



Developing a Management Model of Early Education Services for Children With Autism

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Abstract

Early education services for children with autism are a place for early intervention for autistic children of pre-school age as a bridge to further education. Autism is a neurological development disorder under the age of 3 years with characteristics of communication and behavioral disorders. Pre-school age is a period of rapid brain development so early intervention or early education for children with autism is an attempt to reduce the manifestation of autism clinics. Development of early education service management for children with autism aims to intervene with autism from an early age in a comprehensive manner and in accordance with their growth and development. This study applies the Research and Development approach through four stages, namely (1) preliminary research, (2) model development, (3) validation, and (4) final model. Data were drawn using open and closed questionnaires and interviews in four early education service institutions for children with autism in Semarang. The data were processed using descriptive analysis, percentage, average, and qualitative analysis. The final model of early education service management for children with autism focuses on aspects of management which consist of (1) comprehensive planning based on the standard parameters by considering comorbidities and health status and (2) early education for children with autism carried out comprehensively and sustainably between teachers, parents, and medical personnel.

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INTRODUCTION

Autism is one of a group of disorders known as Autism Spectrum Disorder. Autism is a brain development disorder characterized by barriers in social interaction, communication, and limited as well as repetitive behavior in children under 3 years of age (APA, 2013). Autistic children rarely look at the faces of others, are less responsive to calls, and are not developing sign language like pointing when wanting something. Increasing parents' attention to children's development and the number of publications regarding autism is one of the causes of the increasing prevalence of autism from year to year. The prevalence of autism in America in 2014 was around 16.8 per 1000 children or 1 in every 59 children with autism; there is no difference in socio-economic status or race but the incidence of autism in boys is higher than that in girls, i.e. 4.5:1 (Balo, 2018). Meanwhile, there are no confirmed data about the prevalence of autism in Indonesia. Until now, the cause of autism is not known with certainty; whether the causes are genetic, environmental, or complications during labor (Johnson, 2007).

Autism is a neurological development disorder that cannot be cured and requires long-term management. Children with autism will continue to show symptoms of the disorder until adulthood, although the degree can be reduced. The main purpose of managing autism is to reduce the symptoms of spectrum disorders and improve the quality of life by fostering independence and alleviating family suffering (Meares, 2016). Management of children with autism includes (1) administration of drugs if the disorder is accompanied by other diseases such as epilepsy, depression, tantrums, sleep disorders, indigestion. This treatment aims to provide therapy with drugs so that children can receive early intervention well, not disturbed by the disease, and can improve their quality of life; (2) early intervention in autistic persons in the form of educational interventions to improve communication skills, socialize, fulfill daily living needs, play, improve academic performance, and reduce maladaptive behavior; (3) deliver children to attend further education such as inclusive schools or autistic schools (Matheus, 2017)

Education is defined as the development of the acquisition of skills and knowledge to help children improve self-reliance and personal responsibility that includes academic learning, socialization, adaptive skills, communication, behavioral improvement, and abilities in various fields (Meares, 2016). The principle of early education for children with autism is (1) as early and as soon as possible in getting early intervention; (2) initial intervention should be 25 hours per week for 12 months a year; (3) small classes with a ratio of 1:1 between teacher and student; (4) involvement of parents; (5) giving the opportunity to interact with peers through daily activities to spur the growth of new skills; (6) the use of an educational curriculum that promotes improvements in communication, socialization and cooperation, reciprocal interaction, the ability to adapt to its environment, training in independence and responsibility, and sharpening cognitive and academic skills; (7) Minimalization of maladaptive behavior (Dausal, 2017).

