

# Responsiveness of Parents in Early Detection and Access to Autism Spectrum Disorder (ASD) Services

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**Abstract:** The increasing number of Autism Spectrum Disorder (ASD) children requires more attention from all parties. ASD treatment has massive impact on the quality of life for them and their families. Researchers interacted with clients and families and were directly involved in services at the Research and Development Laboratory for Children with Special Needs in Surabaya. The analysis was carried out on 33 family data of ASD children who visited the Laboratory for Children with Special Needs in 2019. The results showed that 1) Parental monitoring of children's growth and development was still lacking, 2) Parental responsiveness was still weak in the early detection of ASD cases, and 3) Responsiveness of parents to access ASD's services was shown by the following phenomena; a) most parents brought their children to assessment or diagnostic services for the first time when they were more than three years old, b) there was a shopping diagnostic phenomenon and shopping for autism therapy. In conclusion, parents' response to early detection of ASD children was still lacking. Recommendations, it is necessary to socialize to provide training by related parties to each parent about the importance of monitoring child development, stimulation, and early detection of children with autism.

## 1 INTRODUCTION

Autism awareness day, which has been set on April 2 by the United Nations, can remind us about the need for public awareness and support for the rights of people with autism, including the right to determine the direction of their development, independence, and autonomy, as well as access to education and employment on an equal basis (Ramadhani, 2021). Individuals with autism are grouped in ASD (Autism Spectrum Disorder). It is a group of neurodevelopmental disorders that have characteristics of impaired communication and social interaction, limited interests, and repetitive behavior. Early warning signs of ASD include at the age of 12 months, the child shows a lack of social interaction, at the age of 18 months, the child does not use single words that are meaningful, and at the age of 24 months the child lacks interest in other children, and still unable to use spontaneous two-word phrases. Individual ASD severity and impairment vary greatly (Tsang et al., 2019). Estimates of the individual incidence of ASD are between 50-60 per 10,000 school-age children. Singapore stated that ASD was

the most common cause of "disease burden" in children aged 0-14 years in 2004. Even other references state that the incidence is 1 in 150 individuals. The American Centers Disease Central (CDC) figure in 2018 states 16.8 per 1000 individuals, which means that 1 in 59 children is autism. This condition is an increase of 15% compared to 2014, boys compared to girls is 4:1. Research on ASD reaches 5000 studies per year (Directorate General of Disease Prevention and Control, 2020).

Data on service visits at the Research and Development Laboratory for Services for Children with Special Needs, the Functional Implementation Unit for Health Technology Innovation, the Research and Development Center for Humanities and Health Management shows that the number of ASD cases dominates the number of visits, both for assessment and therapeutic services, in 2019 at 50.8%, namely 33 cases out of a total of 65 cases of children with special needs who visited. Children with special needs are children who experience limitations or extraordinariness compared to other children of the same age, whether physical, mental-intellectual, social, or emotional, which have a significant

influence on the process of growth or development (Winarsih et al., 2013). ASD is one of the types of Children with Special Needs served at Laboratory for Children with Special Needs. There are several factors that increase the risk of ASD, including genetics/heredity, parental history of psychiatric disorders, maternal age ( $\geq 40$  years) and father ( $\geq 50$  years) when having children, short intervals between pregnancies ( $< 2$  years), non-specific factors during pregnancy (including hypertension during pregnancy, presence of bacterial/viral infection, family history of autoimmune, fetal exposure to certain drugs/psychotropics/insecticides), premature birth ( $< 32$  weeks), and low birth weight (LBW) (Lord et al., 2018). Although these factors are not clear as causes or markers, children who have these risks should be monitored for development during infancy to toddler age.

