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FAMILY PARTICIPATION MODEL WITH CHILDREN WITH DISABILITIES IN REALISING AN INCLUSIVE SOCIETY

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Abstract. *This research aims to find a model of family participation with children with disabilities in realising an inclusive society in Ngawonggo Village, Tajinan District, Malang Regency. This research was conducted with a qualitative approach of the descriptive type. The research subjects were determined by the purposive method. Data collection techniques were carried out by observation and interview. Data analysis was conducted using the interactive model (Milles and Huberman). The results showed that the forms of family participation with children with disabilities include: 1) Participation in decision-making, 2). Participation in implementation, 3) Participation in benefits, and 4) Participation in evaluation. with socialisation programs, family parenting and therapy, can create an inclusive society, such as: 1) Religious and community leaders understand the importance of supporting the growth and development of children with disabilities, 2) The community treats children with disabilities as normal, 3) Children with disabilities can play and learn with normal peers, 4) There is support from the local government for children with disabilities through the allocation of the Village Fund Budget, 5) Parents with children with disabilities have gradually opened up and provided public access to their children.*

Keywords: Family Participation, Children with Disabilities, Inclusive Society

Abstrak. *Penelitian ini bertujuan untuk menemukan model partisipasi keluarga dengan anak penyandang disabilitas dalam mewujudkan masyarakat inklusi di Desa Ngawonggo, Kecamatan Tajinan, Kabupaten Malang. Penelitian ini dilakukan dengan pendekatan kualitatif dengan tipe deskriptif. Subjek penelitian ditentukan dengan metode purposif. Teknik pengumpulan data dilakukan dengan observasi dan wawancara. Analisis data dilakukan dengan menggunakan model interaktif (Milles dan Huberman). Hasil penelitian menunjukkan bahwa bentuk-bentuk partisipasi keluarga dengan ABK antara lain: 1) Partisipasi dalam pengambilan keputusan, 2). Partisipasi dalam pelaksanaan, 3) Partisipasi dalam manfaat, dan 4) Partisipasi dalam evaluasi. Dengan adanya program sosialisasi, pola asuh keluarga dan terapi, dapat menciptakan masyarakat yang inklusif, seperti: 1) Tokoh agama dan tokoh masyarakat memahami pentingnya mendukung tumbuh kembang ABK, 2) Masyarakat memperlakukan ABK sama seperti anak normal lainnya, 3) ABK dapat bermain dan belajar bersama teman sebaya yang normal, 4) Adanya dukungan dari pemerintah daerah terhadap ABK melalui pengalokasian Anggaran Dana Desa, 5) Orang tua yang memiliki ABK berangsur-angsur membuka diri dan memberikan akses publik terhadap anaknya.*

Kata Kunci: Partisipasi keluarga, ABK, Masyarakat inklusif



INTRODUCTION

Background

Children are an investment for the nation, and their physical, psychological, social and religious growth and development need maximum attention and fulfilment. Children will experience good growth and development if they, their immediate environment, and their social environment are supportive. There are still children who experience limitations, which are caused either by factors within themselves, or factors from outside themselves. These limitations are especially prevalent among children with disabilities.

Law No. 8/2016 on Persons with Disabilities classifies five classifications of disability, namely physical, intellectual, mental, sensory, and multiple/multi. According to the National Socio-Economic Survey (Susenas, 2019), the number of people with disabilities in Indonesia is 9.7 percent of the total population, or around 26 million people. Based on the category of disability, physical disability is a form of physical disability that has the characteristics of being physically abnormal so that their functioning in society is hampered, which can affect their psychological condition. People with disabilities can feel inferior and close themselves off from the surrounding environment due to their lack of self-confidence. Ryff & Singer (Yanuaristi, Ervina, & Rahmawati, 2015) explain that the physical limitations of children with disabilities are often unable to manage daily activities, take care of themselves, are unable to control external influences; lack meaning in life, have few life goals, and have no confidence in life; experience *personal stagnation*, cannot improve and develop themselves, feel bored and uninterested in life, feel unable to develop new attitudes or behaviours. Given that the maintenance of children's welfare cannot be carried out by children themselves, the intervention of the closest people around them, especially the family, is needed.

The family is the smallest unit that is first and foremost known by children, in any condition the family has full responsibility for physical maintenance, health, and childcare, including survival and sustainability of life, it is the duty and responsibility of parents to care for their children (Putri & Lestari, 2015). Yusi Desriyani (2019), Erlita Normasari (2020). As social beings, ensuring that children with disabilities can coexist and be accepted by the surrounding community requires family participation in supporting a community environment that can accept various forms of diversity and differences and accommodate them

into various orders and infrastructures that exist in society, better known as an inclusive society.

