

The Role of Social Organization on Children Down Syndrome Admission in Society

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Abstract: This study examines the role of social organizations in the acceptance of children with Down Syndrome in the society, casestudy: at Rumah Ceria Anak Down Syndrome South Jakarta. This research aims to analyze how the role of POTADS organization in encouraging society to accept the down syndrome children in the community. This study uses a qualitative approach with observation and direct interview. The theoretical framework that the researcher uses is the social exchange theory by Peter M Blau. From this results, the programs, norms, and values can overcome the case of accepting down syndrome children in the family and society in POTADS organization. POTADS, plays an important role to give benefits to parents like new friends and family who feel the same way; making parents no longer feel alone, getting information about down syndrome children, getting support from other parents, mutually reinforcing, getting love and affection, and getting appreciation of what their down syndrome children do. It also makes parents slowly accept the presence of their children. Although this admission case has not been entirely carried out well, POTADS will continue to try to educate the public about Down syndrome children so that they can be accepted in the family and community.

1 INTRODUCTION

You're the problem of people with disabilities in Indonesia is considered a big problem. People with disabilities often get unfavourable treatment from society who think that the disabled people are a parasite or a person who is not useful in the family or the society. Various types of disabilities in Indonesia still cannot be accepted in the family or society, one of them is people with Down syndrome. The number of children with Down syndrome is increasing every year. In Indonesia, it is estimated that there are more than 300.000 cases (3.75%) obtained from Badan Pusat Statistik (BPS). The data from Persatuan Orang Tua Anak Down Syndrome (POTADS) state that there are 600 children with Down syndrome join the organization from around Indonesia.

Down syndrome is the most common form of congenital mental retardation, which is caused by chromosomal abnormalities and occurs in 1 in 700 births in the United States. Even though women of any age can give birth to children with Down syndrome, this risk increases sharply for a mother who is over 35 years old (Agustyawati & Solicha,

2009). Down syndrome is a problem of mental retardation such as imperfections of standard human physical form and delays in children development. Those with a common disorder have a face or body shape that is different from ordinary people in general.

The negative response given by the environment to children Down Syndrome is also a problem that is often encountered in everyday life which is one of the concerns of parents. Similar to Mangunsong's opinion which stated that, generally the source of parents' concerns came from the negative treatment of the normal community towards their disabled children. A mother who has Down Syndrome children, even often gets negative views and ridicule from the surrounding community regarding the limitations of their children. Mangunsong said that parents will easily get criticism from others about their problems in dealing with the child's condition, besides that parents also often bear the burden of negative responses given by the community (Ghonyah and Savira, 2015: Vol 03). Not only set aside and get a negative response by the community but, parents of Down Syndrome children also get rejection or discrimination in terms of

education and health. Seen from the schools that are devoted to those with special needs and distinguished

The problem of mental retardation as expressed by Budhiman in the journal of Hendriani et al. needs attention given that some writings since the period of 1981 have suggested that retardation or mental retardation is a considerable problem in Indonesia, regardless of the conditions experienced. Everyone has the same rights to get happiness in life as well as the right to grow and develop in a conducive and supportive environment, including those who are mentally retarded. Nevertheless, the reality does not always meet the expectation. In many places, both directly and indirectly, those with special needs tend to be "set aside" from the environment. The Refusal is not only done by the people who live around them but even by their family (Hendriani & al, 2006)

According to POTADS organization, children abnormalities cannot be handled from the medical approach only, but these disorders have sociological or social dimensions as well as psychological dimension. In other words, physical abnormalities of people living with Down syndrome are closely related to the readiness of parents who have Down syndrome children (POTADS organization data source).

The organization is a unity of people organized regularly with certain division of tasks. Whereas social means everything related to human interaction in society. Social organization is an arrangement or structure of various human relations that occur in society, where the relationship is a regular unity (Soelaeman, 1987)

The organization is a unity of people organized regularly with a specific division of tasks. Social organization is an arrangement or structure of various human relations that occur in society, where the relationship happens regularly unit (Munandar, 1987).

This research is fascinating for the researchers because some families still cannot accept the presence of down syndrome children. People who are still afraid, and those who refuse to socialize with down syndrome children. From this cases, researchers know a social organization that overcomes these problems, namely Organisasi Persatuan Orang Tua Anak Down Syndrome (POTADS).