Treating individuals with ASD was among the most difficult and expensive treatment categories has an impact on the quality of life for them and their families (Bryson et al., 2004). Handling of Children with Special Needs including cases of ASD (Autism Spectrum Disorder) requires appropriate accuracy and speed, starting from how parents recognize and respond to early symptoms that appear at the early age of a child's development to efforts to provide the necessary interventions (Ministry of Health of the Republic of Indonesia, 2016). ASD when diagnosed on time and given early behavioral intervention and intensive education can lead to better long-term outcomes (Bryson et al, 2004; Zwaigenbaum et al , 2019). Parents of ASD children have their own challenges in carrying out this big role. Parents need to have responsiveness or the ability to respond to what their child is experiencing appropriately and responsively. Parent's response in carrying out their role in supporting the handling of their children, will increasingly positively impact children's development. Responsiveness is the ability or form of effort to provide or take action quickly and quickly (Hamid et al., 2020; Hasnih et al., 2016). The role of family and the closest community is very important in providing support by creating a safe and comfortable atmosphere while at home and providing assistance for ASD individuals. Therefore, this study aims to determine the responsiveness of parents in carrying out the role of handling children with autism, especially in the early detection phase. Therefore, this phase is the starting point for handling the development of the next autism child.

## 2 METHOD

This research was a qualitative descriptive research. Data collection was carried out for 1 year 2019, in a participatory way, researchers interacted directly with ASD children and their families while providing services at the Laboratory for Children with Special Needs at the Health Technology Innovation Functional Service Unit, Research and Development Agency of the Ministry of Health of the Republic of Indonesia. This study uses secondary data, secondary data from medical record documents of ASD clients, as well as qualitative data from families of ASD clients that were collected by researchers in a participatory manner for one year 2019. Medical record documents containing records of the results of history taking and assessment to clients and families, as well as developmental records documents child since birth and a record of the child's health history attached to the medical record. Researchers interact and directly involved while providing services at the Laboratory for Children with Special Needs in Surabaya. The secondary data analyzed were 33 families of ASD children who visited Laboratory for Children with Special Needs in 2019. Laboratory for Children with Special Needs is a service-based research and development for children with special needs. As a service-based research laboratory, in carrying out its activities it is equipped with informed consent, which consists of informed consent for services (assessment and therapy) and informed consent for research activities. Informed consent for research activities, containing the consent of parents/families of children with autism, that all data contained in the patient's medical record documents and questionnaires included in the service can be used for research and development activities so that they become material for publication, socialization and advocacy for the improvement of children's services. special needs.

The response of parents in the role of handling children with ASD in question is how parents recognize and respond to early symptoms of developmental delays experienced by ASD children, so that appropriately and in sufficient time they seek assessment services and efforts to provide needed interventions to professional service centers for children with special needs. Descriptive data analysis with tables and graphs, equipped with narration based on qualitative data from parent/family statements related to the aspects studied.

### 3 RESULT

#### 3.1 Characteristics of Children with ASD in the Laboratory for Children with Special Needs

Based on data from visits to Laboratory for Children with Special Needs, ASD children who access services come from the city of Surabaya and districts/cities around Surabaya (Gresik, Lamongan, Sidoarjo, Mojokerto and Jombang). Table 1. shows that the characteristics of ASD children were mostly male (78.79%), aged >5 years (51.52%) and domiciled in Surabaya (72.73%).

Table 1: Characteristics of Autism Children's Visits at Laboratory for Children with Special Needs, 2019

No.	Characteristics of Autism Children	Amount (%)
1.	Child's age	
	- < 3 years	4 (12,12)
	- 3-5 years	12 (36,36)
	- > 5 years	17 (51,52)
2.	Gender	
	- Female	7 (21,21)
	- Male	26(78,79)
3.	Domicile	
	- Surabaya	24 (72,73)
	- Outside Surabaya	9 (27,27)

Source: Secondary data in Laboratory for Children with Special Needs Surabaya

#### 3.2 Responsiveness of Parents in the Role of Early Detection of ASD Children

The response of parents in the early detection of ASD cases (Table 2), shows that more than half do not have a child growth record document (54.54%), most parents begin to realize their child's developmental abnormalities at the age of 2-3 years (48.49 %). However, the majority of new parents seek help from professional services for initial assessment or diagnosis after the child was 3 years old or older (60.6%).

