

Development of Rumah Inklusi support group for children with special needs

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ABSTRACT

Handling Children with Special Needs (CSN) requires special knowledge and expertise, so parents and schools with children/students with special needs sometimes experience difficulties in nurturing and implementing inclusive education. The Community Service Team from Universitas Sebelas Maret and the Yayasan Lembaga Pendidikan Al Firdaus developed the Rumah Inklusi and ARCHANA to provide CSNs and their families. This study examines the development of support groups for inclusive homes and the implementation of assisting parents with special needs through support groups. The approach used is Participatory Action Research (PAR), which assists parents with special needs at the Al Firdaus Inclusion School with psychologists, pedagogues, and sociologists. Data collection techniques were done through literature studies, Focus Group Discussions, observations, and documentation. The results of the research show that the PAR approach in this service is carried out in four stages: (1) Reflection to determine the problem; (2) Problem-solving design by designing activities for forming support groups and assisting parents with CSN; (3) Implementation through Focus Group Discussion presenting parents and experts in the field of inclusive education; and (4) Evaluation of the implementation of community service activities. Developing inclusion houses is still needed to reach families with special needs, and the benefits can be felt more broadly. This community service activity found the construction gap for children with special needs between schools and families with special needs, which impacts self-acceptance of children's conditions.

Keywords: *inclusive education; inclusion house; support group*

INTRODUCTION

Communities/ groups for parents with Children with Special Needs (CSN) are urgently needed as a place for parents to share information and experiences in raising and educating children and consulting with experts. Parents with special needs can participate in support groups to increase knowledge and other benefits. Research on the benefits of support groups has been carried out based on variations in the type of CSN, Down syndrome, cerebral palsy, autism spectrum disorder (ASD), and attention deficit hyperactivity disorder (ADHD) (Hapsari & Maulana, 2011; Satiningsih, 2013; Wahab & Md. Monoto, 2018; Sharma et al., 2022). Handling children with special needs requires special knowledge and expertise. Children with special needs are cared for at home by their parents or family; while studying at school, they receive education from the teacher. Parents and teachers who handle CSN have a burden that tends to be heavier when they must care for children who have different characteristics from other normal children. Much research has been carried out on the burden on families with CSN, and even several studies have shown a positive relationship between parents with CSN and psychopathological symptoms, including depression (Yusri & Fithria, 2016; Rasyid et al., 2019; Eky Vikawati et al., 2019).

Children with special needs have different developmental learning barriers and learning needs. The learning barriers experienced by every child are caused by three things, namely: (1) environmental factors; (2) factors within the child himself; and (3) a combination of environmental factors and factors within the child (Sukadari, 2020). CSN depends on their parents at home and teachers at school who care for them. Being a caregiver for children with special needs is challenging because they have duties and responsibilities that can become an excessive burden. This overload can potentially cause many emotional problems and affect caregivers' psychological well-being (Anggraini et al., 2022). The caregiver's poor emotional and mental condition can affect the service and care provided to CSN. Children with special needs need someone who helps them to meet all their daily needs (Yusri & Fithria, 2016). Therefore, CSN requires special assistance and education from parents and schoolteachers.

The Republic of Indonesia Law No. 20 of 2003 concerning the national education system provides another color in providing education for children with special needs. Education for students who have a level of difficulty in participating in the learning process due to physical, emotional, mental, or social disorders and have potential intelligence and special talents (Law (UU) Number 20 of 2003 Concerning the National Education System, 2003). One of the ways of education for children with special needs is inclusive education. Inclusive education educates CSN and other (normal) children to optimize their potential. In society, there are normal children and children with special needs who cannot be separated from the community where these children live (Yuliasuti, 2019). Schools implementing inclusive education have Special Advisors (SST) to assist students with special needs during learning activities. One of the inclusive schools in Surakarta City is the Al-Firdaus Inclusion School, with education levels at the Al-Firdaus Inclusion School including preschool (TPP), Elementary School (SD), and Middle School (SM). The management of the Al-Firdaus Inclusive School under the auspices of the Al Firdaus Educational Institution Foundation (YLPAF) has an International Baccalaureate (IB) qualification and is the first in Central Java.

The diversity of children with special needs sometimes makes it difficult for parents and teachers at inclusive schools. Satiningsih (2012) explains that parents with CSN often feel alone, have no friends to share, are frustrated, and blame themselves for having CSN or because of their limited knowledge and skills in caring for CSN. The results of Yusri & Fithria's research (2016) show that families with children with special needs at SDLB Labui Banda Aceh experience a caregiver burden in the heavy burden category, 59.1%. The caregiver burden referred to in this study is the excessive burden experienced by caregivers/families with special needs where they must care for, work, and perform other tasks.