Ngawonggo Village, Tajinan Sub-district, Malang District, has 19 children with disabilities. These children live together and remain in the care of their families (parents). The family is the foundation of life for children with disabilities considering that children with disabilities require special attention not only to the fulfilment of their needs and care but also to the continuity and sustainability of life as social beings who live side by side and are accepted with the surrounding community environment, it is necessary to create an atmosphere that supports a community environment that can accept various forms of diversity and differences and accommodate them into various orders and infrastructures that exist in society, better known as an inclusive society. To fulfil the physical, psychological, social and religious needs of children with disabilities requires the participation of all elements in the community, especially family participation.

Previous Research

Firstly, the results of Erlita Normasari's research (2020), on Parents' Acceptability of Children with Special Needs in Yogyakarta City, resulted in findings that parents have reached the *acceptability* stage of their children with special needs, by going through several stages of *denial, anger, bargaining, depression, and acceptance*. The relevance of this research is that the family is the first and main milieu known by children, parents have an urgent role in the growth and development of children, especially children with special needs, children's inability to carry out daily activities is very dependent on the family. Parents have been able to accept their children's conditions even though the decision to accept them has been a long and difficult process. The results of this study have a close relevance to research on the participation of families with children with disabilities in realising an inclusive society. Family participation is the most important part of efforts to create an inclusive society that characterises the surrounding community environment supporting the growth and development of children with disabilities. *Second*: The results of Wan Isyraf Naufal's research (2020), The parenting experience of mothers who have children with physical disabilities with achievements: a descriptive phenomenological study, resulted in findings that there are five synthesis themes regarding the parenting experience of mothers with adolescent children with physical disabilities with achievements, namely, (1) the existence of treatment efforts that have been made,

(2) the importance of getting help from the social environment, (3) efforts to support children to excel, (4) various efforts made when caring for children, and (5) acceptance of the child's condition. The relevance of the results of this study is that the family, in this case, parents, plays an important role in the growth and development of children, as well as children with disabilities, with physical limitations that children have, they can still achieve thanks to the participation and support provided by the family, in this case, parents, especially mothers. The participation of parents with children with disabilities is not only limited to individual family and group approaches but requires broad participation at the community level, this is intended to create a conducive environment that supports the growth and development of children with disabilities, namely realising an inclusive society.

Family Participation

Family participation is a form of participation or involvement of the family in an activity programme that has been agreed upon. Family participation shows that families have duties and responsibilities in improving children's welfare, especially children with disabilities. Participation by both families/groups and communities will have a value on the successful implementation of an activity programme (Soetomo, 2012).

Parental participation plays a role in the improvement of children's abilities, the term may have several meanings such as parental ideals and expectations, parental participation in activities to improve knowledge, a home environment that supports learning activities and communication between parents and children about things that happen around them. Parental participation reflects the extent to which parents are present and insert themselves into their children's daily lives. It is only by providing genuine love and affection from parents that a child can show his or her potential. Therefore, in the family, children are given many experiences so that the personality of the child is formed from the beginning. This transactional process among family members is a proactive step to reduce dysfunction and create positive adaptations to face future challenges (Walsh, 2016). Parents who experience stressful situations when caring for children with disabilities experience anxiety about the child's future, social stigma, social and career limitations, awkward relationships with others, financial constraints, poor emotional and well-being, and lack of adequate services (Chadwick in Rajan, Srikrishna, & Romate 2016).

Forms of Participation

Participation or involvement of a person in an activity either with efforts towards social change on a small, medium, or large-scale including development is a form of participation that certainly requires serious attention. There are 4 forms of participation in general, namely: 1) *participation in decision-making*, which is the participation of the community in decision-making through programme planning, the indicators are as follows: a) involvement in meetings or deliberations, b) willingness to provide data and information, c) involvement in the drafting of programme plans, d) involvement in determining the priority scale of needs and e) involvement in decision-making. 2) *participation in implementation* Participation in implementation is community participation in development in the form of contributions, including a) participation in resources, b) participation in administration and coordination, and c) participation in programme registration. 3) *participation in benefits* Participation in benefits is participation in providing more positive benefits for the government and the community. This participation is in the form of participating in activities to maintain environmental cleanliness, participating in religious activities, maintaining environmental security and participating in regional defence economic business group activities to improve the economy. And 4) *Participation in evaluation* Evaluation is carried out in addition to what is done by the established plan. (Cohen and Uphoff quoted by Siti Irene Astuti D, 2011: 61-63).

