

Autism, the Treatments, and the Society

Introduction

The purpose of this research paper is to obtain basic knowledge on the types and possible causes of autism in children, the therapies that are available to them to improve their condition, the efficacies of the therapies, and the role of society in providing the therapies to those who are in need of them. Since the research focuses on the issues regarding the development of autistic children, it will mention little about the effective therapies applied to autistic adults.

Over the past few decades some very important findings and establishments of therapies, treatments, and interventions for autistic children came about. In addition, the efficacy of the interventions was assessed, and the refinements of the therapies were carried out based on the evidence based research. The research has shown that such intervention does have positive effect in helping autistic children develop the impaired social skills. With these effective therapies and intervention programs established, the society should work to help those who are in need of such programs have easier access to them.

What is Autism

The word autism was brought up by an Austrian-American pediatric psychiatrist

Leo Kanner (Koegel, Koegel, and Brookman 341). Kanner “chose the term (auto, “self”, -ism, “condition”) to refer to the child’s apparent self-absorption” (Carlson 594). He observed eleven autistic children, and found that although precise details on each are different, all eleven children shared some common characteristics in their behaviors (Kanner 242). One of them was their “inability to relate themselves in the ordinary way to people and situations” (Kanner 242) such as not paying attention to anyone they were accompanied with (Kanner 242).

People with autistic disorder tend to not respond to attention directed at them or pay attention to others, or initiate attention (Yamamoto). Nor are they comfortable with eye-to-eye contact (Yamamoto 1). Pierce’s group examined the brain functioning of normal and autistic people’s activities in fusiform ‘face area’ (FFA)¹ and found that those of autistic people were weaker compared to those of normal people (Pierce, Müller, Ambrose, Allen, and Courchesne 2067). Instead of using FFA, autistic people use different parts of the brain when looking at people’s faces (Pierce, Müller, Ambrose, Allen, and Courchesne 2067-2068).

The word “Pervasive Developmental Disorder” (PDD) is used to express a variety of characteristics of autism (Okuzumi 61). The term “autism” refers to the type which

¹ the areas in brain which functions most actively when processing someone’s face

only one-word utterance or no verbal skill develops and it lies under the Autistic Spectrum which is also the term that shows the wide variety of autism (Okuzumi 61). There is also a type called High Functioning Autism which the symptoms are less severe in terms of mental retardation and verbal skills. In general, the term Autistic Spectrum is used to conceptualize the autistic disorder as a range of spectrum whereas the term Pervasive Developmental Disorder is used to categorize the types of autism (Okuzumi 61).

Other characteristic of autism is a sensory sensitivity (Okuzumi 61). One of the boys Kanner observed “had failed to adjust his body to being held” (Kanner 225) by his mother. Mothers in fact sometimes find it uneasy to hold her autistic baby. The reason for this can be accounted on by the tendency of autistic children to dislike physical contact because of sensory sensitivity². Also, they tend to be very sensitive to loud noises, having hard times catching and discriminating important sounds such as speakers’ voices from other irrelevant surrounding noises (Okuzumi 61).

According to the Diagnostic Statistical Manual for Mental Disorders 4th Edition (DSM-IV), the three diagnostic behavioral standards to diagnose autism are qualitative impairments in social interactions, in verbal and nonverbal

² An explanation from Mr. Takeuchi, the teacher of Developmental Clinical Psychology at Keio University

communications, and restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities (Koegel, Koegel, and Brookman 341; Lovaas and Smith 325; Yamamoto 2007). The qualitative impairments in social interactions is such that the child does not respond to person who is calling his name, or makes any eye contacts (Yamamoto 1). An example of impairments in verbal and non-verbal communications is that a child can not ask for something but instead shows tantrum in order to have someone do something what he wants. Rocking his body repeatedly is an example of restricted, repetitive, and stereotyped patterns of behaviors and activities.

Autistic children having lower IQ scores are commonly known but it is not quite an accurate fact. The scores are used as a standard to judge the severity of the child's autism, but the IQ scores depend on various factors such as the experience they have had. Among the eleven children Kanner observed, some of them had IQ score of above 100 (Kanner 232-234; Nakane 517-518). Therefore, IQ score is not included as a criterion for diagnosing autism. However, it is used as a measure to compare and see the improvements made as an effect of the intervention programs.

