

Social Work Services – An Effective Intervention in Dealing with Problems of Families having Children with Autism

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Abstract

In Vietnam, autism has only been known for more than 10 years but has quickly become a problem of social concern. Although there is no officially published data from 2000 to now, the number of children diagnosed and treated with autism in care facilities is increasing, each year is higher than the previous year (General Statistics Office, 2019). Research results also show that families with children with autism are facing many problems such as financial difficulties, lack of care knowledge, stress, fatigue, and discord in the family (Morris, Muskat, Greenblatt, 2018; Newsome, 2001). Models of care, intervention, and support for children with autism and their families around the world are moving towards a holistic approach and emphasize on the providing of social work services because these services range from Prevention, Intervention, Restoration and Development content for children with autism and their families (Strunk, Leisen & Schubert, 2017; Shuai, 2018). In Vietnam, social work as a profession is still quite young when it was officially recognized as a profession through Decision No. 32/2010/QĐ-TTg “Development of the social work profession in the period 2010 – 2020” and recently continued to be developed in Decision 112/2021/QĐ-TTg “Social work development program for the period 2021-2030”. However, the national report summarizing 10 years of social work development shows that social work plays a major role in supporting disadvantaged groups (Department of Social Protection, 2021). Through assessment based on 150 parents having children with autism in care facilities in Hanoi, Hochiminh and Quangninb, this study aims to discuss problems of family having children with autism and recommend effective social work services to support them in this current context.

Keywords: *Children with Autism, Families Problems, Social Work Services*

INTRODUCTION

In Vietnam today, autism has only been known for a few years, but it has also quickly become a problem of special social concern. Recent data show that the number of children diagnosed and treated for autism in public health facilities is increasing, year after year is higher than the previous year (Dau Tuan Nam & Vu Hai Van, 2015). In the current context, many children have autism for a very long time, but are not detected by their parents and relatives and use social services to intervene. This situation comes from the lack of understanding or incorrect understanding of parents about autism syndrome (Strunk, Leisen, and Schubert, 2017). Therefore, they also lack understanding about services in general and social work services in particular in supporting and intervening for this syndrome of their children (Karns, 2017). Along with that, the awareness of the community and society in caring for, protecting and ensuring children's rights is still limited, leading to many children with autism not being detected and intervened in time, unable to integrate into the social environment, having to depend on the care of family members, being discriminated against in the community (Lindsay et al, 2014)... Experts in this field have affirmed that the care and support of children with autism relies on the great role of the child's family because this is the closest environment to the child (Hoang Duong, 2017). However, those families still have many different problems, thus it will limit the effectiveness of care (Morris, et al., 2018). Therefore, in addition to providing interventions for children with autism, families of those children also need intensive and comprehensive support through the provision of social work services (Strunk, Leisen & Schubert, 2017; Shuai, 2018). Stemming from the above context, this article assesses the status of problems facing families of children with autism, thereby discussing, and proposing effective social work services in this field.

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RESEARCH METHODS

Questionnaire Survey Method

To obtain statistical data reflecting the status of access to and use of social work services for families of children with autism, the research team used a questionnaire survey method. The questionnaires were distributed for the purpose of surveying to assess the current situation of problems and difficulties that families of children with autism are currently facing in Hanoi, Quang Ninh and Ho Chi Minh. Specifically, the questionnaire will be designed for families/guardians of children with autism in 5 care facilities (in 3 public and 2 non-public care facilities).

Based on statistics from the Ministry of Labor, War Invalids and Social Affairs (MOLISA), the research team selected 5 care facilities with the largest number of children with autism 2 in Hanoi and 2 in Hochiminh city and 1 in Quang Ninh. Then, based on the list of each care facility, the research team randomly chose the number of respondents until the research sample has enough 30 respondents in 1 care facility. After reviewing filled questionnaires, a total of 150 valid questionnaires were included in the analysis.