The responsiveness of parents in the role of monitoring the growth and development of children was indicated by the ownership of document records of children's growth and development and filled in. Most of the children in the study did not have documented growth and development records from birth. Even for children who have documents, the recording and monitoring of children's development

Table 2: Parents' Responses in the Role of Early Autism Case Finding and Accessing First-time Assessment Services.

No.	Parents' Responses in the Role of Early Autism Case Finding and Accessing First-Time Assessment Services	Amount (%)
1.	Monitor and record children's growth and development	15 (45,45)
	- Yes	18
	- No	(54,54)
2.	Begins to recognize and feel a child's developmental disorders, since the child was:	14 (42,42)
	- < 2 years	16 (48,49)
	- 2-3 years	3
	- > 3 years	(9,09)
3.	The response of parents in responding to symptoms of abnormalities in children by accessing professional assessment services	15 (45,5)
	- Directly access professional assessment	18 (54,5)
	- Indirect	(54,5)
4.	The time it takes for parents to be aware of a developmental disorder in their child to access assessment services	15 (45,5)
	- < 1 year	14 (42,4)
	- 1-3 years	4
	- > 3 years	(12,1)
5.	The child's age when parents bring him or her to a professional diagnosis or assessment service for the first time:	13 (39,4)
	- < 3 years	15 (45,4)
	- 3-5 years	5
	- > 5 years	(15,2)

Source: Secondary data in Laboratory for Children with Special Needs Surabaya

has not been done completely by parents. Some of the signs that parents were starting to notice include; cannot speak even though they were more than 3 years old, children tend not to focus, children tend to play alone, cannot play and interact with other children. The factor that caused new parents to realize their child's differences was the parents' lack of understanding about the child's developmental milestones, so that when there was a difference or developmental delay, it was not immediately detected. In addition, the influence of the parent's social environment seems to be able to trigger parents to be aware of the differences in the development of their children with other children. The awareness of this difference arises because it was triggered by moments when children gather with other children, when parents gather with relatives or other children's parents who asked about the child's developmental abilities, until when the child had started school.

“...after observing from school, I just started to realize that my child is different...” (Mama Ad)  
 “...after being asked what your child can do, I think yes, my son can't speak yet.” (mom Fr)  
 “I observed myself, how come my son is not like his brother who can connect if he is taught, this (child) does not understand, yes, he does not understand. I urge my husband to want to check at the HP Hospital..” (mama C)

There were 54.5% of parents still did not directly access professional assessment services when they begin to feel developmental disorders in children. It was said directly if in less than 1 year after the parents become aware of the child's developmental disorder, they make efforts to access professional assessment services. This study showed that parents need time (not immediately), from the stage of starting to realize the difference in their child's development to the stage of immediately seeking professional assessment services (diagnoses) early in their child. Parents still feel the need to wait for children aged 3 years or more to make sure. This was as stated by the following parent respondents:

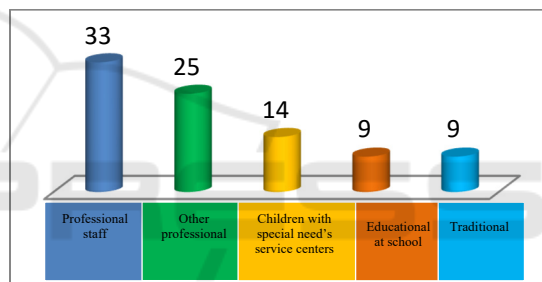
“...began to notice symptoms at the age of 3 years old, indifferent, unable to speak...” (Mama Mt)  
 “I only realized when I was 3 years old, because I thought later I would be able to speak for myself” (Mama Zn)  
 “Ages 2.5-3 years old already said mama, papa. But after a few months it was gone. Contact does not exist. I think it will appear again.” (Mama Gy)  
 “I haven't...(don't want to check it out yet), I wish I could teach myself. My husband also said just wait, later it will be done.” (Mama Fr)

### 3.3 Responsiveness of Parents in Accessing Professional and Non-professional Service Centers for Children with Special Needs

