Mohd Yusof Zulkefli, Norfishah Mat Rabi (2018). Drink From Waterfall: Challenges Of Having Autistic Children On Communication And Social Behavior. *Idealogy*, 3 (3): 60-70, 2018

Drink From A Waterfall: Challenges Of Having Autistic Children On Communication And Social Behavior

Mohd Yusof bin Zulkefli¹ and Norfishah bt. Mat Rabi²,

- 1 Faculty of Arts and Social Science, Universiti Tunku Abdul Rahman
- 2 Faculty of Human Developmet, Universiti Pendidikan Sultan Idris

yusofz@utar.edu.my norfishah@fpm.upsi.edu.my

ABSTRACT

Socialising and communicating can be challenges for many autistic kids. Communication difficulties among autistic are very common. Some of them can speak very fluently whereas there are also facing with speech impaired to varying degrees and there have kids with ASD who are unable to speak at all. To those who can speak, they will often use language in a limited or unusual way (Foggo & Webster, 2017). Therefore, it will disturb the way they interact with others hence will making them behave abnormally. This study was undertaken to analyse the challenges of having autism kid towards communication and social behaviour. Objectives of this research is to find out the communication and social behaviour problem that occur among ASD children and at the same time to find out the best solutions to overcome this matter. Data were obtained from an in-depth interview with parents who lived with diagnosed autistic children, special education teachers, and caregivers. Observations were made to understand their communication cues.

Key Words: Autistic, Communication, Social Behaviour, Challenges

60

1. INTRODUCTION

Autism spectrum disorders (ASD) and autism are both terms for groups of complex brain development disorders (Autism Speak, 2015). Basically, this disorder is characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviours like stimming and flapping. Different child diagnosed with autism will have different type of behaviour. Most of the parents sometime might confuse with the characteristics of the autism behaviour. Because of that, most of the expert agreed that, where ever the kids showing the symptoms that resemble to autism disorder, either asperger, mild or even severe characteristics, so they will fall under an umbrella (Hansen, Schende, & Parner, 2015). Autism actually is a complex disorder in term of social interaction and learning disabilities. It is not easy to detect a person to have autism because on the surface they look normal as other kids. According to Norfishah Mat Rabi (2015), generally Autistic Spectrum Disorder (ASD) occurs at the age of three and ranging from mild to major. In addition, ASD refers to a range of conditions characterised by challenges with social skills, repetitive behaviour, speech, and nonverbal communication as well as by unique strengths and differences (Autism Speak, 2017; Norfishah Mat Rabi, 2015 and Bardhan-Quallen, 2005).

How do we detect the symptoms of the autism disorder or ASD? This question always been asked by any parents or guardians in order to know well or to treat well of their kids before things get worse. According to Autism Spectrum Disorders Health Center, there are three major core symptoms of the ASD and they are social interaction and relationship, verbal and non-verbal communication and limited interest in activity. Social interaction and relationship means the kids will have significant problem in developing their non-verbal skills for instance likes facial expression, gestures, and so on. Besides, they are also lack of interest very easily in doing something and normally, generally, they have difficulties to understand another people's feeling such as pain. This is because, some of the kid diagnosed with autism, they will have sensory issue whereby they presume to attack people but actually they are not just because of their sensory issue (Yee & Manisah, 2008).

In terms of verbal and non-verbal communication, according to McPartland & Volkmar (2009), children with ASD will face with verbalization problems, where they delay or lack of learning to talk. About 40% of people with autism never speak (McPartland & Volkmar, 2009). Even though they are capable to speak or verbalised some words, however they still have problem with echolalia. Echolalia means repetitive use of language or they will repeat over and over the phrase they have heard (Quill, 1995). Most of the parents really look into this program. Most of the parents really wants to have speech therapy in order to help their kids to communicate and at least can be able to request something commonly use. In term of early intervention, this is how what have been projected by Rauf Kaufman about Son-Rise Program where they are trying to help those kid to get out from their own world and help them to get rid their 'foreign' language (Houghton, Schuchard, Lewis, & Thompson, 2013).

2. LITERATURE REVIEW

Autism and Rhetoric

Most of the people including teachers, parents, therapist or even people who lives with autistic agreed that autism is actually knowingly as legion, what they too have in common is a focus on language use in the social realm (Heilker & Yergeau, 2011). This is shows that lacking of the focus on communication in social interaction. Again, these depends on the types of the diagnosed; Asperger, mild or severe autism (Hanse et al, 2015).

