FAMILY-CULTURED EARLY INTERVENTION FOR NATIONAL CONFERENCE IN SIBU SARAWAK MALAYSIA

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Family-Cultured Intervention Model

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Abstract

In the field of special education, intervention is really common and early detection of impairment by family is more important. To avoid the growing consequences of disability, family puts a big concern on assessment and intervention. This family-cultured intervention aims to describe: (1) parents' involvement in intervention, (2) knowledge of early years of infants to the later development, (3) understanding many ways of early detection of the infants being at risk or disabled, (4) introducing the local wisdom of early intervention.

This research is a descriptive qualitative research designed on the basis of the grounded data from the snowballed sample. Interview was used to collect the data and verified by personal experience both as a researcher and the subject of the research. From the analysis, the description shows that (1) parents take very important role in the intervention process. (2). parents are involved in the intervention since the beginning of the gestation of infants in mother's womb.(3), intervention can be conducted through medical and cultural approaches (4) This family-cultured early intervention remain existed in the community, particularly in the rural areas. In addition, parents with significant problems usually makes referral to different professionals; medical, psychologist, as well as education specialist for further development of the child.

Key words: intervention, cultural, clinical, at risk, infant.

A. NTRODUCTION

Along with the development of intervention in center-based model, the attention to children at risk or impairments and disabilities has been given from many ways. Each of the professionals focuses on different point of view; medical, developmental, psychological, social, and educational services. The endeavor of services in each field of special education begins from early intervention.

The most recent scientific reviews of early intervention program recommend four models of early intervention programs. Two of the programs focused on the power of family. The first is *centered-based and home visiting models*, and the second is *family focused and culturally competent model* (Gray & McCormick, 2005). This makes sense since the family is the key care provider for the child. Intervention begins from the family both before and after child's birth. Hence, the family is expected to be more competent. More often than not, unfortunately, the family is not always ready to work alone. The family needs to refer to the professionals in the case of their children being at risk or disabled.

In a different perspective, the family-cultured early intervention model is local wisdom. It is a belief system remaining in the society, particularly in Javanese tradition. Despite their competence in early childhood intervention, the family takes the most important role regarding their children's development. It means parents do the best they can do for their children by avoiding any single sinful and harmful behavior. Parents keep this belief from generation to generation that the child's birth is strongly influenced by the either parents' good or bad deed since the beginning the congestion time. It is the culture that makes them feel guilty for doing wrong during pregnancy as what their ancestors have always suggested to avoid so far. The family is the basic environment. A child grows and develops as a member of the family. Parents are the first persons who notice certain signs about their child. So parents are supposed to have adequate knowledge about both normal and peculiar development of the child.

The final outcome of early intervention is to bridge the young children who are at risk or disabled and their family to the right decision and necessary services. For the child, the services cover health care, social welfare and education. To give the appropriate services a child should be assessed as early as possible. The reason is that the importance of the early years to later development human infant has incredible capabilities (Piaget, 1980). In addition, the effect of the infant's environment on learning is significant. Early years are crucial period of development because the period becomes the foundation of later development throughout the life span. It is believed that behavior patterns and subsequent growth are set in this period. Failure to address the earliest interaction of the child with the environment may result in waste of time. Moreover, when the disadvantage of the child is untouched it causes developmental lags. Early intervention may inhibit these problems. Hence, awareness of the importance of parenting and family relationship should be raised for promoting the child 'early years of development (Miller & Devereux, 2004).

B. METHODOLOGY.

This study on the family-cultured intervention is a descriptive qualitative study of field work. The design of the research was based on the grounded theory where the data was taken from the contextual setting (Asmadi, 2004). The sample was of newly married couples in different areas in Central, West, and East Java assigned in the snowballing technique of sampling. Interview was used to collect the data on the tradition, habit, as a culture in doing the assessment and intervention in the respective areas.

The collected data was crosschecked through the interview with the other informants living in the same areas and culture. This kind of data resulted from the interview was strengthened by personal experience as a research instrument. The analysis of the data was focused more on the description of the process rather than the results (Creswell, 2002).

