services.
- Samadi, S. A., & McConkey, R. (2011). Autism in developing countries: Lessons from Iran. *Autism Research and Treatment*, 2011. doi: 10.1155/2011/145359
- Saracino, J., Noseworthy, J., Steiman, M., Reisinger, L., & Fombonne, E. (2010). Diagnostic and Assessment Issues in Autism Surveillance and Prevalence. *Journal of Developmental and Physical Disabilities*, 22(4), 317-330. doi: 10.1007/s10882-010-9205-1
- Sayers, N., Oliver, C., Ruddick, L., & Wallis, B. (2011). Stereotyped behaviour in children with autism and intellectual disability: an examination of the executive dysfunction hypothesis. *Journal of Intellectual Disability Research*, 55(7), 699-709. doi: 10.1111/j.1365-2788.2010.01370.x
- Scarpa, A., Reyes, N., Patriquin, M., Lorenzi, J., Hassenfeldt, T., Desai, V., & Kerkering, K. (2013). The Modified Checklist for Autism in Toddlers: Reliability in a Diverse Rural

American Sample. *Journal of Autism and Developmental Disorders*, 43(10), 2269-2279. doi: 10.1007/s10803-013-1779-x

Schneider, B. (2000). *Friends and enemies: Peer relations in childhood*. London: Arnold.

Schopler, E., Reichler, R. J., Bashford, A., Lansing, M. D., Marcus, L. (1990).

Psychoeducational Profile Revised. Volume 1 (PEP-R). Austin, TX: Pro-Ed.

Schopler, E., Reichler, R. J., DeVellis, R. F., & Daly, K. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders*, 10(1), 91-103. doi:10.1007/BF02408436

Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. (2010). *Childhood Autism Rating Scale (2nd ed.)*. Los Angeles, CA: Western Psychological Services.

Scott et al (2002). Childhood Asperger's Syndrome Test (CAST), *Autism*, 6, pp.9-31.

Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbati, M., . . . Gaddour, N. (2008). Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry*, 20(3), 281-289. doi:10.1080/09540260801990324

Shah, A., & Frith, U. (1983). An islet of ability in autistic children : A research note. *Journal of Child Psychology and Psychiatry*, 24(4), 613-620. doi: 10.1111/j.1469-7610.1983.tb00137.x

Shah, A., & Frith, U. (1993). Why do autistic individuals show superior performance on the block design task? *Journal of child psychology and psychiatry, and allied disciplines*, 34(8), 1351-1364.

Sidjaja, F. F., Sofronoff, Kate., Newcombe, Peter., & Irwanto. (2015). *Understanding developing countries' challenges in applying the best practice: The diagnosis of autism in urban Indonesia*. Manuscript submitted for publication.

- Siegel, B. (1991). Play diagnosis of autism: the ETHOS play session. In C. Schaefer, K. Gitlin & A. Sandgrund (Eds.), *Play Diagnosis and Assessment*. New York: John Wiley & Sons.
- Siegel, B. (1998). *Early screening and diagnosis in autism spectrum disorders: The Pervasive Developmental Disorders Screening Test (PDDST)*. Paper presented at the NIH State of Science in Autism, Screening and Diagnosis Working Conference, Bethesda, MD.
- Siegel, B. (2004). *Pervasive Developmental Disorder Screening Test-II (PDDST-II)*. San Antonio, TX: Harcourt.
- Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9-22. doi: 10.1016/j.ridd.2005.09.003
- South, M., Williams, B. J., McMahon, W. M., Owley, T., Filipek, P. A., Shernoff, E. (2002). Utility of the Gilliam Autism Rating Scale in research and clinical populations. *Journal of Autism and Developmental Disorders, 32*(6), 593-593-599.
doi:10.1023/A:1021211232023
- Sparrow, S. S., Balla, D. & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales (expanded form)*. Circle Pines, MN: American Guidance Service. Bruininks, R., Woodcock, R., Weatherman, R. & Hill, B. (1984). *Scales of Independent Behavior*. Allen, TX: Teaching Resources/DLM.
- Sparrow, S.S., Balla, D.A., & Cicchetti, D.V. (1998). *Vineland Social-Emotional Early Childhood Scales (SEEC)*. Circle Pines, MN: American Guidance Service.
- Stone, W. L. & Hogan, K. L. (1993). A structured parent interview for identifying young children with autism. *Journal of Autism and Developmental Disorders, 23*, 639-652.