Children with Disabilities

Persons with disabilities are everyone who experiences physical, intellectual, mental, and/or sensory limitations for a long period who in interacting with the environment may experience obstacles and difficulties to participate fully and effectively with other citizens based on equal rights (Disability Law No. 8 of 2016). There are 3 categories of disability conditions: mild, moderate, and severe. The mild category is someone who has limitations in performing physical activities but can be improved through therapy. The moderate category is someone who has motor limitations and sensory coordination disorders. And finally, the severe category is those who have full limitations in performing physical activities and are unable to control physical movements. The cause of disability can be caused by two factors, namely congenital from birth and illness/accident. The number of people with

disabilities will continue to increase given the high accident rate in Indonesia and the increasing poverty rate.

Inclusive Society

Inclusiveness is an attempt to put oneself into another person's perspective in viewing or understanding a matter or problem. On the other hand, an inclusive or exclusive attitude is the way a person views a difference. Inclusive attitudes also tend to be associated with a positive view of differences and exclusive attitudes are a negative view of differences. Inclusive is a term to describe a society that is open to cultural diversity, has high tolerance and accepts and easily interacts with other cultures. One of the groups represented in an inclusive society is the disabled community, people with disabilities in an inclusive society have differences in terms of physical and thinking abilities because there are deficiencies or imperfections. The challenge is how the public responds to these differences and tries to help the rights of groups with disabilities that have not been well accommodated and social protection that is not optimal and maximum for them.

An inclusive society can be defined as a society that can accept various forms of diversity and differences and accommodate them into various arrangements and infrastructures in society. Various forms of differences and diversity include cultural diversity, language, gender, race, ethnicity, and economic strata, and include differences in physical/mental abilities, which we also call disabilities.

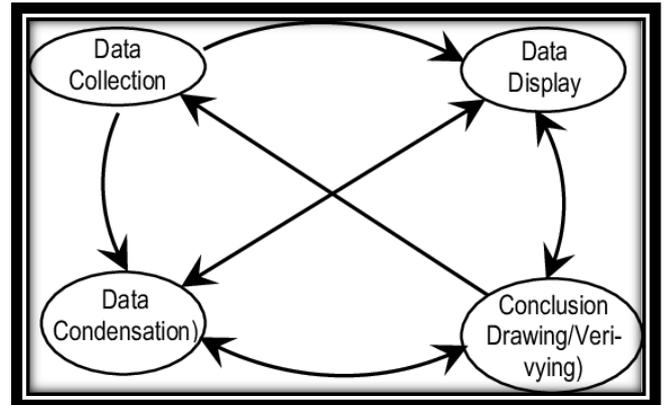
An inclusive environment has an inclusive "attitude" too because an inclusive environment is a social environment that is open, friendly, eliminates barriers and is fun because every member of the community without exception respects and embraces every difference. In an inclusive society that consists of many differences, such as religion, race, ethnicity, and culture, one can accept and appreciate the differences that exist. One of the groups of people represented in an inclusive society is people with disabilities. People with disabilities in an inclusive society have differences in terms of physical and thinking abilities because there are deficiencies or imperfections, empirically in the field there are still rights that have not been properly accommodated and social protection that is not optimal and maximum that they receive. An inclusive society is reflected in all of us taking responsibility for each other to strive and provide services and facilities so that each of us can fulfil our needs, carry out our obligations and obtain our rights. Simple and practical changes characterise an inclusive

environment. In an inclusive environment, simple and practical changes are an effort to make it easier for everyone to carry out every activity in daily life.

METHOD

This research is qualitative research with descriptive type (Denzin & Lincoln, 2009). According to Marvasti (2004), qualitative research provides a detailed explanation of the substance or human experience of the implementer. Qualitative research is research that departs from facts/phenomena, this research seeks to reveal the "meaning" behind events/phenomena. This research was conducted in Ngawonggo Village, Tajinan Sub-district, Malang Regency, with the subjects being parents with children with disabilities. The technique of determining the research subjects was carried out *purportedly* (Babbie, 2008, Neuman, 2007), while data collection techniques were carried out by *observation, in-depth interviews*, and documentation. The data analysis technique uses the interactive model data analysis method developed by Milles, Huberman, and Saldana (2014) with stages: *data collection, data display, data condensation* and *conclusion/verification*. The systematic work of the Interactive Model data analysis component is as follows:

Figure: 3.1 Data Analysis Interactive Model



Source: Miles, Huberman, Saldana, 2014

The **data collection stage**, at this stage the researcher carries out the process of collecting data on the subject, namely parents with children with disabilities by applying the data collection techniques of observation, in-depth interviews, and documentation analysis to answer the formulation of problems that have been determined in this research, First, the researcher meets directly face-to-face with the head of the family association with children with disabilities: Mrs Tatik, as well as with Mr Ghozali's public relations. From these two people, we obtained document data about the identity of families with

children with disabilities and then our research team was allowed to conduct interviews as well as observations with families with other children with disabilities. In the **data condensation stage**, at this stage the researcher conducts a process of selecting, simplifying, abstracting, and transforming data, written field notes, transcripts of interview results, analysis of document data and observation results and other empirical data. The selection and sorting of data is carried out to answer the formulation of the problem so that irrelevant data is discarded. In the **data display stage**, at stage, the researcher presents the research data, both data in tabular form and narrative data to support the next step, namely making conclusions. The data display is intended to make it easier to understand the results of data findings in the field.

Conclusion/verification stage, at this stage the researcher formulates the **conclusions** of the research results and verifies the conclusions through comparison with the concepts and theories of participation that are used as references and provides recommendations from the research data.

RESULT AND DISCUSSION

Description of the Research Area

This research was conducted in Ngawonggo village, Tajinan sub-district, Malang district. East Java Province, Indonesia. Reporting from data taken from the site Ngawonggo village has an area of 375.628 Ha. The existing land area is divided into several designations that can be grouped such as public facilities (for offices 0.136 Ha, schools 0.284 Ha, Sports Infrastructure 0.600 Ha and for public cemeteries 0.638 Ha), land area for settlements 3.596 Ha, agricultural land area 126.645 Ha, plantations (182.313 Ha of land and moor), economic activities and others,

Ngawonggo Village is located on a plain with an average altitude of 700-800 m above sea level. Administratively, the village is located at the southern end of the Tajinan sub-district, directly adjacent to the Wajak sub-district, with the following village boundaries: 1) Northside: Purwosekar village, Tajinan sub-district; 2) East side: Ngembal Village, Wajak Sub-district; 3) South: Kidangbang Village, Wajak Sub-district; 4) West side: Pandanmulyo village, Tajinan sub-district.

Ngawonggo Village's distance to the Subdistrict capital = 4 km, which takes about 15

minutes, while the distance to the Regency capital = 20 km, which takes about 0.7 hours.

The visualisation of the administrative area of the village can be seen in the map below.



Source: Ngawonggo Village Profile Document, th 2022

Identity of Research Subjects

Table 5.1. Data on the Identity of Research Subjects

No.	Name	Gender	Age	Education	Employment	Parent of (Initial) children with disabilities
1	TS	Female	50	Bachelor's degree	High school teacher	Andini (9 years old) - physically disabled
2	NGZ	Male	43	Bachelor's degree	Teacher Islamic School	Yasmin. (16 years old) - Mentally disabled
3	SKH	Female	38	Elementary Graduate	Housewife	Yusnia (13 years old) - Mentally disabled
4	AA	Female	32	Senior Graduate	Housewife	Navia (4 years old) - physically disabled
5	FRH	Female	40	Bachelor's degree	Housewife	Bintang (6 years old) - Mentally disabled
6	BL	Female	43	Senior Graduate	Housewife	Agung (14 years old) - physically disabled

Source: Data processed in 2022

Participation of Families with Children with Disabilities in Realising an Inclusive Society in Ngawonggo Village, Tajinan Sub-District, Malang District

The family is the smallest unit that is first and foremost known by children, in any condition the family has full responsibility for physical maintenance, health, and childcare, including survival and sustainability of life, it is the duty and responsibility of parents to care for their children (Putri & Lestari, 2015). Yusi Desriyani (2019), Erlita Normasari (2020). As social beings, so that children with disabilities can live side by side, and be accepted by the surrounding community, requires family participation in supporting a community environment that can accept various forms of diversity and differences and accommodate them into various orders and infrastructures that exist in society, better known as an inclusive society. The forms of participation of families with children with

disabilities in realising an inclusive society are as follows:

Participation in decision-making

Participation in decision-making is carried out by families with children with disabilities who are members of the association. All core administrators have high responsibilities, so their participation is needed, especially in decision-making, for the continuity of the association and the achievement of the objectives of the association.

The results of the interview with Mrs Tatic as well as the head of the parents' association with children with disabilities "Bintang Harapan" stated that:

"...I as the head of the association certainly participate directly in various meetings/deliberations, I am well come, ready and willing to provide information related to the condition of my child's disability, I am also involved in the preparation of the draft programme in decision making for the progress and independence of children with disabilities..." (interview with the head of the association, 15 September 2022)

This statement is supported by the statement of Mr Nur Ghozali (as Public Relations of the association), who stated that:

"...I have been committed since the beginning to be involved in efforts to create an environment around children with disabilities that supports the lives of children with disabilities reasonably, this I did long before joining this association. Alhamdulillah, now there is an association, so we are solid, and work together for the sake of children" (interview on 15 September 2022).