Documentary Research Methods

In this method, the research team focuses on researching documents related to laws and policies for children with autism. Specifically, the research team will learn and analyze: Decision No. 23/QD-TTg of the Prime Minister *approving the National Action Program for Children in the period of 2021 - 2030*; Decision 32/QD-TTg: *Development of the Social Work profession in the period of 2010-2020*; Decision 112/QD-TTg: *Promulgating the Social Work Development Program for the period of 2021-2030*. Decision 1215/QD-TTg: *Approving the project on social assistance and rehabilitation for mentally ill people and people with mental disorders based on community for the period 2011 – 2020*; Decision No. 1929/QD-TTg: *Approving the social assistance and rehabilitation program for the autistic children and people with mental health problem based on community in the period of 2021 – 2030*.

Furthermore, previous studies and research also have been reviewed to have more data for discussing. The analysis of those documents helps to have additional content related to the direction, viewpoint, and orientation to develop care services to solve the problems faced by children with autism and their families. On the other hand, it aims to understand comprehensively about problem of child autism and their families. The team also analyzed case records of children with autism and their families as a basis for deeply understanding their problems.

In-Depth Interview Method

The research team will interview experts in the field of providing social work services for children with autism and their families. Experts scheduled to be interviewed include policy makers, leaders, and social workers in care facilities and those with deep knowledge in the field. In addition, the study also focused on interviewing staff in public and private centers (who are leaders or staff directly providing services to children with autism and their families) and parents having children with autism.

The use of this method will help the research team have in-depth explanations of the problems and needs of those families. Moreover, expert opinions are also the basis for the research team to make recommendations for the efficiency of social work services in this area. Specifically, the in-depth interview form will be selected with the following structure:

Policy making officer: 1 person.

Leaders and social worker in care facilities: 7 people.

Parents having children with autism: 10 people.

Problems Faced by Families of Children with Autism

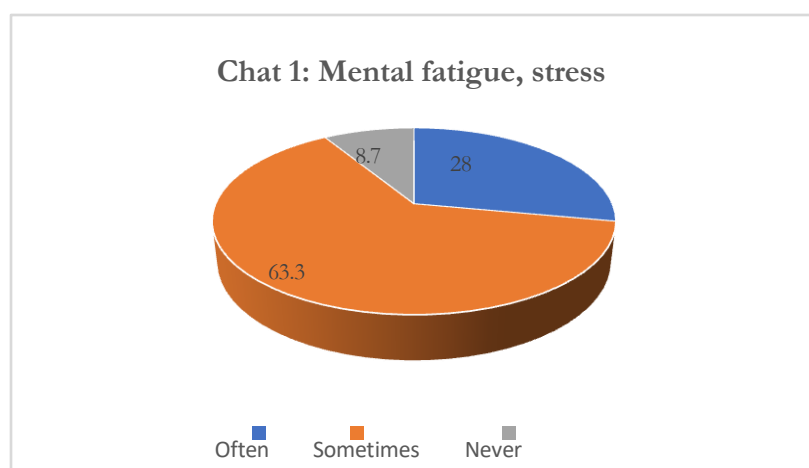
Although autism is a problem of children but families with children with autism have been facing many different problems and difficulties. Indeed, studies show that parents of autistic children have faced many problems

including psychological, economic, and social... (Oanh, 2017; Emilie, 2018; Ewa, 2020). These issues affect the family, thereby also affecting the family's attention and care to the child and reduce the effectiveness of interventions at the facility. A systems approach implies that it is difficult for children with autism to be cared for effectively when they belong to dysfunctional systems (families). Experts believe that interventions and supports for children with autism at home play an equally important role as interventions at the facility (Cong & Diep, 2020; Preece, 2008). Therefore, families with children with autism also need support from services to be able to overcome the difficulties which they are facing, thereby contributing to improving the effectiveness of caring for children with autism (Avery, Van, & Maich, 2022; Strunk, Leisen, & Schubert, 2017).

-Stress, mental fatigue

In Vietnam, when a family has a baby, they are always loved and cared for them. Because of such great value, when a family learns that their child has autism, they will experience certain mental shocks and the resulting psychological stress (Karns, 2017; Fuld, 2018). In addition, in daily life, along with the pressure at work and taking care of autistic children also create certain problems that cause families to experience mental fatigue (Preece, 2008; Fuld, 2018).

