

STUDY ON DEVELOPMENT OF FAMILY AND COMMUNITY EMPOWERMENT MODELS IN HANDLING AUTISTIC CHILDREN IN SURABAYA CITY

Rukmini*, Sholikhah HH, Tumaji and Laksono AD

*National Research and Innovation Agency Republic of Indonesia, Jakarta 10340,
Indonesia*

Abstract

Background: The COVID-19 pandemic has seriously impacted children's efforts to develop Autism Syndrome Disorder (ASD). The role of the family and the closest community is significant in providing support and assistance for ASD individuals while at home. The study aims to develop a family and community empowerment model for handling autistic children by integrating multisector stakeholder policies and programs. **Methods:** This study is qualitative approach carried out in the city of Surabaya in 2021 with purposive sampling. Data collection by in depth interview with ASD parents and FGD with 16 multisector stakeholders. **Results:** Family and community constraints in handling autistic children in Surabaya were the low parental responsiveness to monitoring child development, early detection, therapy assistance, lack of communication, information and access to professional ASD health service and education facilities, and limited access to services for autistic children, neglected, and social problems. In addition, the study identified challenges in implementing policies and program strategies for dealing with ASD stakeholders: health service facilities and ASD education are still lacking, lack of infrastructure, curriculum, implementation of human resources and financing, and the dissemination of regulations has not been intensive and sustainable. **Conclusion:** The study developed a family empowerment model in handling autistic children involving multisector stakeholders by synergizing policies and programs, especially in health, education, social, religion, women's empowerment, and child protection supported by governments. We can implement the model by advocating stakeholders to pursue with a shared commitment and formulating program activities, also financing needed to implement activities.

Keyword: ASD, family, community, policy and program, empowerment, stakeholder

Introduction

Autism Spectrum Disorder (ASD), a group of neurodevelopmental disorders that have characteristics of impaired communication and social interaction, limited interests and repetitive behavior (Hodges, Fealko, & Soares, 2020). WHO estimates the prevalence of ASD at 0.76%, this data is only about 16% of the global child population (Baxter et al., 2015). Data from the American Center of Disease Central (2018) mentions 16.8/1000 individuals, meaning that 1 in 59 children is diagnosed with ASD, this condition is an increase of 15% compared to 2014 (Baio et al., 2018). In Indonesia there is no definite ASD prevalence data, but in 2018 it is estimated at 2.4 million people with the addition of

Corresponding Author: *ruk007@brin.go.id



new people with around 500 people/year (Kementerian PP&PA RI, 2018). The challenge in predicting the prevalence of ASD is to establish the age of onset because ASD is difficult to detect in very young children (non-verbally) because it overlaps with normal developmental behavior in children (De Bildt et al., 2004). In addition, it is difficult to distinguish between ASD and intellectual disability because low mental age causes social and communicative behavior to be less developed (DiLavore, Lord, & Rutter, 1995; Wing, 1997). Based on Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5), has updated the concept of a "spectrum" ASD diagnosis, combining the DSM-IV's separate pervasive developmental disorder diagnoses, such as autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified, into one (Hodges, Fealko, & Soares, 2020).

The problems with autistic children that are often encountered are 1) At the family level, namely awareness and knowledge of early detection is still lacking, parents are often in denial, and have difficulty determining the choice of place for treatment and interventions; 2) Community level, namely the stigmatization of parents who have autistic children, especially those with low education and poor families; 3) The level of health care providers, namely assessment is often late and difficult, indecision and lack of professionalism in providing early diagnosis and insufficient time for screening (Elder, Brasher, & Alexander, 2016; Elder, Kreider, Brasher, & Ansell, 2017; Oduyemi, Okafor, Eze, Akodu, & Roberts, 2021).

Handling of Special Needs Kids (SNK) such as autism requires the accuracy and speed of parents in recognizing and responding to symptoms at an early age of child development until the effort to provide the required intervention (Menteri Kesehatan RI, 2016). The prognosis of ASD cases will be better if diagnosed on time and given behavioral intervention and intensive education early on (Zwaigenbaum, Brian, & Ip, 2019). The challenge of ASD therapy is because it can't be cured but can be managed well, at the family level and at the community level, intervention as early as possible is independent according to the level. Treatment for each child with ASD can be different, but generally in the form of behavior and communication therapy, family therapy and medication (Haroon, 2019).