From the interviews above, families with children with disabilities participate in decision-making about creating an environment that supports the growth and development of children with disabilities, namely creating a disability-friendly environment, as well as creating a family and community environment that can accept differences, both physical and psychological, due to disability.

Participation in implementation of activities (Participation in implementation)

This form of participation is the implementation of the programme plan. With efforts to create an inclusive society, the participation of parents with children with disabilities is shown through physical/energy involvement, starting from socialisation activities both to families with children with disabilities and the surrounding community and

the wider community, program implementation including family parenting and therapy for children with family assistance, as well as being active in coordination and administration activities (recording activities and preparing reports).

The results of the interview with Mrs SKH (a parent with a child with intellectual disabilities) stated that:

"Every time there is an activity, I try to attend ma'am, because I need knowledge about how to behave and behave with children who have privileges, such as my child who has an intellectual disability, how to meet children's needs, especially the need for affection and appreciation. Alhamdulillah, I got extraordinary knowledge, especially before the covid 19 pandemic, the activities ran smoothly and up to therapeutic activities with children directly". (Interview, 15 September 2022)

The statement above is corroborated by the results of observations which show that: when there is an activity all the association administrators are present plus parents with children with disabilities who are not members of the association. The parents participated in the activities, and some brought snacks to share, it was clear that there was a sense of togetherness called *guyub* among the parents with children with disabilities. This shows that parents of children with disabilities in Ngawonggo village, Tajinan sub-district, Malang district, have a high level of enthusiasm and motivation to gain knowledge about how to care for children with disabilities, as well as a commitment to provide the widest possible space for children to grow and develop naturally.

Participation in benefits

Participation in providing more positive benefits to the surrounding community, by participating in activities to maintain environmental cleanliness, participating in religious activities, maintaining environmental security, and participating in economic business group activities (*home industry* training) to improve the family and community economy.

The results of the interview with TS's mother with a physically disabled child stated that:

"So far, ma'am, we are in the association as part of the association, but we parents with children with disabilities are also part of the community, we also participate in various activities here, starting from the community service event every 2nd week of the month, We also actively participate in activities at the mosque (where we live 0.5 km from the mosque), we also

participate in community empowerment activities through economic business group activities (with home industry training), but because of the covid 19 pandemic, ma'am, so it stopped, all activities stopped and we just restarted ma'am." (Interview dated 14 October 2022).

The results of observations when the research was conducted obtained data when the Sunday morning community service was held, the parents carried out activities to clean the sewers along the village road, the children also helped, as well as children with disabilities (especially the physically disabled) who could still carry out activities to help provide cakes (snacks) to the fathers, mothers who were on the move. The children helped cheerfully, smiles, jokes, and laughter coloured the Sunday morning activities.

Participation in evaluation

Actively involved in supervision, monitoring, and evaluation of the programme, through joint coordination activities in each programme implementation that are carried out regularly with the aim that if obstacles/constraints occur, solutions can be found quickly and appropriately.

The results of the interview with Mrs TS (a parent with a child with a disability), stated that:

"I happen to be the chairman, so I also participate in evaluation activities, as the person in charge of the association, I evaluate at the end of each activity to find out what obstacles are faced during the activity, from the obstacles we find we are scheduled for a joint coordination meeting to discuss solutions to improve future activities, in the hope that the next activity can run smoothly and successfully". (Interview dated 14 October 2022)

Participation of families with children with disabilities in realising an inclusive society

No.	Form of Participation	Activity Performed
1	Participation in decision-making decisions providing data and information, active in the preparation of raft programme plans, active in prioritising needs and active in decision making.	Leading the process of the meeting, willing to make.
2	Participation in the implementation Physically/energetically involved in	Participation in the implementation of the programme starts from socialisation

implementation of activities	activities, implementation of the programme both family parenting and therapies for children with the help of families, to being active in administrative and coordination activities.
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3	<i>Participation in benefits</i>	Participation in benefits is more positive for the surrounding community, by participating in activities to maintain environmental cleanliness, participating in religious activities, maintaining environmental security, and participating in economic business group activities (<i>home industry training</i>) to improve the family and community economy.
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4	Participation in Evaluation	Actively involved in supervision and monitoring. activities and programme evaluation, through joint coordination in every programme implementation that is carried out periodically with the aim that if obstacles/constraints occur, solutions can be found quickly and appropriately.
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Source: Data processed in 2022