The results from the chart show that parents of children with autism often get involved in stress and mental fatigue in their daily life which are caused by difficulties in caring for and treating children with autism.

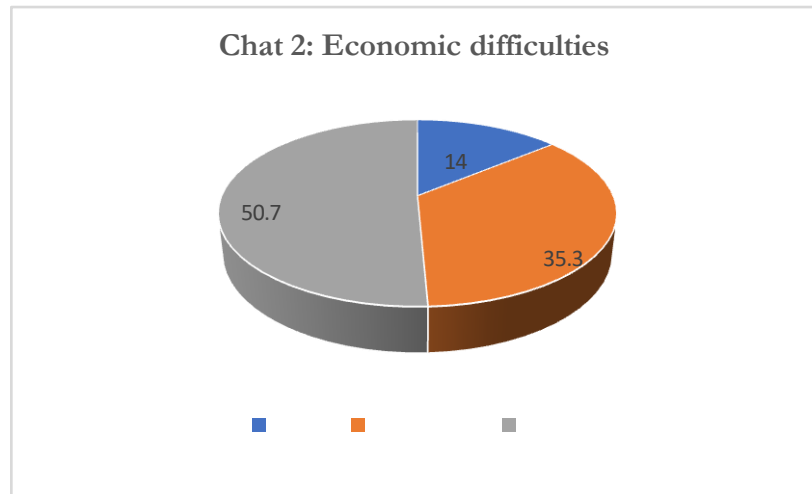


The problem that parents of children with autism often face regularly is the problem of stress and psychological fatigue (28% of families often have this problem, 63.3% sometimes and only 8.7% of families do not have this problem). In fact, these are inevitable psychological states for families with children with autism, especially in the early stages of learning that their child has autism spectrum disorder. *“When I was informed that my child has autism, both my husband and I seemed to collapse, although I was mentally prepared, I really could not believe my ears. Then in the days that followed, we always lived in a heavy and stressful feeling, not understanding why our children were like this, whether we behaved unethically or not”* (In depth interview, Parents, Female, 28 years old). Even after the initial shock period when learning about autism has passed, the difficulties and pressures in the process of taking care of children also bring a lot of stress and fatigue to parents of children with autism. So, stress problems are the most families with children with autism have faced. However, if they know accurate information about autism as well as have support from other people surrounding them or professional staff, it will help parents of children with autism overcome these negative emotions.

The family's economic difficulties

As analyzed above, many families have faced the problem of economic decline when their child has autism (Nam, D.T. & Van, V.H, 2015; Emilie, 2020). This is even more evident from the results of the chat below when the results show that 14% of families regularly face economic difficulties and 45.3% of families experience this problem occasionally. *“The cost for the care and treatment of my child is also about 10 million/month. Before, it was within my family's ability. However, now, it has become an issue with my family because autism is a lifelong problem, and we have*

to spend a lot of money for that. Furthermore, my wife has to quit her job and stay at home to take care of my child”. (In depth interview, Parent, Male, 30 years old).



According to Emilie (2020) and Emilie (2018), the reason for the economic decline comes from the following two main reasons:

- *Long-term funding for the treatment and care of autistic children*

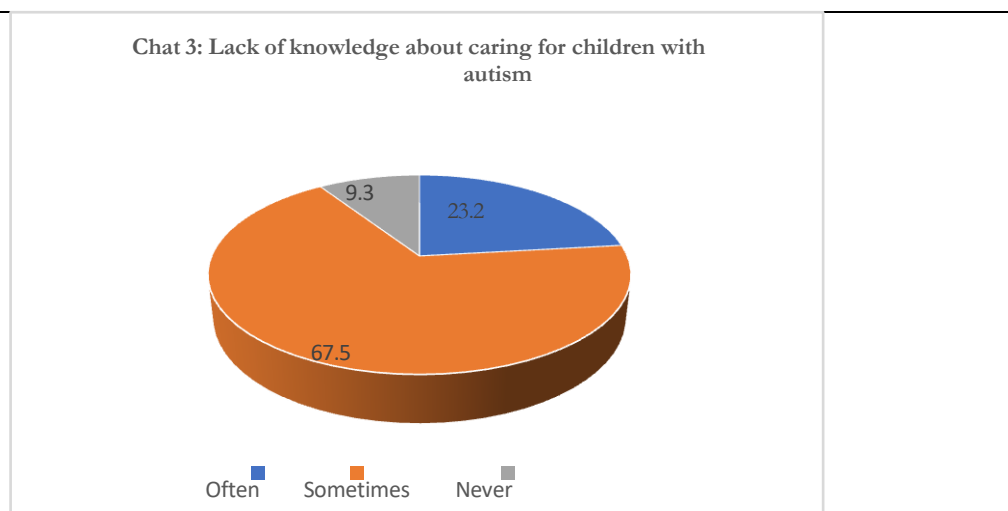
As described above, especially for children with severe and especially severe autism, the treatment of children is one of the burdens that reduce the family's economy. With such autistic children, they are often cared for in specialized facilities which have more expensive fees. Children at a slightly better level will usually receive care and inclusive education in specialized institutions and in conventional cultural education institutions. That means funding for children will also have to increase. Even those who are not well off, because of their love for their children, young parents are willing to sell their properties and borrow money to treat their children. However, how long the family can stand it and how it will be after that, they still have no answer.

Declining family labor force

This is also a factor that causes the family's economic decline. The reason is that parents of children with autism must spend time taking care of their children. When having to spend more time taking care of children, the time to work to generate income have to decrease. Therefore, the total income will be less, causing the family economy to decline. Thus, if childcare is not effective, or services and childcare models are not diversified, parents of children with autism will lose part of the family's productive force and reduce the productive forces of society.

Lack of Knowledge About Taking Care Of children With Autism

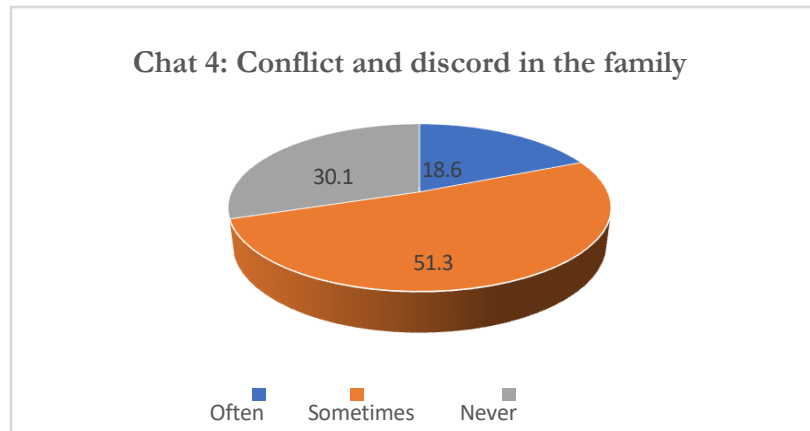
The results in the study showed that a large percentage of parents of autistic children still do not have enough knowledge of childcare or are not confident about their knowledge and understanding about autism (Nam, D.T. & Van, V.H, 2015). One of the reasons is because Autism is a relatively new issue in Vietnam, so there are not many documents or accurate information about this issue (Emilie, 2018). Through research and through synthesizing opinions from case studies of parents of autistic children and deep interview from staff in facilities, many cases do not know or are not confident about their knowledge of taking care of children with autism. Furthermore, even though they want to have information and knowledge, it also confuses them because of having many different sources. *“My family does not have conditions to take my child to care, so I have searched online for information about autism as well as ways to care for my child, but there is not much information, and it is quite vague. My family or I also consult friends and acquaintances, but each person has their own opinion”.* (In depth interview, Parent, Female, 36 years old).