- Stone, W.L. , Coonrod, E.E. , Turner, L.M. & Pozdol, S.L. (2004). Psychometric Properties of the STAT for Early Autism Screening. *Journal of Autism and Developmental Disorders*, 34 (6), 691-701.
- Sun, X., & Allison, C. (2010). A review of the prevalence of autism spectrum disorder in Asia. *Research in Autism Spectrum Disorders*, 4(2), 156-167. doi: 10.1016/j.rasd.2009.10.003
- Sun, X., Allison, C., Auyeung, B., Matthews, F. E., Baron-Cohen, S., & Brayne, C. (2013a). What is available for case identification in autism research in mainland China? *Research in Autism Spectrum Disorders*, 7(5), 579-590. doi: <http://dx.doi.org/10.1016/j.rasd.2012.11.003>
- Sun, X., Allison, C., Auyeung, B., Matthews, F. E., Murray, S., Baron-Cohen, S., & Brayne, C. (2013b). Service provision for autism in mainland China: A service providers' perspective. *Research in Developmental Disabilities*, 34(1), 440-451. doi: <http://dx.doi.org/10.1016/j.ridd.2012.08.010>
- Sun, X., Allison, C., Auyeung, B., Baron-Cohen, S., & Brayne, C. (2013c). A review of healthcare service and education provision of Autism Spectrum Condition in mainland China. *Research in Developmental Disabilities*, 34(1), 469-479. doi: <http://dx.doi.org/10.1016/j.ridd.2012.08.013>
- Supartini, E. (2012). Program Son-Rise untuk Pengembangan Bahasa Anak Autis [Son-Rise program for children with autism's language development]. *Jurnal Pendidikan Khusus*, 1(3).
- Thorndike, R. L., Hagen, E. P., & Sattler, J. M. (1986). *Stanford-Binet Intelligence Scale: Fourth Edition*. Chicago: Riverside.

- Turner, M. (1997). Towards an executive dysfunction account of repetitive behaviour in autism. In J. Russell (Ed.), *Autism as an executive disorder* (pp. 57-100). Oxford: Oxford University Press.
- United Nations (1989). *Convention on the Rights of the Child*. Retrieved from <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>.
- Venter, A., Lord, C., & Schopler, E. (1992). A Follow-Up Study of High-Functioning Autistic Children. *Journal of Child Psychology and Psychiatry*, 33(3), 489-597. doi: 10.1111/j.1469-7610.1992.tb00887.x
- Ventola, P. E., Kleinman, J., Pandey, J., Barton, M., Allen, S., Green, J., (2006). Agreement among four diagnostic instruments for autism spectrum disorders in toddlers. *Journal of Autism and Developmental Disorders*, 36(7), 839-839-847. doi:10.1007/s10803-006-0128-8
- Wechsler, D. (1974) *Wechsler Intelligence Scale for Children-Revised*. Psychological Corporation, New York.
- Wechsler, D. (1967). *Manual for the Wechsler Preschool and Primary Scale of Intelligence*. San Antonio, TX: The Psychological Corporation.
- Welsh, M.C. & Huizinga, M.C. (2005). Tower of Hanoi disk-transfer task: influences of strategy knowledge and learning on performance. *Learning and Individual Differences*, 15, 283-298.
- WHO & World Bank. (2011). *World report on disability*. Geneva: Author.
- Wignyosumarto, S., Mukhlas, M., & Shirataki, S. (1992). Epidemiological and clinical study of autistic children in Yogyakarta, Indonesia. *Kobe Journal of Medical Sciences*, 38(1), 1-19.