The tendency to increase ASD requires an integrated system between various stakeholders and multidisciplinary, making it a challenge that must be faced by autistic children, families, communities, and especially the government as policy makers to synergize with each other in various related fields. Therefore, community empowerment is very necessary. Community empowerment aims to improve health and disease control in the community, which is carried out through community mobilization and organizing strategies, health promotion, advocacy and multi-sector partnerships, as well as increasing human resources, financing, and facilities related to community empowerment (DR. R. Hapsara HR, 2015). Parents and the community play a major role in providing support and assistance for autistic children in their environment, so that they are able to develop and be independent. With this background, a study was conducted to develop a model of family and community empowerment in handling autistic children in Surabaya City.

Materials and Methods

The study is qualitative research, with a sample of parents of autistic children and multi-sector institutions that have duties and functions related to handling Special Needs Kids (SNKs), selected purposively. Collecting data with indepth interviews with parents of autistic children who visited the

laboratory of SNKs at functional implementing units of health technology innovation (FIU HTI), with a total of 10 informants. In addition, collecting data by Focus Group Discussion (FGD) with stakeholders conducted at a meeting in Surabaya City (June 29, 2021), attended by 16 cross-sectors namely 1) FIU HTI; 2) Research and Development Center for Humanities and Health Management, The Ministry of Health; 3) The Indonesian Spouse Group; 4) East Java Provincial Health Office; 5) Surabaya City Health Office; 6) Surabaya City Education Office; 7) Social Service of Surabaya City; 8) Department of Population Control, Women's Empowerment and Child Protection of Surabaya City; 9) Krembangan Health Center Surabaya City; 10) Peneleh Health Center Surabaya City; 11) Surabaya State University; 12) Autism Awareness NGOs; 13) Psychology of School partners; 14) National Center for Children Development (NCCD) Partner Therapists; 15) Companion Teacher; 16) The inclusive schools. The method of the meeting was the presentation of resource persons from the Surabaya City Health Office and FIU HTI, followed by a question-and-answer session and followed by a focus group discussion (FGD) guided by the researcher.

Analysis of the data by processing the recordings of the question-and-answer session and FGD, by transcribing the recording, then encoding the transcription data using analytical coding to identify themes, explore and develop categories and concepts. At the initial stage, coding was carried out to identify broader concepts in the data, then axial coding was focused on certain concepts and the final stage was selective coding to analyze each individual and stakeholder conceptual category in depth (Richards & Morse, 2013). From this categorization, it is possible to identify family and community barriers in handling autistic children as well as challenges in implementing multisector stakeholder policies and programs related to ASD. From this concept, this study aims to develop a model of family and community empowerment for handling autistic children in Surabaya City by integrating policies and activities of multisector stakeholder programs.

Results

Family and Community Obstacles in Handling Autistic Children

Based on the results as seen in Table 1., the study identified seven aspects of parents and community barriers in handling ASD children. The seven were the responsiveness of ASD early detection, access to professional SNKs services, therapeutic assistance, acceptance and fulfillment of the rights of autistic children, community-based facilities, access to educational information, and access to services for poor and neglected children with autism. In these seven aspects, the study described related subthemes.

Table 1. Obstacles of Parents and Community in Handling Autistic Children in Surabaya City.

No.	Aspect	Obstacles of Parents and Community
1.	Responses regarding detection	Monitoring of children's growth and development is still lacking . Knowledge and skills about autistic children and early detection are still low.

2.	Responsiveness to access Professional SNKs Services	<p>Access to information and utilization of professional crew service facilities is still lacking.</p> <p>Knowledge of SNKs services at the Puskesmas and SNKs cadres is still lacking.</p> <p>Parents often shop for professionals (doctors, psychologists, psychiatrists), places of education and places of therapy.</p> <p>SNKs services that focus on increasing knowledge, motivation and psychological support for parents are still lacking. SNKs therapy services are still focused on the child's side only.</p>
3.	Responsiveness in assisting the therapy of children with autism	<p>Roles of the family in assisting the therapy of children with autism has not been optimal.</p>
4.	Acceptance and fulfillment of the rights of autistic children	<p>Unreadiness to accept and care for autistic children resulting in late assessment and therapy.</p> <p>The rights of SNKs have not been fulfilled, especially protection against acts of verbal and non-verbal violence.</p>
5.	Community resource service facilities for autistic children	<p>The availability of community-based service facilities is still limited.</p> <p>The existence of communication forums for parents and the community is still lacking, as a forum for communication, socialization, education and promotion.</p>
6.	Access to information and educational programs for autistic children	<p>Limited access to information about educational programs (schools, teachers assistance).</p> <p>Parents want their children to attend regular schools, not inclusive schools.</p>
7.	Access to special services for poor and neglected children with autism	<p>Limited access to health services, education and job skills for autistic children who are poor, neglected and with social problems</p>

Primary Data Source: indepth interview, 2021.

