

Parent Education as Effort to Improve Sleep Quality Handling in ASD Children at Sekolah Luar Biasa Cimahi City

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ABSTRACT

Autism Spectrum Disorder (ASD) is a condition that affects the development of a child's brain, leading to issues in verbal and nonverbal communication. Children with ASD often exhibit distinctive symptoms related to sleep problems. The cause of these sleep issues in children with ASD is linked to differences in the heritability of melatonin biosynthesis, which is lower compared to serotonin, with a prevalence rate of about 50-80%. The impact of sleep problems in children includes cognitive and behavioral disorders such as increased activity, inability to control emotions, learning difficulties, aggression, and more. These conditions pose challenges for parents and teachers at school, necessitating educational activities for both parents and teachers to improve sleep quality management in children with ASD. This activity aims to provide parents with understanding and insight into identifying sleep problems and efforts to enhance the quality of sleep in children with ASD. The method employed involves educational activities in the form of lectures and discussions with parents of students with ASD at special schools in the Cimahi City area. This activity uses an analytical observational method with a cross-sectional study approach. The results show that parents from 5 SLBs participated in the education, with N=126 parents attending. Among them, 52 children with ASD were identified, and 36 of these 52 children had sleep problems. Most parents practiced sleep hygiene, and a few used pharmacological methods to improve sleep quality.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a set of neurobiological developmental problems in which children experience issues in communicating (verbal and non-verbal), interacting socially, repetitive behaviors, and limited interests and activities (Hodges et al., 2020; Lubetsky et al., 2011; Volkmar et al., 2014). Sleep problems often occur in children with ASD compared to children with other disabilities. It found about 50-80% of sleep problems that occurred in ASD children compared to 9-50% in normal children with striking development (Reynolds & Malow, 2011). Children with ASD exhibit characteristic sleep issues due to differences in the heritability of melatonin biosynthesis at lower levels than serotonin. Melatonin and serotonin play roles in circadian rhythm regulation, and disruptions in clock genes can result in circadian rhythm disorders. Several neurotransmitters, including GABA, serotonin, and melatonin, contribute to sleep disturbances. Sleep pattern problems in children with ASD disrupt sleep quality, leading to cognitive and behavioral issues such as hyperactivity, emotional regulation difficulties, reduced concentration, learning challenges, and aggression. These issues pose challenges for parents and teachers. Parents may also experience sleep disturbances as they must take turns caring for their child throughout the night. Consequently, children's learning activities at school may suffer, compounded by schools' limited collaboration with therapists and psychologists. Therefore, screening and addressing sleep quality issues in children with ASD in special schools in Cimahi City is necessary.

The main goal of this community service activity is to provide parents with understanding and awareness to identify sleep issues in their children and to recognize efforts to improve sleep quality, such as sleep hygiene and pharmacology. This activity also aims to inform parents about ways to enhance their child's sleep quality and introduce them to holistic, non-pharmacological complementary therapies that involve bio-psycho-socio-cultural aspects. This way, parents are expected to more actively support their child's sleep development with broader knowledge and a comprehensive approach. The benefits of this community service are twofold. For parents, it is expected to improve their ability to identify potential issues in their children and encourage efforts to enhance sleep quality management through pharmacological and non-pharmacological means. For institutions, the report on this community service is anticipated to serve as a valuable reference in developing insights and experiences, particularly in the field of nursing science, especially in pediatric nursing. Thus, the benefits of this activity are felt by parents and contribute positively to the development of nursing science at the institutional level.

According to the British Columbia Ministry of Children and Family Development (2017) and the National Institute of Mental Health (2019), autism's main characteristics include diminished social interaction, such as inappropriate eye contact, absence of broad smiles or warm expressions by six months or later, lack of sharing interest or enjoyment, and poor response to one's name. Other features involve communication disorders, including the inability to share sounds, smiles, or facial expressions by nine months, lack of showing body movements such as pointing, reaching, or waving by 12 months, poor coordination of non-verbal communication, and failure to babble by 12 months with unusual intonation. Additionally, autism is marked by repetitive behaviors and restricted interests, such as repetitive movements with objects and body movements or postures involving arms, hands, or fingers.

