

The Role of Social Worker for Children with Down Syndrome and Their Family

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Abstract- The number of people with Down syndrome in Indonesia is more than 300 thousand. Down syndrome is a genetic disorder causing those who suffer from it have both physical and psychological abnormalities. In everyday life, people with Down syndrome have to deal with issues from within and outside their environment. Public acceptance is very sensitive, not all people understand Down syndrome thus influencing the way the people with down syndrome being treated. This research is using literature study method. The result shows various issues have to be addressed by down syndrome. Toward various issues faced by people with down syndrom, social workers have the professional responsibility in providing services and intervention aiming at increasing the people with down syndrome's social functioning.

Keywords: down syndrome; services for down syndrome; social worker role

I. INTRODUCTION

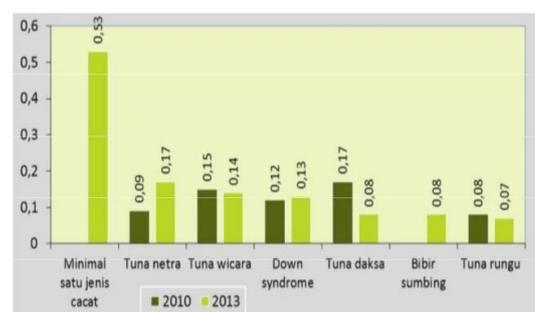
Down syndrome is a genetical disorder experience by an individual with developmental delay physically and psychic, as stated by Buckley [1] that down syndrome is caused by the 21st chromosome during insemination of sperm and ovum. The individual with down syndrome is characterized with visible physical uniqueness. They are also experience mental retardation which could be different from one person to another.

The birth of children with down syndrome are occuring all over the world. Indonesian Center for Biodiversity and Biotechnology (ICBB) record more than 300 thousand children are with down syndrome in Indonesia, yet in the world, the number of people with down syndrom is predicted to reach 8 million people. The occurance number of down syndrom is reaching 1 person per 1000 birth rate. In Indonesia, the prevalence is more than 300 thousand individuals.

Based on Basic Health research data at 2013, the number of people with down syndrome in Indonesia have increase compare to 2010, as shown in the graph below:

Graph 1.1

The number of children with disabilities in Indonesian year 2010 and 2013



Source: Riskesdas 2013, Ministry of Health .The data gained from the research indicated that on 2013, for every 100 babies delivered, 13 of them are borned with down syndrome. As for 2010, 12 out of 100 babies delivered are with down syndrome. Thus indicate the elevation of down syndrome prevalence by 0,01 percent.

Other than health issues, people with down syndrome also have to deal with issues from the society. The children with down syndrome who have unique feature in the face (such as the mongoloid race) often becoming the centre of attention. Other than that, not all parent or family of people with down syndrome are accepting their condition. Some societies still believe that down syndrome is a curse for a family, thus the family consider the person with down syndrome as the embarrassment for the family. As the effect of that believe, many parents are covering the fact that their children are having down syndrome.

It has been known that people with disabilities also have the similar rights like the non disabilities, including the people with down syndrome. The rights of people with disabilities have officially admitted through the disabilities rights convention, agreed on 13 December 2006 by the United Nations [2]. The convention is developed to guarantee, protecting and advancing the rights and freedom of the people with disabilities.

In practice, the human rights fulfillment for children with down syndrome need to be strengthen and fight for, in order to achieve the goals of disabilities rights convention. The family strengthening program as the nearest environment for the children with down syndrome serves as the key to main success achievement for children with down syndrome's rights fulfilment.

Social work as a human service profession take on roles to provide services to children with down syndrome and their family. Family often experience problems due to lack of knowledge and skill of caring and treating children with down syndrome. Other than that, the family's attitude toward people with disabilities are often bringing up problems for children with down syndrome, some families believe that children with down syndrom is disgraced to the family thus influencing the attitude of the family into negative and even rejecting the existence of the children with down syndrome.

Social workers main task in assisting individu, group and community is to help them to functioning socially. Similar to that, social workers can assist family to function well toward the children with down syndrome. Family functioning toward children with down syndrome refers to the ability of the family in supporting and fullfiling the needs, solve problems and conducting roles and functions of the family members.

II. METHOD

This article is using literature and documentation study, in the form of books, papers and other scientific writing products, and also study of various documents connecting with the role of social workers for children with down syndrome and their families.

III. DISCUSSION

Down Syndrome is a damage or physical defect along with mental retardation, thick and cracked tongue, the feature is flat and slant eye. James & Philip state down

syndrome occured at genetical disorder chromosome causing mental retardation, unique features and hypotonia.

According to Indonesian Law No 8 year 2016 concerning Disabilities, down syndrome is one category of intellectual. Intellectual disability is disability where the people of this disability experience disturbance in their brain function due to the below average of intellectual. People with down syndrome is categorized as mentally disabled or retardation mental group. According to PPDGJ (Pedoman Pengolongan dan Diagnosis Gangguan Jiwa di Indonesia) Health Department of RI, based on the level of intellectual disturbance, there are 4 level of mental retardation which are mild, moderate, severe a Social Work with Children and Families 2nd ed (Lumbantobing, 1997). The mental retardation of the child with down syndrome is signed with the value of their IQ between 35 – 40 or 50 – 55.

Children with down syndrome experience intellegency deficit different from normal children. Children with mild and moderate retardation are able to use language for daily activities, independence and are able to self care. They can be assisted with specifically designed education plan to increase their skill and address the obstacle.

