

Ecological Model in Empowering Families of Children with Special Needs

Imas Diana Aprilia, Tjutju Soendari
 Universitas Pendidikan Indonesia
 Bandung, Indonesia
 imasdiana@upi.edu

Abstract—Barrier to early intervention remains that lack of clarity over learning children with disabilities means that parents often fall between the gaps in services. In this obvious issue, conducted through descriptive qualitative research method, the current study draws attention to design a model based on an ecological approach as an early intervention guide for families of children with disabilities. The data were collected from three families who possess mentally retarded children, deaf children, and children with autism through interviewing, observation, and document analysis. The results showed that the different parenting patterns among parents tend to lead to authoritarian and over protective behaviour. Parents generally meet great difficulty intervening their children with disabilities. The formulated model encompasses an early intervention scheme that refers to the concept of Family Quality of Life (FQOL). The five associated stages are as follows: (1) setting goals, objectives, and results, (2) setting materials, (3) implementation of strategies (4) practice or simulation (4) evaluation, (5) follow-up. Through early intervention training based on the principles of andragogy and the principles of intervention, it gives the family the opportunity to be the main environment for children to frequently engage their appropriate roles. Early intervention training program is a noteworthy part of attempts to empower families of children with special needs. Openness early on, support and family commitment to their respective roles and responsibilities in implementing an ecological model have delivered valuably positive effects, and it is therefore argued that an ecological model can be utilized as a guide for teachers and therapists in applying appropriate interventions.

Keywords—*ecological model; early intervention; family empowerment; children with special needs*

I. INTRODUCTION

Early intervention is an activity to enhance children development and minimize their confronted barriers and underdevelopment. The quality of intervention services depends on the family's perspective and understanding towards the problems of children with special needs [1]. The changing paradigm from the medical model to the social model provides an opportunity for the family to be part of the intervention effort and has broad implications in its practice. As well, shifting in perspectives of children with disabilities are also accompanied by a shift in the practice of early intervention from the traditional approach (child-centered) to the family-centered approach [2]. The traditional approach (child-centered) figures out children and families based on lack of

children and families. Interventions are directed and determined by professionals, both regarding crucial matters that must be addressed, when, and how parents should specifically intervene the children [3]. Whereas the family centered approach (bio ecology) considers that in helping children development, efforts must pay emerging attention to the interactions between the characteristics of children and their environment in natural situations. In this respect, this is in line with the Bronfenbrenner's concept [4], that "the family environment as part of environmental microsystems will contribute positively to the growth of children." Bronfenbrenner's perspective towards the environment confirmed the importance of roles and family involvement in supporting the achievement of children's developmental abilities [5].

Most importantly, some children with special needs experience more barriers and developmental delays, which require considerably serious attention and treatment. They will be very dependent on assistance from the nearest environment. Children with special needs generally do not take independent decisions and must rely on their parents or caregivers to help and monitor their daily activities due to mental or physical limitations [6]. Family support and services must be concerned to redress negativity and strengthen positive impacts [7]. Family outcomes are the impacts (both positive and negative) that families experience as a result of support and services for them or their children with disabilities [7]. This has discovered that children with special needs are very dependent on the closest environment, and thus they necessarily acquire extra handling from the environment. Family involvement, especially parents, also plays an important role in the effectiveness of interventions for children with special needs [8]. Family as the smallest system for children must have acceptance and qualified skills, forasmuch it will bring positive impacts on optimizing the children development [9].

Besides, lack of clarity in parenting is a culprit that makes parents feel overwhelmed, riding around circles and stuck in the same problem over and over. Not to mention, lack of parental understanding of the characteristics of development and the needs of children, inaccuracies in stimulating children, the application of different parenting styles, and unclear patterns of interaction between families are some of the real problems faced by families who have children with special needs. The current condition has illustrated that it is not easy

for parents of children with special needs to be able to meet the demands of development and provide a developed environment and learning environment that suits their children condition. The complexity of these real problems certainly requires a systematic effort to consider the opportunities oriented towards the development of an empirically ecological model tested which can be confirmed by its contribution to improving early intervention services. The ecological model is selected as one of the early intervention models that emphasizes the process of providing the environment by empowering family members [10]. Such formulated model has emerged as an area for attention to develop services and early intervention by involving family members to provide appropriate services for one of their family members who experience developmental barriers.

