

Relationship Maintenance in Family with Special Needs Children

Nur Ainun Najah¹, Frida Kusumastuti², M. Himawan Sutanto³

Abstract

A family that has children with special needs must maintain the relationship among its member more than any other family. The extra effort is to consider that the family handles more complex issues than a family with normal children. The divorce risk in the family with children with a special need is high in the first eight years of the marriage, but the risk reduces in the following years. This research aims at finding the Relationship Maintenance in families with children with special needs. This research is a qualitative descriptive study. Data collection technique was done using the interview. The subject of this research is families with children with special needs who study at Maharani Elementary School for Exceptional Children at Paciran village in Lamongan regency. The result of the study shows that Relation Maintenance requires a positive attitude that includes critics delivery and reaction towards different methods between the couple. The results of this study indicate that in Relationship Maintenance positive attitude behaviors include how to convey criticism and how couples deal with differing views. the behavior of openness involves an open attitude between partners. the guarantee includes mutual support in carrying out work and caring for children. Owned networks include the nuclear family, friendship environment, community environment, and experts. While the division of tasks includes the division of domestic tasks in the family and also tasks in parenting.

Key Words: *Children with Special Needs, Relationship Maintenance, Family*

INTRODUCTION

This study aims at describing Relationship Maintenance that occurs in families that have children with special needs. The birth of a child in a family is definitely expected and becomes the source of joy and happiness Every family always long for the birth of a child as the successor to their descendant. Parents consisting of father and mother certainly expect that their children

Author's Affiliation

¹ Department of Communication, Faculty of Social and Political Sciences, University of Muhammadiyah Malang
Email: nurainunnajah19111996@gmail.com

² Department of Communication, Faculty of Social and Political Sciences, University of Muhammadiyah Malang

³ Department of Communication, Faculty of Social and Political Sciences, University of Muhammadiyah Malang

will become smart, can become the pride of their parent and have devotion towards the parent. However, sometimes not all parents are blessed with a child as they wish. Some parents are given more trust by God to raise children with special needs that are different from normal children in general. One of the children with special needs is a child born with autism.

Is a syndrome that affects three important aspects of the life of a person. These three aspects are disturbances in communication, disturbances in the process of social interaction and behavioral disorders. These three disorders certainly affect significantly the lives of individuals with autism, they will appear different from normal individuals in general. For example, the communication process that is different from individuals, in general, makes people with autism difficult to understand. That difference also sometimes makes them considered as "strange" individuals in the community. The existence of these differences makes individuals with autism need special treatment.

The family of children with autism is certainly also different from the family in general. Greater effort is needed for a family that has children with autism to go through their days, both in the form of patience and the funds to afford the family needs. This difference in running the family may result in the breakdown of relationships in families with children with autism. These families must have patience and good coordination in running their daily life due to more house chores, expenses, and stress factor especially in handling their child with a special need.

There are many things that can happen to families who have children with autism, such as the occurrence of negative effects on the family. These negative effects do not only occur in merely one aspect, but also in several ones all at once. These aspects include financial problems or other resources for the family, the emergence of stress on parents, and the risk of problems within the marriage. According to Scieve in Anjali and Aguirre (2012: 71), families that have children with autism face more financial problems when compared to families that have children with special needs other than autism. The second aspect that is affected by the presence of autistic children in a family is the stress level of parents; the stress is higher in dealing with their children. Stress occurs in parents, both mother, and father, the effect of which occurs because of the behavior of autistic children who tend to be aggressive, irritable, unable to follow the rules. Stress experienced by parents can be in the form of depression, anxiety, and anger.

The third effect is the effect that occurs in marriage. In Anjali and Aguirre (2012: 73) the existence of children with autism in a family makes parents experience pressure in their marriage and also experience a decrease in satisfaction in marriage relations. The marital issues in association with this situation included the division of tasks at home and the denial of the couple about the child's diagnosis.

