DEMOGRAPHIC CHARACTERISTICS, BEHAVIORAL PROBLEMS, ANDIQ PROFILEOF CHILDREN WITH DYSLEXIA AT DYSLEXIA ASSOCIATION OF INDONESIA FROM JANUARY-JUNE 2019: A QUANTITATIVE STUDY

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Abstract

One of the most frequent causes of learning difficulties in children is dyslexia. Dyslexia Association of Indonesia as a center of diagnostic and intervention of children with dyslexia has served more than 800 cases since 2005. However, studies on dyslexia in Indonesia were still very few comparing to the extent of the problem which need solutions. The study was conducted to know the demographic characteristics, behavioral problems, and IQ profile of children with dyslexia during the study period. Data were collected from medical record. There were 133 children with dyslexiaadministered in the study and dominantly male (76%). Most of them were diagnosed at the age of 4-6 year old (56.5%) and 7-9 year old (33.8%) with median age of diagnosis at 79months. About 49.6% were primary school students and 39.9% were preschoolers. Result showed that 3% of children have mild dyslexia, 33% have moderate dyslexia, 42% have severe dyslexia, 13% were at risk of dyslexia, and 9% have no severity defined, yet. Seventy nine children (60%) had comorbidities, among them 68.4% had dyscalculia and dysgraphia, 27.8% had dyspraxia, 24.1% with poor self-esteem and anxiety disorders, and 36.1% had behavioral problems (ADHD, conduct disorder, and oppositional defiant disorder). The IQ profiles (WISC, Griffith, or WPPSI) showed that 45.8% children had average IQ, 21.3% with superior IQ, 6.4% with very superior IQ, and 2.1% was gifted (FIQ median: 101.5). Gap were found between the VIQ and PIQ (median 14.5), whereby most children (69.2%) had VIQ less than their PIQ. These findings gave vivid picture to understand the IQ profile of dyslexic children and that dyslexia is not only about reading difficulties, but also includes comorbidities like behavioral problems that might cause academic problems despite progression of child's reading ability.

Keywords: dyslexia, characteristics, IQ profile, behavioral problems

INTRODUCTION

Dyslexia is one of the most common learning difficulties with a prevalence ranging from 5 to 17.5% among school age children (Rajinder et al, 2017). The prevalence may vary depending on the criteria used to define dyslexia. Dyslexia is neurobiological in origin and affects 80% of all learners with learning difficulties. It can be found in all socio-economic classes and cultures as well as identified from childhood to adulthood. Failure to identify and to provide intervention in early life, leads to poor self-esteem, under-achievement of academic performance, emotional stress, and increased chances dropping out from school (Cheruiyot et al, 2015). Knowledge and awareness about dyslexia is gaining ground all over the world.

However, in the developing countries, raising awareness about dyslexia is still a challenge. Children with dyslexia struggling through their school-time, unidentified without getting any helps. As an addition to this condition, studies in the area of dyslexia in developing countries, including in Indonesia, is limited comparing to the extent of the the problem, so thus its prevalence and profile are not fully known.

Demographic and Clinical Characteristics

It is well known that children with dyslexia have difficulties at the phonological level so thus they are difficult to identify letters sounds, to mapthe name or symbols of letters (grapheme) to their sounds (phonetics), and to break a word into its constituent sound. They also have difficulties in spelling, writing, or in letter formation (Fawcett and Nicolson, 2004, Scheepers, 2009, Cheruiyot *et al*, 2015).Muter and Likierman, 2008 found that when they are reading, adyslexic reader will stumble, guess or sound out words. Furthermore, the speed or fluency is much slower than non-impaired readers of their age. That is why reading is always a heavy task for dyslexic learners (Muter and Likierman, 2008). Besides those difficulties related to reading, they also have difficulties following instructions, distinguishing left from right, short term or working memory, balance, lack of organization among others (Cheruiyot *et al*, 2015). Researchers proposed the double deficit hypothesis that postulates phonological deficits and processes underlying rapid automated naming represent two distinct sources of reading dysfunction (Wolf and Bowers, 1999, Wolf *et al* 2002, Bishop and Snowling, 2004, Savage and Frederickson, 2005). Willcutt *et al*, 2005 also reported that along with rapid naming and verbal working memory, phonological awarenessis consistently linked to the word reading disorder regardless of comorbidities. This founding helped to explain the word reading problem that is the main fundamental feature of dyslexia.