Early education services for children with autism consist of five points as follows. (1) Behavioral therapy programs such as Applied Behavior Analysis (ABA). The ABA method aims to reduce maladaptive behavior or maintain and enhance desired adaptive behavior by teaching new skills so that children can adjust their behavior to the environmental situation. TEACCH is a behavioral therapy method for children with autism by increasing adaptive behavior and reducing maladaptive behavior (Corsello, 2005). (2) Speech therapy is very important and must be done during the developmental period of speech because autistic children face shortcomings in communication. (3) Occupational therapy is needed to train autistic children to be able to care for themselves (dressing, eating, bathing) and mastering academic skills such as writing, cutting, drawing (Aziz, 2003; Hayati, 2003). (4) Sensory integration aims to overcome deficiencies in neurological processes and integration of sensory information so that children can interact with the environment (Setiyono, 2003). (5) Support is not only directed at children with autism but also to those of their families. Parents and siblings of autistic children suffer more stress and depression than families who have children who grow up normally.

Support to families by ensuring their emotional and physical health is a very important aspect of overall autistic management (Myers, 2007).

The research of a meta-analysis of early intervention in children with autism was carried out by Fernell (2008-2012). The study, which focused on early intervention and the subsequent impact on the prognosis, showed limited evidence that "early intervention" is an effective program in changing long-term outcomes for children with autism who can be diagnosed as early as possible. Kuhl (2013) examined the ability of autistic patients in language at the age of 2 years to be a predictor of cognitive abilities, language skills and addictive behavior in children aged four and six years. This finding can give an understanding that early identification and early intervention need to be done as early as possible. Under five years of age is a period of rapid brain development so that early intervention is believed to optimize brain plasticity, namely the brain's ability to make changes, interconnect nerve cells and adapt to stimulation or environment. Early intervention designed in accordance with children's development aims to improve the delay or developmental disorders that occur in the early stages of development. Early intervention will be good if it receives support from the family (Leblanc, 2012). Stahmer (2007) who examined the application of early intervention programs in children with autism, found problems in implementing early intervention programs in the community so that it needed training, improved early intervention systems that were being implemented, and monitoring the quality of programs in the field.

Based on the research mentioned above, it is necessary to evaluate the management of early education services for children with autism with the consideration that the initial education services for children with autism in Indonesia, known as the center of therapy for autism, do not have service guidelines. Autism therapy centers play an important role in early education services for children with autism; improved management of early education services for children with autism will improve outcomes better and children with autism are expected to be better prepared to continue their education.

RESEARCH METHODOLOGY

This research used a Research and Development (R & D) approach. The research was used to identify problems in the implementation of services for autistic early education, factors that influence them, and factors that hinder the implementation of early education services for children with autism while Development is intended to develop a model of early education service management for children with autism. The results of this study are a model of early education service management for children with autism. The research was carried out at the early education service institutions of autistic children in Semarang. The study sample was teachers, parents with autism in four early education service institutions in Semarang

This research was conducted in four stages, namely (1) preliminary research, (2) model development, (3) validation, and (4) finalization of the model. The preliminary research was carried out through literature review and field surveys using open and closed questionnaires aimed at leaders, teachers/therapists, and parents regarding the management of early education services for children with autism, which include (i) how leaders and therapists on early education services with persons autism conduct early detection, initial assessment, and planning therapy for children with autism, (ii) how to implement and evaluate early education services for children with autism, (iii) how the parents of autistic parents respond to early education for children with autism so that factual model data is obtained.

The development phase includes field needs analysis, collecting data about the management model needed. Indicators about early education services for children with autism obtained from literature studies are used to formulate a "needs assessment" instrument. The data above is used to design a management model for early education services for autistic institutions (hypothetical models). Furthermore, the hypothetical model was validated through the Focus Group Discussion forum by autistic management experts (agency leaders, doctors, and therapists), psychologists, and education management experts. By using a semi-open and semi-closed structured questionnaire, a team of experts was

asked to assess the draft design of the early education service management model for children with autism. Data obtained in the form of qualitative data obtained from respondents who provide written input in the form of suggestions, improvements, comments, and opinions. Data is processed and presented descriptively, percentage, average, and qualitative explanation.