II. LITERATURE REVIEW

A. Ecological Theory

The main focus of the ecological theory developed by Bronfenbrenner is on the social context in which children live or interact and people who will influence their development [4]. This framework proposes a view that the environment strongly influences development because the family environment is the main and first environment in child development [9]. It is also known as the basis of early intervention that focuses on the family, based on Bronfenbrenner's ecological principles of child development principles [4].

B. Early Intervention

Chua, A.C.K, has argued that Early Intervention (EI) is a broad spectrum of activities designed to enhance a child development, usually from the birth to age six [11]. The early years of a child's living are recognized as very essential for the development of skills such as motoric, cognitive, adaptive, communication and social. Early intervention is very important to help develop children abilities or to minimize factors or risks of disability [3,11,12]. Early intervention that focuses on the family emphasizes the provision of support to the family to be able to optimize the growth of children who experience developmental barriers.

C. Family Quality of Life (FQoL)

Family Quality of Life (FQoL) is described as a degree where the needs of each family member meet each other, enjoy each other's time together, interact with others and can jointly carry out meaningful activities to the family [13,14]. FQoL is also described as a meeting point between QoL from each family member individually and is a factor that affects the family as a whole [15]. For such reason, parental involvement in the education of children with special needs is very essential [16]. Family Quality of Life (FQoL) is one approach expected to be able to help all family members look after the children with special needs as part of family members. Quality family functioning is illustrated in nine associated dimensions as follows: 1) family health. 2) family economic welfare, 3) family relations, 4) other people's support, 5) institutional support for children with special needs, 6) influence of the

value system, 7) career and career preparation, 8) leisure and recreational use, 9) interaction with the community [15].

D. Children with Special Needs

Greenspan and Wieder suggested that traditionally "Children with special needs" is a term taken from the term syndrome [17]. It is generally used to give labels, among others, to children with autism, mental retardation, and down syndrome. The term Children with special needs emerged as a result of changes in the perspective of the community towards Exceptional Children. This new view believes that all exceptional children have the same rights as children in general. Lynch, has asserted that children who need special education are children who are permanently or temporarily need special handling of education from the teacher, institution, and system during their school levels as a result of their disorders either physical diseases, mental illness or in combination or emotional conditions, or for further reasons of unfavorable situations [18]. Based on Lynch's opinion that these conditions can interfere with the growth and development of children either physically, spiritually and or socially, And thus, they cannot take respectable education. In other words, children with severe disability and feeding problems have the potential to lead and responses barriers once they are given guidance services or appropriate interventions.

III. METHOD

The current formulated study uses a descriptive qualitative approach. The research process is carried out in three stages. The first stage is portraying factual conditions about family profiles, obstacles and family efforts to intervene. Conducted in Bandung, the research data were extracted from three families of mentally retarded child, deaf child, and autistic child, through interviews, observation, and documentation studies. The instrument used refers to The Family Quality of Life Survey (FQoL Survey).

The second stage is designing ecological framework for families with special needs children. This model was developed based on needs analysis in the field and based on theoretical studies of early intervention. To validate the design of ecological models a Focus Group Discussion (FGD) was conducted by involving experts in the field of special education, practitioners, and parents. The results of FGD presented several inputs to be revised or developed into feasible models to be tested.

The final stage, known as the trial model, is tested limited to several families. The implementation of the model provides an overview of the feasibility and acceptability of the family on the tested ecological model and is expected to be a guide in empowering other families of children with special needs.

IV. RESULTS AND DISCUSSION

A. Results

1) *Objective condition of family profile:* The aspects observed were related to socioeconomic status, level of

education, and parenting. An overview of these conditions might be seen in Table 1.

TABLE I. OBJECTIVE CONDITION OF FAMILY

Aspect	Family 1	Family 2	Family 3
Socioeconomic Status	Middle	Low	Middle
Profession	Father works as a seller, and wife as a housewife.	Father works as a driver, and wife as a housewife.	Father works as a private employee, and wife as a housewife.
Education Level	SMA-SMA	SMA-SMA	University level-SMA
Parenting Style	Parents tend to apply permissive-over protective parenting	Parents tend to apply authoritarian-over protective parenting	Parents tend to apply authoritarian parenting

In general, those three families of children with special needs are in middle to lower socioeconomic status. Regarding the parents' profession, fathers have diverse types of jobs such as seller, driver, and private employee. On the other hand, all mothers work as housewives. Education level of parents, the average is senior high school graduates (SMA). The results of such observation disclose that in the three families, parents adopt different parenting styles, yet tend to lead to authoritarian and over protective behaviors.