Parents who refer to documents from autistic childcare facilities are also confused. The fact that there are many autistic childcare facilities, especially in urban areas, but these facilities are developing in the direction of 100 flowers blooming, spontaneously and self-deploying care activities. That makes the care knowledge of the facilities vary from place to place, which makes parents themselves confused when accessing inconsistent documents from many different sources. “I want my child to be taken care of in the best place, so my family has taken him to several different facilities, both private and public. In general, each place is different, but I see the documents in those institutions are not very similar and each place has different suggestions” (In depth interview, Parent, Female, 29 years old). Agreeing with the above point of view, when interviewing experts, there was also an opinion that there should be an official channel/sources, a legal website address, and posting up-to-date advanced care knowledge so that everyone can have a reliable address in accessing information and knowledge of childcare.

Conflict and Discord in The Family

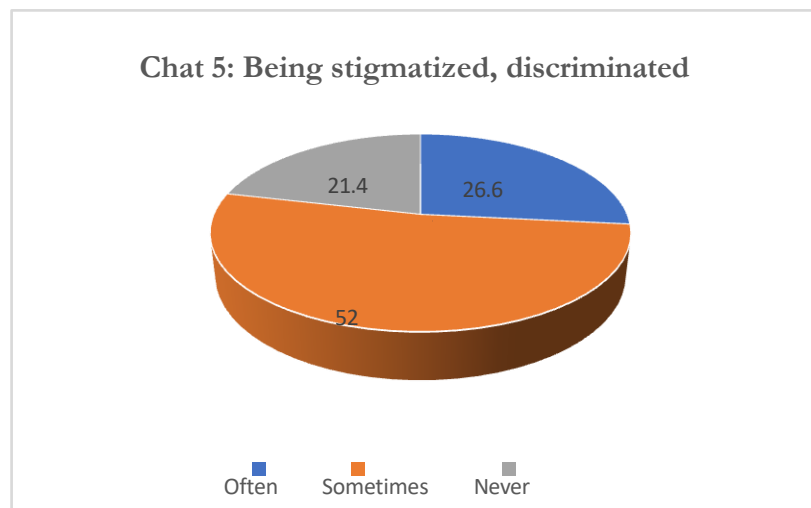
Although there are not often problems of conflict and discord in the family. However, Fuld (2018) and Ewa (2020) showed in their studies that the percentage of families who sometimes encounter disagreements when having children with autism also accounts for a proportion worthy of attention. In fact, through research and in-depth interviews, autism does not directly cause conflicts but indirectly creates these problems. Experts say that pressures from lack of knowledge in childcare, economic decline, or failure to meet expectations about children... make the family atmosphere always tense (Ewa, 2020). Stress will put people in an insecure mood and make emotions, thoughts, and behaviors subject to negative impacts and influences, making it difficult to control themselves (Fuld, 2018). Therefore, when the factors related to autism are not resolved, it will make parents or even family members more likely to lose control of their behavior, causing disagreements or conflicts. *“Taking care of children and the stress and fatigue in the family is difficult to avoid. Many things keep pouring into their heads, which often leads to arguments and leads to quarrels. Not only between husband and wife, but also with grandparents. Just going around and doing this and that and that does not work, so it becomes a big deal in the house”.* (In depth interview, Parent, Male, 42 years old).



If discord and conflicts in the family happen for a long time, it will be the main cause of domestic violence thus negatively affecting the child's development and, in this case, on caring for children with autism (Chan, 2020). Therefore, it is necessary to have services to support and deal with factors that lead to discord in the family to ensure a stable and happy living environment, which is the condition for the most effective childcare.

Being Stigmatized, Discriminated

For issues of discrimination, nowadays, along with the promotion of communication, the stigma is also decreasing (Chan, 2022). Furthermore, since this research was conducted in urban areas, people's awareness of stigma issues is also better. However, this does not mean that there is no stigma for example parents normally does not want their child to play with autism child. This issue is quite clearly expressed in the education and training environment. Specifically, as analyzed above, some provinces and cities have posed the problem of not refusing to accept students with disabilities, but the difficulty is that schools do not have enough conditions, human resources, and no methods to taking care and educating children with psychological and behavioral disorders, most autistic children in the locality, although admitted to public schools, cannot really integrate with their friends (Justin, 2019). Even in many places, children with autism are refused or accepted, but parents must commit to working with the school to train their children to meet the same academic standards as other normal children, and unusual problems occur, the school does not accept. Responsibility (Lindsay, at all., 2014). Therefore, many parents of children with autism do not dare to send their children to school when their children are at primary school age. There are children 8-9 years old who are still trying to get permission from their parents to stay in kindergarten because they can do personal hygiene on their own.