On the other hand, there are also families who have children with autism that are able to make achievements through their work. Indeed, the process of engraving this achievement may take longer and requires more effort, but if parents have the determination and consistency in developing the child's talent, autistic children are also able to achieve it. Support from family

MEDIO

Vol 1, No 1, January-June 2019, pp. 33-43

is one of the most important things for this achievement. Family is a system of support that is most needed by children with autism.

On the other hand, an increase in the birth of children with autism syndrome also occurs in Indonesia. According to UNESCO data in 2011 the ratio of births of children with autism worldwide is in the ratio of 6: 1000 childbirths. In addition to global data that shows an increase in the number of people with autism, noted that in Indonesia in 2013 there were approximately 112,000 children in the age range of 5 to 19 years who were affected by autism syndrome. According to Ni'matuzahroh and Nurhamida (2016: 31) the percentage of autistic children currently is at 0.6% or about 1 in 166 children born with autism, this percentage has increased many times when compared to the survey conducted in 1970- and where the percentage of births of children with autism is 0.04% or 1 in 2500 births. This number will continue to increase which is directly proportional to the high birth rate of children in Indonesia. Children with autism syndrome generally experience difficulties in carrying out social interactions in the community and become a group of individuals who are considered "strange" by the surrounding community.

Based on the data above, the presence of autistic children requires more intense support from the surrounding environment, the support of which especially comes from the family which is the earliest circle of interaction that each a child has. A harmonious family who always provides positive support will make it easier for children with autism to face a wider environment. Families who are open to the conditions of their children and always provide support will facilitate the formation of inclusive conditions in the surrounding community. The inclusive condition means a situation where people can accept the state of autistic children who are different from normal individuals in general. According to the Indonesian dictionary, inclusive itself means has been calculated or included, while inclusive society means a society that is open, universal, accepting and can respect differences. The inclusive community itself is a very suitable and supportive environment for children with autism. But in fact, there are still many people who have not matched the classification in becoming a member of inclusive communities. People who do not match the quality of an inclusive society occurs due to the lack of attention, empathy, and public acceptance towards individuals with autism.

Lack of awareness and acceptance of individuals with autism can be due to various factors. One of the most important factors is because of the communication problem with children with autism. Not everyone can understand the meaning of their words or behavior. Children with autism often have their own way of responding to a stimulus given by their interlocutor. Unfortunately, the different communication methods of children with autism often become an issue to understand them, and eventually reduces the intensity in having interaction with these children. Communities sometimes minimize interactions with autism children because they are aware of issues in the communication process. Though children with autism are also part of the community that has the potential to be developed even with more effort and patience than children in general, especially considering that the birth of children with autism year after year increases according to the increase in birth rates in Indonesia. This means

that eventually interactions with children with autism cannot be avoided by the community and people must begin to accept the presence of autism children in the community.

The acceptance here is not only interpreted by acknowledging the existence of a child with autism but also involves him in community activities when he grows up, although he cannot play a total role like a normal individual in community in general. Therefore, deeper knowledge is needed to be able to understand communication in children with autism, because they have a different process. So that later it will be easier for people to communicate with children with autism, and make the socialization process easier. The process of communication carried out by autism children both verbally and nonverbally has differences from the society in general. For this reason, it is necessary to learn more deeply about how to communicate with children with autism, both verbally and nonverbally so the community can understand better these children. That way it will be easier for people to interact with autistic children. Eventually, in addition to facilitating interaction with the community, by understanding the communication of children with autism it is expected that cases of abuse and neglect by parents to their children who suffer from autism will not occur again.

Research Method

In this study, researchers used a qualitative approach. According to Nawawi and Martini (1994: 174), qualitative research is a research that has characteristics in which data from the study are presented in a reasonable state or as it is (natural setting) without any change in the shape of the symbol or data that has been obtained. It is expected that the data obtained presents information as it is without any additional or engineering information on the data.

The type of research that will be used in this study is descriptive research. According to Travers in Umar (2008: 22), a descriptive type is a study that aims to describe the nature of an ongoing situation at the time of research and examine the causes of a particular symptom. By using descriptive type, it is hoped that later researchers can carry out a full description during the research process.