RESULTS AND DISCUSSION

The study was conducted in four private autistic early education service institutions in the city of Semarang, Central Java. Interviews with principals in early education service institutions for children with autism have the following problems. In carrying out its functions, management of early education service institutions for children with autism is based on the skills/experience of the principal who is also the owner of an early autistic education service institution. Autism curriculum or learning guidelines are not obtained from the government through the Ministry of Education and Culture but are based on the literature and experience of the institution owner. Operational permits for early education service institutions for children with autism or therapy centers are non-formal education courses while early education service institutions for children with autism who join Special Schools use the management manual for children with special needs. The complaint expressed was that the government manual was not only general but also difficult to apply to students. Another obstacle is the availability of human resources; it is very difficult to find teaching staff who are graduates of exceptional school education so that many institutions accept graduates of D3 Physiotherapy and S1 all majors who are able to teach after 3 months of internal training. Teachers/therapists with physiotherapy education background are 44.5%, educating 19% elementary school teachers, psychology graduates 12.5%; the rest are graduates of education, physics, and high school technology. Due to the limitations of the system of career development and family reasons, teachers cannot last long in teaching in early education service institutions for children with autism. The development of human resources, especially teachers, is very limited in

addition to the scarcity of continuing education on autism and the limited allocation of funds for development. Most students (50%) have autism at the age of 2-3 years, while others under the age of 2 years and over 3 years. This diagnosis is carried out by pediatricians (45.8%), psychologists (29.2%), and mental specialists (25%). Autism sufferers enter the early education service institutions of autistic children through doctors or psychologists. The initial assessment in school is carried out by teachers or therapists (88.2%), without the help of professionals such as doctors or psychologists even though they consider that collaboration with professional staff is very necessary (47.06%) because initial screening along with professionals can identify comorbidities and severity from autistic patients. The initial assessment was carried out by observing and interviewing the family. Therapy/education provided is behavioral therapy (75%), speech therapy (75%), and occupational therapy (50%). Duration varies every week: 4 hours, 6 hours, 10 hours and 15 hours, under the recommended duration of education. Parents' participation in their children's education is still felt lacking even though some parents hope that their children's early education can be independent (39.5%), two-way communication (18.4%), growth according to age (13.2%), socialization (7.8%), the rest hope their children are not tantrums, good behavior, discipline, and can develop their talents. The implementation and progress of education are monitored every three months by teachers and reported to parents. Control and monitoring include (1) educational service programs, (2) evaluation of teachers/therapists, (3) students, (4) evaluation sheets.

The steps taken in compiling the development hypothesis model are as follows. (1) Literature review of early education services for children with autism using the keywords early intervention-autism spectrum disorders or autism spectrum disorders – early intervention pre-school children; (2) Preparation of a hypothetical model of management of early education services for children with autism considering a factual model of early education services for children with autism, conditions in Indonesia that are adjusted to the literature review of early education for children with autism; (3) some things that need to

be improved include initial assessment, education planning tailored to the objectives to be achieved, implementation, monitoring, and evaluation; (4) Discussion of the hypothesis model of early education services for children with autism through the Focus group discussion with experts and users/practitioners of early behavioral interventions or early intensive behavioral intervention is highly recommended in the management of early education for children with autism.

Some of the designs proposed in developing a hypothetical model of management of early education services for children with autism are as follows. (1) The initial assessment for students is expected to obtain comprehensive information about their health status and behavior by using measurable parameters that include diagnostics, birth history, development history, growth history, and a history of family disease for at least three generations. Physical and neurological examinations include degrees of autism severity, social ability levels, behavioral disorders such as hyperactivity, anxiety, aggression, feelings of discomfort, self-mutilation, comorbidities such as epilepsy, sleep disorders, allergies and digestive disorders (Sanchack K 2017). Interviews and observations regarding emotional and social abilities, ranges of concentration and attention, abilities and general knowledge that are appropriate to age such as body members' understanding, concepts of color, form, communication skills, fine motor skills and gross motor skills, self-care ability, and severity of autism using Childhood Autism Rating Scale (CARS), which is a tool used in the initial evaluation and for the assessment of educational progress. (2) Early education service management planning for children with autism must be based on the educational objectives to be achieved which can be seen from the vision and mission that are aligned with the needs of children with autism. Planning includes the goals of education to be achieved and education and learning methods both at school and within the family so that they can meet the ideal education hours. The early intensive behavioral intervention is highly recommended in addition to other supportive therapies (AMS-MOH, 2010; Dalwal, 2017). Collaboration with health personnel and parents