However, according to The National Institutes of Health, as quoted in Heilker & Yergeau (2011), they define autism as spectrum that encompasses a wide range of behaviour but whose common features include impaired social interactions, impaired verbal and no verbal communication and restricted and repetitive patterns behaviours. Then, according to Control and Prevention (CDC) argued, autism spectrum disorder (ASDs) are group of developmental disabilities defined as significant impairments in social interaction and communication and the presence of unusual behaviour and interest. Thus, to understand the verbal and nonverbal communication among autistic children is very important as they need people to assist them rather than forcing them to talk and at the same time will reduce their motivations.

The Autism Language

Severe language delays early in the life of child with autism can be overcome in order to understand their needs especially if a child exhibits nonverbal intelligence (Marcus, 2013). There are an effective ways to overcome and help children to communicate effectively. Most of the therapists would use The Picture Exchange Communication System (PECS) which actually helps children to develop their verbal language (Berman & Rappaport, 2008) as well as decrease tantrums and odd behaviours and allows for increased socialisation. PECS was developed to teach children with autism spectrum disorder and related developmental disabilities a functional communication system (Travis & Geiger, 2010).

PECS allows children with autism who have little or no communication abilities, a means of communicating nonverbally (Hansen, Schende, & Parner, 2015). Most of the parents also use PECS as teaching tools for visual learners. PECS works well in the home or in the classroom. Other than that, most of the people such as parents, therapists and psychologists were agreed that there still have ways to help the autism kids to verbalise some of the major words like "I want", "Poo", "Pee", "Eat" and "Rest" through interactive methods (Kaufman, 2014). According to Kaufman & Kaufman (2015), one of the effective tips to breakthrough their language is talking through puppets and figurines. This can be a great first step for autism kids to practice their conversation skills.

Communication and Behaviour

Behaviour in ways that others identify as "challenging" or problematic is not exclusive to people with autism. It is part of being human. Most of our behaviours reflect attempts to meet our needs, satisfy our desires, cope with frustrations and high levels of emotion" (Mukherji, 2001). Behaviour is communication. For individual with autism, behaviour may be the only means by which they have to communicate a need or frustration. Individuals with autism will communicate using the 'most effective and

efficient means possible' (Clement & Zarkowsa, 2000). In addition, according to Cumine, Leach, & Stevenson (2000), when challenging behaviours occur they used to control one's environment and serve with four purposes and they are first to fulfil a sensory need, to escape the demands of undesired situation or event, to gain attention ad lastly to obtain a tangible object.

There are so many ways which can help with the challenging behaviour. One of it is by using visual support are those things parents can see that can improve communication, interaction and understanding (Mukherji, 2001). Visual support are photographs, symbols, line drawing or words that can be used to reduce some of the anxiety, confusion and frustration that many individuals with autism may feel when they come across unexplained of unfamiliar events. Visual support work for individuals with autism because they often demonstrate impairments in attention and information processing. They may also demonstrate significant deficits in the ability to focus attention on selective communication messages. Studies have shown that children with autism have

Early Intervention

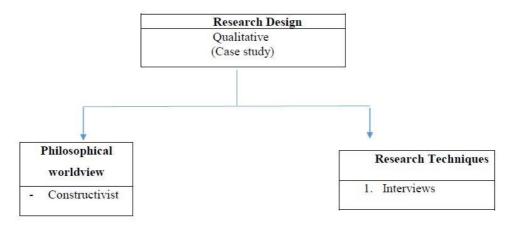
Over the years, there have been many treatment developed for children with autism, evolving from different philosophies. These include behavioural interventions and cognitive behavioural interventions (Corsello, 2005). Two aspects of intervention that are common to most intervention programs designed for ASDs and have empirical support include the intensity of the program and the age at which children should begin intervention. There is no debate or doubt about early intervention is the children's best hope for the future. Early attention to improving the core behavioural symptoms of autism will give cildren and the rest of the family several important benefits that family members will not gain if they a wait and see approach until their children enters school at the four or five (Autism Speak, 2015).

There are several services and approaches to utilise when working with a child diagnosed with autism (Norfishah Mat Rabi, 2016). One study found that parents of children diagnosed with ASD were in need of consistent therapy with their children as well as assistance from knowledgeable professionals (Gaus, 2011). MacFarlane & Kanaya (2009), found that speech therapy being the most common services for children diagnosed with autism as 87.3% of families utilised this source followed by occupational therapy with 67.5% of families utilising this source. This study also indicated 45.6% utilised behavioural management programs while 42.7% utilised learning strategies and study skills assistance. Speech therapy is the highest demand among parents with autistic children (Kenny, et al., 2016).