2) *Obstacles and intervention efforts:* Based on interviews with those three chosen families, the results showed that most families experienced problems in several dimensions of family quality of life, known as the dimensions of family relationships, support from others, the influence of value system, career and career preparation, utilization of leisure and recreation, and interaction with the community.

These obstacles deal with the lack of knowledge and understanding of the family regarding the development conditions and potential of the children, thus the family feels confused to carry out their role effectively especially when stimulating their children. Nevertheless, the efforts that have been accomplished by the family related to interventions in the family health dimension are families implement a healthy lifestyle and families sometimes consult with a paediatrician or general practitioner. Another effort is in the dimension of support with other institutions, the family has built communication and collaboration with schools.

3) *Formulation of ecological models:* The purpose of formulating such model is to provide guidance for families of children with special needs. Ecological model patterns or schemes can be seen in the following picture;

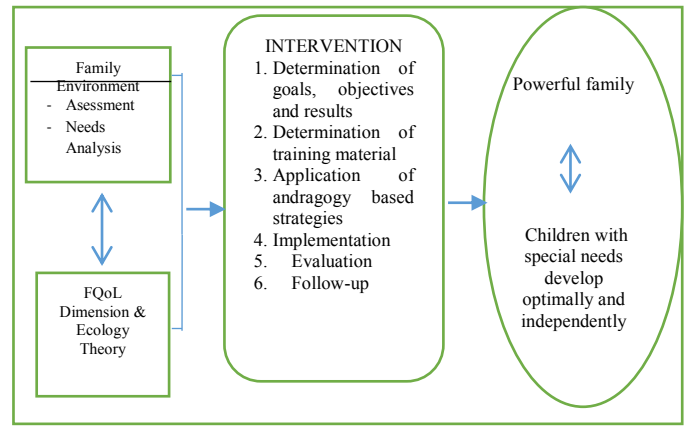


Fig. 1. Ecological model.

This ecological model is developed based on the following steps;

- Explore and analyze the family environment through assessment and needs analysis. This first step is conducted to get an overview of the roles and functions of the family in empowering interaction styles, relationships, and parenting accomplished by families of children with special needs. This first phase is also expected to obtain data about the obstacles and potential or family efforts. The process of analyzing the sustainability of family roles and functions refers to the nine dimensions of Family Quality of Life (FQoL) and the principles of ecological theory.
- Carry out intervention training or workshops. This formulated activity is intended as an attempt to improve understanding of the conditions and needs of children with special needs, as well as to assist families in training their children to intervene. For this reason, the steps that should be accomplished are a) determining goals, objectives and results. Such initial phase is based on the empirical condition of family profiles and field needs analysis. Furthermore, the next phase to be conducted is determining the results or targets that will be achieved by referring to the FQoL dimensions and ecological principles. b) set material. c) strategies in the form of training by taking into account the principles of andragogy (the learner needs to know; self-directed learning; prior experiences of the learner; readiness to learn; orientation to learning and problem solving; motivation to learning); d) implementation e) evaluation, and f) follow-up.

4) *Model implementation test:* Referring to the perception delivered by Kolb in Herlina that the implementation of either training or workshop programs for parents needs to received serious attention to the following phases [19], such as (1) starting with the assessment of parental needs for training, (2) the researcher or trainer identifies and communicates the goals, objectives and results of the training, (3) establishes relevant content, which is directly teaches and discusses various material considered important, known as an understanding of the profile of children with special needs,

classification and barriers that arise from conditions of specificity, efforts to fulfill the ideal family role based on FQoL dimensions, (4) active demonstration, in which the trainer or researcher may actively demonstrate techniques or strategies for intervening children. Special programs offered are as follows family of deaf children is given basic training in developing communication of sound and rhythm perception (PKPBI), besides family of mentally retarded children is given self-development programs, and family of autistic children is given communication development programs and social behavior. (5) parents possess the opportunity to practice the results of training in the natural situation of children and their families. (6) parents get regular feedback from the trainer during training. (7) parents have the opportunity to develop skills acquired during training.

Based on the implementation of the training steps, through interviews with the three families, a clear illustration was obtained that training provided several benefits for parents, such as: 1) increasing parents' understanding of children with special needs, 2) enhancing parental knowledge about how to educate and develop children with special needs, 3) improving the understanding and awareness that parents can intervene independently at a lower cost. 4) increasing parents' confidence in achieving children's progress as a result of the intervention.

5) *Discussion:* Brofenbrenner emphasized that family is the most important ecological development for human beings, the first environment in a child's life to learn. And if he gets a good start in the family, it will be easier to enter the wider environment. Ecological theory confirms that the development experienced by an individual is the influence of the closest environment to the individual who will determine the form of intervention to be given.