Sleep disorders in ASD manifest as symptoms like insomnia, characterized by difficulty initiating or maintaining sleep, prolonged sleep latency, bedtime resistance, reduced sleep efficiency, decreased sleep duration and continuity, and increased awakenings. Other symptoms include sleep-related breathing disorders like Obstructive Sleep Apnea (OSA), which can affect daytime behavior and may be corrected by adenotonsillectomy. Parasomnias, including REM sleep behavior disorders, indicating lower REM sleep percentages in children with ASD, are also common. Sleep-related movement disorders such as restless legs syndrome, periodic limb movement disorder, and periodic limb movement disturbances can also occur in children with ASD. Understanding these aspects is crucial for more effective sleep management in

individuals with ASD, involving approaches such as maintaining good sleep hygiene, regular routines, and considering potential pharmacological or non-pharmacological interventions as needed.

Children with ASD often have comorbid psychiatric diagnoses related to sleep issues such as anxiety, depression, and ADHD, where these disorders can disrupt self-soothing learning from an early age. (Lubetsky, et al, 2013). Clinically medical children with ASD are at increased risk of having seizures, and seizures at night can interfere with sleep and changes in sleep patterns in children with ASD. (Richdale, A. L. & Schreck, 2019). Problems in children with ASD are often accompanied by other medical and behavioral disorders, namely intellectual disability (45-60%), convulsions (11-39%), Indigestion in eating habits and food selection, food sensitivity, allergies, as well as constipation or diarrhea are most commonly encountered (50%). In the age range of 4-18 years, 50% (n = 1307) of children reported gastrointestinal disease (GID); these complaints caused sleep problems on a severe moderate/severe scale of 60.9%. (Johansson, et al, 2018). The results of specific studies in ADHD children conveyed that the ratio of sleep disorders tends to be relatively higher in ADHD children aged 3-14 years. Most problem characteristics are that children have trouble starting and maintaining sleep, and children with poor sleep hygiene have much more severe sleep disturbances(Permatawati et al., 2018).

Sleep problems in children with ASD are generally caused by various factors such as the child's temperament and development, parenting style, interaction between the child and parents, and environmental factors. One problem that can occur is parasomnia, which is unwanted episodic behavior during sleep. An example is nightmares, which occur during the Rapid Eye Movement (REM) sleep phase, usually in the morning, and are most commonly experienced by children of primary school age. However, they also occur in 1.9-3.9% of preschool-aged children. Treatment includes avoiding scary television shows, games, books, or movies that can affect dreams, providing comfort, and, most importantly, maintaining good sleep hygiene with a routine and getting enough sleep. (Bathory, E., & Tomopoulos, 2017).

Children with ASD in Cimahi City, especially in the age group of 6-12 years, show a high prevalence of sleep problems. The study, using the Children's Sleep Habits Questionnaire (CSHQ), revealed that the majority of ASD children in that age range experienced severe sleep disturbances. Although this study provides significant analysis, some limitations need to be considered. The small sample size and focus on one developmental stage, 6-12 years of age, limited the study's ability to generalize the findings to other age groups. Therefore, the researchers recommend the following steps, including expanding the study sample to include ASD groups from preschool to adolescence and reconsidering appropriate treatment planning to address sleep disorders in ASD children (Kulsum & Oktavia, 2022).

METHOD

This community service method is used to conduct educational activities through lectures and discussions with parents of students with ASD children in the SLB Cimahi City area. This activity uses observational analytical methods with a cross-sectional study design approach. This educational activity aims to provide parents with understanding and insight into identifying sleep problems that occur in ASD children and exploring or identifying strategies or efforts to improve children's sleep quality. The setting of the activity situation is depicted in Figure 1.

