

## **Problems Faced by Families of Children with Autism – Implications for Social work Services**

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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 are no officially published data but 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. 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.

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.

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”. In this article, through a situational assessment of the problems facing families of children with autism, the study will discuss and recommend effective social work services to support families of children with autism in this context.

**Keywords:** Autism, Families of children with autism, Social work, Social work services

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### **1. Introduction of research**

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. 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. 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... 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. 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. Stemming from the above context, this article assesses the current status of problems facing families of children with autism, thereby discussing and proposing effective social work services in this field.

### **2. Research methods**

#### **- Questionnaire survey method**

In order 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 use a questionnaire survey method. The questionnaire will be 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 care facilities in Hanoi, Quang Ninh and Ho Chi Minh. A total of 150 questionnaires were distributed randomly based on the list of facilities.

#### **- Documentary research methods**

In this method, the research team focus on researching documents related to policies for autistic children and their families. In addition, applying this method, research teams also study previous article and researches related to child autism. 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 understanding deeply about 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 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 family members. The use of this method will help the research team have in-depth explanations on 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 deployed with the following structure:

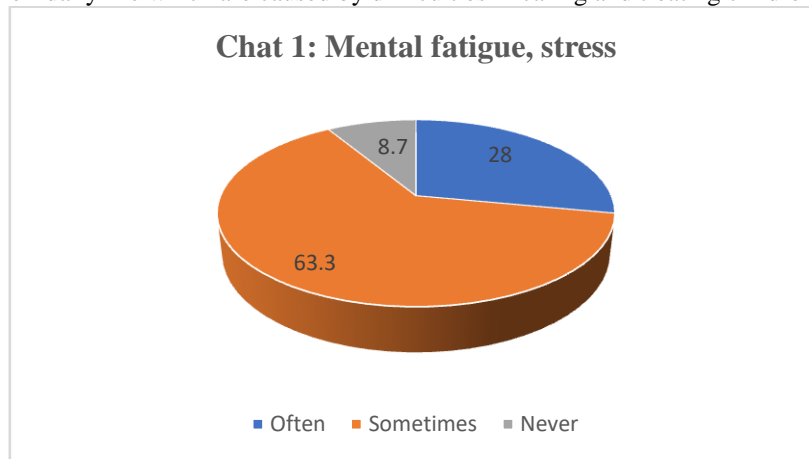
- Policy making officer: 1 person
- Leaders and staff at social work service providers: 7 people
- Parents/family members: 10 people

### 3. Problems Faced by Families of Children with Autism

Although autism is a problem of children but families with children with autism have been facing with many different problems and difficulties. Indeed, studies show that parents of autistic children have faced with many problems including psychological, economic, and social... (Le Thi Oanh, 2017; Emilie Cappe, 2018; Ewa Piula, 2020). These issues more or less 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 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 (Le Minh Cong & Ngo Xuan Diep, 2020). 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 improve the effectiveness of caring for children with autism.

- **Stress, mental fatigue**

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

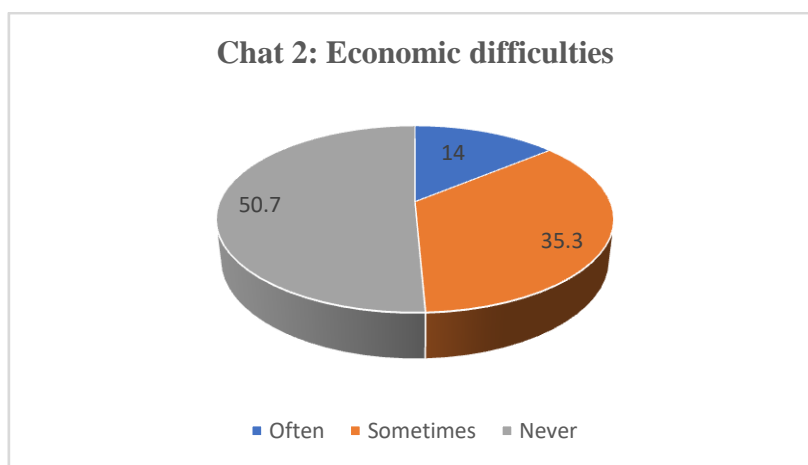


The problem that parents of children with autism often face regularly is the problem of stress and psychological fatigue (28% of families often have this problem, 63.3% sometimes and only 8.7% of families do not have this problem). In fact, these are inevitable psychological states for families with 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 it can be seen that 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 surround 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 with the problem of economic decline when their child has autism. This is even more evident from the results of 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 becomes an issue with my family because autism is a lifelong problem and we have to spend much money for that. Furthermore, my wife has to quit job and stay at home to take care of my child". (In depth interview, Parent, Male, 30 years old).



The reason for the economic decline comes from the following two main reasons:

(1) 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 having more expensive fee. 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.