Barriers to the Implementation of Stakeholder Policies and Programs in Handling Autistic Children

Based on the results as seen in Table 2, the study identified seven multisector stakeholders in Surabaya. They have duties and functions related to handling autistic children, either directly or indirectly, namely the Health Office, Education Office, Women Empowerment and Child Protection office, Local Government, Non-Governmental Organization (NGOs) and Ministry of Religion office.

Table 2. Barriers to the Implementation of Stakeholder Policies and Programs in Handling Autistic Children in Surabaya City.

No.	Aspect	Barier of stakeholder
1.	Health Office	The availability and quality of professional SNKs health service facilities are not optimal, such as supporting

		<p>infrastructure.</p> <p>Human Resources: Concern, ability, type and qualification of officers are not optimal.</p> <p>The funding budget is still lacking</p>
2.	Education Office	<p>Availability and quality of educational facilities for autistic children are still not good, number of inclusive schools, educational programs, teachers assistance, infrastructure and financing.</p> <p>Educational institutions that focus on stimulating the development of SNKs according to the abilities and needs of children are still lacking</p>
3.	Women Empowerment and Child Protection (WE & CP) Office	<p>Roles are not optimal in increasing the role of families and communities to protect the rights of SNKs</p>
4.	Social District Office	<p>Roles are not optimal in guaranteeing health services, education and work skills for poor, neglected and socially problematic autistic children.</p>
5.	Surabaya government	<p>Regional regulations governing SNKs are not yet available and there is still a lack of financing.</p> <p>Monitoring and evaluation of the government (relevant stakeholders) for service facilities for autistic children is still lacking.</p> <p>Autism child service partnership network is still lacking, each working independently by sector and not yet integrated.</p>
6.	NGO	<p>The availability of community-based service facilities for autistic children is still limited.</p>
7.	Department of religion	<p>Roles are not optimal on prospective a bride and groom coaching program to increase knowledge and understanding of parents regarding ASD child care recordance to religious teaching.</p>

Primary Data Source: FGD of Cross-sector meeting, 2021

Development of Family and Community Empowerment Models in Handling Autistic Children Based on Integration of Multi-sector Stakeholder Policies and Programs

The involvement of parents, families and communities as well as the government is an important component in handling autistic children, but the facts on the ground show that the ability of parents, families and communities in handling autistic children is still low. From these obstacles, a mapping of stakeholders who have duties and functions related to the problem was carried out, so that policies and programs can be synergized and integrated to overcome these obstacles. For this reason, an empowerment model is needed to increase the role of families and communities involving cross-sector and multidisciplinary for comprehensive handling, autistic children.

The model was developed through stages, namely 1) Identifying problems faced by families and communities on managing autistic children; 2) Identifying stakeholders which have related duties and functions, followed by mapping of the family and community problems; 3) Setting goals of the

model; 4) Formulating potential programs to be achieved; 5) Determining the potential output to be achieved by the programs; 6) Formulating activities to solve family and community problems in handling autistic children. Figure 1. shows A Model of Family and Community Empowerment in Handling Autistic Children Based on Integration of Multisector Stakeholder Policies and Programs.