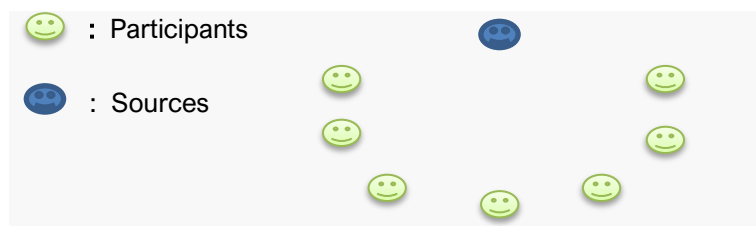


FIGURE 1. Setting the activity situation

This activity planning uses a flow following the "The stages of Community service activities" from the research (Mamuroh & Nurhakim, 2022) as below on describe Figure 2.

Planning Stage

Preparation for this community service activity was carried out in December 2022 and January 2023. The activities took place at five special schools on December 2022 are; Sekolah Luar Biasa-BC Tut Wuri Handayani, Aras, Nurani, and on January 2023 are Sekolah Luar Biasa Hasrat Mulia, Kasih Ibu. The preparation steps included communicating with team members to identify parents' understanding and insights regarding the issues their children face and finding ways to improve the children's sleep quality, which was the focus of the education; conducting literature reviews and group discussions on children's sleep quality and strategies to address it. Tasks were distributed among the team, including providing media for lectures, preparing materials, and compiling a list of participants. Preparation also involved arranging projectors, projector screens, laptops, sound systems, chairs/carpets, power point presentations, assigning an operator, and selecting the special schools that the team would visit. The stages of community service activities (Mamuroh & Nurhakim, 2022) include several stages that are carefully described in the flow stages of Figure 3.

Implementation Stage

The implementation of this community service activity involves a continuous educational approach through webinars, with the following steps:

- We are identifying the presence of parents based on particular schools, identifying the educational background of parents, identifying the age groups of children, identifying children with sleep problems based on gender, identifying ASD children with and without sleep problems, and identifying efforts using pharmacological/non-pharmacological (sleep hygiene) methods.
- We are conducting practice presentations of the material to address potential technical and non-technical issues during implementation.
- Education was conducted in December 2022 and January 2023, beginning with attendance registration. Following the opening ceremony, participants' perceptions were evaluated, followed by the presentation of material and a question-and-answer session lasting 1 hour.
- To identify the changing knowledge of participants about sleep quality and security strategies to improve the quality of sleep
- A question-answer and discussion session with parents was conducted

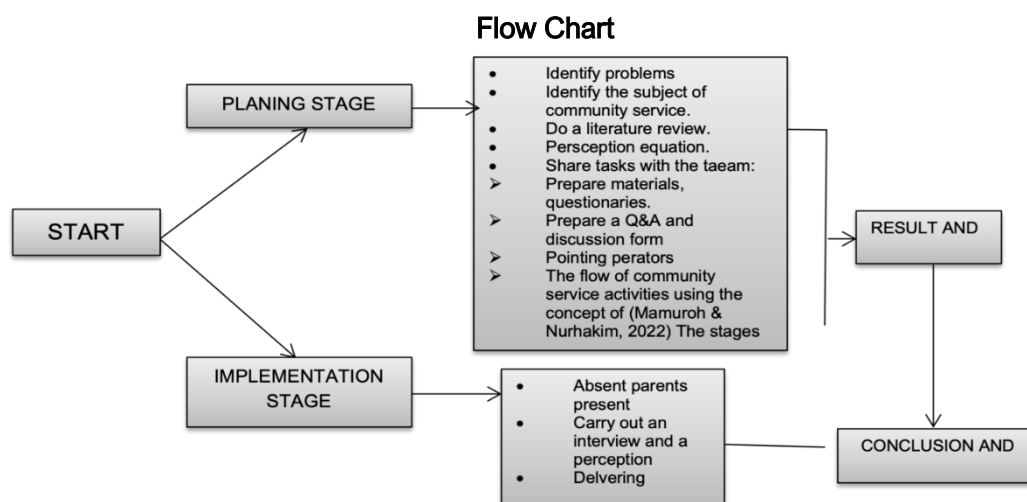


FIGURE 3. The stages of Community service activities (Mamuroh & Nurhakim, 2022)