The response of parents to access the professional service center for children with special needs referred to in this study includes all handling services for children with special needs, both those that provide assessment and therapy. These services consist of 1) Professional staff in clinics or hospitals, namely Pediatricians, Psychiatrists and Psychologists; 2) Other professionals, namely other health workers at hospitals and clinics who serve speech therapy, behavioral therapy, occupational therapy (OT), biomedical therapy, sensory integration therapy (SI

and physiotherapy); 3) Children with special need's service centers, namely consisting of therapy centers, Puspaga (Family Learning Centers), hospitals and 4) Educational services at school, namely inclusive schools, shadow teachers and regular schools. Meanwhile, non-professional services were services that were accessed by parents of children with ASD, in addition to professional services such as traditional health services or other services.

Figure 1. shows that most of the children who visited Laboratory for Children with Special Needs Surabaya had previously received professional services at several children with special need's service facilities, most visited professional children with special need's service centers, namely professionals (33 children), other professionals (25 children), children with special need's service centers (14 children) and education services (9 children). There were even parents who seek help from traditional (non-professional) services for 9 children.



Source: Laboratory for Children with Special Needs's secondary data.

Figure 1: Responses of Parents Accessing Professional and Non-Professional Children with Special Needs Service Centers who visited at Laboratory for Children with Special Needs Surabaya 2019.

The phenomenon of professional shopping (doctors, psychologists or psychiatrists) occurs in children in Laboratory for Children with Special Needs, as well as shopping for therapy centers and other non-professional services. Before accessing services at Laboratory for Children with Special Needs, their parents were taken to various places, to confirmed the diagnosis and tried to find various therapies that were expected to be good for the child's development.

“After waiting in line for 4 months, the doctor at dr. S Hospital gave a diagnosis of ASD. Speech therapy was recommended. So far, he had had speech therapy (4 years), smart kids therapy (4 years), neurosensory, edutherapy, occupational therapy, great class therapy at his school (currently), studying at school using shadow, and edutherapy at Ks”.... ”Ky was

advised by a school psychologist to go to the Laboratory for Children with Special Needs because they still can't focus, speech delays and they still can't communicate in 2 directions" (mom Ky).

"Initially to Clinic A, SI therapy was suggested, carried out for 1 year. After that, I went to P doctor at N Hospital, it was recommended for speech and occupational therapy, the therapy had been since after clinic A, until now"... "In addition, to Dr. Rt, it was recommended that occupational and speech therapy again at clinic T". "Then since school, accompanied by Mrs. A's team, after being evaluated, it was recommended to go to the Laboratory for Children with Special Needs for consultation with dr. E" (mama Mt). "...until the age of 4 years, take Gy to Al (therapy center), for ABA therapy, until the age of 5 years. Then to MH (therapy center) until the age of 6 years. Been to dr RI too, got diet therapy. School and accompanied by GPK at home. Up to Mrs. L, because of her lack of control over her emotions. Then it was recommended to come here (Laboratory for Children with Special Needs)" (Mama Gy).

From the observations of researchers and discussions during the service process, there were several reasons for parents to do therapy and other professional shopping, including; parents want the best treatment, but unfortunately it was not based on sufficient knowledge and understanding about autism. Parents still did not understand which treatment had good scientific evidence. In addition, parents' lack of acceptance of their child's condition make parents believe and continue to seek answers about their child's recovery.

"I want the best for my sister (Ky), according to what doctors, psychologists and friends suggested" (Ky's mother).  
 "...hope Mt has good development, what is suggested to be done..." (Mama Mt).  
 "...we continue to look for efforts because we feel Gy's emotional development has not improved. Still likes tantrums, hurting himself and those around him..." (Mama Gy).

The impact of this professional and therapeutic shopping was that the handling of children had not been carried out in accordance with the priority needs. A lot of time was spent on various therapeutic services that were not yet mainstream. Whereas children should received behavioral therapy, as the first and foremost treatment, then followed by other therapies that were really needed.

"I was 2 years old, I checked with Dr. St., after waiting in line for 4 months, the doctor diagnosed ASD". "Ky's age is now 6 years, 11 months". "Currently there is no two-way communication. The focus is still lacking" (Mama Ky).