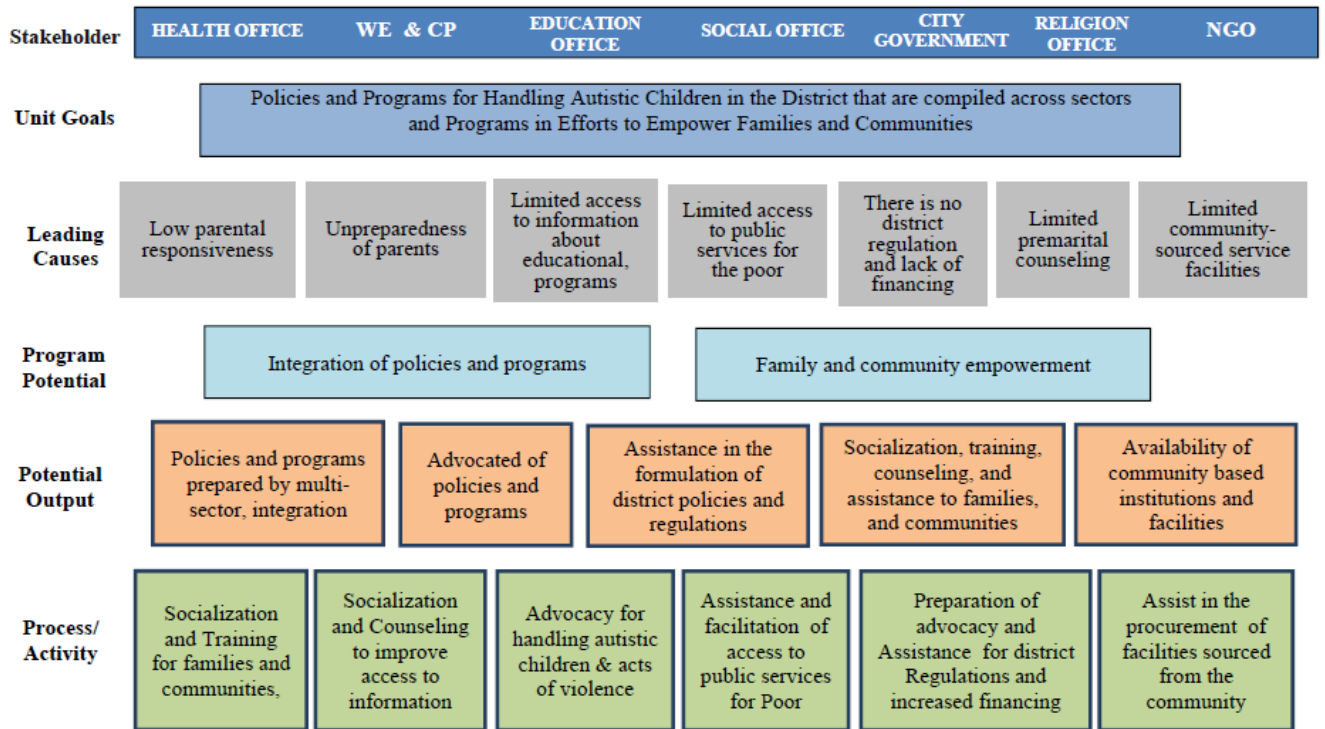


Figure 1. Family and Community Empowerment Models in Handling Autistic Children Based on Integration of Multi-sectora Stakeholder Policies and Programs.

Discussion

The research findings show that the problems faced by families and communities in handling autistic children are synergized with obstacles in implementing policies and programs faced by multi-sector stakeholders. The obstacle for health stakeholders in handling autistic children is that the availability and quality of SNKs professional service facilities is still low, both in infrastructure, implementing human resources and financing. The Ministry of Health issued Permenkes No.25 of 2014 concerning Child Health Efforts, which is expected to be able to detect autistic children. Articles 21 and 23 state that growth monitoring is developed in a comprehensive and quality manner according to the inspection schedule, through stimulation, detection and early intervention activities for growth and development in basic service facilities and in kindergartens. If there is a deviation in growth and development, a referral must be made by a health worker (Menteri Kesehatan RI, 2014a).

Barriers to families and communities are the lack of information and access to professional SNKs service facilities. Parents often shop for several doctors, to seek confirmation of a diagnosis of speech delay in their child (Tiel, 2011). This condition is due to the staff's lack of knowledge and professionalism in diagnosis (Elder et al., 2016). Many families have difficulty accessing early

intervention services after ASD diagnosis and only get 6.81 hours/month of service (Braddock & Twyman, 2014). It is necessary to increase the awareness and ability of health workers to recognize autism so that families can find support early on (Doherty, Haydon, & Davidson, 2021), by creating an efficient system for early detection (McCarty & Frye, 2020). In Indonesia, it is regulated in the Regulation of the Minister of Health of the Republic of Indonesia Number 66 of 2014, it is stated that early detection can be carried out, namely 1) At the parent and community level, with maternal and child health (MCH) books; 2) Pre-screening is carried out by integrated health post cadres, health workers, sub-public health centers, and public health centers (Puskesmas), using stimulation, detection, and early developmental intervention guidelines; 3) Screening of children at risk according to age stages with a modified instrument checklist for autism in toddlers, revised (M-CHAT R), if the result is positive it must be followed up with an assessment (Menteri Kesehatan RI, 2014b).

The responsiveness and knowledge of parents is still low in monitoring growth and development, early detection and assistance in therapy for autistic children. In fact, early detection can be carried out by parents and the community with MCH books available at the Puskesmas and midwives, but family understanding is still lacking. Basic Health Survei data, shows the low ownership of MCH books in children aged 0-59 months by 30.5% (2010), 30.9% (2013) and 49.7% (2018) (Balitbangkes Kemenkes RI, 2019). Research using birth records found that very low birth weight babies were at high risk for developmental delays. This means that information from birth records, such as the MCH handbook, is useful for targeting screening and early intervention for high-risk children (Delgado, Vagi, & Scott, 2007). Parents are late in realizing that their child has autism because of the lack of knowledge and information about autism (Kurniawan, 2021).