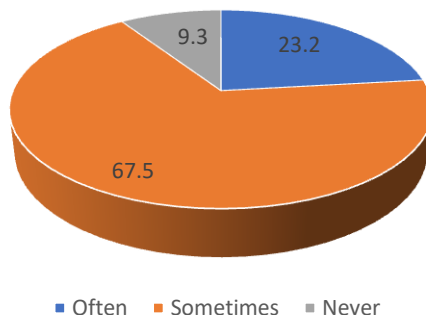
(2) Declining family labor force

This is also a factor that causes the family's economic decline. The reason is that parents of children with autism have to spend time taking care of and treating their children. When having to spend more time taking care of children, it is clear that the time to work to generate income will have to decrease. Therefore, the total income will be less, causing the family economy to decline. Thus, if child care is not effective, or services and child care models are not diversified, parents of children with autism will lose part of the family's productive force, and also 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 child care or are not confident about their knowledge and understanding about autism. Through research and through synthesizing opinions from case studies of Parents of autistic children and deep interview from staff in facilities, it can be seen that many cases do not know or are not confident about their knowledge of taking care of children with autism. Furthermore, even they want to have information and knowledge but 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 from friends and acquaintances, but each person has their own opinion". (In depth interview, Parent, Female, 36 years old).

**Chat 3: Lack of knowledge about caring for children with autism**

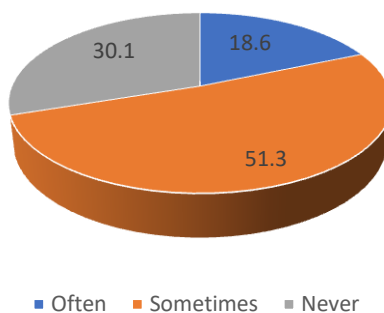


Parents who refer to documents from autistic child care facilities are also confused. The fact that there are many autistic child care facilities, especially in urban areas, but these facilities are developing in the direction of 100 flowers blooming, spontaneously and self-deploying care activities. 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 in 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 child care.

**- Conflict and discord in the family**

Although there are not often problems of conflict and discord in the family. However, the research results show that the percentage of families who sometimes encounter disagreements when having children with autism which also accounts for a proportion worthy of attention. In fact, through research and in-depth interviews, it can be seen that autism does not directly cause conflicts but indirectly creates these problems. Experts say that pressures from lack of knowledge in child care, economic decline or failure to meet expectations about children... make the family atmosphere always tense. 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. 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 on 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 doesn't work, so it becomes a big deal in the house. (In depth interview, Parent, Male, 42 years old).

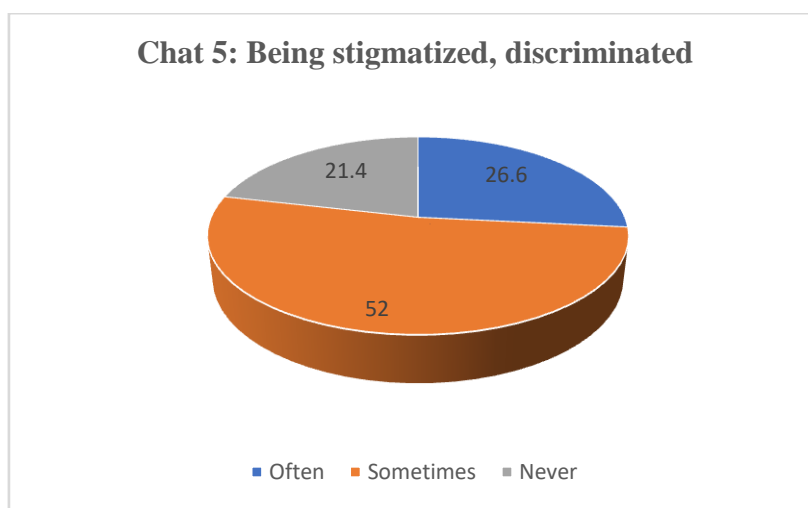
**Chat 4: Conflict and discord in the family**



If discord and conflicts in the family happen for a long time, it will be the main cause of domestic violence thus effecting negatively on the child's development and in this case, on caring for children with autism. Therefore, it is necessary to have serices 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 child care.

**- Being stigmatized, discriminated**

For issues of discrimination, nowadays, along with the promotion of communication, the stigma is also decreasing. Furthermore, since this research was conducted in urban areas so people's awareness of stigma issues is also better. However, this does not mean that there is no stigma for example parents normaly does not want their child to play with autism child. In reality, 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. 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. 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't do personal hygiene on their own.



It also has to acknowledge that there are cases where, children with autism also cause harm to other children or having abnormal behaviors thus affects to other children around them. It will partlylead to the stigma and discrimination attitude. Effective models show that, the education for autistic children are separated quite specifically. 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 exensive 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.

**4. Discussing on social work services to support families of children with autism**

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 (Nguyen Hai Huru, 2017). 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. 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. 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 in order 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 and the community 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. 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. 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.

- **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. 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. 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. 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. 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, 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, 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 with this service, it is not simply social work staff who only connect and send, but also accompany and support the subject in the whole process of using it. Use the service to ensure that in the end the problem is solved and their needs are best 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 best. 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. 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. 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.

## **5. Conclusion**

Children with autism are a vulnerable group, so they need the attention of the community and society. However, caregivers of children with autism such as parents and young family members 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 autistic children and their families

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