C. RESULTS

In the process of intervention, the family takes the biggest part of contribution to the child's life for the following reasons. In the family-cultured intervention people believe: (1). Parents are the most important people in the child's life, (2). Early intervention can be done in two ways; traditional and medical models, (3). Parental involvement in the intervention begins from the early time of pregnancy, (4). Familycultured intervention is a tradition that reflects the basic philosophy of early understanding about the child's needs in term of holistic development.

D. DISCUSSION

Intervention begins as early as possible. To start with an intervention, assessment conducted in many ways. In the traditional approach, assessment is prior to medical assessment both before and after birth.

1. Prenatal Assessment

In a traditional model of intervention, cultural approach of early intervention may be conducted in some societies in Indonesia on the basis of living local wisdom. Particularly in Java, intervention may be done at least in kinds of celebration; four and seven months of celebration. The first is four month celebration. It is a celebration within the first four months (16 weeks) of pregnancy after marriage. Most families with four-month pregnant women usually have this kind of celebration. For the family, such a celebration does mean intervention. Instead, the family thinks is the best to do to avoid being mistaken for the possibility of defected child. It is nothing but a tradition inherited from generation to generation. It is a culture where the pregnant women wish and pray to God for having the best and perfect child in the future safe and sound.

In the day of celebration, the special food called "kupat" and "lepet" with plain taste of vegetables is served and given to the neighboring people. *Kupat or ketupat* is rice packed in braded and boiled in young yellow coconut leaf, while *lepet* is sticky rice packed in coiled young coconut leaf as well. In addition to these two sorts of food, all other kinds of the food, particularly vegetables served in the celebration should be plain or tasteless.

The celebration begins with *siraman*. It means taking a holy bath cleaning the body and hair. In Javanese philosophy, *siraman* depicts the importance of cleaning the body and soul to clean all the evil deed during the life. On the other side, *kupat* and *lepet*, which mean wrong or mistakes, are symbols of food depicting the action of revealing mistakes and apology to God for the previous sins. The *ketupat* and *lepet* should be packed in young and yellow coconut leaves. Young and yellow coconut leaf do not only mean clean and holy, but also mean high expectation as high as its tree. Plain taste of vegetables means the young pregnant woman cleans herself and

eats only the tasteless food; no salt, no chilly, and sugar or other seasonings during the day. In this way, praying to God for apology, one should be clean in body and mind. (gist of interview).

This celebration is very important since the society believes that in the 16 weeks of pregnancy God blows the soul of life in fetus to indicate the start of life. It means it is a critical time for the fetus. People believe that the wrong deed and sinful action within the pregnancy will affect the feeling guilty during the time of pregnancy. If the young pregnant woman does not hold this celebration, she feels being mistaken by the myth and will affect the infant's development during the pregnancy accordingly. Such a feeling may lead to psychological impact to the fetus development in the womb, hence may cause the child' defect or disability.

The other celebration is called *mitoni* which means seven. It is a celebration in the seven months or 28 weeks of the first pregnancy. In addition to the four-month celebration, *mitoni* signifies more spiritual power of celebration. This celebration is the time when the mother wishes to God that the fetus in the womb be safe and sound. Like in the four-month celebration, *mitoni* is started by *siraman*. It is a strong belief that the pregnant woman should take a bath and clean the hair which symbolizes the clean body and mind. Being clean in body and mind, people believe God may fulfill the wishes for the baby in the womb.

Mitoni is typically characterized by grated fruit called "rujak" made from seven kinds of fruit served with all kinds of market food. This activity symbolizes the thankful attitude for food given from God. The guests invited to the party are supposed to pretend to buy the *rujak* and market food in toy coins made from roof tile. These all mean to provide nutrition for the baby to grow healthy before birth. Meanwhile, the selling activity symbolizes the prosperous food God may give to the future baby.

In the celebration day, the couple; the pregnant women and the husband should carve a couple of a beautiful girl and a handsome boy named "Kumojoyo-Kumoratih" on a young yellow coconut. These two figures of carving symbolize the perfect couple they wish for the baby born later. They pray to God for a boy as handsome as *Kumojoyo* and a girl like *Kumoratih*. These two figures of young coconut dolls are put together to the food of which is then given to the invited guest and the neighboring people during the feast.