2 THE ROLE OF POTADS ORGANIZATION IN THE CASE OF ACCEPTANCE OF CHILDREN WITH DOWN SYNDROME IN THE SOCIETY

POTADS is a Parent of Down Syndrome Children. Where this organization was formed by three great women. They are parents who have children with Down syndrome. (Data Source Website of POTADS Organization, 10 April 2107) The POTADS organization was formed aimed at those who have Down Syndrome children who can easily find information about their child's growth and how to care for DS children according to the condition of the DS child. Because in POTADS Organization they don't want their parents to waste children who have Down Syndrome. The POTADS organization seeks to help restore the confidence of parents who have children with Down syndrome so that they can educate children with Down Syndrome to become independent according to their shortcomings and strengths.

In addition POTADS Organization also informs the public that children with Down Syndrome are not a hereditary disease or a curse, the karma that parents receive to their children. (POTADS Organizational Website Data, 10 April 2017) However, those Down Syndrome children only experience delays in how to think and grow and develop due to the chromosomal deficiency or excess that the child has. So with his parents' love and maximum parental guidance and not differentiating their treatment from other normal children trained and educated, they will be able to achieve more than other normal children. In essence, the main goal in POTADS Organization is to empower Down Syndrome parents to always be enthusiastic in helping to develop their special children optimally, so that their children are able to become independent individuals, even able to achieve so that they can be accepted by the wider community. Because basically those with Down Syndrome have the same rights and treatment as other normal children in the family and the wider community. (Data Sources Website POTADS Organization April 10, 2017)

POTADS organization is a non-profit organization formed by the chairman, secretary, treasurer, and others. The POTADS organization is also assisted by sharing fields such as in the fields of psychology, health, education and fields related to Down Syndrome child development. However, the fields of health, psychology, and education and others were

only presented when holding seminar events conducted by POTADS organizations. At first the POTADS organization association only lasted three months, usually called KOPDAR or ground coffee, which was held from house to house the parents of Down Syndrome children. This meeting aims for parents to share, share information with other Down Syndrome parents in terms of education, health, child development, and other information. This is because POTADS does not have a permanent home to hold these meetings. However, now the POTADS Organization already has a halfway house, namely the Ceria Down Syndrome House or often called RCDS, this RCDS was only established a year ago.

The role is someone who has done his rights and obligation by his position. Between roles and positions, both have functions that are interrelated like two sides of a currency which means there is no position without a role (Setiadi & Kolip, 2011).

From the result of an interview with the Chairman of the external department of this organization has been established since 2003 until now, stated that the organization officially legalized in 2003 that POTADS was established and developed until now (AR, 2017)

Since the establishment of POTADS organization, an organizational structure has been created which includes the general chairperson, chairperson I, chairperson II, treasurer, secretary, volunteer instructors, and others. They all have their respective roles to achieve common goals within POTADS social organization. There are several programs within POTADS organizations:

2.1 Kopi Darat (Kopdar)

Kopdar is an activity like a meeting, made for the parents who visit another parent with Down syndrome child. This KOPDAR activity was initially carried out every three months with an objective is to share about the development and condition of their down syndrome children.

2.2 MLM HATI

MLM Hati is a program that related to the heart; there is a personal conversation between parents with administrators through electronic media which they have a hope that the more extended network becomes wider to support parents who have down syndrome children. This MLM Hati is held as an alternative to parents who are blocked by a distance that is too far or have no time to come to the RCDS. The

objective of MLM Hati is the administrator can help to provide solutions for the problem that parents have from Whatsapp, Website, Facebook supports. This social media service used by POTADS to make it easier for parents who want to share and find complete information about down syndrome children.

2.3 Scientific Seminar

Scientific Seminar is a discussion forum which invites experts in their fields. The purpose of this scientific seminar is to educate parents and people about down syndrome development, both regarding education, health, and work.

2.4 Buku dan Compact Disk (CD)

The POTADS organization has also made several books and CDs that contain how to take care and the nurture new born down syndrome children with appropriate therapy for down syndrome children.

2.5 Classes at Rumah Ceria Down Syndrome Children

Rumah Ceria Anak Down Syndrome has established POTADS organization. It holds an activity by opening classes to train the interests and talents of down syndrome children. The activity started about a year ago and was filled by competent teachers in their fields. In this Rumah Ceria Down Syndrome, every members or administrator can register their children to join some classes such as Djembe, cooking, swimming, hip-hop, drum, arts and draft and Music. This activity charges Rp. 250.000 per activities with frequencies of meetings four times a month. The purpose of the formation of these classes is to train motoric and sensory children so they can focus, increase self-confidence, discipline and have a sense of cooperation. Although at first, it was challenging to teach down syndrome children, it did not become an obstacle for teachers to keep teaching them. One of the classes that excel in RCDS is Djembe. This Djembe class has been running for about one year. This class is superior because down syndrome children tend to like music because with a lively song they can build their enthusiasm and from that moment they will work with the team to build musical rhythms. Those who take part in the djembe class have appeared in various places not only in the city but even abroad.