- Williams, K., MacDermott, S., Ridley, G., Glasson, E. J., & Wray, J. A. (2008). The prevalence of autism in Australia. Can it be established from existing data? *Journal of Paediatrics and Child Health*, 44(9), 504-510. doi: 10.1111/j.1440-1754.2008.01331.x
- Williams, M. E., Atkins, M., & Soles, T. (2009). Assessment of autism in community settings: Discrepancies in classification. *Journal of autism and developmental disorders*, 39(4), 660-669. doi: 10.1007/s10803-008-0668-1
- Wimmer, H., & Perner, J. (1983). Beliefs about beliefs: Representation and constraining function of wrong beliefs in young children's understanding of deception. *Cognition*, 13(1), 103-128. doi: 10.1016/0010-0277(83)90004-5
- Wing, L. (1993). The definition and prevalence of autism: A review. *European Child & Adolescent Psychiatry*, 2(1), 61-74. doi: 10.1007/bf02098832
- Wing, L. (1997). The History of Ideas on Autism. *Autism*, 1(1), 13-23. doi: 10.1177/1362361397011004
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9(1), 11-29. doi: 10.1007/bf01531288
- Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The diagnostic interview for social and communication disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry*, 43(3), 307-307-325. doi:10.1111/1469-7610.00023
- Witkin, H. A., Oltman, P. K., Raskin, E. & Karp, S. (1971). *Manual for the Embedded Figures Test*. Consulting Psychologists Press, California.
- Wolff, S. (2004). The history of autism. *European Child & Adolescent Psychiatry*, 13(4), 201-208. doi: 10.1007/s00787-004-0363-5

- World Health Organization (2010). *International Statistical Classification of Diseases and Related Health Problems, 10th Revision*. Geneva, World Health Organization.
Accessed 25 February 2015 at: <http://www.who.int/classifications/icd/en/>
- World Health Organisation.(2014).*International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)*. Geneva: WHO.
- Yayasan Autisma Indonesia. (2013). *Pusat Terapi [Therapy centre]*. Retrieved February, 10, 2013, from <http://autisme.or.id/pusat-terapi/>
- Yayasan Autisma Indonesia. (2014). *Pusat Terapi [Therapy centre]*. Retrieved December, 10, 2014, from <http://autisme.or.id/pusat-terapi/>
- Young, R. L. (2007). *Autism Detection in Early Childhood: ADEC Manual*. Camberwell, VIC, Australia: ACER Press.
- Young, R. L., & Rodi, M. L. (2013). Redefining autism spectrum disorder using DSM-5: The implications of the proposed DSM-5 criteria for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, <http://dx.doi.org/10.1007/s10803-013-1927-3>
- Young, R.L., Brewer, N.f, & Pattison, C., (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism*, 7(2), 125-143.
- Zhang, X., & Ji, C.-Y. (2005). Autism and mental retardation of young children in China. *Biomedical and environmental sciences*, 18(5), 334-340.

Appendices

- Appendix A : Indonesian Practitioners' Survey Form
- Appendix B : Questionnaire for Parents
- Appendix C : Descriptive Statistics of ADEC-IND, ADI-R, and CARS Total Scores

Appendix A
Indonesian Practitioners' Survey Form

SECTION A

In this section you will be asked about your professional background and the number of autism cases with which you have been dealing. Please read and respond to each question.