CSN also requires assistance from a Special Supervising Teacher (SST) when studying at school. Al Firdaus Inclusion School still has a limited number of special supervising teachers accompanying CSNs. Data on the number of CSN and SST at the Al Firdaus Inclusion School shows an imbalance where 107 CSN spread across Kindergarten, Elementary School, and Senior High School are accompanied by 69 SST

(Kartono, Mundayat, et al., 2022). Assistance to CSN at school ideally, 1 SST accompanies every 1 CSN because each type of CSN requires different handling. Comparative data between CSN and SST at the Al Firdaus Inclusion School shows that 1 SST assists more than 1 CSN where these conditions are not optimal for CSN assistance. SST also finds it difficult if there are students or even parents with special needs who do not accept that their children need assistance from SST. In addition, SST and schoolteachers also sometimes get stories from CSN parents about their difficulties in raising their children.

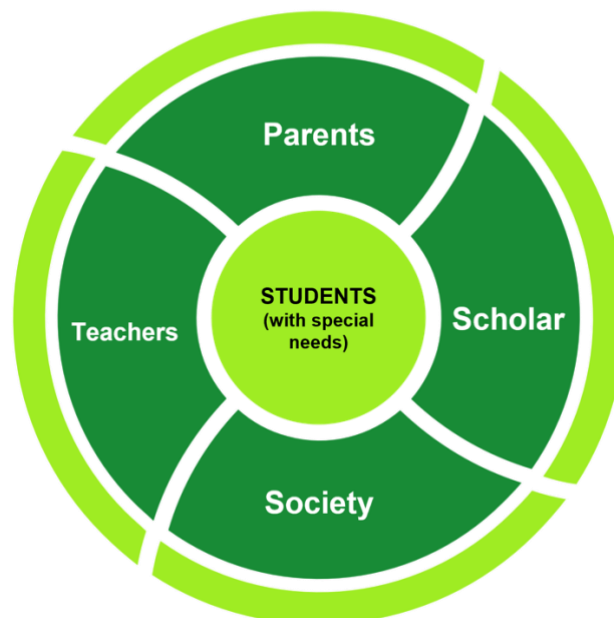
The limitations of CSN can affect the development process in society. As part of a group with social welfare problems, CSNs need to receive more attention regarding fulfilling their rights and needs in carrying out their social functions (Pairan & Abdullah, 2021). Even though parents with special needs have fulfilled their basic needs at home and teachers and inclusive schools provide education, children with special needs also need social activities with others in their social environment. An environment that supports children with special needs is also needed so that the rights and obligations, as well as the needs of CSN, can be met and provide support for their families. Support that the social environment can provide for CSN families includes sharing stories, information and participating in other social activities so that CSN families do not feel isolated.

Based on the problem description, community service activities are designed to overcome various problems CSNs, parents, and inclusive schools face. The Community Service Team from Universitas Sebelas Maret and partners from the Yayasan Lembaga Pendidikan Al Firdaus (YLPAF) and ARCHANA developed the Rumah Inklusi to support SST and assist with CSNs and their families. The inclusive home concept was developed by establishing the Child Learning Assistance Mother Forum as a means for consultation and information sharing between parents and CSNs, along with teachers in inclusive schools and experts in the social and educational fields (Kartono, Akbar, et al., 2022). Furthermore, establishing an inclusion house in 2022 located at the ARCHANA Office and collaborating with YLPAF as a community service activity partner has carried out caregiver training for CSN learning assistance (Kartono, Mundayat, et al., 2022). Inclusion as the

development of an inclusive society has a role in training caregivers, connecting caregivers with service units in need, approaching parents for assistance, and collecting data on crew members in Surakarta City. The Inclusive House approach to developing an inclusive society is presented in Figure 1.

Figure 1.

The Inclusive House Approach in the Development of an Inclusive Society (Kartono, Mundayat, et al., 2022)



Rumah Inklusi is determined to continue developing various programs that can support the creation of an inclusive society where everyone can support CSNs and their families. One of the inclusive society programs is establishing a support group for parents with special needs, which will be studied in this study. This study examines the community service activities carried out by the Universitas Sebelas Maret Service Team through the development of an inclusive housing support group and the implementation of assistance for families with special needs through support groups. Researchers have the view that community service activities are a form of community empowerment where the Community Service Team as the executor of the activity, collaborates with partners who play a crucial role in it, has relevant

information about the social system (community) being studied, participates in the design and implementation of action plans based on research results. Therefore, the Participatory Action Research (PAR) approach was applied in this study to answer the following research questions: (1) How is the development of support groups formed by inclusion houses? (2) How is the implementation of support group activities in assisting CSNs and their families? This study involved psychologists from ARCHANA, Sociologists from Universitas Sebelas Maret, families with special needs, and pedagogues from the Al Firdaus Inclusion School.