3 SOCIALIZATION PROCESS OF DOWN SYNDROME SUBMISSION IN THE COMMUNITY

This Socialization is one fundamental thing to our development as a human. By interacting with others, we learn how to think, feel, and behave. The result of this socialization is the formation of our behavior including thoughts and emotions by the wishes of the community (Henslin, 2006).

The POTADS organization also has events every year, which is the commemoration of down syndrome children's day, on March 21st. This program aims to socialize and introduce down syndrome to the whole community so that the environment can well receive people with down syndrome, so they can socialize and even create a functional environment for the children to grow well.

This activity is a form of activity where POTADS introduces down syndrome children and provides information to the community that the presence of down syndrome children is not a disgrace, a shameful thing, a curse and not useful for others, but they also have advantages and rights to get the same treatment as other children in general.

People who underestimate down syndrome children are because they do not know it. People do not know that down syndrome children have the equal rights of being trained and educated just like other healthy children. Therefore, in every commemoration even of the global Down Syndrome Children's Day, POTADS always introduces and provides information and displays the talents of Down syndrome children.

Based on this statement, the researcher also knows that the central socialization is from parents who play an essential role in educating their children. Gertrude Jaeger suggested that in this early stage, parents are the most important agent of socialization. The importance of this socialization agent lies in the ability to interact and communicate with others. (Sunarto, 2004).

In the statement, parents must be the primary agent to teach their children in any condition, both their children with special or ordinary needs. However, if the children do not get the best treatment from the parents, they will not be able to be what we expect them to be. For example, parents want their children to be able to interact with other people, but their children are never trained to do those interactions, of course, they will not be able to do those actions, they will feel afraid. Conversely, if we

teach them, give examples, and educate them, they will be able to socialize in their daily life.

The POTADS organization in this socialization activity also aims to give self-confidence to parents so that they are not ashamed and introduce their children to the community. Because there are still some parents, who are ashamed to show their children with special needs. Not only in the remembrance of Down Syndrome children's day, but the researcher also knew that at present the POTADS organization had added its socialization activities to the Posyandu about Down Syndrome to people in the city and village. This activity aims to inform and socialize down syndrome children to people who do not know about down syndrome.

These benefits that are exchanged are intrinsic such as love, affection, and appreciation and extrinsic such as money or other material goods.

1. Intrinsic advantages (such as love, affection, and appreciation)

From the case studies that researchers carefully researched, POTADS's organization saw social exchange within the organization. social exchanges were realized from several programs held in POTADS organization. One of the benefits gained from joining the POTADS organization is that parents who have Down Syndrome children find it easier to find information about their children's growth, not only through social media but also with seminars held by POTADS organizations.

In addition, the benefits can be in the form of love and affection that is manifested from the KOPDAR program, which is sharing parents with administrators and other members. This sharing makes them not feel alone but, since joining them it is like having friends who also feel the same way, thus making its members like having a new family that strengthens, supports and gives love to each other. From these advantages the researcher saw that there was a social reality with this blunt theory that was in accordance with the facts on the field that the researchers found.

Not only love and affection, the benefits gained are in the form of awards. Since joining the POTADS organization DS children have also been given the opportunity to participate in activities that exist to train the interests and talents of DS children. The realization of these activities made them have many achievements not only at the national level but also at the international level. From the achievements and talents of the DS children, also as a realization of the benefits of

getting the appreciation and appreciation gained from their efforts.

2. Extrinsic benefits (such as money or other material goods)

The benefits gained in the POTADS organization are extracurricular in the form of donations obtained from several private institutions or companies that care about the existence of Down syndrome children. Usually these donations are used for the activities carried out by POTADS and to help Down syndrome children in need.

Benefits in the form of money can also be obtained from the sale of cassettes or CDs that are freely traded to the community who want to know more information about caring for DS children. From this sale, the community who bought it did not only donate their donations to POTADS, but also gained useful information and knowledge from the contents of the CD. Likewise POTADS organization not only can help people who want to know about Down syndrome but also get donations in the form of money that can be used to sustain POTADS organization activities

4 SOCIAL EXCHANGE ON POTADS ORGANIZATION

Use Based on the idea that expressed by Blau, social interaction initially occurred within social groups. Where individuals are attracted to a particular group because they feel that they relate to that group and will get more rewards than other (Ritzer & Goodman, 2004).