Some dificulties are also found in dyslexic learners such as disorganization and a poor sense of time,which is often associated with memory problems. They also have poor awareness of space which is often associated with dyspraxia. These conditions tend to make many people with dyslexia difficult to have effective time management. Dyslexia also affects numeracy skills in about 60% of cases. The difficulties can be in the form of calculating or copying of digits inacurately, failure to remember procedures of calculation, and/or remembering multiplication tables. Mathematicians and scientists, who are gifted yet also dyslexic, are sometimes have unexpected weak computational skills (Lucid, 2006).

The conventional approach to identify dyslexia in children with problems in literacy development have remained unchanged. It is based on the principle that a child with specific learning difficulty must show and evidence of a significant difference between intelligence and literacy skills; and when the child show such discrepancy, if he also show cognitive deficits in memory and/or phonological processing, this is evidential for dyslexia. Afamily history of dyslexia, developmental of speech or language problems history, or history of difficulty in acquiring phonics, would support the conclusion (Lucid, 2006) as sumarized in Figure 3.The first three points cover the discrepancy and exclusionary criterion.

These criterionsuggest that dyslexia can only be identified when there is a significant discrepancy between intelligence and achievement, so thus exclude all other potential causes of reading difficulty (Lucid, 2006).

Conventional Methods for Diagnosing Dyslexia

Establish whether:

- Reading and/or spelling age of the child is significantly behind his/ her chronological age (≥ 2 years behind).
- Intelligence of the child is not significantly below average.
- Reading difficultyis not caused by cial, emotional or educational factors.
- There are no serious problems of general health such as sight problems, hearing loss, or apparent brain damage.
- There are some phonological difficulties or memory problemsas 'positive signs' of the disorder.

Figure 3 Conventional Methods forDiagnosing Dyslexia (Source:Lucid, 2006)

Comorbids

Other cognitive and neuropsychological skills are also found to be associated with dyslexia, such as language and attention problems, math problems, motoric problems, and other (Pennington, 2009). Behavior problems have also been reported as comorbids of dyslexia. Behavior problem is a deviation from the accepted pattern of behavior on the part of an individual when he is exposed to inconsistent social and cultural environment in society. Typically, problem behaviorin children refers to two major classes: externalizing and internalizing behavior (Achenbach and Rescorla, 2001). Externalizing behavior is expressed outward towards others or has an impact on the child's environment, thus oftenly disruptive, such as aggression, hyperactivity, orconduct problems. Internalizing behavior, is a self-focused expressions of distress. Because it is less visible and bothersome to other people, this behavior often is ignored or goesunrecognized by adults. Such internalizing behavior problems are depression, anxiety, and somatization (Campbell, 2002, Patil and Patil, 2015).

A significant overlap between attention deficit disorder with or without hyperactivity (ADD/ ADHD) with dyslexia can also be found. A short attention span and/or a high level of distractibility can undermine the whole educational process. Associated characteristics are an inability to get started when faced with certain mental activities and also trouble switching from one type of activity to another. Dyslexia can also overlap with dyspraxia or 'developmental co-ordination disorder', where usually known a "clumsy child" (Lucid, 2006).

The most indicative behavioral correlates of dyslexia are anxiety and stress which affect performance. When people with dyslexia are in some situations where they cannot cope, they will experience 'panic' reaction. Thus, we should not underestimate the cumulative effect of tiredness required by additional effort at every educational level (Lucid, 2006).Many of these children experience low self-esteem, emotional trauma, and usually tend to havetroublesome behavior. Furthermore, they also clowning to hide their learning difficulties (Cheruiyot, 2015). The problem of significant differences between obvious ability and poor academic performance may be unrecognized for years. Literacy problems may persist through childhood despite the child's satisfactory oral and intellectual skills in their school. This condition will lead to low self-esteem, lack of confidence, and frustration assecondary effects of dyslexia. (Lucid, 2006).