and siblings in the family and community is needed to obtain maximum results in early education for children with autism (Swezy, 2008). Collaboration between parents, relatives in the family and community can help meet the ideal hours of education recommended. Parents, siblings, and caregivers of autistic children need emotional support and play an active role in early education programs for children with autism, receive an explanation or consult with experts on autism. (AMS-MOH, 2010). Human resources: competencies needed in the development of human resources include facilities and infrastructure, the cooperation of experts. increasing parental participation, counseling and training, and the results to be achieved from education. (3) Organizing: The organizational structure can show different roles and responsibilities for each position and the existence of optimal support supervision for the therapist or teacher. This is in accordance with the rules of the organization such as Staffing, which is the placement of staff in the right position according to their competence; Distributing, namely the distribution of work to each staff; Procedure & evaluating, namely the determination of work procedures and criteria and methods of evaluation; Delegating, namely the process of giving authority to decide according to the duties and functions of each staff (Terry 2009). (4) The implementation of early education includes the schedule of student admissions, the initial education curriculum for persons with autism that is tailored to the needs of children which includes early behavioral intervention therapy; supportive therapies such as speech therapy, occupational therapy, sensory integration; learning methods at school and at home; counseling and education to parents so that their participation and participation in education, especially at home, can increase; additional education for teachers/therapists. (5) Monitoring and evaluation are carried out on the method.

Final Model of Early Education Services for Persons with Autism.

The final model was developed after input was obtained from experts. The early education service management model for children with

autism includes planning, implementation, monitoring, and evaluation.

(1) Initial assessment: The parameters used are parameters that can be used to evaluate and monitor educational progress. These parameters include interview sheets that contain diagnostics, birth history, development history, history of growth, history of disease in the family for at least three generations; physical and neurological examination; degree of severity of autism; level of social ability; behavioral disorders such as hyperactivity, anxiety, aggression, feelings of disturbance, and self-mutilation; co-morbidities including epilepsy, sleep disorders, allergies, indigestion. The parameters used were confirmation of autism diagnosis using the Diagnostic and Statistical Manual (DSM V), the severity of autism measured using the Child Autism Rating Scale (CARS) to evaluate language and behavioral abilities. (ABC Abberant Behavioral Checklist) The community version is used to evaluate the existence of behavioral disorders. Nutritional status of children under 5 years is evaluated using WHO Anthro. Hearing loss is evaluated by the Brain Evoked Auditory Response (BERA) test or hearing power and vision function tests.

(2) Planning includes education planning which includes behavioral therapy such as Applied Behavior Analysis (ABA). This therapy was chosen because this model is very well known in Indonesia. Supportive therapies include sensory integration, speech therapy, and occupational therapy. Learning methods are planned at school and at home; parenting counseling and training; Human resources include teachers graduating from health polytechnics who have competencies in the fields of behavioral therapy, speech therapy, occupational therapy, sensory integration therapy, and physiotherapy. Psychologists and teachers with extraordinary teacher education backgrounds

and teachers with counseling education backgrounds; consulting with experts; facilities and infrastructure.

(3) Organization and implementation include an organizational structure that describes all organizational functions including an organizational structure that describes the duties and authority of the therapist, the path of consultation and if there are problems. Monitoring by senior therapists and principals for all therapists.

(4) The implementation includes a new student admission schedule; a curriculum which includes early behavioral intervention therapy, supportive therapy, academic activities such as understanding colors, shapes, and sizes. Joint activities including sports, dancing, eating together, playing, singing are useful as a therapy for socializing behavior and to train visual, audio and motoric coordination. Counseling includes teachers/therapists, psychologists, parental training about autism; learning model; internal and external training for teachers/therapists, according to the level of competence; create a network of consultations with experts that are needed.

(5) Assessment. The aspects assessed included improving language skills and communication, improving behavior, improving the ability of social relations that had been reflected by using CARS and ABC CV.