Blau intends to analyze a more complex social structure, surpassing Homans's focus on basic social forms. Homans is satisfied working at the level of behavior, but according to Blau such work is only a tool to achieve greater goals: "The main purpose of sociology that studies face-to-face interaction is to lay the foundation for understanding the social structure that develops and gives rise to social forces that mark its development that "(Ritzer and Goodman, 2004: 368)

Blau focuses on the exchange process which he thinks governs most human behavior and underlies relationships between individuals and between groups. Blau imagines four sequential steps, from the exchange between personal to social structure to social change:

Step 1: exchanges or transactions between individuals that increase to ...

Step 2: Differentiation of status and power leading to ...

Step 3: Legitimacy and organization that spread seeds from ...

Step 4: Opposition and change.

Micro to Macro. At the individual level, Blau and Homans are interested in the same process. However, Blau's concept of social exchange is limited to actions that depend on the reaction of giving gifts from others. Actions that stop immediately if the expected reaction does not come. People are attracted to each other for various reasons that persuade to build social groups. After the social group is formed, the gifts they give each other will help maintain and enhance ties. Gifts exchanged can be in the form of something intrinsic, such as love, compassion, and respect, or extrinsic values such as money and labor and physical labor. People who are involved in group ties do not always get equal prizes because that will lead to differences in power within groups (Ritzer and Goodman, 2004).

Blau's opinion in Ritzer's book is in accordance with the case that the researcher wants to do that the researcher knows that the individuals who join the POTADS organization join because they want to benefit from the interactions carried out within the organization. the benefits are information about the growth and development of Down Syndrome children.

If one person cannot get something from another person, then there are four possibilities. First, the person will force others to help him. Second, the person will look for other sources to meet their needs. Third, the person will try to continue to get along well without expecting anything from others. Fourth, the person will submit to others thereby giving others the same respect (Ritzer and Goodman, 2004).

To this point, Blau's opinion is the same as Homans, but Blau's theory extends to the level of social facts. The example he says is that we cannot analyze social interactions apart from the surrounding social structures. This social structure arises from social interaction, but after a separate social structure emerges its existence and influences the interaction process (Ritzer and Goodman, 2004).

Social interaction first occurs in social groups. Individuals are attracted to one particular group because they feel that intercourse offers gifts more than any other group offers. Because they are interested in one particular group, they want to be accepted, they must offer gifts to other group members. The efforts of newcomers to impress group members generally lead to group unity, but competition, and finally social differentiation will occur if too many people make an impression. The

person who gives the best prize, the greatest chance is to occupy the position of leader. Inevitable differentiation in group life so that being a leader and followers creates new needs as integration. as soon as they recognize the leader's status, the followers' needs for integration are even greater. (Ritzer and Goodman, 2004).

All these descriptions are reminiscent of Homans's discussion of exchange theory. However, Blau moves at the level of society and distinguishes between two types of social organizations. The organization is the first type of process of exchange and competition. The second organization did not just appear but was deliberately set up to make a profit. In observing this social organization, Blau focuses on the subgroups contained in it. He stated that groups of leaders and opposition exist in both types of organizations. both groups were born from the interaction process. In the second type of organization, leaders and opposition groups are built in organizational structures (Ritzer and Goodman, 2004).

Norms and Values. Hiring Blau, the mechanism that mediates between complex social structures is the norms and values that exist in society.

Collective agreements on values and norms are used as a medium of social life and as a link that connects social transactions. Norms and values allow social exchange in complex social structures and determine organizational development and social reorganization in it (Ritzer and Goodman, 2004).

There are other mechanisms that strengthen the social structure, but Blau focuses on consensus and values. This consensus and value replace exchanges that indirectly become direct. A member must conform to group norms and get approval because the adjustment is due to the fact that self-adjustment contributes to maintenance and stability (Ritzer and Goodman, 2004).

The concept of norms according to Blau diverts attention to the level of exchange between individuals and collectivities, but the concept of value shifts its attention to the level of social life on the widest scale. Blau said: Shared values which consist of various types can be imagined as social transaction media which extends the boundaries of social interaction and social relations structures through time and social space. Consensus in social value provides a basis for expanding the distance of social transactions beyond the boundaries of direct social contact and perpetuating social structures beyond the age brick of man (Ritzer and Goodman, 2004).