1. How old are you today? _____ years

2. What is your gender?

Male

Female

3. What is your ethnic cultural background?

Javanese

Sundanese

Minangkabu

Malay

Betawi

Chinese

Madurese

Batak

Buginese

Others (please specify) _____

4. What is your highest level of education completed? (please specify the major)

Diploma _____

Undergraduate _____

Postgraduate _____

Others _____

5. Where do you currently working? (you can tick more than one option)

- | | |
|--|--|
| <input type="checkbox"/> Nanggroe Aceh Darussalam | <input type="checkbox"/> Kalimantan Barat |
| <input type="checkbox"/> Sumatera Utara | <input type="checkbox"/> Kalimantan Tengah |
| <input type="checkbox"/> Sumatera Barat | <input type="checkbox"/> Kalimantan Selatan |
| <input type="checkbox"/> Bengkulu | <input type="checkbox"/> Kalimantan Timur |
| <input type="checkbox"/> Riau | <input type="checkbox"/> Bali |
| <input type="checkbox"/> Kepulauan Riau | <input type="checkbox"/> Nusa Tenggara Barat |
| <input type="checkbox"/> Jambi | <input type="checkbox"/> Nusa Tenggara Timur |
| <input type="checkbox"/> Sumatera Selatan | <input type="checkbox"/> Sulawesi Barat |
| <input type="checkbox"/> Lampung | <input type="checkbox"/> Sulawesi Utara |
| <input type="checkbox"/> Kepulauan Bangka Belitung | <input type="checkbox"/> Sulawesi Tengah |
| <input type="checkbox"/> DKI Jakarta | <input type="checkbox"/> Sulawesi Selatan |
| <input type="checkbox"/> Jawa Barat | <input type="checkbox"/> Sulawesi Tenggara |
| <input type="checkbox"/> Banten | <input type="checkbox"/> Gorontalo |
| <input type="checkbox"/> Jawa Tengah | <input type="checkbox"/> Maluku |
| <input type="checkbox"/> DI Yogyakarta | <input type="checkbox"/> Maluku Utara |
| <input type="checkbox"/> Jawa Timur | <input type="checkbox"/> Papua Barat |
| | <input type="checkbox"/> Papua |

6. During your formal education, did you receive any training on how to conduct assessment for autism cases?

- Yes**
- What kind of training? _____
- No**

7. What is your current profession?

- Psychologist
- General Practitioner
- Paediatrician
- Child Neurologist
- Psychiatrist
- Occupational Therapist
- Speech Therapist
- Behaviour Therapist
- Physiotherapist
- School Counsellor
- Other: _____

8. How long have you been working in your profession? _____ year(s)

9. How long have you been dealing with autism cases? _____ year(s)

10. How many autism cases on average do you usually assess in a week? _____

11. How old are the children on average?

- 0 – 2 year
- 3 – 5 years
- 6 – 12 years
- 13 years and older

12. If you are working in a therapy centre, how many children with autism are currently following therapy regularly in the centre? _____

13. How old are the children on average?

- 0 – 2 year
- 3 – 5 years
- 6 – 12 years
- 13 years and older

SECTION B

In this section you will be asked about the assessment and diagnosis procedure you usually conduct. Please read and respond to every question.

1. In assessing children suspected as having autism;

A. On average, you usually need _____ meeting(s) where each meeting takes _____ hour(s) before you make a diagnosis.

B. Do you interview the parents?

- Yes (go to B1)
- No (go to B2)

B.1. if you answered YES

How long would this interview take?

- Less than 5 minutes
- 5 to 10 minutes
- 10 to 30 minutes
- 30 to 60 minutes
- More than 60 minutes

What information do you collect from the interview?

B.2. if you answered NO

- Why not?

C. Do you observe the child?

- No (go to C1)
- Yes (go to C2)

C.1. If you answered NO

- Why not?

- Do you devise your own assessment tools?
 - Yes (please specify)

- No

C.2. if you answered YES

How much time does the observation usually take?

What are you looking for in these observations of the child?

Do you use any standardized observation tools?

Yes, what are they?

Why do you use these specific tools?

- No. I do not use any standardized observation tools. Why not?

2. How do you share the assessment findings with the parents? (you can tick more than one option)

Face to face session

- How long does the meeting usually take?

- What kind of information do you communicate to the parents in the meeting?

Written report

- From the time the assessment is completed, how long will it take to hand over the written report to the parents?

What kind of information do you communicate to the parents in the written report?

Other (Please specify):

3. Do you usually refer the child to other professionals?

No (go to 3a)

Yes (go to 3b)

3. a. If you answered NO

Why not?

3. b. If you answered YES

Who are these professionals?

- When do you usually refer the child?
 - After I complete my assessment and diagnosis process.
 - In the middle of my assessment, before I make a diagnosis.
 - Other _____

- Do you communicate with the professionals?
 - Yes.
 - How do you communicate with them?