Data collection was carried out on December 1 to December 31, 2018, which was continued with the preparation of research reports until January 8, 2019. The research took place in the residence of the subject, where the researchers conducted direct interviews. This study focuses on the process of maintaining relationships in families with children with autism. The relationship referred to in this study is the relationship between mother and father as the main pillar of a family.

The focus of the study can be used as a limitation and criteria in the study (Moleong (2014: 93-94). Based on Moleong's description, the focus of the research is the main benchmark during the research process so that the research will not lead to the wrong data domain. focusing on the aspects contained in the Relationship Maintenance carried out by the father and mother after having children with autism in their family, The focus of this study is some aspects in the Relation Maintenance between the father and mother after the presence of a child with autism

MEDIO

Vol 1, No 1, January-June 2019, pp. 33-43

in the family. the first aspect is a positive attitude between partners which includes how couples give criticism or input to one another, the second is the existence openness, where the couple communicates openly to foster mutual trust in each other. The third is the commitment that is agreed upon between the couple. The fourth aspect is the network of friends or family that provides positive support in the life of the couple. The last aspect is the clarity of tasks divisions carried out by each family member. By focusing on these five aspects, the researchers hope that more specific and conical research results will be obtained.

The subjects in this study were mothers whose children attended an exceptional elementary school of Maharani which is located in the village of Paciran, Lamongan Regency. An exceptional elementary school of Maharani has a total of 30 students. This study used Purposive Sampling techniques to determine the subject. In this study, researchers conducted in-depth interviews with the subject of research to explore information in full and in-depth about aspects of aspects that researchers want to know about the subject.

In this study, researchers used the method of data analysis model Miles & Huberman. The data analysis method of the Miles & Huberman model consists of stages of data collection, data reduction, data presentation, and conclusion drawing. The validity test of the data in the study was used to obtain accurate research results. In qualitative research, the validity test of the data is carried out in several ways including credibility, transferability, dependability, and confirmability tests (Sugiyono, 2012). In this study, the researcher conducted the credibility test. This test is carried out to justify the result of the study as a scientific work.

Finding and Discussion

Previous data is presented to identify the behavior of Relationship Maintenance that occurs in families that have children with special needs. Therefore, in this study, researchers refer to five behaviors that can maintain the quality of a relationship. According to Canary and Stafford in Griffin (2012: 152), those five behaviors include the existence of a positive attitude, openness, commitment, network and the division of tasks in the relationship. according to the Canary and Stanford, the five behaviors are a description or reflection of the 4 characteristics contained in the relationship that takes place in the long term, these four characteristics include the likes, beliefs, commitments, and mutuality of the relationship.

From the data that has been obtained, it can be explained and elaborated with the concept of Relationship Maintenance described by Canary and Stanford. In accordance with the five behaviors that can maintain the quality of the relationship possessed by the subject. In presenting the data it can be divided into several points, including (1) positive attitudes, (2) openness, (3) existence of guarantees, (4) existence of networks, and (5) division of tasks.

First, it relates to a positive attitude which is proven by the openness of the subject and partner in giving criticism to each other if there is a difference in each other's views. According to the data presented above, there are subjects claimed to give criticism to their partners if they have a different opinion in their relationship; the methods used to criticize are also of various

kinds. Khusnul Khotimah (Subject 1) claimed to give criticism in a gentle manner to her husband if there were differences of views. The same thing also happened to Arti (Subject 4) who stated that if there were differences of views in his family there would be inter-family talks. Both Khusnul Khotimah and Arti stated that the partner always responded in the form of agreement to any criticism given without any prior negotiations. while Sri Astutik (Subject 2) and Siti Nur Afidah (Subject 3) claimed there was always talk in the form of giving clarity if there were differences that emerged and was followed by negotiations between the subject and his partner. A different thing was found in the Li'ulin Nuha family (subject 5) which stated that she and her husband did not give open criticism or conversation if there was a dispute or difference of views, Li'ulin Nuha claimed to be silent with his partner more often when differences of opinion appeared and opinions in the family.