3. METHODOLOGY

Qualitative research is a research strategy that focuses on word of the results of studies that have been carried over from the quantification (Bryman, 2008). Hence, a qualitative study was examined on how and why the qualitative research done by identifying the results of the study of the arguments available to the possibility of validity

and reliability in qualitative research. This method being used in order to achieve the objectives of the research that was accomplish a better result. Previous researcher have a different idea about research design. According to (Bryma, 2016) research design is a framework used in a research to collect and analyse the data. However, according to Robson & McCartan (2016), the function of the research design is a process of translating a research to a systematic process in order to achieve the objectives, to answer the research questions, to enhance or develop theories, and strategy to develop a suitable method. In addition, according to Creswell (2014), research design is a plan or idea to formulate a research, consist of the paradigm of philosophical worldview, research strategy, and research techniques.



Source: Creswell (2014)

In conducting this research, a qualitative data collection method provides the opportunity to collect depth, descriptive data about people's behaviours, attitudes, and opinions. They can be used as an individual research method or as particular part of a multi method design, depending on the requirements of the research. It is a useful approach for understanding the story behind a person through the interview. Ravitch & Sharon (2016), stated that, interviewing allow the interviewer collect in-depth data around the topic after interview session. The examiner situated the interviewees at eased and listened, observed along with lead them throughout the dialogue specifically in terms of answering the questions given up until the main objective of the research is discovered (Bryman, Social Research Methods, 2016). For the purpose of achieve the research objective, there are few strategies selected by the examiner to enhance the quality of the interview.

Marshall & Rossman (2016) explained that an in-depth interview is one of the oldest and most respected data collection strategies in social science. It is used to stimulate an overall picture of the participant's perspective on the research topic. During in-depth interviews, the person being interviewed is called the informant and the interviewer is considered as researcher. The researcher's must acquire interviewing skills that capable to study everything shared by the informant that is relevant to the research topic (Miles, Huberman, & Saldana, 2013). Researcher have to be neutral when he posing question to the informant and listen attentively to their responses to prevent bias from happen. At the same time researcher can ask follow-up questions based on those

responses. In-depth interviews are usually conducted face-to-face and involve one interviewer and one participant.

4. FINDING AND DISCUSSION

The Parents are often the First to Detect Signs of Concern

Basically the step in the process of seeking a diagnosis is the recognition that some aspect of developmental is not proceeding as expected. Whatever the period explored, the answer were similar indicating that signs raising concern did not vary. However, parents of young autistic children more readily referred to professional. Parents reported impairment in social skills, play and communication skills, behavioural disturbances and sensory motor disorders. Failure to respond to name, and the lack of eye contact were the earliest and most frequent signs and pinpointed;

He starts using speech which not so called speech like bubbling around six month but with so much stimming actually. I thought it was normal, but until two years old I realised he still cannot speak. (Informant 1)

He seems normal at early development milestone, totally normal at that point. He also responds to his name, eye contact very good but after that, flop... however by the time one year and half he sleeping away. Such as less eye contact, stop talking and isolating himself. (Informant 2)

The Change in the Mean age at Diagnosis and the Words Used

The mean age at diagnosis was five. For the children born from 2000 to 2002, the mean age at diagnosis was three (Chamak, 2008). These results illustrate the fact that many but not all professionals have adopted new practices since some parents still do not get an early diagnosis for their child. However, recently most of the parents are aware of this and most of them will not procrastinate to assess their children before thing get worse. Hence, if they can detect early, so they can help their children well.

They are special, method should we used also must be different with others kid. We need to know what is their problem is. We cannot simply send them to any institution without acknowledge their problem. Meet up with consultant then discuss and keep tracking on the progression. If we do this, we do really help our kid. We can help them to get early intervention. (Informant 3)

More on method which is to a count more on the cognitive part of the brains. This means that we have to help them and understand at the same time. Even there are kids good in grammar and rich with vocabulary even they are diagnosis with autism however, they are not in socializing, so we have to help in to socialise and apart from it they will change and can improve very well. Meet up with the professional is the best alternatives to get clear picture to help our kid. (Informant 1)

Communication Tool

Positive relationship between home and school are very important to improve parental involvement and at the same time can help in maintaining child in socializing and enhance their communication skills. The nature of the communication between home and school can have a significant impact on the quality of this relationship, as well as on a kid's program at school and the ongoing development and generalization of skills. Many parents report that they wait expectantly to read the communication book at the end of each day and that their emotional state can be cognizant of the message that are sent and how the message are stated.