"...if we want to add therapy here (Laboratory for Children with Special Needs), the time for Mt is not available, because it is in conjunction with other therapies, yes, speech...". "...Mt is 5 years old now". "I have been in therapy since clinic A for 1 year, ... to therapy at P Hospital, speech therapy... and clinic T, yes it's the same" (Mama Mt).

"Since after 1 year the speech is gone, pa and pa are gone. until the age of 4 years, take Gy to Al...., for ABA therapy, until the age of 5 years. Then to MH age until the age of 6 years. Been to dr RI too, got diet therapy. School and accompanied by GPK at home. "I feel that Gy's emotional development has not improved. Still likes tantrums, hurting themselves and those around them..". "Up to Mrs. L, because of her lack of control over her emotions. Then it was recommended to come here (Laboratory for Children with Special Needs) "Gy's sister is now 10 years old" (Mama Gy).

The phenomenon of shopping therapy was one of the reasons for 18 (54.5%) parents who did not directly access professional assessment services. Parents got information from various sources so that they accessed other services (therapy) before coming to professional assessment services, both professional and non-professional therapy.

#### 4 DISCUSS

The results showed that the characteristics of ASD children who visited Laboratory for Children with Special Needs were mostly male, aged > 5 years and domiciled in Surabaya. From this data, it was known that parents had visited other professionals before visiting Laboratory for Children with Special Needs, so that the ASD children who visit were more than 5 years old. These results also support that most people with autism were men, compared to women (1:5) (Kementerian PP&PA RI, 2018). Another study found that most people with autism were firstborn (45%) and boys (75%) (Asmika et al., 2006).

The response of parents to monitor the growth and development of ASD children showed that more than half did not have a document of child growth and development records, while those who had

documents were mostly development records from hospitals/clinics and had more than one document (Card for Health/KMS, Mother and Child of Health/MCH or KIA books, progress notes from hospitals or clinics). This was in accordance with Riskesdas data on ownership of MCH books, showing that less than half of children aged 0-59 months had MCH books, namely 30.5% (2010), 30.9% (2013) and 49.7% (2018). Similarly, for monitoring the growth of children in Indonesia, the proportion of weighing children under five according to the standard was still low, namely 45.4% (2007), 44.6% (2013) and 54.6% (2018). The development index of Indonesian children aged 36 -59 months was 88.3 (2018), lower than neighboring Thailand's 91.1 (2015) (Health Research and Development Agency, Ministry of Health RI, 2018). The response of parents in monitoring children's growth and development was very important to know if there were problems that could be immediately addressed. Some of the roles that parents need to play in dealing with children's developmental disorders include; 1) monitor the development of children starting from birth to the present age, 2) identify early developmental disorders in children, 3) immediately consult professionals (doctors, psychologists, educators) for different developmental symptoms in children, 4) find out the needs therapy for children, 5) provide support for children to get further treatment according to their therapeutic needs, 6) support and assist children in the process of developing their abilities (Ministry of Health RI, 2016; Winarsih et al., 2013). Early identification of ASD disorders is important. Experts recommend that this detection screening be carried out at the age of 18 months and the child should be brought to a developmental service at the age of 24 months (Shanchack & Thomas, 2016).

In this study, most children accessed diagnostic services for the first time at the age of more than 3 years. This is consistent with another study in which African-American children on average accessed diagnostic services after the age of 3 years, after parents experienced concerns about language development, behavior and child development for an average of 23 months or nearly 2 years. Even in New York and St. Louis, childhood diagnoses ranged in age from 54 months and 80 months or more to 5 years, respectively (Constantino et al., 2020). The cause of parents accessing early assessment services when the child was 3 years old and over in this study was due to a lack of understanding of developmental milestones and their hope for child development and they did not record their child's development in the context of independent detection based on the records

in the MCH's book they had. Most parents need time that was considered sufficient, in the range of 3 years or even more than the child's age to ensure that their child's development was normal or not. A study of African-American children revealed that 35.6% of families reported delays in accessing diagnostic services and experienced significant waiting time to see a professional (Constantino et al., 2020). Parents spend varying lengths of time ready to access professional services for their children. The experience of parents describes them going through several steps before understanding the signs that lead to symptoms of autism in their children, starting from questioning the signs of a child's delay, knowing that something was wrong in a child based on meanings and interpretations built by parents themselves or influenced by external interactions, to leading at the stage of realizing that there was something different in a child's development to be suspicious of the symptoms of autism (Gentles et al., 2020).