Ultimately, parents are people who are responsible for the development of their children, parents as caregivers and educators for their children really need to have the ability, knowledge and skills to provide optimal education and care to their children. This is in line with the perspective of Negri & Castorina, that the program guarantees that family members support and engage in collaborative partnership with professionals who provide treatment [8]. The involvement of parents in handling children makes intervention (therapy) effective and low in cost [20].

Early intervention is basically an attempt to empower families through the process of enhancing one's knowledge, skills, and motivation to achieve the desired results, and referring to an experience continuum that gives individuals the opportunity to use their competencies to learn new information and skills [21]. Early intervention for children with special needs should place parents as their main focus. In line with the statement in the Individual with Disabilities education Act Amendment (IDEA) in 1997 mandating parents to focus on improving children's communication, cognitive, social, emotional and motoric development [22].

From such observations, children with special needs certainly need awareness and intervention as early as possible from their parents or family. The effectiveness of various strategies for handling and improving the life skills of children

who have special needs will depend on the participation and full support of the family and community [23]. The earlier the intervention is given, it is expected to provide better benefits in overcoming the impact of the developmental obstacles experienced by the child.

Ideally, families of children with special needs is the involvement of mothers and fathers and other family members consistently and openly in dealing with their children's development problems [1], filling quality free time, and establishing intense communication interactions and synergy school and therapy or professional center [24].

Even though these indicators have not been optimally achieved by the three families of children with special needs, the results showed that with the principles of andragogy, the learner needs to know; self-directed learning; the learner prior experiences; the readiness to learn; the orientation to learning and problem solving; motivation to learning [25], applied through early intervention training, demonstrated positive changes from parents.

Nevertheless, there are several obstacles including parents having difficulties in continuing their role in educating their children with special needs, providing training materials that are still common and the role and potential of other unexplored family members. These constraints may reinforce several arguments debating about parents who have implemented early intervention for their children, such as: 1) Parents actually do not give up on their primary roles as parents in their duties as teachers for their children. 2) It is very essential if family-centered services support parents in identifying their needs. 3) Provision of stigma from professionals that parents do not receive the ability to support the development of children with special needs [26].

V. CONCLUSION

This report presented the findings of research that children with special needs experience developmental barriers thus the demand to develop like normal children requires systematic and integrated intervention from the closest environment. It found family feel acutely unprepared for the challenges and tasks they are faced with, and there is a dearth of resources to help them, lack of understanding the characteristics and developmental needs of their children, inaccurate stimulation, and different parenting patterns among family members, also become obstacles to the implementation of intervention. The formulation of the ecological framework contains systematic patterns and steps aimed at guiding the family as the main environment of children in conducting early interventions developed based on indicators of family functioning (Family Quality of Life). In this regard, the implementation of intervention training is based on the principles of andragogy and the principles of intervention. It also provides opportunities for families to carry out their appropriate roles and turns into important attempts in empowering families of children with special needs.

Based on the above conclusions, the implications are cited as follows:

- To be able to implement interventions for children with special needs, parents are necessary to change their mindset and behavior patterns towards their children with special needs, keep commitment and openness to their respective roles and responsibilities and provide full support from other family members.
- Based on the benefits obtained by parents in attending intervention training program, the patterns and steps of early intervention prepared more operationally, systematically and comprehensively can be utilized as a guide and reference for teachers and therapist experts to properly implement such essential intervention.