Scientifically, these two kinds of celebration do not mean anything, for the couple, and the whole family members, both *ngupati* and *mitoni* should be held. Otherwise, they feel regret just in case of their child born defected. It means the psychological impact of the culture is considerable in the intervention activities. Whoever deals with the intervention in term of child care should be alert to the belief and culture of the family having with children being at risk or disabled. Intervention should consider the habit and culture of the family (Laverick & Jalongo, 2011). In the cases of imminent problems, the family refers to nurses in the hospital for futher intervention on medical basis.

In medical model-based intervention, a child who is at risk or disabled can be detected as early as when it is the utero. Parent's involvement in the intervention can be manifested in this period. A pregnant mother can ask the doctor for help to detect whether or not the fetus in her utero is at risk. Prenatal diagnostic technique can detect genetic, metabolic, anatomical, and immunological disorder in the developing fetus. There are many medical advances in prenatal diagnosis. The physician can provide information for parents about the fetus through amniocentesis, fetoscopy, ultrasonography, alphafetoscopy, and chorionic villus sampling.

Amniocentesis is a medical diagnostic procedure that is widely used to determine the presence of chromosomal or metabolic disorder in the fetus. Numerous conditions can be diagnosed using this procedure including Down Syndrome, anencephaly. Fetoscopy is another way of prenatal detection by visualizing the fetus in the utero through endoscope pregnancy. Spina bifida and trisomy 13 are examples of genetic and metabolic abnormalities that can be identified by this procedure (Suryo, 2001).

Utrasonography is another system of detection by transmitting high frequency and low intensity sound waves through the woman's abdomen. The conditions such as; encephaly, encephalocele, meningomyelocele, and hydrocephaly can be detected through this kind of procedure. Alphafetoprotein is also a medical diagnostic procedure. This way of intervention is used by measuring alphafetoprotein (AFP) in the mother's blood between 16th and 18th weeks of gestation. From the AFP screening, conditions such as Down Syndrome, twins, neural tube defects, and fetal death can be detected.

2. Postnatal Assessment

The aim of assessing children who are at risk or with impairments is actually focused on finding out the children's needs for services. Based on the stages of assessment procedure as previously discussed, the professionals and the parents conduct assessment to infants and preschooler. Prior to the professional assessment, the parents are supposed to acknowledge certain traditional signs of different kinds of impairment. For the comprehensive assessment the professionals will work on more meticulous measures of visual, hearing, intellectual functioning, motor, and behavioral areas.

In the old tradition, as a part of family-cultured intervention, a mother who is delivering a baby is usually helped by a midwife living nearby. Soon after the newly born baby is cleaned, in the bare body, the baby is put on bed made from bamboo. The midwife bangs the bed in all of a sudden by saying "*aja kaget!*" (Javnese words which mean "do not be surprised"). Philosophically, this action means to remind the newly born baby not to be surprised with the sudden action of burst made by the midwife. The midwife is actually making the burst to buster the evil spirit that will disturb the baby. The evil spirit always disturbs the health of the baby, because it does not feel happy with the new creature coming in the world (personal experience from interview with a midwife, 1985). Seen from the scientific point of view, this culture means a lot of assessment. It is to identify the sensibility of the baby in terms of reflexes, perceptual-motor, hearing sensitivity, and intellectual functioning.

As the child grows naturally, the parents and other members of the family as well other people and the environment contribute major of influence to the development by nurture.

a. .Vision Assessment

Parents will easily recognize the clear symptoms of their child having visual problem when the child has physically poor eyes. But they must also be aware of behavioral indicators that their child is visually at risk. These are the symptoms or behavioral indicators the parents must be aware that child may have visual problems . The parents should be cautious of their child for having; frequently tearing eyes, rapid and involuntary eye movement, crusty eyelids, no blink reflex, Reddened eyes or lids, Parents should also notice if the child does not move eyes together, tilt head when viewing an object, bumps into object when moving, hold objects closed to eyes for visual examination, does not respond directly for objects, Squints eyes frequently, and visually scan or track by moving head.