In the field of education there are obstacles, namely the lack of quantity and quality of educational facilities for children with autism, this is in accordance with the obstacles experienced by families and communities. Data from the Director General of Primary and Secondary Education of the Ministry of Education and Culture, states that the number SNKs in Indonesia (2015) reached 1.6 million children, but only 10-15% received education services. Obstacles in the implementation of inclusive schools are the lack of regular schools as program organizers, the limited number of accompanying teachers, the lack of knowledge and understanding of the curriculum and the presence of SNKs students. (Wahyudi & Kristiawati, 2016).

The challenge in the WE&PC field is that the role of the Office is not yet optimal in increasing the role of families and communities to protect the rights of SNKs. Research has found that mothers' unreadiness in accepting autistic children has an impact on passive coping strategies and emotional exhaustion (Troy, Connolly, & Novak, 2007). Special needs kids are still considered a family burden and community acceptance is still lacking, besides that, autistic children face internal problems such as self-confidence, which has an impact on children withdrawing from the environment which shows discrimination and deviant behavior in SNKs (Dini, Sujianto, & Retnaningsih, 2015). Research shows father's employment status has a significant impact on the social support of children with disabilities and quality of life for families of autistic children (Kuru & Piyal, 2018).

Barriers to NGOs are limited rehabilitation services for autistic children who come from community resources, so that families and communities have very limited access and information. Rehabilitation activities with a community-based approach are known as Community Based Rehabilitation, which focuses on efforts to empower and participate in all community potential (Kristiawan, Wijayanta, &

Suminah, 2016). The program can be carried out for SNKs, but the community based institution for SNKs are still very limited (Menteri Negara PP&PA RI, 2011). The findings of the study were to determine the various types of social support for families with autistic children to improve family function and maintain the family unit (Lei & Kantor, 2021).

Barriers to stakeholders in the social sector, such as families, are limitations in providing services for poor, neglected children with autism and social problems. In handling autistic children, both for therapy, education and skill development, it definitely requires a lot of money. Research reports that autistic children from lower-middle families are relatively underserved and underserved compared to those with high economic status (Durkin et al., 2010). Barriers to access to individual ASD services for poor families are financial factors, transportation needs, inflexible work schedules, and limited family support (McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009; Raspa, Hebbeler, Bailey, & Scarborough, 2010). Poor and neglected autistic children, if not handled properly, can cause social problems, not only in the family but also in society.

Surabaya has no regulation regulating SNKs, and the existing regulation is the East Java Provincial Regulation No. 2 of 2016 and Surabaya Regulation No. 2 of 2017 concerning Public Health Efforts. However, various central regulations have regulated the handling of ASD children in Indonesia. According to the Minister of WE&CP (Menteri Negara PP&PA RI, 2011), regulations related to SNKs have not been intensified and triggered, so commitment is low. There is no good data related to the prevalence of autistic children, due to the low level of detection at the community and health service levels. Public services in Indonesia have not been responsive to people with SNKs, including vulnerable groups, people with disabilities, the elderly and remote communities (Pramudiana, 2016).

Parents who have autistic children experience the burden of parenting related to parental aspects, barriers to children, partners and the environment. The study showed that the factors that strengthened parents in raising autistic children were sincerity in accepting the child's condition, closeness to God, as well as positive thinking and social support, especially from partners (Yanti, Kumara, Hastjarjo, & Adiyanti, 2018). The main task of the family is to lay the foundation for moral education and a way of life about religion. Therefore, the role of the Ministry of Religion can be activated to increase family empowerment to be more accepting and able to provide parenting according to the needs of children according to religious instructions.

Based on policies and challenges faced by families and communities, a solution is needed to overcome these problems by developing an empowerment model. Stakeholders must be able to empower families, namely (a) Families understand the strengths, abilities, and special needs of their children; (b) Families know their rights and advocate effectively for their children; (c) Families help their children develop and learn; (d) The family has a support system; and (e) Families can gain access to desired services and activities in their community. Stakeholders can implement the model to achieve the expected results and provide families with measurable benefits (Bailey et al., 2006).

Conclusion

The conclusions of this study are the study developed a model of family empowerment in handling autistic children involving multisector stakeholders by synergizing all policies and programs, especially in health, education, social, religion, women's empowerment and child protection, and ngo

supported by local governments. The model can be implemented through advocacy to relevant stakeholders, building joint commitments, formulating activity programs, financing to achieve the goals. Therefore, further research is needed to implement the model.

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Declaration of Interest Statement

The authors declared no potential conflicts of interest concerning this article's research, authorship, and publication.

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