Inclusive Community in Ngawonggo Village, Tajanan District, Malang Regency

An inclusive society is a society that can accept various forms of diversity and differences and accommodate them into various arrangements and infrastructures in society. Various forms of differences and diversity include differences in physical/mental abilities or people with disabilities. People with disabilities as an inclusive society have

differences in terms of physical and thinking abilities because there are deficiencies or imperfections. The challenge is how the public responds to these differences and tries to help the rights of groups with disabilities that have not been well accommodated and social protection that is not optimal and maximum for them. An inclusive environment has an inclusive "attitude" because an inclusive environment is a social environment that is open, friendly, eliminates barriers and is fun because every citizen without exception respects and embraces every difference. In an inclusive society that consists of many differences, such as religion, race, and ethnicity.

The characteristics of an inclusive society are a society that is open, friendly to anyone without exception, respectful and appreciative of each other and heeds the differences that exist, coexisting in a natural atmosphere without any awkwardness.

There are indicators that a society can be called an inclusive society, namely:

Religious and community leaders have understood the importance of supporting an environment that provides space for children with disabilities to grow and develop naturally

The results of interviews with informants of Islamic religious leaders (Mr MAD) suggested that:

"Children with disabilities are the gift of Allah SWT, if asked, anyone does not want to give birth and be born with disabilities, madam, in fact, in my opinion, with this condition, Allah SWT loves them and is happy for the parents who are given these children because they are getting a test from HIM, a person's deeds are not from his physical condition, but his pious deeds. Alhamdulillah, children with disabilities (physically disabled) diligently recite the Quran at the mosque) We do not discriminate against children with any condition. The important thing is their faith, so we parents and the surrounding environment are obliged to create safe and comfortable conditions for the growth and development of children, especially children with disabilities." (Interview dated 14 October 2022).

The statement of religious leaders is reinforced by a statement from a community leader (chairman of the association) who argued that:

"I try as much as possible to educate the parents of children with disabilities about how to take care of, care for, educate children in this disability category, as well as to the wider community, to the community I convey that

children in any condition have the right to live safely and comfortably, so that one day they become good and useful people for religion, country and nation, children also have the right to get a livelihood, proper education. To realise all of this, it takes the participation of the community to make it happen by treating children as normal children, not underestimating, accepting the presence of children with disabilities as part of the community members here" (Interview dated 14 October 2022).

The statements of the two figures were corroborated by the statement of Mr MU (village official) who stated that:

*"This village is indeed the village with the largest number of disabilities, but with this many disabilities, it is a challenge how we can provide rights for all citizens in Ngawonggo Village to respect and appreciate fellow human beings regardless of their condition. Alhamdulillah, this village became a **pilot village in the category of Disabled Child-Friendly Village**. This is proof that children with disabilities in this village have the space to grow and develop naturally according to their age." (Interview dated 27 October 2022).*

Observations show that these community leaders understand the importance of a supportive environment for the development of children with disabilities. They are fully aware that the development of children begins with the family environment of the child with a disability, then the immediate environment, neighbours and then develops into the wider community. In daily life, family, friends, parents, and the wider community have participated in supporting the growth of children with disabilities in a natural way.

Society treats children with disabilities as normal

The surrounding community plays a major role in supporting the realisation of an inclusive society. An inclusive neighbourhood has an inclusive "attitude", which is a social environment that is open, friendly, eliminates barriers and is pleasant because every member of the community without exception respects and embraces every difference. In an inclusive society that consists of many differences, such as religion, race, and ethnicity.

Based on the results of interviews with Mr NGZ (parents with children with disabilities) as well as the secretary of the association of parents with children with disabilities, he stated that:

*"The community environment here, Alhamdulillah, can be said to accept the existence of children with disabilities, this is an asset for children to be able to grow and develop naturally, I believe that the naming of this village as a pilot village for the category of **child-friendly villages with disabilities**, is proof that the community environment of this village has been able to appreciate the differences that exist, has been able to accept children with disabilities, has been able to provide space for children to grow and develop optimally; although it cannot be denied that there is a small part of the community that still considers disability a disgrace, disability is a curse from the creator. But I believe with time it will all go away". (Interview dated 27 October 2022)*

Children with disabilities do not feel awkward (playing and learning together with normal children)

The results of the interview with Andini (a child with a disability with a left hand only up to the elbow), stated that:

"I used to play and study with other friends, also recite the Koran at the mosque together, I was very happy, my friends were normal, and no one asked about my disability, (Interview dated 27 October 2022).

At the time of this research (the researchers also made observations) the child had just returned from school still wearing his scout uniform, looking cheerful and smiling as he greeted us. This shows that the child is oblivious to his disability, he does not seem to have any problems with himself. The participation of parents of children with disabilities has been able to strengthen children and provide space for maximum and natural child development.