PROBLEM STATEMENTS

According to International Dyslexia Association (IDA, 2002), dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decodingabilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading

experience that can impede the growth of vocabulary and background knowledge. British Dyslexia Association, 1995, defines dyslexia as a complex neurological condition which is constitutional in origin. The symptoms may affect many areas of learning and function, and may be described as a specific difficulty in reading, spelling and written language. Almost all of those definitions include the same main problem of dyslexia, that is learning to read in children with adequate intelligence.

Dyslexia Association of Indonesia (2019), proposed a more comprehensive definition of dyslexia as a condition characterized by occurrence of learning difficulty in a person who, despite of his/her normal or above average intelligent level, shows significant difficulties in language based, particularly phonemic awareness deficit. However, it also affects language used in writing skill and language used in social context (interpreting body gesture, attitude, body posture). Moreover, dyslexia also shows executive function impairment, and most likely accompanied by other kind of specific learning difficulties such as dysgraphia and dyscalculia, and other co-morbidities such as Attention Deficit Hyperactivity Disorder and Developmental Coordination Disorder. This definition is tailored along with the development of knowledge about dyslexia based on the available empirical evidence.

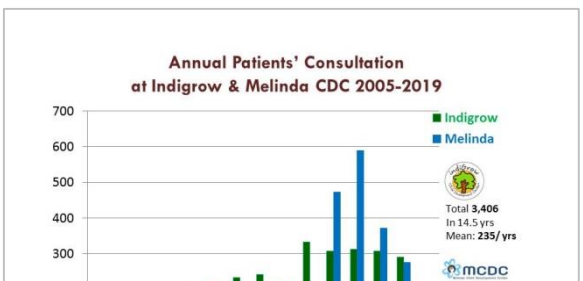
There are several theories of dyslexia etiology, among them are genetic factors, neurobiological factors, and environmental factors. Dyslexia runs in families and is heritable (Shaywitz *et al* 2008). According to Pennington and Gilger, 1996, (as cited in Shaywitz *et al*., 2008) the risk of children being dyslexic is around23% to 65% when their parents are dyslexic and around 40% when their sibbling is dyslexic. Recently, genetic studies foundinherited factors involved in the development of dyslexia has a proportion between 40% to 80% (Schumacher *et al*, 2007).

Some experts in neurology stated that the brain of a dyslexic child has a slightly different functionfrom the brain of a non-dyslexic child. The functional Magnetic Resonance Imaging (fMRI) studies have indicated that the left hemisphere posterior brain regions fail to function properly during reading activity. Three brain regions which have important role in reading, in particular the Broca's area which has role in articulation and word analysis, the parieto-temporal region which also has role in word analysis, and the occipito-temporal regions which has role in fluent reading, have been shown to be less active as they are under-stimulated during reading in dyslexic learners (Shaywitz and Shaywitz, 2004).

Factors from the environment such as poverty, delay development, inadequate stimulation, school conditions, and literacy environment have an important role in developing dyslexia. They may affect the working memory, verbal memory, verbal and visual processing speed among others. However, phonological ability is relatively not affected by environmental factors (Samuelsson and Lundberg,1996).

OBJECTIVES

Indigrow and Melinda Child Development Center in Bandung, Indonesia, have been receiving referral for diagnosis and intervention of special needs children from almost all parts of Indonesia. The centers have an average of235 and 400 annual patient's consultation, respectively (Figure 1). They also have an average of 1,300-1,500 patient's monthly visits and 1,400-2,200 hours of monthly therapy session (Figure 2). Under supervision of Dyslexia Association of Indonesia, the centers have served more than 800 cases of dyslexia since 2005.