In addition to the method of giving criticism, a positive attitude is also seen from how the subject and partner respond when they receive criticism. As explained above in the subject family 1 Khusnul Khotimah and subject 2 Arti explained that the couple openly accepted criticism but only gave a response in the form of affirmation. In the second and third subjects, they admitted that in responding to the criticism, there was a negotiation process in the form of giving explanations from a partner's point of view, and the negotiations took place to address the criticism. Whereas in the fifth subject, Li'ulin Nuha claimed to not giving each other criticism, only to let the problem subside on its own without discussion. But Li'ulin Nuha also explained that whenever there were problems with her partner, the problem only happened in a short time, and would disappear by itself.

Criticism is a sign of a positive attitude between the subject and their partners. The existence of a positive attitude that continues to occur is certainly one of the causes of the continuity of a relationship. In addition to the process of giving criticism, what is equally important is how the criticism is responded to. A good response to criticism is also a supporting factor for the strength of the relationships. Giving a response can be various kinds such as those found from the data presented. The subject and the partner have various characteristics in giving the response, it can be by affirming and accepting criticism, it can be by giving an explanation, or through negotiation process first.

In the subject family 1 Khusnul Khotimah and subject 4 Arti, when they had differences in views and opinions, they resolved it in no hurry, with a gentle tone, and without negotiation first, each partner's subject received criticism by just agreeing. This occurred because the two subjects have been married for quite long when compared to the other three subjects Khusnul has been married for 26 years, while Arti has been married for 36 years. The age of marriage allows Khusnul Khotimah with a partner and Arti and her partner to understand the characters of their spouses better. In addition, besides having gotten married the longest, these two couples also are the subjects with the oldest age among all five subjects. During the study, Khusnul Khotimah was 48 years old and her partner Muhammad Sholeh was 56 years old. While the second couple, Arti and Murip, are both over 50 years old, Arti is 56 years old and Murip is

MEDIO

Vol 1, No 1, January-June 2019, pp. 33-43

61 years old. Ages that are already relatively old make both partners respond to all differences of views in a gentle way and eventually accept the criticism made by their partners.

In the subject family 5, Li'ulin Nuha and her partner Khoirul Hafidz, take a different view by keeping silent to each other. This is different from 4 other subjects who resolved their differing views by negotiating and accepting criticism. This can occur in the family due to both husband and wife have different activities and job. As known that this subject family, Li'ulin Nuha and Khoirul Hafidz both worked in their respective jobs, Li'ulin Nuha worked as a sewing worker at the factory and her husband worked as a gold craftsman. The busy life makes this family does not resolve the differences that occur and only keep silence each other until the situation returns to normal without discussion or resolution.

In the second point, openness plays an important role in a relationship, given that openness can be a foundation of trust between one another. Openness in this study is seen from how subjects and partners are open to each other in telling activities and problems faced in daily life. In this study, all subjects said they were always open with their partners. The things that are told also vary from daily to the child's behavior.

The openness of the subject with a partner is also not limited to sharing happiness, but also includes resentment and sadness experienced in daily activities whether it is related to children or not. The openness that exists between the subject and the partner is also an indication or the cause of a strong relationship. As in Khusnul Khotimah (Subject 1) who stated that she shared everything including their children issues/behavior to her partner. while Sri Astutik (Subject 2) stated that there were no boundaries between her and her partner, she explained that she must tell everything with her partner. Siti Nur Afidah (Subject 3) also stated the same thing, she admitted that she always told everything to her partner, including the behavior of her child who often made a problem at school by damaging her friends' belongings. Li'ulin Nuha (Subject 5) also stated this, she explained that she always shared stories with her partner about various things including stories about the development of their child. In contrast to the four previous subjects, Arti (Subject 4) claimed that apart from her partner, she also shared her experience with her third child who stayed with her. The openness found in the families of the five subjects certainly can maintain the quality of their family relationships and to minimize any distrustfulness. An open relationship is also an indication of the good process of interpersonal communication that is intertwined with each other.

The third point relates to the existence of guarantees; how the subject and their partners form a commitment to support each other in childcare. Based on the data, it was found that all subjects admitted to being mutually supportive with their partners. The agreement and commitment are not verbally spoken, but rather in the form of direct action. It is proven from the statement of all subjects who said that their partners always provide support during the parenting. The support provided is in the form of actions to help care issues, both in family finance, education and children's health.