According to Blau, this value is seen as a media or social tool that serves to expand social transactions.

In this case there are four values. First, values that are specific or particular. particularistic values function as a medium of integration and solidarity. This value helps unite members with a group with regard to things such as patriotism or about the quality of the school or company. Second, universal values. Third, values that are legitimizing authority. Fourth, opposition values. (Rahod SVD, 2007)

Blau replaces this individual role with various types of social facts for example, Blau discusses groups, organizations, collectivity, society, norms and values.

In the case, the researcher found that the beginning of the formation of POTADS organization, POTADS organization is from the interactions of parents whose are waiting for their Down Syndrome children to do therapy at Harapan Kita Hospital. From their meeting, they usually discuss their child's growth and development, education, and how they can be accepted in society. These meetings and discussions continued until 1997. Moreover, in 2003 this organization, namely the Persatuan Orang Tua Anak Down Syndrome (POTADS) are legally and formally established. POTADS organization is a place for parents to interact and also exchange information.

Many parents joined the POTADS organization. The reasons for those who joined this organization are they want their children to interact with others, get information, and share about their child's growth and development. Blau in Ritzer states in his book that they hope for a reward from the interaction they have in the POTADS organization.

According to Blau, differentiation of power is inevitable in a group so there will be leaders and followers and it will create new needs for the integration (Ritzer and Goodman, 2004: 370). This differentiation is in KOPDAR, MLM Hati activities, Scientific Seminars, socialization at Posyandu and other activities. Usually, these activities are coordinated by small and integrated committees. There are a leader and followers in every activity. When the researcher took part in the socialization activities at Posyandu, the researcher only saw several parents of Down Syndrome children who participated in this activity. There were parts played by the organizers in the socialization activities at Posyandu, and some of them became informants who gave information about the growth and development of Down Syndrome children and others.

Difference creates legitimacy or trust in every activity that will be held by POTADS organization. So later every activity will be made by the committees. From the committee will be chosen who

can occupy the role that is in the structure of the activities committee. This legitimacy aims to strengthen every program or activity that POTADS organization will make. The opposition arises where every formation of an organizational structure of each program will create conflict or disagreement about the individual who occupies the position or role within the structure. However, this opposition is not in the POTADS organization. The researcher has not found a conflict from the structures of each program in POTADS organization.

4 CONCLUSION AND SUGGEST

Based on the results of the data and analysis that the researchers got in the POTADS organization about the concept of social exchange triggered by Peter M Blau, it turned out to be true. The data and findings are obtained by researchers from the results of observations and direct interviews with the administrators, members and communities involved in the activities of the organization. The concept of social exchange that exists within this organization is in the role played by cases of acceptance of Down Syndrome children in the community and manifested in programs run by the social organization POTADS.

Added The concept of social exchange that exists within this organization lies on the role that is in the effort to educate people and community to accept down syndrome children and manifested in the program that runs by the social organization POTADS.

There is a social exchange of action in the interaction behavior that carried out by the management in the program. Parents and the community who expect that the interaction or relationship that they do will have a positive impact on them. The effects are intrinsic such as love, affection, and appreciation), and extrinsic such as money or other material goods. Also, the benefits exist in the norms and values of POTADS organizations.

The results of the socialization that carried out by POTADS organization are successful in raising awareness among people and community who participated in the event. Although some people were initially afraid, after following this activity, the society knows the information about the down syndrome children. It also makes people accept the existence of down syndrome children.

The norms and values that exist in social exchanges are manifested in the regulations that are in the POTADS organization. Where members must

comply with existing regulations so that they can be gazetted as members of the organization as well as not being able to discuss the issue of SARA and Politics.

Whereas the value in social exchange in POTADS organization is realized in four values. First, the special value of providing comfort and well-being for its members to strengthen POTADS's organizational ties. Second, general values, namely by sharing with each other with members. Third, the value that legitimizes authority, namely the value of the POTADS organization leader who has social control to its members to supervise and ensure the organization is in a stable condition. Fourth, the value of the opposition, which is manifested in the values of change desired by its members, namely the existence of new programs that support the growth of DS children.

The research her suggests to the next researchers in the field of sociology, especially the sociology of the organization, to be able to continue this research which focuses on the socialization and stigma that exist in the society by analyzing in-depth and complete study. The researcher also suggests furthering the discussion of children with special needs in other organization in order to enrich the knowledge and information about it. This research can also be carried out around the area where there are down syndrome children.

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