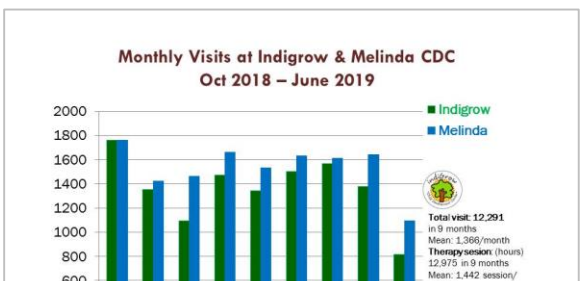


Figure 1*Annual patients's consultation at Indigrow and Melinda CDC, 2005-2019*

Figure 2 *Monthly Visit at Indigrow and Melinda CDC, October 2018-June 2019*

The study was conducted to know the demographic characteristics, behavioral problems, and IQ profile of children withdyslexia in both centers from January-June 2019. Considering Dyslexia Association of Indonesia as a center of referral dyslexic cases across provinces in Indonesia, hopefully, the research will be representative enough to give a brief description of children with dyslexia in Indonesia.Many definitions of dyslexia have been proposed. The ICD 10 (1993) defines dyslexia as a disorder manifested by difficulty learning to read despite conventional instruction, adequate intelligence and socio-cultural opportunity (WHO, 1993) whereas DSM IV-TR, defines dyslexia as the reading achievement that is substantially below what is expected for the person's chronological age, intelligence, and age-appropriate education (APA, 2000). The DSM V has dyslexia under the category of Specific Learning Disorders (SLD) and defines it as persistent difficulties in learning and using academic skills as indicated by either inaccurate or slow and effortful word reading or by difficulties with spelling or both (APA, 2013).

METHODOLOGY

All dyslexic children, 4 to <18 years of age, diagnosed by the experts of Dyslexia Association of Indonesia (neurodevelopmental and behavioral pediatric consultant and pediatrician) and registered at Indigrow CDC and Melinda CDC from January – June 2019 were administered for the research. IQ test was performed using WISC, Griffith, or WPPSI by the psychologists in both centers. Data were collected from their medical record. Those who have incomplete record and not given informed consent were excluded from the research. Data were analyzed and then presented using descriptive statistics which include pie charts, bar graphs, tables, and narratives.

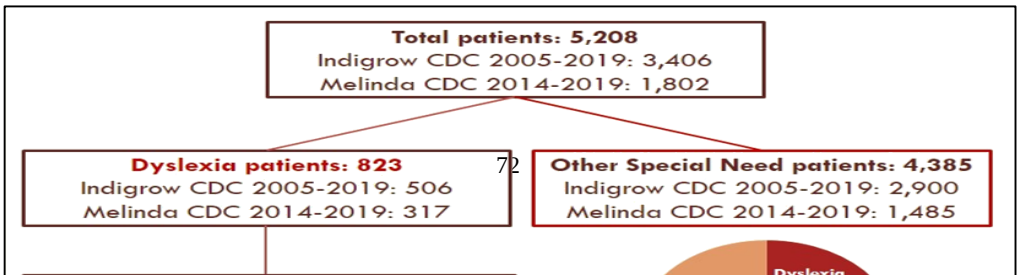


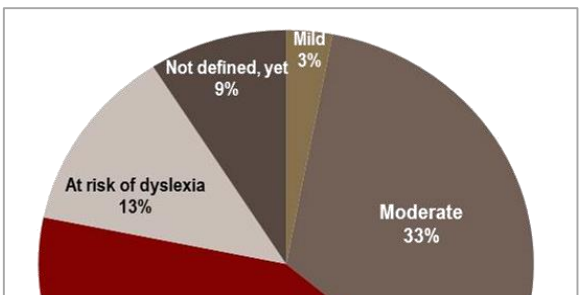
Figure 4 *Population, sample, and the proportion of children with dyslexia at Melinda and Indigrow Child Development Center undersupervision of Dyslexia Association of Indonesia*

RESULTS AND DISCUSSION

During the period of 2005-2019, there were 5,208 patients visited the two centers, Indigrow and Melinda Child Development Center. Among them, 823 patients (15.8%) were diagnosed as having dyslexia as seen in Figure 4. Eventhough this is not the actual prevalence of dyslexia in Indonesia, thenumber give a figure closely in line with the prevalence reported in several studies which reported dyslexia prevalence ranging from 2-17.5%. Patil and Patil (2015), reported the prevalence rate of dyslexia is around 9.87% among Indian school children and one in every 10-12 children is at the risk of dyslexia. Mogasale *etal* (2012) found out the prevalence of dyslexia in a South Indian city was 11.2%.