This study showed that parents had made efforts to access many children with special need's service centers, both professional and non-professional. The most visited professionals were pediatricians. Most parents tried to access more than 1 type of service for therapy, while access to education services was more to regular and inclusive schools. There were also ASD children who use traditional health services or non-professional workers. This search for many professional services was also experienced by African American ASD children, in fact around 41.6% reported parents seeking many professionals before receiving a diagnosis of ASD for their child (Constantino et al., 2020).

Professionals must be aware of and sensitive to early behavioral patterns of ASD, thereby promoting reliable early diagnosis. So that they can become a referral center for parents to consult. The results of the study stated that early ASD behaviors in infants and toddlers that can be identified early are 1) Social attention aspects, namely lack of eye contact, social interaction, social smiles, imitation, orientation to name calls, appropriate facial expressions and interest and pleasure in people. other; 2) Communication aspects, namely lack of vocal communication, joint attention skills (following points, monitoring gazes and object/event references), behavioral abnormalities, gestures and hypersensitivity to sound (Barbaro & Dissanayake, 2009; Truffino & Villamisar, 2004). However, poor families living in the state were less likely to access professional services for early detection. Other barriers to access to early detection and therapy were financial problems,

transportation needs, inflexible work schedules and limited family support (Braddock & Twyman, 2015).

Education services are one of the professional services that have been accessed by parents. Parental involvement is absolutely necessary in the development of children with autism, but parents have limitations, therefore the role of schools and social workers is needed to help deal with situational pressures during the child's education period (Mujahiddin, 2012). Inclusive schools are educational services for children with special needs regardless of physical condition, intelligence, social, emotional and other conditions. Inclusive schools are effective in helping children with autism avoid discriminatory attitudes, creating community acceptance and getting the same treatment as normal children, open attitudes from peers and school teachers, so that children with special needs are able to develop their potential. Research shows that inclusive schools have an important role in the development of children with autism in social interactions (Pratiwi, 2015). Family participation is needed, to follow every teaching procedure with high integrity and commitment (de Oliveira et al., 2019). The existence of inclusive schools needs to be socialized to families and the general public, thereby increasing understanding and support for autistic children and their parents (Sari et al., 2021). Therefore, access to information related to inclusive education is absolutely necessary (Agustin, 2016). Other studies had found that setting in inclusive classrooms was able to make treatment to increase positive social interactions and development in children (Aller, 2017).

However, the facts on the ground showed that there were obstacles in the field of children with special need's education, namely the lack of parental access to inclusive schools, both access to information and the limited availability of inclusive schools. Data from the Directorate General of Special Education of the Ministry of National Education in March 2010, the number of children with special needs in Indonesia was 324,000 people, while only 75,000 children attended school. Based on the Regulation of the Minister of National Education Number 70 of 2009 concerning Inclusive Education for Students with Disabilities and Potential Intelligence and/or Special Talents, in practice inclusive schools were still constrained by the lack of regular schools that organize this program and the limited number of shadow teachers for children with special needs in inclusive schools (Minister for Women's Empowerment & Child Protection of the Republic of Indonesia, 2011). Research showed that

the obstacles for persons with disabilities in the field of education were the unavailability of curriculum (teaching materials) that are appropriate to the needs of students, the absence of educators who had the ability to communicate, an environment that was not ready for the implementation of inclusive education, the absence of adequate and supportive facilities and infrastructure and the absence of budget (Jayanti & Marlina, 2018).

