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## EARLY INTERVENTION FOR CHILDREN WITH DEVELOPMENTAL DISORDERS WITH EMPHASIS ON THEIR RELATIONSHIP WITH CAREGIVERS

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In 1982, the first author began to conduct on an intervention program for disabled children including autism and mentally retarded children aged from two, at Research and Clinical Center for Child Development in Hokkaido University (The program will be referred to RCCCCD program). Their mothers also participated in this program. Since the children were so young, some children in a “gray zone”, not yet clearly identified as disabled, were included. As a result, some of them were proved not to be “disabled”. These experiences helped us to understand the development of children with disabilities as well as normal children. Especially, we have learned the more sophisticated and more detailed processes of development. Based on these experiences, we identified four propositions regarding early intervention programs.

### **Proposition 1. Enriched Environmental Stimulation**

No parents expect their child to be born with disabilities. Thus, the facts that an infant has any delay in development impacts on the parents seriously. It also has impacts on the parent’s stability of mind. Sometimes, it takes several years until they can accept the reality that their infant was born with disability. During these periods, they may not be able to provide enough care for him, especially providing adequate environmental stimulation such as emotional, cognitive and social stimuli. Stern (1985) stated that in order to provide enough interactions with their infant, the caregivers need to have stability of mind and a feeling of happiness about their life. The caregivers of the children with disabilities also must keep these status of mind on caregiving, even if they are beginning to be aware and anxious that their infants has disability. At this age before two, it is important for parents to decide that caregiving for the infant is the primary concern, and solving their own problems (i. e. denial, grief or despair) is a secondary problem.

Generally, parents need to have some visible evidences to accept the disabilities

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of the infant. In the cases of cerebral palsy and Down's syndrome, parents can realize and accept the child's disability at an early age, since these disabilities are evident. On the other hand, the parents, who have an infant with autism or mental retardation, may take a longer time to accept the disability and to discuss how to change their situation for better development. One day, they focus the facts of development and neglect the delay. Another day, they find the facts of disabilities and worry about them. The more supportive evidences of his normal development they have, the more time is needed to accept their infant's disabilities. According to Furutsuka's Inventory of Parents who had an infant with disabilities, most found some delays in sensory-motor and emotional developments at the age of six months. Thirty five percent of parents reported that they had some evidences of disabilities by one and half years old. Most parents still have a hard time accepting these facts. It usually takes around three years after the birth of the child for their parents to reach a point of acceptance and readiness to discuss the preferred methods of parenting. During this period, the study at the RCCCCD indicated that parents took the following three major attitudes in parenting behavior (Furutsuka et al. 1993).

#### (1) Inappropriate Emotional Interaction

There was less appropriate emotional interaction between the parents and infants with disabilities. Although there was interaction, they interacted in an inappropriate manner, such as negative or neutral emotional expression to the infant's positive emotional activity (i.e. smiling to mother). These attitudes may exacerbate delay of development.

In order to change these attitudes, the RCCCCD program offered counselling for the parents, focusing on their own problems such as their distress. However, the change of their attitudes was impossible without any change in development of their child. Based on this problem, the program focused on the facilitating the development of their child. Therefore the program was designed to counsel parents regarding problems in parenting their child.

To facilitate their infant's development of emotion, as well as cognitive development, it is a critical factor for the parents to have stability in their own emotions and responsiveness. Specifically, it is necessary to provide consistent emotional response to specific child behavior, because the infant learns and socializes his emotional expression through the interaction with his parents, especially during the first two or three years of life. For example, we found that one autistic child had a tendency to smile when she felt some anxiety, and to show aggressive behavior (i.e. punching or pushing to others) as a greeting ("nice to meet you"). Therefore, it is important for the parents to understand their infant's emotion correctly, in spite of the peculiar expression, and then, to modify them to socially-acceptable expression. Consequently, the parents need to provide various emotional expressions consistently and continuously, in their interaction with their infant. Researches of social referency reported that the infant decides the appropriate emotion for a particular context through reference to his parents' emotion (Campos and Sterberg, 1981).

## (2) Inappropriate Demands

When parents feel anxiety over the disabilities of their infant, they tend to give developmentally inappropriate demands. Specifically, the demand is too easy or too difficult for the child to perform.

These parental attitudes were called “ambivalent type”, either “overprotective” or “constant punishment or correction”. Both attitudes suppress the infant’s developments.