The prevalence of dyslexia in children grade 7-9 in Nairobi, Kenya was 7.49% (Cheruiyot, 2015), while in the USA it's prevalence estimated to range between 5% to 17 (Shaywitz and Shaywitz, 2003), and in UK the prevalences of dyslexia among school-age children were ranging between 3% to 6% (Miles, 2004).These differences may be due to the difference in definition, methods and tools used, different geographical areas that varied with respect to age, language, and size of the sample. The high proportion of children with dyslexia in our study was found may be not only due to problems of reading and writing but also due to problems in executive function, motor co-ordination, emotional problems, and behavioral problems which are problems frequently found in individu with dyslexia according the dyslexia definition by the Dyslexia Association of Indonesia.

There were 133 children with dyslexia during the study period that meet the inclusion and exclusion criteria, so thus administered in the study (Figure 4). Most of the children have moderate to severe dyslexia, 33% and 42%, respectively (Figure 5). Roongpraiwan *et al* (2002) revealed that prevalence of dyslexia and probable dyslexia were 6.3 % and 12.6 % respectively. The high proportion of severe dyslexia children in our center maybe due to our center being one of the referal center of diagnostic in the country. We found one third of the children refered to our center from outside the city (Figure 6), and usually parents have brought the children to several places before. We also found 13% children who were at risk of dyslexia (Figure 5). Dhanda and Jagawat (2013) reported that 21.62% were with risk of dyslexia. This finding shows that Dyslexia Association of Indonesia has been trying to identify children with dyslexiain early life and thus have a chance to give earlier intervention and prevent a more complicated problems in later life.



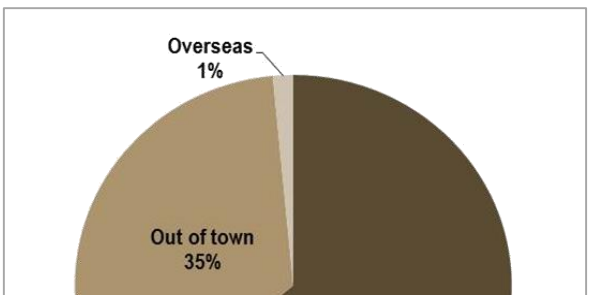


Figure 5 *Classification of children with diyslexia at Dyslexia Association of Indonesia*

Figure 6 *Place of origin of children with diyslexia at Dyslexia Association of Indonesia*

The gender proportion was dominantly male (101 cases, 76%), gives a ratio of male to female dyslexics at 3.2:1 (Table 1). Though estimates of sex ratios (males to females) in dyslexia incidences vary from one study to another, the various studies are all consistent with having the number of male dyslexics being more than female dyslexics. Miles *et al (1998)* reported male to female ratio as 4.51:1, Hawke *et al*(2009) as 2:1.3, Vlachos *et al*(2013) and Cheruiyot *et al*(2015) as 2:1. Bin and Bolhasan (2009), reported in his study that boys are far more likely to have dyslexia than girls. Rajinder *et al* (2017), also reported in his study that the prevalence of dyslexia was higher in male children 81% while only 19% female children were dyslexic.