Other than experiencing a delay intellectual development, children with syndrome are also experiencing issue in their physical health. The overt chromosome in their body causing the malformation of body organ and tissues in their body. However, the effect of that is different among the children with down syndrome.

The family's behaviour and attitude toward the condition of the children with down syndrome are different, because naturally, every parent would want their children to be borned in perfect body and healthy in physical and mental. Anggreni & Valentina [3], found from their research that most parents gifte with children with down syndrome are experiencing feeling of sad, dissapointment and shocked when they learned that their children were borned with down syndrome, although in the end, the parents are accepting the condition of their children with down syndrome.

Parents of children with down syndrome have to carry heavier responsibilities compare to those of normal children due to the challenges and obstacles they are facing as the consequences of the condition of down syndrome

The intellectual health condition that different from other children make them need more attention and special treatment from their parents. The parents usually experience several problems such as how to communicate the condition of their children to other family members, the expenses and budgeting managerial, treating other family member because the parents often pouring down more attention to the children with disability, treating children with down syndrome itself becoming another issue as well as providing good education thus the children with down syndrome can grow up independently and better in the future [3].

Children with down syndrome need time, attention, expense, effort and patient. Children with down syndrome are also need assistance from their parents in various daily

activities such as bathing, clothing, toileting and other activities.

Accepting the child condition is not an easy decision, because the parent are also have to deal with attitude and behavior from the extended family and society toward the children with down syndrome as the disgrace to the family. The condition often being related into curse from God to the parent because the parents have done mistakes in the past. Thus, many parents refused the fact that their children are experiencing down syndrome and they believe that their children only experience a usual developmental delay. Parents are ashamed to admit that they have children with down syndrome, which then will be the barrier for the children to be actively involved in activities and socializing in the society.

Not only parent, other family members especially siblings are also experiencing adjustment toward their family member with down syndrome [3]. According to Hurlock in Anggraeni that the older children are expected to also be responsible in taking care their siblings with down syndrome. This demand the siblings to be more patient, caring, and accepting the children with whatever limitation they have.

The way the family of children with down syndrome treat and react toward the situation will different, and depending on the knowledge and understanding on down syndrome. The more family comprehend what is down syndrome and how to address it, then the earlier they would deal with the situation, for example from the moment they child was born, the parent would do various treatment and bring their child to therapist thus the child can develop optimally.

Children with down syndrome often experience difficulties on learning to speak, this is because their hearing function is also disturbed. Sometimes, their language is also difficult to comprehend. In many cases, need longer time to understand the situation and learning new things. During their infancy, the motoric development was delayed. They learned to crawl or walk at later age.

Children with down syndrom issue is connected with the way the parent conduct parenting to their children with down syndrome[4]. One of the field of social work is social work with children and family. In social work practice with children and family, social worker need to understand who are the focus of the work and intervention, whether the child or the family. Child welfare is the most important focus, however, in order to achieve the child welfare, the social worker need to work together with the family [4].

In term working with children with down syndrome, social worker take on role in assisting the children with down syndrome to obtain social support and enable them mto access the resources and potential to fulfill their needs. This of course acquire the social worker to work together with the family of the children with down syndrome. The social worker can help the family of children with down syndrome in addressing the problems they face by conducting their roles as social workers such as:

A. Enabler

As an enabler, a social worker assist individuals, groups and communities in accessing the available resources,

identifying problems and developing their capacity in order to overcome their problems of achieving needs. Family of children with down syndrome can be assisted by bring the family closer to access of services on education, health and other support sources, thus the family can be helped to fulfill the needs of children with down syndrome by using the available resources.

B. Broker

As a broker, a social worker connecting the individuals, groups and communities to social service provider institution, such as social affair office, community development institutions and other government bodies. Social worker can connect the family of children with down syndrome with health service office, education service, social affair office to gain access of support and resources needed to parent the children with down syndrome. Other than that, social worker can also connect the parent with self help group of parent of children with down syndrome, this is useful for the parent to strengthen their emotional and bond, support and motivating between the parents of children with down syndrome.

C. Facilitator

As a facilitator, social worker works to stimulate and support in community integration. Social worker serve the family and children with down syndrome with their closest environment and community thus the family and the children can function socially and the community is able to accept the existence of the children with down syndrome as part of the community member as well as diminishing the negative lable and humiliation toward the family and the children with down syndrome.

D. Social Planner

A social planner collect data on social problems faced by individuals, groups and communities, analyzed and providing alternative rational movement in accessing the available systems to overcoming the problems of fulfilling the needs of individuals, groups and communities. Social worker can provide support to the family and children with down syndrome through policy planning which is able to help them to access the available support needed and help the children with down syndrome to function socially.

Although the children with down syndrome experience various limitation, however they also have the similar need with the normal children. The children with down syndrome are also have thoughts, feelings to be loved, needing attention, wishing to make an achievement along with other rights. Their circumstance force the children with down syndrome and their family needing special treatment and effort to achieve the rights.

With active role and social work profession involvement in addressing various issues faced by the children with down syndrome and their family, it is expected can lessen the burden faced by the family and open up the opportunity for the children with down syndrome to achieve their rights and functions socially.

IV. CONCLUSION

The condition of problems faced by children with down syndrome and their family, along with social work profession attention and role as described above explained that children with down syndrome are still capable of being

developed their potential when their self esteem can be supported, thus their behavior and social interaction with the family and their environment will work well.

The expectation is that children with down syndrome and their family gain self esteem, have courage to do good, thus they will try to overcoming their limitation. This is one strong motivation for them to be able to behave like other normal children.

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