Khusnul Khotimah (Subject 1) describes that her partner always supported her even from the baby's childhood. In Sri Astutik's family (Subject 2) also appeared mutual support. As Sri Astutik said that she and her partner each had a big assignment, namely as a family caretaker and her husband as the family provider. In the family of Siti Nur Afidah (Subject 3), there was a commitment to always support and provide the best for education and the future of children. The same thing came from Arti (Subject 4) and Li'ulin Nuha (Subject 5). Arti stated that she only depended on her partner and their child to provide support in taking care of their children with special needs. While Li'ulin Nuha explained that her partner had shown his commitment and support, she and her committed partner would raise their children together and give the best they could.

In the concept of maintaining the relationship between Canary and Stanford, there is a guarantee of a positive effect. This is because certain commitments can provide certainty about the future of a relationship. With certainty, it will eliminate doubts and uncertainties about the future of a relationship. The fourth point is the existence of networks. The existence of a positive network will be one of the support systems in a relationship. The network referred to here is a quality circle of friendship and family, so that a solid and long-lasting relationship can be built. A circle of friendship and good family is another alternative for individuals in a relationship to share existing problems and find other support outside the nuclear family.

After an analysis of the data presented above, it was found that four out of five subjects had supportive networks outside their core families. Some of the supporting networks come from large families, friend circles, and other parties such as teachers and doctors who handle children from the subject. The four subjects acknowledged being able to share various kinds of things on their networks, including health, education and child development.

Khusnul Khotimah (Subject 1) claimed that she had a network outside her core family, the network of which comes from a neighboring environment, fellow guardians of students and their child's doctor. This network always gave a positive attitude to her and her family. Sri Astutik (Subject 2) also said that she had a good network of friends with fellow guardians at her children's school. The same thing said by Siti Nur Afidah (Subject 3) that she had a good network of friends with fellow guardians at her children's school, but besides that, she also explained that she had another network, her mother. Both Sri Astutik and Siti Nur Afidah claimed that the network they owned had a positive effect. In contrast to the previous three subjects, Li'ulin Nuha (Subject 5) claimed that the network she owned was very limited and only a few parties, namely from the school and those who gave therapy to their children. But Li'ulin Nuha also explained that people in her network always gave a good response to her. This can be due to the limited time owned by the subject (family 5) to interact with the surrounding environment, considering that in this family Li'ulin Nuha as a wife and a mother also worked as a factory worker.

Whereas Arti (Subject 4) claimed that she did not have a network outside of her core family. Based on her explanation this is because there is no good response or support from the network outside the nuclear family. It is added with the disappointment about people around

MEDIO

Vol 1, No 1, January-June 2019, pp. 33-43

them. Nevertheless, the family was still able to maintain their relationship well. This was not only caused by the disappointment in the past but also because Arti had a place to tell stories in her family. She could share it with her husband and daughter who were also married and lived together with her. With the presence of these daughters. She felt more comfortable to share stories about the problems faced without involving people in the surrounding.

The last point relates to the division of tasks. Sharing tasks in daily life has a positive effect on a relationship, avoiding inequality and injustice between each individual in the relationship. Division of tasks does not only refer to the main task according to the role in the family but also refer to how each member of the family is willing to replace the role of each other in certain circumstances.

Khusnul Khotimah (Subject 1) explained that she and her partner had their respective duties to carry out, she was in charge of caring for the child and taking care of the house while her spouse was in charge of delivering and picking up his child at school. But Khusnul Khotimah also explained that her partner did not mind if he had to replace work that was not his job. Sri Astutik (Subject 2) said that she and her partner worked on everything together, their partners were also willing to replace it in doing house chores. Siti Nur Afidah (Subject 3) recounted that in her daily life she and her partner took turns to take and pick up their children at school, she also said that in managing the house, her partner was not involved and was only involved in parenting. Almost the same as the previous three subjects, Arti (Subject 4) and Li'ulin Nuha also explained the same thing, of course with a difference in the implementation of their duties. Arti's family did the of house chore also aided by their third child, while financial problems were also supported by their sons. For the child care of their special need child, Arti did it with the help of her husband and third child. Whereas Li'ulin Nuha claimed to always take turns doing homework with his partner, even parenting was done together, she also explained that she and her partner did not mind if they had to do a task that was not their duty.