The Causes

Since the publication of Kanner's article, many theories on causes were made. One of the earliest theories was the parental causal theory (Koegel, Koegel, and

Brookman 341-342). According to this theory, children become autistic because of bad parenting and mothers were blamed at for their children's social disability. Kanner did mention in his paper how "there are very few really warmhearted fathers and mothers" (Kanner 250) among those he observed. However, whether this accounts for such a child's condition he left as a question (Kanner 250). The contemporary notion regarding this theory is that this is not the case, and in fact, parents should actively involve in training their children (Autism Conference Nippon 2006; Koegel 386; Koegel, Koegel, and Brookman 342).

It is said that malfunctioning in central nervous system causes autism (Okuzumi 62; Carlson 597-598). Kanner did mention in his paper about the difference in size of the head and other physical features of autistic children that are different from ordinary people. This suggested the possibility of biological factor that is causing the autism (Carlson 596). Lately, studies on developing brains have been carried out using various instruments such as Magnetic Resonance Imaging (MRI).

Courchesne's group examined the brain growth of sixty autistic children using the MRI and found abnormal patterns in their brain growth (Courchesne et al. 247-249, 251). In this study, Courchesne and his group found many abnormal developmental patterns in autistic children's brains, including the growth rate at different ages

(Courchesne et al. 247-249)³

The disorder is known to be genetic, with much evidence to support it.

About 2 to 3% among those people who have autistic siblings are autistic (Carlson 597).

This is 50~100 times higher than the frequency of having autism within regular group

(Carlson 597). A study on twins regarding the genetic factors of autism was done in the

past by Flostein and Rose-Scheidly (Carlson 597). The findings were such that chances

of both of the twin being autistic was as high as 70% among identical twins, whereas

0% among fraternal counterparts (Carlson 597).

Therapies

Since the growing interests in the subject of autism, ways to cure it were

attempted to establish. Some of the therapies and treatment were established based on

untrue theories such as the one mentioned earlier. And some that were established

showed no strong evidence to show that the therapy was actually effective (Richman

14-18).

³ For more details, please refer to the article: Courchesne, E., C.M. Karns, H.R. Davis, R. Ziccardi, R.A. Carper, Z.D. Tigue, H.J. Chisum, P. Moses, K. Pierce, C. Lord, A.J. Lincoln, S. Pizzo, L. Schreibman, R.H. Haas, N.A. Akshoomof, and R.Y. Courchesne. "Unusual brain growth patterns in early life in patients with autistic disorder: An MRI Study." *Neurology*. 57 (2001): 245-254.

In 1960s a psychologist O. Ivar Lovaas came up with a treatment therapy using applied behavioral analysis. Behavioral analysis is a study of behavior including learning. Lovaas used the principle of “Operant Conditioning”⁴ in coming up with treatments for autistic children. He applied the behavioral analysis to teach autistic children appropriate behavior and reduce inappropriate ones (Lovaas 621-622). The discovery of autistic children’s ability to learn and the application of behavioral analysis to the treatment of autism, was the significance of Lovaas’ findings in establishing his treatment therapy (Lovaas 622).

Lovaas attached importance on inductive and empirically supported therapy rather than those of mere theory-based (Lovaas 617). He carried out an experiment where that the therapists would “teach” 38 mute autistic children who were around the age of 4 at the time of intake which was aimed to improve the children’s language ability as well as social skills (McEachin, Smith, and Lovaas 361). Lovaas “provided approximately 40 hours per week one-on-one behavioral treatment for a period of 2 years or more” (McEachin, Smith, Lovaas, 360). According to the follow up research for the experiment, Lovaas reports that the experimental group had a higher average IQ score compared to those of control group, lower Maladaptive Behavior, and in contrast,

⁴ Operant Conditioning: a procedure of reinforcing behavior using reinforcement (Mazur 130).The most famous and well known behavioral analyst is B.F. Skinner, the founder of Behavioral Analysis.

higher Adaptive Behavior , claiming the treatment to be effective (McEachin, Smith, and Lovaas 364-365). The findings also include that the children of experimental group “had maintained their level of intellectual functioning between their previous assessment at age 7 and the present evaluation at mean age of 13” (McEachin, Smith, and Lovaas 367). Some of the children, described as “best out-come” subjects by Lovaas, “were able to hold their own in regular classes (McEachin, Smith, and Lovaas 368).