REFERENCES

- [1] K. Sullivan, The Prevalence of The Medical Model of Disability in Society, AHS Capstone Projects, Paper 13, 2011. Rerieved from: http://digitalcommons.olin.edu/ahs_capstone_2011/13 (26Maret 2016)
- [2] S. Ozdemir, "A Paradigm Shift in Early Intervention services: from Child-centeredness to Family centeredness". Ankara Universitesi Dil ve Tarih-Cografya Fakultesi Dergisi, vol. 47(2), pp. 13-25, 2007.
- [3] D.B. Bailey, M. Raspa, B.P. Humphreys, Promoting Family Outcomes in Early Intervention. Handbook of Special Education. Oxon United Kingdom: Francis & Taylor e-Library, 2011.
- [4] J.W. Santrock, Perkembangan Anak 11th Edition. Surabaya: Airlangga, 2007.
- [5] C.G. Coogle, "A Study of Family Centered Help Giving Practices In Early Intervention. Florida: The Florida State University". International Journal, pp. 1-11, 2012.
- [6] H.Y. Liu, J.R. Chen, S.Y. Hsiao, S.T. Huang, "Caregivers' Oral Health Knowledge, Attitude and Behavior Toward Their Children with Disabilities". Journal Of Dental Sciences, 2017.
- [7] J.A. Summers, D.J. Poston, A.P. Turnbull, "Conceptualizing and Measuring Family Quality of Life". Jurnal of Intellectual Disability Research, pp. 777-783. 2005.
- [8] L.M. Negri, L.L. Castorina, Family Adaptation to a Diagnosis of Autism Spectrum Disorder. Handbook of Early Intervention for Autism Spectrum Disorders: Research, Policy, and Practice, hlm. 149-174. New York: Springer Science+Business Media, 2014.
- [9] U. Bronfenbrenner, P.A. Morris, Bioecological model of Human Development. Handbook of child psychology, 6th ed. Vol. 1: Theoretical models of human development (hlm. 793-828), New Jersey: John Wiley & Sons, Inc., 2006.
- [10] J.S. Payne, P. Polloway, Strategies for Teaching the Mentally retarded (Second Ed.), USA: Bell & Howell Company, 1981.
- [11] A.C.K. Chua, "A triple-e framework on parental involvement of children with autism spectrum disorder in early intervention". International Journal of Multidisciplinary Research and Development, vol. 2 (9), pp. 579-586, 2015.
- [12] B. Bruder, M. Beth, "Early childhood intervention. A promise to children and families for their future". Council for exceptional children: Sage.pub.com, vol. 1 (3), pp. 339-355, 2010.
- [13] A. Turnbull, L. Hoffman, J. Marquis, D. Poston, J.A. Summers, "Assessing Family Outcomes: Psychometric Evaluation of the Beach Center Family Quality of Life Scale". Journal of Marriage and Family, vol 68, Nov 2006, pp. 1069-1083, 2006.
- [14] J.C. Hartono, Studi kasus tentang FQoL pada keluarga-keluarga yang memiliki anak down sindrom di lembaga pendidikan X Bandung. (Tesis) Sekolah Pascasarjana, Universitas Pendidikan Indonesia, Bandung, 2013.
- [15] I. Brown, R.I. Brown, N.T. Baum, B.J. Isaacs, T. Myerscough, Family quality of life survey, main caregivers of people with intellectual or developmental disabilities. Toronto: Surrey Place Centre, 2006.
- [16] M. Mereoui, C. Bland, N. Dobbins, J.A. Niemyer, "Exploring perspectives on child care with families of children with autism". Early Childhood Research & Practice, vol.17 (1), pp. 1-13, 2015.
- [17] S.I. Greenspan, S. Wieder, The Child with Special Needs (Encouraging Intellectual and Emotional Growth). NY: Perseus Books, 1998.
- [18] J. Lynch, Provision for Children With Special Educational Needs in the Asia Region, USA: The World Bank, 1994.
- [19] H. Herlina, Pengembangan Program Intervensi Mandiri Untuk meningkatkan Keterampilan Sosial Anak penyandang Autism Spectrum Disorder. (Disertasi). Sekolah Pascasarjana, Universitas Pendidikan Indonesia, Bandung, 2017.
- [20] L.J. Rudy, Should parents provide their own children's autism therapy?. 2013.
- [21] M.M. Murray, L.M. Handyside, I.A. Straka, "Parent Empowerment: Connecting with Preservice Special Education Teacher". School Community Journal, vol. 23 (1), pp. 23-32, 2013.
- [22] Individual with Disabilities Education Act Amendment (IDEA). (online). 1997. Retrieved from: http://www.ed.gov/policy/speced/guid/idea/idea_2004.html.
- [23] D.P. Hallahan, J.M. Kauffman, Exceptional Children Introduction to special education. New Jersey: Prentice-Hall, Inc., 1986.
- [24] A.M. Steiner, L.K. Koegel, R.L. Koegel, "Issues and Theoretical Constructs Regarding Parent Education for Autism Spectrum Disorders". Journal of Autism and Developmental Disorders 2012 Jun, vol. 42 (6), pp. 1218-1227, 2012.
- [25] M.S. Knowles, E.F. Holton, R.A. Swanson, The Adult Learner: The Definitive Classic in Education and Human Resource Development, 6th ed. California, USA: Elsevier, Inc., 2005.
- [26] A.P. Kaisher, T.B. Hancock, "Teaching parent new skills to support their young children's development". Infants and Young Children, vol. 16 (1), pp. 9-21, 2003.