- What kind of information do you communicate to them?

- No. I do not communicate to the professionals to whom I refer the child.
 - Why not?

SECTION C

In this section you will be asked about the interventions that you usually recommend. Please read and answer each question.

1. What interventions do you usually recommend for autism cases? (tick all that apply)

- Pharmacological therapy
- Behavioral therapy
- Speech therapy
- Occupational therapy
- Sensory Integration therapy
- Physiotherapy
- Diet therapy
- Sport
- Horse riding therapy
- Dolphin therapy
- Family therapy
- Recommend the child to go to a special school
- Recommend the child to go to a mainstream school
- Other (please specify)

2. What is the basis for recommending each of the type of interventions recommended?

3. Do you suggest the parents to return to you periodically after the final counselling?

- Yes. For what purpose?

- No. Why not?

4. Do you regularly communicate with parents and professionals (therapist / teacher / etc) who involve in the intervention?

- Yes, always
 Sometimes
 No, why not?

5. If you answer yes, what are the content of your communication with parents and professionals who involve in the intervention? (you can tick more than one option)

- The child's progress
 The effectiveness of the intervention
 The child's behaviour during the intervention
 Barriers experienced in the intervention
 Others (please

indicate)_____

6. Do you suggest parents involve a parent support group or community?

- Yes, please (continue to question number 7)
- No, why?

7. To what extent do you think it is important to involve parents in a parent support group or community?

<i>Not important at all</i>	<i>Slightly Important</i>	<i>Moderately Important</i>	<i>Very Important</i>	<i>Extremely Important</i>
1	2	3	4	5

SECTION D

In this section you will be asked about the challenges you might encounter in working with autism cases.

1. What are the challenges you usually encounter in assessing children with autism? (you can tick more than one option)

- My skill is not sufficient in assessing autism cases.
- I am not familiar with assessment tools provided
- It is difficult to find standardized instruments in Indonesian language
- The time provided to assess autism cases is insufficient
- The fee for assessing autism cases is insufficient
- Other (please specify)

2. From the challenges that you have mentioned in question no.1, which challenges do you feel as the most and least challenging? Please provide rank (1, 2, 3, etc) from the greatest to the least challenging.

- _____
- _____
- _____
- _____
- _____
- _____
- _____

3. What are the challenges you usually encounter in intervening with children with autism? (you can tick more than one option)

- The availability of therapy centres is not sufficient
- The availability of resources for parents of children with autism (e.g. information booklet or handout, website informing about autism, etc) is not sufficient
- Intervention programs are not available
- I do not have the skills to develop interventions for individual children or families
- Other (please specify)

4. From the challenges that you have mentioned in question no.1, which challenges do you feel as the most challenging? Please provide rank (1, 2, 3, etc) from the greatest to the least challenging.

- _____
- _____
- _____

- _____
- _____
- _____

5. What suggestions would you recommend to overcome the challenges in assessing children with autism? (you can tick more than one option)

- More professional training in assessing autism cases should be provided
- More training in using assessment tools should be provided
- More assessment tools in Indonesian language should be provided
- The amount of time in assessing children with autism should be increased
- The fee for assessing autism cases should be increased
- Other (please specify)

6. From the suggestions that you have mentioned in question no.5, which suggestions do you think as the most important? Please provide rank (1, 2, 3, etc) from the most to the least important.

- _____
- _____
- _____
- _____
- _____
- _____

7. What suggestions would you recommend to overcome the challenges in intervening children with autism? (you can tick more than one option)

- Better access to training for practitioners

SECTION E

Using the following 4-point scale, how important do you consider the following in relation to working with children with autism and their families?

The rating scale is as followed:

- 0 Not important at all
- 1 Slightly Important
- 2 Important
- 3 Very Important

Please read and select a number 0, 1, 2 or 3 that most closely reflects your opinion.