(6) Monitoring and evaluation are carried out on learning methods; progress of students; teachers and therapists in carrying out their roles. Monitoring techniques can be direct or indirect. Follow-up includes case discussions, program modification, and training conducted every week for three or six months. Parents, therapists, and doctors or health workers are closed in monitoring and evaluation. The final chart of the management model is as follows.

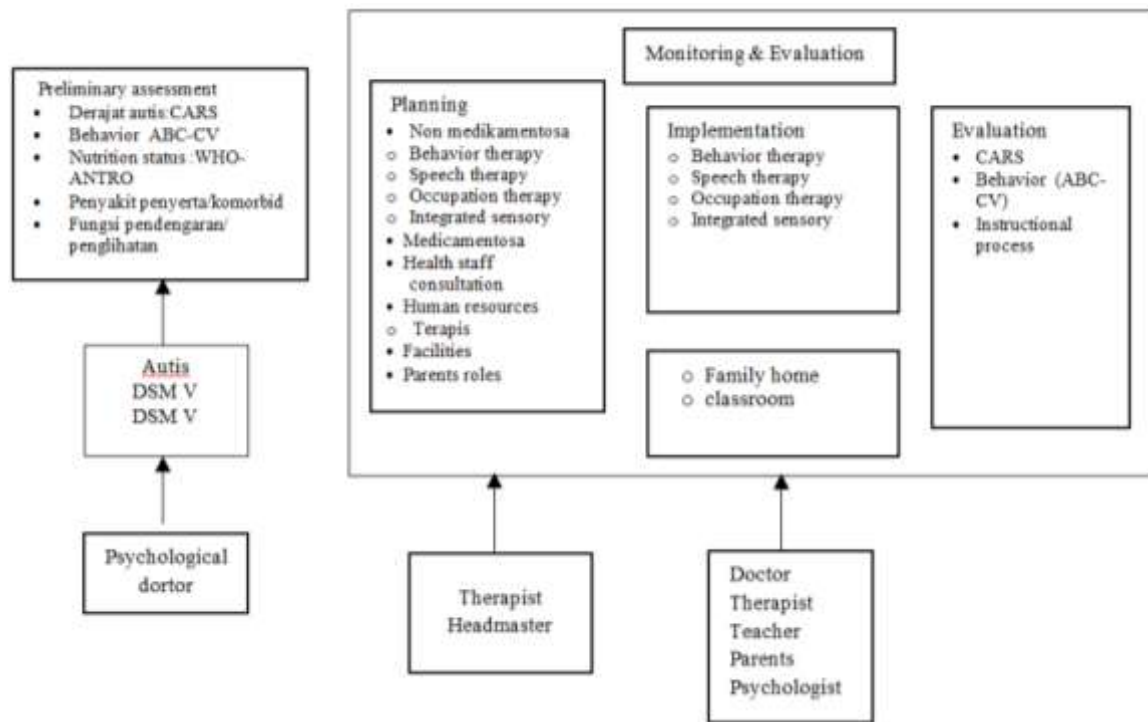


Figure 1. Final Model

CONCLUSIONS

Autism is a neurological development disorder that occurs in the early stages of child development that requires comprehensive management between teachers or therapists, parents, and families and health workers. The goal of managing autism is to reduce autism symptoms such as disorders in communication and behavioral disorders and comorbidities such as epilepsy, sleep disorders, tantrums, depression, and indigestion. Management of autism includes early education for children with autism and the provision of medicines for co-morbidities. The characteristics of early education for children with autism are (i) starting as early as possible; (ii) High education intensity of 25 hours per week, (iii) comprehensive and systematic initial assessment can determine the type of intervention or appropriate education; (iv) educational programs tailored to the needs of children; (v) specific curriculum that focuses on communication skills, socialization, self-care, and reducing behavioral disorders; (vi) trained teachers / therapists; (vii) increasing parental participation in early education in autistic persons. The final model of management of early education service institutions for children with autism improves the

initial assessment process by using parameters as well as evaluating educational progress. The implementation and monitoring of education include the process of education, the progress of students carried out by parents, teachers and health workers.

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