As can be seen, the treatment that Lovaas experimented with had positive effect on autistic children. However, it also had defect. For example, “teaching language skills did not usually improve peer interaction unless peer interaction skills were also taught” (Lovaas and Smith 327) and the “gains tended to be situation specific” (Lovaas and Smith 327). That is, the autistic children could show the acquired ability only in clinical settings, and can not apply it to home or other real life settings (Lovaas and Smith 327).

The Early Intensive Behavioral Intervention (EIBI) that is being practiced at University of California, Los Angeles Young Autism Project (UCLA YAP), has six stages to it (Lovaas and Smith 330-334). The first stage aims at teaching an action such as “sitting” or “coming” when called at, without letting unwanted behaviors like tantrums to interfere, and also to be more responsive to the situation they are taught in

(Lovaas and Smith 331). The second step aims at teaching the children receptive language skills, imitation of actions, and imitation of facial actions (Lovaas and Smith 332). Learning how to imitate is such a beneficial gain for the children, since it will enable the children to observe and learn how to play. From stage 3 on, the autistic children will learn communication and social skills (Lovaas and Smith 331-334). There is an indication from studies that, “when implemented early (beginning prior to 5 years of age) and intensively (more than 20 hours a week for 2 or more years)” (Smith and Lovaas 328), then the treatment will become effective with some autistic children.

As is part of Lovaas’ treatment, mainstreaming the autistic children into regular classes is also said to be effective. A study was done by Smith, Lovaas, and Lovaas to see how interaction with typically developing children will affect children with high-functioning autistic disorder (HAD). The result was such that the HAD children showed significantly more interactive play and speech as well as other appropriate behaviors when paired with typically developing children than with the delayed peers (Smith, Lovaas and Lovaas 140).

Another well-known program for autistic children’s treatment is Treatment and Education for Autistic and Related Communication Handicapped Children (TEACCH), established by an American psychologist Eric Schopler. The TEACCH program was set

in a college, which is an important point of the intervention program, because it allows the findings of research and society to link with each other instead of keeping important findings in a research room (Mesibov⁵). Such structures enable the college to provide the community empirically supported effective treatment, the people in the community to carry out the therapy, and give feedback to the college laboratory for further assessment and refinement (Mesibov).

One of the uniqueness of TEACCH program is that it attempts to make diagnosis of autism at an early age of an individual from various aspects in order to intervene at an early stage, and take care of the children to their adulthood (Mesibov). Therefore, the program takes a lot of time in diagnosing autism, due to the belief based on the fact that “no effective diagnosis can be made without enough knowledge on autism” (Mesibov). The good thing about intervening with autistic children at an early age is not just so they can develop social skills effectively, but also because they experience being praised at through the program, developing higher self-esteem (Mesibov). Without any treatment or intervention, they would have less opportunity to achieve goals or having sense of “accomplishing” something (Mesibov). This is very stressful with autistic children as it is with normally developing children.

⁵ From the notes taken by Chiharu Amemiya, who has also dedicated her time and knowledge on therapies for autism to me with my research on TEACCH as well as further understanding on autism

Using the abilities that the autistic people already have, the program attempts to construct an environment that would make them easier to function. For example, autistic people are not good at understanding auditory information but are good at understanding visual stimuli. Therefore, helping them by modifying or structuring the environment such as creating a schedule board is one of the strategies they use (Autism Nippon Conference 2006; Mesibov). This way, the autistic people live not merely as disabled, but as actually functional (Mesibov).

The ideal of TEACCH program is to change the environment to suit the autistic children and adults to live in (Mesibov). The program envisages the future of the autistic children, all the way to their adulthood and claims the importance of life long support because one of the goals of this program is to have autistic people live productive life (Mesibov). One of the examples would be to help them get jobs and change the job environment so that they can work without any disturbances (Mesibov).

According to the Report of the Recommendations published by the New York State Health Department, “ongoing monitoring of the child’s progress by parents and professionals” (Report of the Recommendations) is recommended because if a particular intervention seems to be not functioning effectively after a certain period of time, then it should be altered. The report gives the intensive behavioral intervention

programs an A rating⁶ on using the ABA in the interventions. The intensity of the intervention, up to 40 hours per week, is also strongly recommended (Report of the Recommendations). It is recommended that they be flexible and use intervention strategies that best suits specific individual in order for the intervention to be fully effective.