b. Hearing Assessment

Hearing loss may be suspected when a child shows marked delays in developing speech and language. In everyday life, parents can notice their child who has hearing problem from the following signs of request of frequent repetition, watches the speaker's mouth, tires easily, speaks too loudly or softly, turns out ear towards the sound source, strain to hear, is attentive when spoken to, makes frequent or unusual mistakes in direction, Is isolated or passive, exhibits tension, or speech defect, changes in achievement after an illness, breathes through the mouth, experience dizziness, has frequent ear infection, complains of ringing or buzzing in the ears, and give, inconsistent responses to question (Directorate of Special Education, 2007).

c. Assessing the Intellectual Functioning

Parent can also be expected to function in assessing their child who is at risk or intellectually disabled. Parents can recognize their child's appearance and learning characteristics. They may recognize typical appearance of a child with "Down Syndrome". This Medical term is usually used to describe a person with intellectual disability.

The parents can also recognize their child from his cognitive development. This child usually has poor learning characteristics because of his poor cognition. He may

have attention and memory deficits. Compared with his friend of his age, he has some delays in learning acquisition. He has a problem with attending to complex or complicated processes. It is difficult for him to stay on task, to get rid of interference, and to recognize the important element of substance. In addition, he has problem with recalling a complex instruction or some digits. Parents who happen to come across with these characteristics on their child may ask professionals for more careful assessment. This kind of knowledge would help the professionals to conduct the assessment, because they can get appropriate information from the parents during intervention.

d. Assessing Motor Skills

The responsibility in conducting assessment of motor skills has been concentrated on physical and occupational therapists. For some reasons special educators and other professionals should be familiar with assessing motor skills (Smith, 1989). Parents' contribution to the assessment endeavor is very significant. Parents who are knowledgeable in normal physical symptom and normal motor development are supportive to meticulous assessment of physical disabilities.

Family-cultured early intervention is traditional. Hence, it is restricted from the modern knowledge and technology. Natural approaches of intervention such as maternal reflective teaching may be carried out for their children with hearing impairment. Similarly, spatial orientation for the visually impaired children might also be done around their house and the neighborhood. Mildly motor problem experienced by their children could be facilitated. Interactive game is typical intervention for all children in rural areas. It is an inclusive area where children with different needs and abilities get together for fun in their spare time. For mild disability, this kind of game could develop their communicative skills and intellectual functioning. Unfortunately, in the case of severe problems, parents could do nothing but complaining and blaming themselves for doing wrong unintentionally during the pregnancy. Being away from the community medical center, clergy men take very important role for them in this kind of situation.

For parents with adequate knowledge usually makes referral to the Integrated Health Service when physically handicapping conditions appear and become noticeable when the child is born. Instead of doing intervention without knowledge, parents refer to professional, especially to the Public Health Center (Pusat Kesehatan Masyarakat). The physicians, for instance, can tell them about the at risk fetus in mothers' gestation. Unless detected within this period, parents may notice whether or not the newly born baby is physically deformed. Even when parents do not notice some deviation during the developmental period, they still contribute some information to the professionals in carrying out necessary assessment. They are worried about the growing consequences of disability unless they go to nearest doctor of professionals.

3. Steps of Early Intervention Program

a. Understanding the Impact of Diagnostic Impairment

One of the purposes of early intervention is to diagnose the mature and extent of disabilities and handicapping conditions. Unfortunately the presence of a child with certain disability will bring up some impact on the family, the society, and the person himself as an individual. The family can be shocked, confused, and distressed. Some parents, particularly mothers feel very protective and maternal towards their baby, but the news that the baby is handicapped may cause them to reject him in the beginning. They may feel ashamed and envious of other with normal babies. They feel that having a disabled child is sort of stigma or low self esteem. Some parents often feel quality at having such feeling and thoughts. They may accuse each other to have done something wrong and consider the handicapped baby is the result of a punishment. This kind of attitude may cause poor interaction and hostility among the family members. Some parents may be worried about their child. They do not know how to cope with all of the problems.

b. Accommodating the Needs and Services for Family.

Having a child with a severe impairment can pose problems for the family who may have to cope with many form of frustration. The experience shows many families who come to professionals during the traumatic periods feel intrinsically supported to sustain themselves in the intervention process (Carpenter, 2005). They need services to care for this child in many ways.