He can with the routine that he used to but similar one with at the center and home. If totally new thing, it will be a little bit hard. We have to prompt him with model. However with the instruction that he used to it such as Isa please carry this and put on table, from there he knew about key word carry or put and table then he will understand it which means at that point we can mix the word and he will understand better if he is already familiar. But if couldn't understand, he will look upset to find out what does it mean. (Informant 1)

Behaviour Engagement

Attention is more frequently given to behavioural engagement. This tendency may reflect the influence of Applied Behavioural Analysis (ABA) and Son-Rise Program. For instance, kids diagnosed with autism display obsessions or preoccupations with specific themes or objects such as likes order and may line up toys repeatedly. In addition they also engages in unusual behaviours, such as rocking, spinning, or hand flapping if we stop them by doing that, they gets extremely upset with changes in routine or schedules and normally they will have an unusual response to loud noises or other sensory stimuli.

... well, he starts using speech not so called speech I mean like bubbling around 6 month but with so much stimming actually. I thought it was normal, but until two years old I realised he still cannot speak. (Informant 1)

He has lots of episode because he cannot speak then when he wants something he which we cannot understand then he will show his tantrum. (Informant 2)

Social Stories

Social story is very important to the kid in regards telling them about what he or she will facing through the day or any activities that he will facing with. Thus, it will reduce the tantrum among them. According to Tannen (2007), social stories provide a brief descriptive story for children to help them better understand specific social situations.

Before we go for a holiday, I will use social story to explain to my kids about our activities on that place. (Informant 3)

Sam always get confuse if we travel from one to another, so the consultant advise us to us social stories to explain to him about something unusual to him. (Informant 4)

Sensory Integration

Children with autism, as well as those with other developmental diasbilities, may have a dysfunctional sensory system. Sometimes one or more senses are either over or under reactive to stimulation. Such sensory problems may be the underlying reason for such behaviour as spinning, hand flapping, mumbling and many more. Those who may have sensory intergration may be unable to respond to certain sensory information by planning and organizing what need to be done in an appriopriate and automatic manner.

Touch

Less sensory integration but now improving a lot. He was born caesarean. Because my wife have some complication so Isa was born by Caesarean. After giving birth, my wife under conscious for about two to three days. Same goes to my son, where facing with colic. Since there, Doctor already warned us about Isa's health which have tendency to have some complication. Now we are realising, most of the autism will have this kind of symptom which is colic issues and sensory integration. (Informant 1)

Hearing

His more on sensory issues, it would be difficult. Attention and focus on something will go down. However now is much better compared to before. But if it is very noisy then it is a bit difficult. (Informant 1)

The first challenges parent of children with autism face is the diagnosis, which can bring heartbreak, anxiety, anger and feeling that life has been unfair. Most of the parents with ASD kid would say that most of the people who do not have kid diagnosis with autism will not know how hard it is.

Another hurdle for parents is the strain having a child with such extensive needs places on the family unit. The tension is actually can enter marriages because dealing with autism is so consuming. Other difficulties for families can be the way siblings feel overshadowed by the needs of the child with autism, while some are able to form a close relationship, others may grieve the loss of a typical playmate. However, there is certainly hope in this realm.

Many parents of autistic children feel the lack of support. Actually, group support can offer parents knowledge, understanding and acceptance they seek. Parents can find comfort, friendship and support in network like the Autism Support Network, Autism Speaks and the Autism Society whose websites provide access to message board, information about local chapters and meet-ups and event.

Sometimes the difficulties of autism can lead to behaviour that are quite challenging parents to understand and address. Most individuals with autism display challenging of some sort at some point in their lives. Since behaviour can be a form of communication, the site states, autistic kids will often voice their wants and needs through behaviours rather than word that can include noncompliance, compulsions, physical aggression and tantrums.

5. CONCLUSION

There are many things parents can do to help children with autism overcomes their challenges. But it is also important to make sure that parents with autism kid get the support that they need. When parents looking after a child diagnosed with autism, taking care of your own self is not an act of selfishness but it is necessarily. Which mean parents also can have some space or your own space to relax and get some fresh air.

Connecting with a child with autism can be challenging because most of the kid could not speak or communicate like others kid do. But, as parents, they do not need to talk in order to communicate and bond. They can communicate by the way they look at their child, the way they touch their kid and by the tone of their voice and their body language to sooth them. In other way around, the child also actually communicate with their parents even he or she never speaks. Parents just need to learn their patterns to understand them.