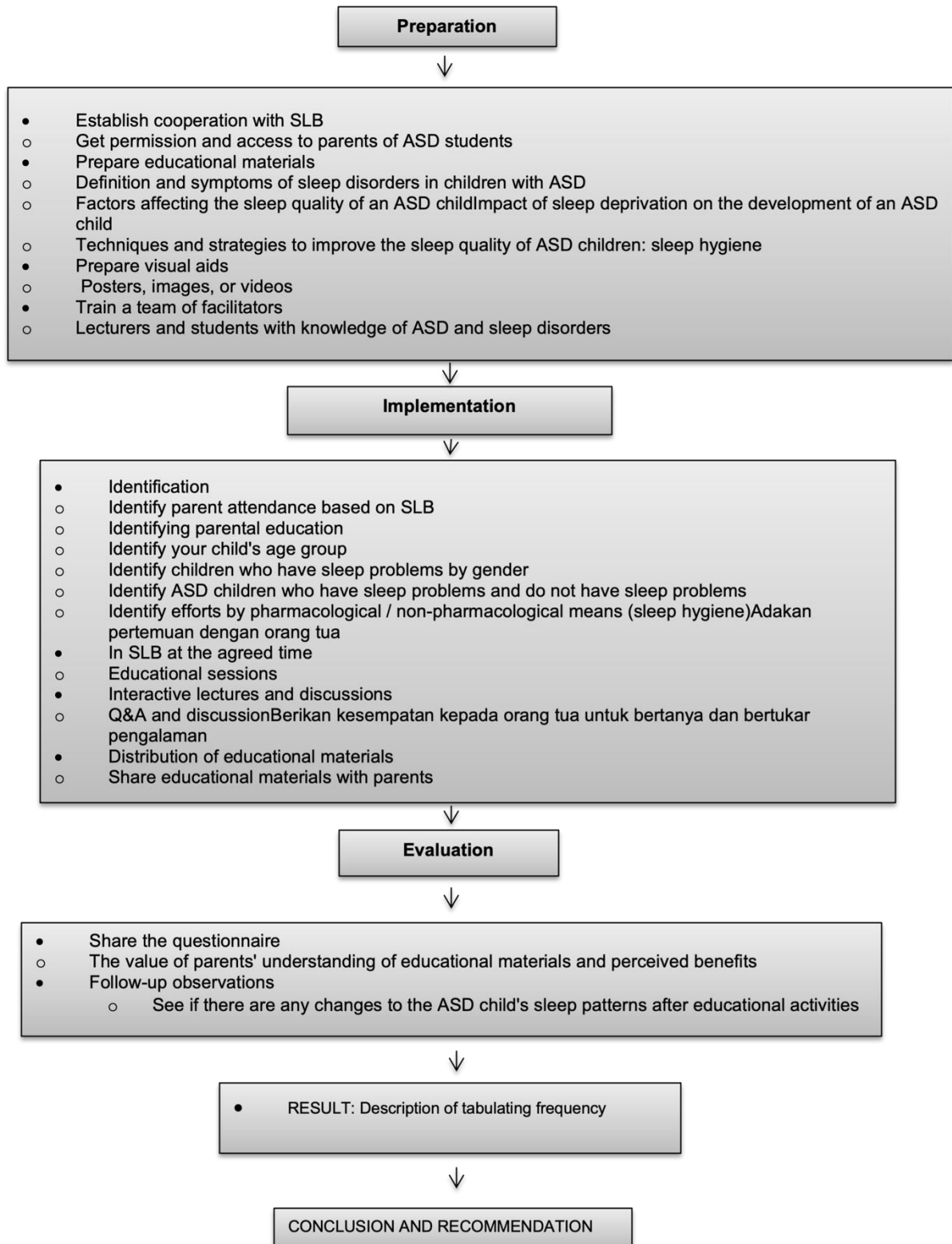


FIGURE 2. Community Service Methods

RESULT

Community service activities in the form of socialization to deal with sleep pattern problems in ASD children in Cimahi City have been carried out in December 2022 and January 2023. The activity was attended by 126 parents of students from Sekolah Luar Biasa in Cimahi City with a total attendance percentage of 90% and 14 absent participants, or if the rate was 10%.