Village government support for children with disabilities and their families

An 'inclusive' environment provides space for children to grow naturally. Realising this requires the support of the local government. In connection with the phenomenon of the large number of people with disabilities in Ngawonggo Village, Tajinan Sub-district, Malang District, it is important to take responsibility for the fulfilment of their rights, including the right to acceptance and good treatment not only from their families (both parents), but more

importantly, acceptance and good treatment from the local community.

The local government's concern to realise an inclusive society is demonstrated by the budget allocation in the Village Fund Budget (ADD), as well as the Decree issued by the Head of Tajinan Sub-district, Malang Regency, No. 461/25/35.07.15/2019, for the term of service 2019-2024. At the same time, Ngawonggo Village was designated as a pilot village for the "Disability Friendly" village category at the Tajinan District level. This proves that with the largest number of people with disabilities, supported by the participation of parents with children with disabilities, Ngawonggo village has become a pilot village for the "Disability Friendly Village" category.

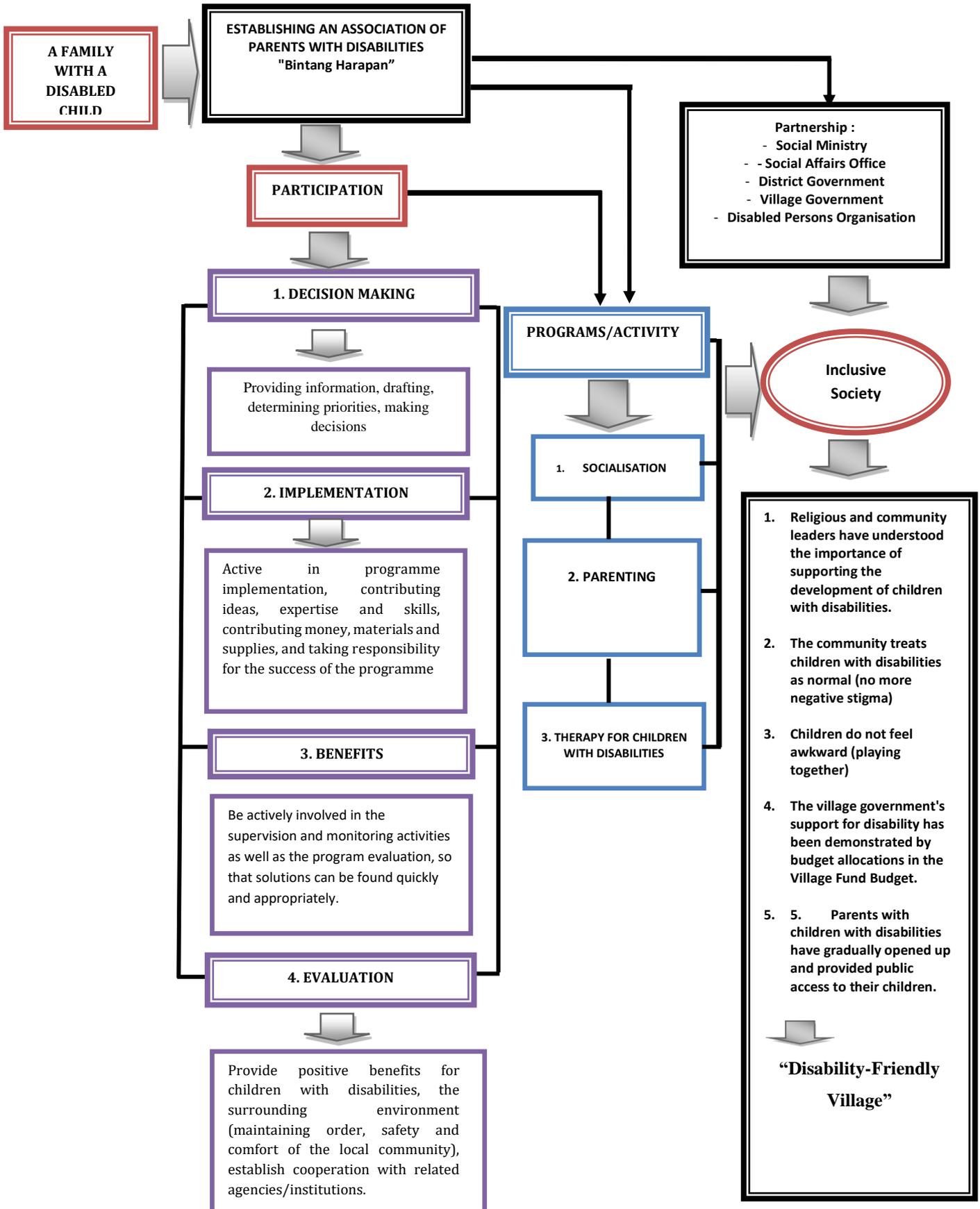
Parents of children with disabilities have gradually opened up and provided public access to their children