The results of the study found that parents also access traditional medicine for the treatment of ASD children, this condition needs further research on the effectiveness of traditional therapy. A study using an electronic database of Randomized Controlled Trial (RCT), which assessed the efficacy of herbal medicines alone or in combination with other Traditional Chinese medicine, involving 567 patients with ASD, showed that herbal medicines significantly increased the Childhood Autism Rating Scale (CARS) score, but the outcome effect on the total effective rate (TER) different between studies. In conclusion, there was an encouraging but inconclusive efficacy of herbal medicines for the treatment of ASD due to the low methodological quality, diversity of herbal medicines, and small sample size of the studies examined (Bang et al., 2017).

This study found that parental responsiveness was still weak in early detection of ASD cases, indicated by parents being late in realizing their child's developmental abnormalities, lack of understanding of the condition of children with autism and not immediately or late seeking help to professional services for assessment and initial assessment was carried out after the child was > 3 years old. This was in line with other studies that parents were often late in realizing that their child had autism due to lack of knowledge and information about autism (Kurniawan, 2021; Suteja & Ruwanti Wulandari, 2013). Lack of knowledge and understanding of parents caused many parents to be late to professionals for assessment, diagnosis and therapy of their children. Although the level of parental knowledge about autism was low, many parents had high motivation for their child's recovery (Asmika et al., 2006). To overcome this, many studies related to expert systems based on information system technology, both computer-based and android-based, were developed to help parents detect ASD early. (Aldrin et al., 2017; Lesmana, 2017). One study succeeded in developing a diagnostic method for ASD children in primary care, thereby reducing waiting time for diagnostic consultations from an average of 144.7 days to 49.9 days, having high levels of family

and provider satisfaction and reducing referrals to expensive tertiary diagnostic centers (Hine et al., 2021).

The role of parents in early detection of children with autism is very important, because it determines the prognosis of therapy. Early intervention can be done immediately so that the negative impact can be reduced as much as possible. The golden opportunity to help people with autism is at the age of less than two years, because the best time to stimulate the child's brain. Parents are expected to be able to carefully monitor children's development and make early detection of children (Kusdiyati, 2000). The results of the study indicated that parents were quite involved in the treatment of their children, starting from confirming the doctor's diagnosis, fostering communication with doctors, looking for another doctor if the doctor in question was considered less cooperative, telling the truth when consulting about their child's development, enriching knowledge, and accompanying children when did therapy (Rachmayanti & Zulkaida, 2007). Other studies had shown that there was a significant relationship between parental adjustment and their role in the therapy of children with autism. The attention of parents with autism's children was very important, because good parental acceptance and adjustment had an impact on an active role in various efforts to deal with autism to support the success of therapy. (Merianto & Risdayati, 2016).

Parental involvement in handling children with autism includes seeking information about the child's diagnosis, seeking appropriate treatment, explaining how the child's condition is to the environment, not distinguishing the parenting given to children, between children with autism and normal siblings, knowing each development's children, giving children the opportunity to be independent and able to form inner bonds with children (Sudarmintawan & Suarya, 2018).

## 5 CONCLUSION

Based on data on visits by children with ASD at Laboratory for children with Special Need Surabaya, it showed that parents responsiveness in monitoring children's growth and development was still lacking, which was shown by most of the parents who did not have documented records of children's growth and development. Parental responsiveness was still weak in early detection of ASD cases, indicating that parents were slow in realizing their child's developmental abnormalities and did not immediately

seek help from professional services for assessment, which was indicated by data access to initial assessment carried out after the child was more than three years old. However, most parents have tried to access professional children with special need's services for diagnosis and therapy of their children.

## 6 SUGGESTION

Based on the results of the study, efforts to increase parental responsiveness regarding monitoring children's growth and development, early detection of ASD and assistance during the process of handling learning or therapy, are very important to do. One of them is by increasing the understanding and skills of parents regarding this matter. Therefore, it is necessary to socialize and train parents related to monitoring children's growth and development, stimulation, early detection and intervention of children with autism as well as skills in home learning assistance and skills to synergize with the medical team as well as teachers and therapists who handle ASD children. Socialization and training for parents can be carried out by various parties, ranging from elements of the government, private sector and non-governmental organizations.

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