TABLE 1. Distribution of attendance of parents based on SEKOLAH LUAR BIASA

Special School	Amount	Percentage
SLB Tut Wuri Handayani	31 orang	22.15%
SLB Aras	22 orang	15.86%
SLB Nurani	24 orang	17.15%
SLB Hasrat Mulia 1 dan 2	27 orang	19.58%
SLB Kasih Ibu	22 orang	15.29%
Total	126	100%

Based on Table 1, the number of attendance at the socialization of parents of students from Tut Wuri Handayani SLB was 22.15%, Aras SLB was 15.86%, Conscience SLB was 17.15%, Hasrat Mulia 1 and 2 SLB was 19.58%, and Mother's Love SLB was 15.29%. So, the final percentage of all parents' attendance is 90%. This indicates that parents are enthusiastic about the socialization of sleep patterns in children with ASD.

TABLE 2. Distribution of child age groups

Age Group	Amount	Percentage
School Age (6-12 years old)	83	65.87
Adolescent (13-18 years old)	43	34.13
Total	126	100

Based on table 2. The number of attendance based on school age groups and adolescents is, school age is 65.87% and adolescents are 34.13%. So it can be concluded that most parents of their children are in the school-age group (6-12 years).

TABLE 3. Distribution of Parents' Education Level

Parents' Education Level	Amount	Percentage
Primary school	11 people	8.73%
Junior high school	25 people	19.84%
High school	77 people	61.11%
College	13 people	10.31%
Total	126	100%

Based on Table 3, the attendance of parents according to their educational level is as follows: elementary school at 8.73%, middle school at 19.84%, high school at 61.11%, and college at 10.31%. Thus, it can be concluded that most parents attending the socialization sessions have a high school education. This

indicates that the parents of the students can understand the material presented by the facilitators well. The parents are also active during discussions, as evidenced by the three questions asked at each socialization session in each particular education school.

Based on the identification of parents' statements, it was found that there are 52 children with ASD. An estimated percentage of children with ASD experiencing sleep pattern problems is over 70%, according to parents' descriptions. The sleep issues these children face include frequent awakenings (staying up late), waking up during the night, irregular sleep patterns (sleeping very late at night or waking up very early), short sleep durations (less than 5 hours per day), unusual movements during sleep (talking or moving), restlessness, anxiety, nightmares, fussiness, or engaging in other activities at night (watching TV or playing with gadgets).

TABLE 4. Estimation of the distribution of children with sleep problems by sex

Age Group	Amount	Sleep problems	No sleep problems
		Amount (%)	Amount (%)
Laki-laki	36	70	30
Perempuan	16	30	70
Total	52	100	100

Based on table 4. It is estimated that of children who experience sleep pattern problems based on gender, 70% are experienced by boys and 30% by girls. So, it can be concluded that many boys experience issues with their sleep patterns.

TABLE 5. Group of ASD children who have sleep problems and do not have problems

Age Group	Amount	Amount %
Sleep problems	36	70
No sleep problems	16	30
Total	52	100

Based on Table 5, the group of children with ASD who have sleep problems and those who do not have sleep problems, the results show that there are 52 children with ASD. Among them, 36 children have sleep problems, and 16 children do not have sleep problems. Some parents reported using pharmacological interventions to help their children avoid sleep problems with various medications, although the specific types of medication were not mentioned. A few medicines were used, while most relied more on different sleep habits. For example, they would turn off the lights, engage in physical touch, or clean up before bedtime. After pre-education, the results showed that, on average, participants had a good basic understanding of the topics discussed. This was evidenced by an average score of 70. Following the education session, a post-education evaluation was conducted to assess the impact of the education. The post-education results indicated a significant increase in participants' knowledge, demonstrated by an average score of 85. Compared to the pre-education average score of 70, this represents a 15% increase. This improvement indicates that the education program positively impacted the participants.