METHODS

This study uses a Participatory Action Research (PAR) approach. PAR focuses on enabling action/action and, in this study, is oriented towards empowering the community of parents with CSN. Action is achieved through a reflective cycle, in which the researchers collect and analyse data, then determines what actions to follow (Baum et al., 2006). Empowerment in the PAR approach is carried out in four stages: (1) Reflection, (2) Design, (3) Implementation, and (4) Evaluation.

The first stage in the PAR approach is the reflection which is carried out by exploring problems at the Al Firdaus Inclusive School through Focus Group Discussion (FGD) involving psychologists from ARCHANA, sociologists from Universitas Sebelas Maret, schoolteachers, and administrators of the Al Firdaus Educational Institution Foundation. The design for the development of the inclusive house was designed by the Community Service Team from Universitas Sebelas Maret together with the Al Firdaus Educational Institution Foundation and ARCHANA. The design plan for action in empowering this community is developing a support group to assist parents with CSN.

The third stage that was carried out was the implementation of empowerment from the design that had been designed by forming a support group for parents with special needs. Support groups are formed through FGDs, and assistance is carried out to parents with special needs. The final stage of this research is an evaluation where the researcher elaborates on empowering the CSN parent support group.

The evaluation phase is carried out to respond to the implementation that has been carried out by considering the shortcomings, strengths, weaknesses, and

strengths of the empowerment actions that have been carried out. Data collection was carried out to implement the four stages of the PAR using several data collection techniques, including literature studies, Focus Group Discussions, observation, and documentation. The informants in this study were two parents with special needs who attended the Al Firdaus Inclusion School, teachers and administrators of the Yayasan Lembaga Pendidikan Al Firdaus, psychologists from the Psychology Bureau of ARCHANA, and sociologists at Universitas Sebelas Maret.

RESULTS AND DISCUSSION

The development of the Rumah Inklusi Support Group begins with reflection. The purpose of the reflection activity is to assist the partners involved in formulating issues, ideas, views, and assumptions more clearly. The Universitas Sebelas Maret Service Team is a facilitator connecting partners with the Al Firdaus Educational Institution Foundation, which manages inclusive schools with experts consisting of ARCHANA psychologists and Universitas Sebelas Maret sociologists. Reflections were held through Focus Group Discussions with the result that a support group for parents with special needs in the Al Firdaus Inclusion School was urgently needed to overcome several problems, namely the lack of parental knowledge in dealing with special needs children and parents' acceptance of the condition of children with special needs.

The following service activity is to design a community empowerment program. The community referred to in this service is a support group for parents with special needs involving experts in inclusive education. Before implementing the program, the service team always makes preparations to equalize perceptions and share roles with the partners and experts needed. The experts presented are adjusted to the results of the assessment of CSN and parents of CSN. In the preparatory stage, the activities designed include two agendas at once, namely the formation of a support group and the main activity in the form of assisting parents with CSN by professionals. YLPAF service partners to present assessment data for CSN and CSN parents as candidates submitted as clients. The service team and partners decided on two names of crew members as clients. Once agreed, the service team and partners invited two parents of CSN to attend the program. The experts involved were clinical

sociologists, clinical psychologists, and pedagogues. The concept used in this program is FGD (Focus Group Discussion). Forming a support group for parents with special needs is one of the programs developed in the Rumah Inklusi to create an inclusive society.

The community empowerment program is implemented by forming a community/ group, which will become a forum for parents with special needs to gain knowledge, consult with experts, and share stories. A support group for parents with special needs was formed on June 15, 2023, through a Focus Group Discussion at the Al Firdaus Inclusion School. As many as two people with CSN's parents were present according to a pre-designed design where 2 CSN clients had been determined who would receive expert assistance. The activity continued with assistance to CSN parents which was carried out in two sessions by presenting CSN parents in different sessions. The implementation of assisting parents with CSN is an act of empowerment program that the Universitas Sebelas Maret Service Team has designed to solve problems studied in the reflection stage.

In the first session, the clients presented were young mothers with no parenting experience. The CSN's mother explains the child's condition with emotional disorders. Even though they are classified as a mild category of CSN, the problems CSN parents face must be solved by experts. Ibu CSN also mentioned conditions where her husband worked out of town. When CSN's father comes home from work, he gives gifts without communicating with his mother. This condition is exacerbated when the child meets his father; any request is always complied with. The impact is that this CSN child is closer to his father because he feels that he is someone who obeys his wishes. When the CSN father worked out of town, the mother found it difficult to educate her children because she often rebelled and ignored advice. This inequality occurs because husbands do not involve their wives in giving gifts to children. So that the child's thinking construction only feels the father's role is essential in his life. Experts suggest that any parenting policy should involve both parents. This is an attempt to deconstruct the thoughts of CSNs that both parents must be valued and respected.