It has to be acknowledged that there are cases where children with autism also cause harm to other children or

have abnormal behaviors thus affect other children around them. It will partly lead to stigma and discrimination attitude (Chan 2022). Effective models show that the education for children with autism should be separated. Children will first be screened to determine the degree of autism and associated behaviors. If the threshold is acceptable, children will be supported to participate in inclusive education but under the supervision of professional staff with extensive services. If the child still has unstable behaviors, it is necessary to attend special education classes to have interventions that combine medical, education and rehabilitation (Anderson, et al., 2017; Justin, 2019).

DISCUSSION ON SOCIAL WORK SERVICES

Based on the above problems faced by families of children with autism, the research suggests some appropriate social work services in supporting families of children with autism. For social work services in the field of supporting families of children with autism, social workers use professional knowledge, skills and methods to help autistic children's families to solve problems and meet their needs (Huru, N.H., 2017; Rueda, et al., 2017; Jolynn, et al., 2016). In addition, social work services also aim to promote the social environment in terms of policies, resources and services related to ensuring the implementation of basic rights for children with autism (Alison, 2021; Mary, 2018, Marsh, 2005). The social work services that support families of children with autism are detailed below.

Communication Services

Communication services to reduce stigma in the community are provided through seminars, propaganda, and training for parents of children with autism, teachers in the community (Chan 2022; Alotaibi, et al., 2006). This is a valuable opportunity for parents to discuss cases of children with autism. Disseminate knowledge related to autism in the media, thereby raising people's awareness about autism to remove the stigma against children, help the children's treatment work better, access intervention services especially early intervention services better. With the goal of prevention, social workers organize communication and education activities to raise awareness and skills for parents of children with autism in school (Foster, 2015) and in the community (Thuong, at all., 2021) through the following activities:

Direct communication: Group consultation; itinerant consulting; media conferences at the community, school; seminars, training,

Mass communication: Through books, newspapers, television, radio, billboards, leaflets, posters, websites, call centers to consult and support children...

These activities help parents and families of children with autism understand and self-recognize problems, analyze, evaluate, and seek resources to solve problems, access policies for children with autism.

Psychological Counseling Service

Studies show that although children with autism are the main target of problems requiring intervention, the caregivers themselves, specifically the child's family, also face many problems, especially problems about stress, fatigue, and other psychological problems (Thuong, at all., 2021; Morris, 2018). The psychological stress of having to deal with stigma, disparagement, or misrepresentation about your child's autism. Avoiding discrimination and the difficulties arising from caring for a child with autism puts a lot of pressure on families with children with autism. That puts the family at high risk of stress, psychological distress, and possibly mental health disorders. It is one of the main causes of problems like domestic violence (Chan, 2020; Chan 2022). Therefore, psychological counseling services for families of children with autism are very important. In this service, the social worker will identify the psychological problems the family is experiencing; assess and analyze the severity of the problem so that together with the family, make an intervention plan to solve those negative psychological problems. Usually, social workers conduct from 5 to 10 psychological counseling sessions for families. Then, if the problem is still severe, the social worker can provide a referral service for more specialized psychologists to perform interventions. When providing psychological counseling services, social workers need to have comprehensive knowledge and good skills to help parents of children with autism overcome psychological difficulties. Psychological counseling services can be provided with individuals (father, mother)

or whole family or group consultations (of parents with children with autism). In counseling activities, social workers play a role as a consultant, providing information and knowledge, listening, sharing, encouraging, and finding useful solutions with the family to create change (Thuong, et al., 2021).