Table 1 *Demographic characteristics of children with dyslexia at Dyslexia Association of Indonesia*

Characteristics	**n (%)**	**Median (SD)**
Gender (rasio M:F = 3.2:1)		
▪ Male	101 (76)	
▪ Female	32 (24)	
Age		79 months (27.5)
▪ 4 – 6 y.o	74 (56.5)	
▪ 7 – 9 y.o	45 (33.8)	
▪ 10 – 12 y.o	11 (8.3)	
▪ 13 – 15 y.o	1 (0.7)	
▪ 16 – < 18 y.o	1 (0.7)	
Level of Education		
▪ Preschool	53 (39.9)	
▪ Primary School	66 (49.6)	
▪ Secondary School	2 (1.5)	
▪ High School	1 (0.7)	
▪ Homeschooling	3 (2.3)	
▪ Not in school, yet (toddlers)	8 (6)	

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In present study, most of the children were diagnosed at the age of 4-6 year old (56.5%) and 7-9 year old (33.8%) with median age of diagnosis at 79 months (SD 27.5 months). About 66 (49.6%) were primary school students and 53 (39.9%) were preschoolers (Table 1). Rajinder *et al*(2017), reported an equal distribution in the age groups 8, 9, 10 and 11 years which is in consistent with various authors (Choudhary, 2012, Dhanda and Jagawat, 2013, Siddqui and Tripathi, 2014)who all have reported the prevalence of learning difficulties in age group of 8-11 years.

Table 2 *Parental demographic characteristics at Dyslexia Association of Indonesia*

Characteristics	**Father**	**Mother**
Age [in years (Median; SD)]	38 (5.6)	36 (5.4)
Level of Education[n (%)]		
▪ High School	12 (9.0)	14 (10.5)
▪ Diploma	15 (11.3)	24 (18.0)
▪ Bachelor	64 (48.1)	75 (56.4)
▪ Master	33 (24.8)	17 (12.8)
▪ Doctoral	4 (3.0)	0 (0)
▪ No data	5 (3.8)	3 (2.3)
Occupation[n (%)]		
▪ Government employee	16 (12.0)	14 (10.5)
▪ Private employee	44 (33.1)	17 (12.8)
▪ Enterpreneur	46 (34.6)	15 (11.3)
▪ Medical doctors	9 (6.8)	13 (9.8)
▪ Housewife	0 (0)	64 (48.1)
▪ Others	18 (13.5)	10 (7.5)

In recent study, the median parental age were 38 y.oand 36y.o for father and mother, respectively (Table 2). In the study by Cheruiyot *et al*, 2015, the median age of the parent was 36 y.o for the non-dyslexics and 35 y.o for the dyslexics with majority of parents were in the age range of 34-37 (66.6%). They reported that age of parent was not statistically significant with dyslexia.

About half of parents, both father and mother, have a Bachelor's level of education. Father's occupation were dominantly private employee and enterpreneur, while mother's were dominantly housewife, as sumarized in Table 2. Cheruiyot *et al* (2015), reported there was no connection between parental age, occupation, level of education, marital status, family type or population with child's dyslexia outcome.

Table 3 *Comorbidities related to dyslexia (n=79)*

Category	**n (%)**
▪ Dyscalculia and dysgraphia	54 (68.4)
▪ Dyspraxia	22 (27.8)
▪ Poor self-esteem and anxiety disorders	19 (24.1)
▪ Behavioral problems (ADHD, ODD, Conduct Disorders)	29 (36.1)

In this study, 79 (60%) children had comorbidities and48 among them (60.8%) have more than 2 comorbidities.About 68.4% of those who had comorbidities, had dyscalculia and dysgraphia (Table 3). Dhanda and Jagawat (2013) reported 22.30% children had dysgraphia, 15.54% had dyscalculia and mixed learning disorder was seen in 40.50% of children. Willcut *et al* (2005) and Rose (2009) also reported that many dyslexics have co-morbid attention and mathematics difficulties.

Other comorbidities were also found in this study. About 27.8% children had dyspraxia, 24.1% with poor self-esteem and anxiety disorders, and 36.1% had behavioral problems which include ADHD, conduct disorder, and oppositional defiant disorder as summarized in Tabel 3.