Not everything of Lovaas' program and early intensive behavioral interventions have a positive effect on every autistic individual. Certain things do not apply to some people. In order to come up with the best treatment and support for an individual autistic child, one needs to plan a therapy program based on various factors such as what the child could already do, the environment they live in, and the possibility of living in normal society (Yamamoto 44).

Autism and the Contemporary Society

The support for autism is becoming more common in Japan. In 2005, the Support for Developmental Disorder Act was established which states the government's support for early diagnosis of developmental disorders, including autism and institutions to educate and treat these disabled children (Nakayama 67-70). The significance of this enactment is the fact it states clearly that autistic people are now the subject of supports

⁶ A rating indicates that the efficacy could be strongly supported by the research and D ratings indicate that no strong evidence to support the efficacy can be obtained.

(Nakayama 71). The governmental support for the early diagnoses and intervention for autistic children is very beneficial not only for their quality of life, but also for the society itself.

It is not rare that people who lies on the autistic spectrum but do not show as strong symptoms are left undiagnosed and those tend to be of high-functioning autistic spectrum disorder (HFASD) (Kamio 491).They show less disability in verbal skills and intellectual abilities (Kamio 491).Even though they seem to be functioning fine, people with HFASD do suffer high social maladaptation (Kamio 491). They start to notice the difference and their own inability to fit into the environment in their adolescence. Many of them were bullied at by their classmates, which mentally scarred them (Kamio 491).

Wing pointed out that grown ups with Asperger's are likely to suffer complications of other mental disorders and exhibit anti-social behavior that are not developmental disorders (Kamio 491-492). Indeed, some social delinquencies are caused by those having PDD (Kumagami 327-328). Those who grew without being aware of being autistic have usually been exposed to harsh circumstance (Toichi 1111). They were not only misunderstood by surrounding people, but in some cases, physically abused by their parents under the name of "discipline" (Toichi 1111). This abuse would make the autistic people over reactive to offensive stimuli, which leads to excessive

panic that is beyond their control which could result in harmful behavior (Toichi 1111).

The most common delinquencies or crime committed by PDD people is sex-offenses. While sex-offense consists of only 0.2% of all the juvenile crimes in Japan, 40% of offenses caused by PDD are sex-offenses (Kumagami 330). Possible reason for this is that people with PDD have difficulty controlling their impulses, and they may have seen the sex-offense or other sexual scenes in the media and imitated it without knowing that it is an inappropriate behavior (Kumagami 334).

As it can be seen, types of PDD such as HFASD can lead to crime. Without appropriate diagnosis, intervention, and behavior being taught, the individual has the likelihood of causing social delinquency. Therefore, it is extremely important to have well-established systems to support people suffering autism, including a program for early detection of autism and experienced specialists (Kamio 494). This may help reduce or prevent the crimes caused by people with developmental disorders as well as maintain their quality of life (Kamio 494).

According to the statistics of Autism Society Japan, most people in Japan know of autistic disorder but only 60% of them knew the actual cause of it. As much as 30 % of the people had misconception about the causes of autism, with many of them thinking it is a mental illness. These misconceptions on autism can cause unnecessary stress on

families with autistic child as well as reluctance in supporting them as a community. The government should therefore work as a provider of accurate information in order to encourage the community to support autistic people.

Conclusion

Autism has an extremely wide range of degrees of severity in social and communication disabilities. Many people exhibit the conspicuous behaviors of autism, while others are never really even suspected of it. As was discussed, some people have been left undiagnosed and ended up with undesired outcomes. Therefore, early detection is very important and well-established system as well as experienced specialists are needed (Kamio 494).

Early detection of autism and early intervention to autistic children is said to be effective in an attempt to develop appropriate social skills, and the efficacy of ABA approach of treatment is empirically supported and recommended. However, there are limits. It is very rare that one grows out of autism. The majority of the people have to live with it. Therefore, life-long support is very important for them in order to let them live productively with a higher quality of life (Mesibov; Kamio 494).

The Japanese government is moving to support those suffering from PDD by financially aiding centers for social skill training and therapies. Their goal is to establish

a system for early diagnosis and early intervention. Even though this is a very desirable assistance, by itself is not quite enough. There are many people who have misconceptions about autism. Providing accurate information to the people who live in the society which autistic people also do is very important and also essential to establish support systems.

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