The results of the interview with TS (head of the association as well as a parent with a child with a disability, argued that:

"We parents with children with disabilities have been able to change our mindset, where parents initially felt embarrassed to have children with disabilities, slowly changed and even now it makes children with disabilities our main concern, we are aware that children are entrusted by Allah SWT, so for the sake of child development and supporting the child's personality I have been able to free my child to go out either to school, play, learn with his peers here or at school ". (Interview dated 27 October 2022)

The 5 characteristics of an inclusive society found in the community of Ngawonggo Village, Tajinan Sub-district, Malang Regency are: 1) Religious and community leaders have understood the importance of supporting the growth and development of children with disabilities, 2) The community treats children with disabilities fairly (no more negative stigma), 3) Children do not feel awkward (playing together), 4) Village government support for disability has been shown by allocating a budget in ADD and 5) Parents of children with disabilities have gradually opened up and provided public access to their children. These conditions have earned Ngawonggo village the title of 'Disability Child-Friendly Village'.

Participation Model for Families with Children with Disabilities in Realising an Inclusive Society



Description: Families with children with disabilities in Ngawonggo Village, Tajinan District, Malang Regency, were encouraged and facilitated by the Karya Bakti Foundation "Bhakti Luhur" through the Community Resource Rehabilitation Development Centre (PPRBM) with the support of NGO CBM German, until 2000, with the formation of an association of parents with disabilities with a board training programme, social inclusion programmes and disability product exhibitions. This association then received recognition from the local government with the issuance of a Letter of Caat Tainan Tajinan District, Malang Regency with No. : 461/25/35.07.15/2019 on the formation of the committee of parents with disabilities of the Tajinan sub-district for the term of service in 2019-2024. The existence of this association makes it a means for administrators and members to actively participate. The forms of participation carried out by the management and members of this association include: 1) *Participation in decision-making*, which is the participation of the community in decision-making through programme planning, the indicators are as follows: a) involvement in meetings or deliberations, b) willingness to provide data and information, c) involvement in the preparation of draft programme plans, d) involvement in determining the priority scale of needs and e) involvement in decision making, 2). ***Participation in implementation*** is the participation of the community in development in the form of contributions, including a) participation in resources, b) participation in administration and coordination, and c) participation in programme registration, 3). ***Participation in benefits***. Participation in benefits is participation in providing more positive benefits for the government and the community. This participation is in the form of participating in activities to maintain environmental cleanliness, participating in religious activities, maintaining environmental security and participating in regional defence economic business group activities to improve the economy, and 4). ***Participation in evaluation*** *Evaluation is* carried out in addition to what is done by the established plan.

Program activities are carried out by socialisation, parenting families with children with disabilities and therapy, which in its implementation has collaborated with the Ministry of Social Affairs, Social Services, Districts, Village Governments, Organisations of Persons with Disabilities, which ultimately results in an inclusive society: 1) Religious and community leaders have understood

the importance of supporting the growth and development of children with disabilities, 2) The community treats children with disabilities fairly (no more negative stigma), 3) Children do not feel awkward (playing and learning together), 4) Village government support for disabilities has been shown by allocating a budget in ADD, 5) Parents of children with disabilities have gradually opened up and provided public access to their children. These conditions have earned Ngawonggo village the title of 'Disability Child-Friendly Village'.

CONCLUSION

Based on the results and data analysis that has been carried out, it can be concluded that: The participation of families with children with disabilities is one of the models of efforts in realising an inclusive society. The forms of participation include: 1). *Participation in decision making*, 2). *Participation in implementation*, 3). *Participation in benefits*, and 4) *Participation in evaluation*.

The Activity Program is carried out by socialisation, parenting families with children with disabilities and therapy, which in its implementation has collaborated with the Ministry of Social Affairs, Social Service, Districts, Village Governments, Disabled People's Organisations, which ultimately results in an inclusive society, namely: : 1) Religious and community leaders have understood the importance of supporting the growth and development of children with disabilities, 2) The community treats children with disabilities fairly (no more negative stigma), 3) Children do not feel awkward (playing and learning together), 4) Village government support for children with disabilities has been shown by allocating a budget in ADD, 5) Parents of children with disabilities have gradually opened up and provided public access to their children.

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