Resource Mobilization Services

Caring for and treating children with autism is a long and expensive process, both in terms of effort and money. There are many families due to lack of funds, so they cannot follow the full course of treatment (Kebede, et al., 2021). Therefore, they need to be supported with resources to help them in the care/treatment process for their child. Social workers will act as a bridge, mobilizing resources to help children with autism from families, communities, schools and agencies and organizations (Jam et al., 2011). Connecting young families with support services, policies and legislation and service organizations to best benefit children with autism and ensure children have access to the best services. Social work workers carry out advocacy activities, connecting the most basic and effective resources from the family, along with the coordination with external resources such as the Party's mechanisms, policies and lines. the laws of the State; Association of parents of children with autism; government, mass organizations, individual businesses in the place where they live (Avery, et al., 2022). Therefore, in this activity, social workers act as a mediator, connecting parents of children with autism with the necessary policies, services and resources for them to access and have more power to solve problems.

Advocacy Services

Advocating policies, helping parents of children with autism and their families to voice their opinions and views to ensure basic rights for children with autism and help them access services and integrate into the community (Dalrymple & Boylan, 2013). Social workers need to help parents of children with autism voice their opinions, or represent parents of children with autism, and strive to ensure that the rights of children with autism are always respected. respect and the needs of children with autism are always met as well as bring the best services to them. In addition, Alison (2021) pointed out that it will contribute to promoting agencies and organizations to provide services that meet their legitimate rights and interests, such as the right to secure education, to integrate into life, and to be cared for health.

Transfer Services

Transfer service is provided when the problems are beyond the capacity of the care facility. For example, although they are all mental health care facilities, it is possible that because the problem of autism is too severe and requires intensive treatment that cannot be met by the facility, the social work staff at that facility may send children to more specialized facilities such as psychiatric hospitals for effective interventions. In addition, this service is provided when the problem, for example of the child's parents, is outside the care facility's mandate. For example, parents of autistic children want psychological counseling or policy advice, but the care facility does not have these services, the social work staff will transfer and connect them to facilities with appropriate services. Specifically, this service is an activity where social workers help autistic children, their families or carers access resources or services in the community or society. This activity requires social workers to have a network of services to be able to connect when needed. For example: Shelters, medical services for those who have been abused, general hospitals, mental institutions, youth volunteer groups to support learning, or transportation to and from school for a child with a problem mild mental illness, loan program for mentally challenged young families from policy banks. Social workers will not directly provide necessary services to the target (children with mental health problems) but will only perform professional duties to connect to resources and monitor to ensure those resources are being used properly when providing necessary services to the subject... That means that social work staff will accompany and support families in the whole process of using it. use the service to ensure that in the end the problem is solved, and their needs are met.

Educating Service

Among the models of care for people with disabilities in general and children with autism in particular, the family-based and community-based models of care are proven to be effective and help children recover and integrate for the best (Mary, 2018). However, one of the necessary conditions in addition to the safe/supportive

community environment is that the children's family members need to know how to take care of the child to ensure that the child's illness is stabilized, minimized unusual behavior (Mavole, et al., 2017). With counseling services, providing knowledge for families, social workers can have a preliminary assessment of the family's understanding of autism, assessment of the family's daily activities. in the care of autistic children to gain an understanding of the condition and understanding of the child's family. On that basis, social work staff will advise and provide appropriate knowledge in effective autism care (Mavole, et al., 2017). The provision of knowledge to families can be done through forms such as: training, group meetings, leaflets distribution, communication, or face-to-face consultation. The contents include:

- + How to monitor the patient, know the symptoms of the disease, record the symptoms, report regularly to the treating doctor.
- + How to detect recurrent symptoms.
- + How to detect dangerous symptoms for emergency treatment and timely treatment.
- + How to administer medication and give medication.
- + How to manage and care at home.

CONCLUSION

Children with autism are a vulnerable group, so they need the attention of the family, community, and society. However, caregivers of children with autism such as parents also need attention and support to help them overcome difficulties in life. Besides medical and educational interventions, social work services also play an important role in helping autistic children as well as their parents. With its role, social work services will help families and parents become aware of their own problems, realize their own potentials and strengths, and have more motivation to enter the "war" to "save" their children, minimize the negative impact of autism syndrome. This study analyzed the current problems that parents of children with autism are facing and proposed appropriate groups of social work services to improve the ability of parents of children with autism to cope and bring the best benefits for children with autism and their families.

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