Some studies reported behavioral problems related to dyslexia. It was reported that there was significant relation between internalizing behavior problems and dyslexia, also

between gender and externalizing behavior problems, and externalizing behavior problems were significant with dyslexia. However, the total behavioral problem in the study were found significant with gender but were not related with dyslexia (Patil and Patil, 2015). Another study also reported that dyslexic children had higher scores on internalizing, externalizing and total problems (Heierang et al, 2001). Similar results have been found with Knivsberg and Andreasses (2008) which depicted that, significantly more problems were seen in children with dyslexia than controls. Results of Eissa (2010) revealed that dyslexic adolescents suffered from internalizing and externalizing problems. Children with such problems need intervention both in the areas of reading and behavioral aspects (Patil and Patil, 2015). Cheruiyot *et al* (2015) reported that of the 9 children found to be dyslexic, 2 of them had math difficulties, 1 had ADHD and reading difficulty, and 1 was struggling with reading since reading was an added language.

The IQ test were performed on 94 children. Aboutthree quarter of children with dyslexia have average or above average IQ, as summarized in Table 4. The median of Full IQ is at 101.5; VIQ is at 97; while PIQ is at 105. Eventhough the IQ test were performed to most of the children, it is not a pre-requirement for diagnosing dyslexia in our center. The discrepancy criterion (significant IQ–achievement discrepancies) has pros and cons. It is difficult to establish that a significant difference doesexists if the child'sintelligence is below average (Lucid, 2006).

Table 4 *IQ profile of children with dyslexia at Dyslexia Association of Indonesia (n=94)*

Characteristics	**n (%)**	**Median (SD)**
IQ Classification		
▪ Gifted	2 (2.1)	
▪ Very Superior	6 (6.4)	
▪ Superior	20 (21.3)	
▪ Average	43 (45.8)	
▪ Borderline	19 (20.2)	
▪ Mild ID	4 (4.3)	
IQ Score		
▪ Verbal IQ (VIQ)		97 (20.5)
▪ Performace IQ (PIQ)		105 (17.2)
▪ Full IQ (FIQ)		101.5 (15.2)
Verbal IQ to Performance IQ Comparison		
▪ VIQ < PIQ	65 (69.2)	
▪ VIQ = PIQ	2 (2.1)	
▪ VIQ > PIQ	25 (26.6)	
▪ No available data	2 (2.1)	
VIQ-PIQ Gap Score		14.5 (12.9)
▪ < 10	39 (41.5)	
▪ 10 – 15	13 (13.8)	
▪ > 15	40 (42.6)	
▪ No available data	2 (2.1)	

In this study, we also found 20% children with borderline IQ and 4% with mild intelectual disability. This condition might be due to the severity of dyslexia condition that the children have. Some of these children have improvement in their IQ after several times after remedial therapy program. The discrepancy criterion approach tends to depend to wait for the child to failbefore action is taken, and this might take several years. Thus, the discrepancy criterion is problematic to a concept of early identification of dyslexia (Lucid, 2006). Vellutino *et al* (1996)

reported that the IQ–achievement discrepancy criterion is no longer guaranteed to be used as a proper metric to define specific reading disability. The intelligence test scores did not differentiate the poor and the normally achieving readers nor the poor readers who were difficult to remediate and those who were readily remediated.Moreover, IQ–achievement discrepancy scores did not predict reading initial progress in poor readers with intensive remediation.

Furthermore, we found that most of the IQ profile of children with dyslexiashows gap between their VIQ and PIQ (median 14.5), whereby most children(69.2%) had VIQ less than their PIQ (Table 4).We also found out that a quater of these children had VIQ more than their PIQ. It will be interesting to see whether this phenomenon might be a risk factor or protecting factor or has any relation to the behavioral problems and comorbidities of the children, thus influences their prognosis in later life.

CONCLUSION

These findings gave vivid picture to understand that dyslexia is not only about reading difficulties, but also includes comorbidities like behavioral problems that might cause academic problems despite progression of child's reading ability. Moreover, it gives such a description of IQ profile of the children that might become a contributor for their long-term outcome, whether as a risk factor or protecting factor. Hopefully, this report will be a preliminary study for a prevalence study and analytical study of dyslexia in Indonesia, thus give us a more comprehensive understanding of the profile and natural history of dyslexia in children in Indonesia.

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