DISCUSSION

Children with ASD in Cimahi City, particularly those in the 6-12 age group, exhibit a high prevalence of sleep problems. This study, utilizing the Children's Sleep Habits Questionnaire (CSHQ), revealed that the majority of children with ASD in this age range experience severe sleep disturbances. Although this study provides significant analysis, several limitations must be considered. The small sample size and the focus

on a single developmental stage, specifically ages 6-12, limit the ability of the study to generalize its findings to other age groups. (Kulsum & Oktavia, 2022).

The distribution of children with Autism Spectrum Disorder (ASD) who have and do not have sleep problems was analyzed. Out of a total of 52 ASD children studied, 36 children (70%) experienced sleep problems, while 16 children (30%) did not. This data shows that the majority of ASD children face sleep difficulties, with only a small portion not experiencing such issues. The distribution of children with sleep problems varies by gender. Of the 52 children studied, 36 were boys and 16 were girls. In the boys' group, 70% (about 25 children) had sleep problems, while 30% (about 11) did not.

Conversely, in the girls' group, only 30% (about five children) had sleep problems, while 70% (about 11 children) did not. Thus, it can be concluded that sleep problems are more common among boys than girls. This discussion may require further in-depth research. The positive and negative effects of using pharmacology to address sleep problems in children can vary depending on the type of medication used and the individual's health condition. The positive effects include, firstly, improved sleep. The use of certain medications, such as benzodiazepines or non-benzodiazepine hypnotics, can help increase the duration and quality of sleep in children with sleep disorders. Secondly, cognitive function improvement. Sleep enhancement induced by certain medications can improve cognitive function and behavior in children with sleep disorders. The adverse effects that may arise include side effects. The use of certain medications to address sleep problems in children can cause side effects such as excessive drowsiness, cognitive impairment, or behavioral disturbances. (Owens, 2009) The long-term use of hypnotic drugs can lead to dependence and tolerance, which, in turn, can worsen sleep problems after the medication is discontinued (Kuhn, Bruce, 2011). It is important to note that the use of pharmacology to address sleep problems in children should be considered carefully and only under the supervision of a doctor experienced in pediatric medicine. Behavioral therapy and lifestyle changes are often safer and more effective approaches to managing sleep disorders in children, while a small fraction of parents use medications. Most parents, however, rely on various sleep habits, such as turning off the lights, engaging in physical touch, or cleaning up before bedtime.

The activities were successfully carried out smoothly and following the planned methods. All necessary steps were meticulously followed, ensuring that the goals of the activities were achieved efficiently and effectively. By adhering to the established procedures, the team successfully overcame any challenges during the implementation, ensuring that all aspects of the activities were well managed. The successful execution of these activities reflects all parties' commitment and hard work and underscores the importance of thorough planning and organized execution in achieving desired outcomes.

CONCLUSIONS AND RECOMMENDATIONS

Based on the community service activities that have been carried out, it can be concluded that the parents of the students were enthusiastic about participating in the socialization, as evidenced by the attendance of nearly all parents. The material presented by the instructor was well understood by the parents, who were able to identify sleep problems in their children and determine appropriate methods to improve their children's sleep quality. This was demonstrated through the active question-and-answer discussions between the parents and the instructor, with an average post-education score of over 85. Additionally, the community service activities revealed that ASD children experiencing sleep disturbances were predominantly school-aged boys.

As we plan to future for the socialization efforts, it is recommended that this activity be continued with more in-depth research. To identify symptoms of sleep problems in line with ASD, screening for both ASD and sleep issues is necessary as the next step after the socialization process to establish a diagnosis for

suspected ASD children. These socialization activities are hoped to be held regularly to expand parents' knowledge and understanding. In the future, the implementation of these activities is expected to be smoother and more effective, allowing for better management of children potentially experiencing ASD and providing maximum support to parents. The results of this educational program are anticipated to encourage positive behavioral changes in parents, enabling them to consistently apply sleep hygiene practices in their children's daily lives.

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APPENDIX



FIGURE 4. Activity Documentation