The parents need information on how to handle the child and find the place for services in the community. They have to decide that consultation to the doctor or psychologist will help them release the burden. As the child grows, they may also need locating baby sitter or respite care providers. They will realize that they have to give the education by looking for information to find the most appropriate day care, preschool or the inclusive educational services.

4. Family-Cultured Early Intervention Practice.

a. Understanding the Child's Needs

For parents, having a child with a disability needs extra attention for intervention. The parents will realize the child first of all is a child (Lewis, 2003). He needs to survive, like other persons. He needs affection, attention, protection from the parents and siblings as the knowledge of the holistic development of the child.

b. Cultural approach of intervention

As a local wisdom, family-cultured intervention makes use of traditional approach. Head Start Program is not really common in the rural area. Hence, intervention of early years is conducted at home and the neighboring children. Natural approaches of intervention such as maternal reflective learning may be appropriate for their children with hearing impairment. Natural sign language is commonly used by family members to communicate with such children. Similarly, spatial orientation for the visually impaired children might also be done around their house and the neighborhood. Natural sign language is commonly used by family members to communicate with hearing impaired child. Interactive game is typical intervention for all children in rural areas. It is an inclusive area where children with different needs and abilities get together for fun in their spare time. Games are needed to develop their communicative skills and intellectual functioning.

In addition to local wisdom of intervention, parents with adequate knowledge usually make referral to the Integrated Health Service. Parents could refer to professional, especially to the Public Health Center (Pusat Kesehatan Masyarakat) located in each of subdistrict areas, supported by Health Ministery. In this center, pregnant women can have heath consultation and medical check for the child in each developmental stage every month. The physicians, for instance, can tell them about the at risk fetus in mothers' gestation. Unless detected within this period, parents may notice whether or not the newly born baby is at risk. They are worried about the growing consequences of disability unless they go to nearest doctor of professionals.

Beside Public Health Center, mothers with under five year-child can go to Integrated Health Service (Posyandu) provided by local women community. Mother can have health guidance, nutrition counseling for their child. Carried out each month, the child can have additional nutrition food, dentistry guide, and eyesight test as well as hearing screening for the new born, and vaccination. Like in Japan and Thailand (Sasipin Sukbunpant, Eriko Shiraishi, and Yoshitaka Kuroda, 2005) recently children with learning disability and attention deficit and hyperactivity, and Asperger Syndrome are also noticed in early detection.

c. Providing Educational Programs.

In rural areas, intervention through educational program is hardly found. In this area, children stay at home with the parents, kins, siblings, or maid (house keeper). There is no structured program intended to the intervention. Otherwise, such children may stay in homes of another together with informal care giver, or informal childcare service, particularly for working mothers. Stimulation through games is normally employed to develop the children intellectual, perceptual motor, and social as well as communication skills.

On the other hand, in urban areas, educational programs are structured and organized in center settings (Boocock, 1995). Part time play groups, for instance, may have some children play together under the teacher's supervision. Most of the activities are development strategies in terms of cognition, sensory, motor, communication, social and emotional stimulation. For older children, childcare and preschools are more commonly focused on the preparation for the pursuing formal primary schools.

E. CONCLUSION

In the process of intervention, the family takes the biggest part of contribution to the child's life. In the family-cultured intervention people believe that (1). Parents are the most important people in the child's life. Early attachment and relationship begin from the parents. Further learning and social emotional development are based on the parents' relationship to the child, (2). Both medical and family-culture early intervention models involve parents in assessment from the beginning of mother's pregnancy. In the family-cultured early intervention, mother believes celebration within the first-time pregnancy will result in better future of the child, (3) In the family-cultured intervention, traditional approach does not mean neglecting the medical aspect of intervention. They admit better service for better referral. It means they come the doctor as the final solution. (4) There is a tendency of movement to medical approach, but family-cultured intervention remains existed in the society. The adoption of movement is in term of providing facilities to develop the child's potentials. (5). Educational programs provided for children stimulation are not mainly belonging to modern approach of intervention. Rather, it would be intended to change the parents' mind set upon the importance of providing learning environment to stimulate the children' capability as a holistic individual.

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