6. RECOMMENDATION

Extend the study to the perspective of teacher/therapist

This study has focused only on parents, future research can be undertaken targeting to different aspects. For instance, they can examine the challenges in dealing with autism kids among teachers or therapist. Other than that, future researcher also can study about child initiating program on which aspect or program could help children to show their improvement in a short time and yet will not make the child feel stressful. In this studies, teacher or therapist can be included because they are the stakeholder who also dealing with the autism kids. Teacher or therapist also one of the important person in dealing with early intervention with the kids

Experimental research

Finally yet importantly, future researcher may complete the research by using experimental research. This is because, in most experimental designs, normally, researcher will use random assignment to create two or more group that they can treat equivalent and hence compare. Experimental research provides precise and relatively unambiguous evidence for a causal relationship. It closely follows principle of a positivist approach to social science and produces quantitative result that researcher can analyse with statistics. The real strength of experimental research is its control and logical rigor in establishing evidence for causality.

7. REFERENCES

Autism Speak. (2015, April 1). *Autism Speaks Inc.* Retrieved from www.autismspeaks.org: https://www.autismspeaks.org/what-autism

Berman, T. F., & Rappaport, A. (2008). Play to Grow: Over 200 games designed to help your special child development fundamental social skills. Ramat Beit Shemesh, Israel: Autism Treatment Center ISBN-13:978-0-615-22814-3.

Bryman, A. (2008). Social Research Method 3rd Edition. Leicester: OUP Oxford.

- Bryman, A. (2016). Social Research Methods. United Kingdom: Oxford University Press.
- Chamak, B. (2008). Autism and Social Movements: French Parents' Associations and International Autistic Individuals' Organizations. *Sociology of Health and Illness*, 76-96.
- Clement, J., & Zarkowsa, E. (2000). *Behavioural Concerns and Autistic Spectrum Disorder:* Explanation and Strategies. London: Jessica Kingsley.
- Corsello, C. M. (2005). Early Intervention in Autism. Infants & Young Children, 74-85.
- Foggo, R. S., & Webster, A. A. (2017). Understanding the Social Experiences of Adolescent Females on the Autism Spectrum. Research in Autism Spectrum Disorder, 74-85.
- Gaus, V. L. (2011). Living Well on the Spectrum. New York: The Guilford Press.
- Hansen, S. N., Schende, D. E., & Parner, E. T. (2015). Explaining the Increase in the Prevalence of Autism Spectrum Disorders. *JAMA Pediatr. 2015;169(1):56-62. doi:10.1001/jamapediatrics.2014.1893*, 56-62.
- Heilker, P., & Yergeau, M. (2011). Autism and Rhetoric. College English, 485-497.
- Houghton, K., Schuchard, J., Lewis, C., & Thompson, C. K. (2013). Promoting child-initiated social-communication in children with autism: Son-Rise Program intervention effects. *Journal of Communication Disorder*, 495-506.
- Kaufman, R. K. (2014). Autism Breakthrough: The Groundbreaking Method That Has Helped Families All Over the World. New York: St. Martin's Press.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 442-462.
- Marcus, M. B. (2013, March 4). *HealthDay News for Healthier Living*. Retrieved from consumer.healthyday.com: http://consumer.healthday.com/cognitive-and-neurological-health-information-26/autism-news-51/most-kids-with-autism-overcome-language-delays-study-finds-674096.html
- McPartland, J., & Volkmar, F. R. (2009). Pervasive Developmental Disorders. In B. Sadock, & V. Sadock, *Comprehensive Textbook of Psychiatry, 9th edition, volume 2* (pp. 3540–3559). Philadelphia: Lippincott.
- Miles, M. B., Huberman, A. M., & Saldana, J. (2013). *Qualitative Data Analysis: A Methods Sourcebook 3rd Edition*. United States: SAGE Publications.
- Mukherji, P. (2001). *Understanding Children's Challenging Behaviour*. Cheltenham: Nelson Thorne.
- Norfishah Mat Rabi. (2016). *Transformasi Pedidikan Murid Kurang Upaya*. Tanjung Malim: Penerbit Universiti Pendidikan Sultan Idris.
- Quill, K. A. (1995). Teaching Children With Autism, Strategeon to Enhance Communication and Socialization. New York: Delmar Publisher Inc.

Travis, J., & Geiger, M. (2010). The effectiveness of the Picture Exchange Communication System (PECS) for children with autism spectrum disorder (ASD): A South African pilot study. *Child Language Teaching and Therapy*, 39-59.

Yee, L. P., & Manisah, M. A. (2008). Amalan Program Intervensi Awal Kanak-Kanak Autistik Mengikut Perspektif Ibubapa. *Pendidikan*, 19-33.