The second session is for parents with special needs with a mild category, namely behavioural and emotional disorders. According to the results of the CSN assessment, they have a manipulative attitude and like to beat their friends. Their parents do not raise CSN but live with their grandparents. The problems faced stem from quite heavy family problems. This problem has made CSN's parents unable to accept the condition and whereabouts of their children. In other situations, children often get the emotional outlet of parents with special needs. For foster parents with special needs, grandparents tend to educate too rigidly, causing psychological pressure on children with special needs. Foster parents often give punishment to CSNs if they make mistakes. The advice given by experts is to improve communication patterns and the concept of family parenting. The attitude of parents and foster parents must be educative because children have the nature of imitation to imitate the attitude of their parents.

The final stage of community service is evaluation. The implementation of the empowerment program is by the designs prepared by the Universitas Sebelas Maret Service Team with YLPAF and ARCHANA partners. Solutions to the problems faced by parents with special needs at the Al Firdaus Inclusive School have been obtained with the help of experts. Parents must build better communication between fathers and mothers and apply appropriate parenting styles to their children. All partners have participated according to their respective expertise and roles so that parents can benefit from the support group that has been formed. It is hoped that the development of inclusive homes through the formation of support groups can reach and involve more parents with special needs so that the wider community can feel the role and benefits of inclusive homes.

The main benefit of the support group felt by parents with CSN is gaining knowledge about handling CSN from experts who can help solve their problems and difficulties. Many emotions run through the minds and hearts of CSN parents, but the awareness that they are not alone is critical. Even though not all parents with special needs experience the same things as one another, at least their experiences are similar. According to Satiningsih (2012), actions that parents with special needs can take include: (1) seeking help from other parents with special needs, (2) talking to relatives,

family, and other trusted people, (3) relying on positive sources of life, (4) grabbing one day at a time / do not be upset about what will happen in the future, (5) learn terminology, (6) seek information, and (7) do not feel intimidated. In addition to these actions, parents with special needs can also seek self-development programs such as support groups. The mother of the first client who attended the CSN parent assistance session admitted that she gained additional knowledge about parenting for her child and ways of handling it that was appropriate for the type of child with special needs in the mild category.

During the implementation of the service, researchers found that there was a gap in the construction of CSN between parents and schools. One of the causes of the problems faced by the partners of the Al Firdaus Educational Institution Foundation is the difference in understanding of children with special needs. Al Firdaus Inclusion School has conducted an assessment test on students so that they can detect whether the student is CSN or a regular child. The assessment test results determine which students need special assistance from a special supervising teacher (SST), such as the second client whose test results have emotional disturbances. Hence, an SST accompanies them during the learning process. However, the SST assistance received a rejection from the second client's family because they considered that the child was classified as a regular student and had no indication of being with special needs. This problem sparked tension between the CSN family and the school. Hence, the Service Team acted as a mediator and facilitated meetings for the two parties to collaborate in finding the best solution.

Rejection from the family regarding the assessment test results and the fact that their grandchildren are classified as CSN and require special treatment often occurs. Being in a family with children with special needs is not easy, especially for parents. Not all parents who have children with special needs can immediately accept their child's condition as soon as they are born (Sujani & Putro, 2022). If rejection continues to occur, it can affect the development of CSN. Wahab & Md. Monoto (2018) explain that the impact on a family can vary, changing the dynamics and harmony of the family. Most parents feel inadequate with the information provided regarding the results of assessment tests by health service providers and schools. Parent support

groups are essential in supporting and providing information and resources to other parents of children with special needs. The mentoring sessions carried out in this service are expected to increase the acceptance of parents and families with special needs for children's conditions. Self-acceptance of parents with children with special needs means parents who can accept themselves and admit their limitations that do have children with special needs without feeling ashamed or blaming themselves (Hapsari & Maulana, 2011).

CONCLUSIONS

The development of inclusive homes through a support group for parents with special needs has been carried out by the Universitas Sebelas Maret Service Team in collaboration with the Al Firdaus Educational Institution Foundation and ARCHANA. The implementation of community service has implemented four stages of the participatory action research approach, including (1) Reflection to determine the problem to find a solution for; (2) Problem-solving design by designing activities for forming support groups and assisting parents with CSN; (3) Implementation through Focus Group Discussion presenting parents with special needs and experts in the field of inclusive education; and (4) Evaluation of the implementation of service activities where parents with special needs have felt the benefits of support groups, but the development of inclusive houses is still needed to reach families with special needs more broadly. This community service activity found the construction gap for children with special needs between schools and families with special needs, which impacts self-acceptance of children's conditions. Assistance to CSN families through support groups is expected to help self-acceptance to CSN families.

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