In the data presentation, the five subjects explained that in their family there was a clear division of tasks. the division of tasks carried out included family finance, childcare, and home management. other family members also voluntarily replace each other's role in carrying out their duties. With the share of a clear task and the willingness to replacing each other's tasks makes a relationship work well because of the lack of inequality and inequity between family members.

Conclusion

Relationship Maintenance that is owned by the family of children with autism at the Maharani Special Extraordinary School has been quite good, although not all of the five behaviors that become benchmarks are met. This shows that in the Relationship Maintenance process not all behaviors have the same value for each family. There are families who have points of a positive attitude. There are those who have advantages in the presence of networks, guarantees, openness and division of tasks. Every family has a unique and different way among them in the process of maintaining relationships.

Many things can affect a family excels in one particular behavior. Among them is the age difference between husband and wife, the difference in age that is quite far between husband and wife makes Relationship Maintenance in the family better. Similarly, the length of the marriage makes the family understand better each other and can establish relationships in the family itself. And the last is the state of the surrounding environment, a supportive and positive environment also affects the quality of maintaining relationships in the family.

The results of this study indicate that in Relationship Maintenance the positive attitude behaviors include how to convey criticism and how couples deal with different point of views, the openness behavior includes open attitude between partners in telling experiences and problems that occur in daily life, the guarantee which includes an attitude of mutual support in carrying out work both inside and outside the home, and supporting each other in caring for the child. Having a good network includes the nuclear family, friendship environment among student guardians in schools, the community, and experts such as teachers and child therapists. While the division of tasks includes the division of domestic tasks in the family and also tasks in parenting.

In this study, there is a finding of the obstacles in the Relationship Maintenance process which includes rush activities of work which reduces the time to interact with each other. And the second is a less supportive environment, the lack of support from the surrounding environment is the cause of the lack of network outside the nuclear family as a sharing place.

As a form of researchers' contributions to academics and families who have children with special needs, the researchers provide advice in the hope of being able to develop and become a consideration for the respective people. For academics, especially Communication Studies students, the concentration of Public Relations who conducts similar research, Relationship Maintenance in families with special needs. It is recommended to try to do more in-depth research and take subjects with more specific criteria. For example, the age grouping range and background of the subject. Further research can also add data collection methods other than interviews to increase the variety of data obtained and facilitate researchers when conducting data analysis.

For families who have children with special needs, it is suggested to maintain the quality of their relationships by presenting five behaviors that maintain relationships, namely positive attitude, remain open to each other, commit to mutual support, have a positive network circle and do the division of tasks fairly. The five behaviors are intended so that relationships in the family can always have a warm and harmonious atmosphere and far from division.

References

- Griffin, Emory. 2012. *A First Communication Theory*. McGra-Hill. New York
- Moleong, Lexy J. 2014. *Metodologi Penelitian Kualitatif*. Remaja Rosdakarya. Bandung
- Nawawi, Hadari and Mimi Martini. 1994. *Penelitian Terapan*. Gajah Mada University Press. Yogyakarta

MEDIO

Vol 1, No 1, January-June 2019, pp. 33-43

Ni'matuzahroh and Yuni Nurhamida. 2016. *Individu Berkebutuhan Khusus dan Pendidikan Inklusif*. Umm Press. Malang

Sastry, Anjali and Blaise Aguirre. 2012. *Parenting Anak dengan Autisme*. Pustaka Pelajar. Yogyakarta

Sugiono. 2012. *Metode Penelitian Kuantitatif Kualitatif dan R&D*. Alfabeta. Bandung

Umar, Husein, 2008. *Metode Penelitian untuk Skripsi dan Tesis Bisnis*. Pt. Raja Grafindo Persada. Jakarta