1	Availability of professional training in assessing children with autism.	0	1	2	3
2	Availability of an assessment guideline for professionals in assessing children with autism.	0	1	2	3
3	Used of measurement tools in assessing children with autism.	0	1	2	3
4	Availability of resources for parents of children with autism (e.g., booklet, website, etc).	0	1	2	3
5	Availability of affordable therapy centres.	0	1	2	3
6	Availability of training for parents of children with autism	0	1	2	3

SECTION F

In this section you will be asked about your degree of satisfaction in dealing with autism cases. Please read and circle the response option that most closely reflects your satisfaction level.

1. To what extent are you satisfied with the training provided for professionals to assess autism cases?

<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Very</i>	<i>Extremely</i>
1	2	3	4	5

2. To what extent are you satisfied with the guidelines provided for professionals to assess autism cases?

<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Very</i>	<i>Extremely</i>
1	2	3	4	5

3. To what extent are you satisfied with the measurement tools in Indonesian language available for professionals to assess autism cases?

<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Very</i>	<i>Extremely</i>
1	2	3	4	5

4. To what extent are you satisfied with the availability of affordable therapy centres for children with autism?

<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Very</i>	<i>Extremely</i>
1	2	3	4	5

5. To what extent are you satisfied with the availability of resources for parents of children with autism (e.g. information booklet or handout, website informing about autism, etc)?

<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Very</i>	<i>Extremely</i>
1	2	3	4	5

6. To what extent are you satisfied with the training provided for parents of children with autism?

<i>Not at all</i>	<i>Slightly</i>	<i>Moderately</i>	<i>Very</i>	<i>Extremely</i>
1	2	3	4	5

SECTION G

In this section you will be asked about your expectation in dealing with autism cases. Please read and answer each question.

1. What would you expect to see in terms of the professional training for assessing autism (e.g., availability of specific professional training in assessing children with autism)?

2. What would you expect to see in terms of the guideline provided for assessing autism (e.g., dissemination of the guideline among professionals)?

3. What would you expect to see in terms of the measurement tools provided for assessing autism (e.g., measurement tool in Indonesian language)

4. What would you expect to see in terms of the availability of resources for parents of children with autism (e.g., informative websites)

5. What would you expect to see in terms of availability of therapy centres for children with autism (e.g., more therapy centres with affordable cost)

6. What would you expect to see in terms of training for parents of children with autism (e.g., availability of specific training on how to improve social skill in children with autism)?

7. What other things or conditions would you expect to see in term of assessing and intervening autism cases?

Thank you for your participation

Appendix B

Questionnaire for Parents

In this section you will be asked to complete your child's and your details. Please read and complete the table.

DETAILS OF YOUR CHILD

Name	
Place and Date of Birth	
Age	
Gender	
Order of child in the family	
Name of Therapy Centers / Schools	

PARENT DETAILS

	FATHER	MOTHER
Name		
Age		
Ethnicity		
Education		
Occupation		
Parent's Phone Number		
Parent's Email		
Parent's Address		

In this section you will be asked to complete the information about current and previous assessment and diagnosis of your child. Please read and complete the table.

ASSESSMENT AND DIAGNOSIS

Type of Assessment that has been or is being conducted	Age of child when the assessment was conducted	Diagnosis	Who conducted the assessment	Who conducted the diagnosis

In this section you will be asked to complete the information about current and previous interventions followed by your child. Please read and complete the table.

INTERVENTION

Type of Intervention / Therapy which has been or is being conducted	Age of child when the intervention / therapy is conducted	Who conducted the intervention / therapy

Appendix C

Descriptive Statistics of ADEC-IND, ADI-R, and CARS Total Scores

Total Scores		TD (n=31)	Non-PDD (n= 31) ^a	PDD (n=20)
ADEC-IND	M	4.65	9.84	19.55
	SD	3.80	5.68	4.91
	Range	14	20	15
	Min	0	0	11
	Max	14	20	26
ADI-R	M	3	16.16	41.05
	SD	5.02	12.48	8.40
	Range	25	46	30
	Min	0	3	25
	Max	25	49	55
CARS	M	-	21.44	33.40
	SD	-	3.58	2.45
	Range	-	12	8
	Min	-	17	30
	Max	-	29	38

Note. ^aIn the Non-PDD group, only 9 participants tested with CARS