When given too easy demands, the infant has less motivation to do any task, which delays his development, especially in self-help activities. On the other hand, when the parents give too difficult demands or tasks, the child cannot accomplish their demand. As he fails, parents punish or correct his activities and then to the parent becoming angry. From the parental point of view, there is sufficient reason for punishment. At the point of children, punishment occurred because the parent gave too difficult demands. It leads the infant to feel helplessness and apathy, or to exhibit aggressive or self-injurious behavior. As it were, the parent and the infant have some reasons to justify their behavior. Ideally, the demand should be set a little higher than the infant’s current developmental level, which infancy indentified as “optimal discrepancy hypotheses” in setting these demand (Kagan et al., 1978).

## (3) Ignorance, refusal, or Exaggerative Response and Deprivation :

Parents’ anxiety of having a disabled infant causes another response, ignorance, refusal or exaggerative response. Therefore, the infant cannot receive or obtain any consistent response to his specific behavior, so he can not associate his behavior with his parent’s response. Lack of contingency causes no learning. The parent’s consistent response to infant’s specific behavior is an essential factor for cognitive development. These three major attitudes can deprive sensory, social and cognitive stimulations from the infant with disabilities, especially, under one year old.

In order to avoid these deprivation, it is important to follow three stages of the ideal course of parents-infant interaction: ① the parents imitate or follow the infant’s behavior, ② they modify these imitation, to highlight specific parts of task, and to elaborate new skills in the chains of reciprocal behaviors, and ③ the parents lead the infant to understand how to think, what is important, and what style of expression is socially acceptable.

These conditions are indispensable for the development of the children with disabilities. Through our intervention programs, it was found that the development of disabled children is facilitated most effectively by these methods. Also, this method can be most effective when the infant interacts with the the person whom he regards as a secure base (mother, father or grandmother).

Under normal development, infants make attachment to a specific person, and fear strangers at around a year old. In other words, he selects the caregiver as the reference of his behavior, especially social behavior. For example, when he cannot decide how to behave, he imitates the behavior of this attached person. As it were, he can interact, at an appropriate developmental level, with only this specific person, but with the other persons he can not interact appropriately, because stangers do not

behave specifically according to his specific expectation. As result, he feels anxiety toward a stranger as called "8 months anxiety or 12 months anxiety" (Spitz, 1950). But it is important to understand that this behavior is brought not by his fear or anxiety but by discrepancy of his expectancy. We found that disabled children making attachments to specific persons more strongly than normal infants. Since their flexibility of behavior is restricted, the separation from the attached person caused more severe behavioral dysfunctions.

After children with disabilities have acquired the attachment person, only the attached person can use behaviors (praise, scold) as social reinforcements.

In summary, to use these methods effectively, it is too late to begin intervention after parents accept the fact of their infant's disabilities. Even if during they are still uncertain and confused, the improvement of the interaction between parents and infant must be started.

### **Proposition 2: Plasticity of Brain and Constraints of Environmental Stimulation on Development**

In 1936, Kennard studied the effects of resections of motor cortexes of rhesus monkey on their behaviors. A monkey who was sectioned early, recovered to walk and feed by himself. On the other hand, a monkey that was damaged after adulthood did not recover to walk. This phenomenon is called "sparing". Namely, the repair of neuronal function occurs when the brain is injured early in life, but when injured later, they can not recover the function. Also, it is well known that some children with damage in the left temporal language area showed recovery of language function. Researchers have reported that patients whose brain was damaged in childhood showed the recovery on various kinds of functions. The "sparing" has been identified as the "Kennard Principle" (Kennard, 1938).

The basic assumption of the Kennard Principle is that all areas of the brain have functional equivalence, which is changeable to the center of any function when young, and exercise makes the localization of some function (e.g. language). Therefore, if the damage occurs before localization is determined, the neighboring areas or another hemispheric areas which correspond to the damaged area substitute this damaged function. If this principle is correct, persons who concern the children with disabilities (parents, teachers and others) can hope for the recovery of children with disabilities.

After the decade of the 70's, it became evident that the Kennard Principle has many restrictions. New trends of research developed a theory of the "plasticity of the brain". The "plasticity of the brain" means that brain have self-repairing functions and can construct new neuronal circuits if innate circuits were damaged. Being different from the "Kennard principle", plasticity has the restriction which is called the "critical period".

Researchers made experiments to answer the following questions. "After brain damage, under what conditions does the reconstruction of neuronal circuits occur? If no repair, why did it not occur?."

Several studies found that localization of various functions occurred at different ages, including the period of fetal development. For example, the localization of visual

function starts after birth and continues until one year old. On the other hand, language function has the plasticity until adolescence. When the damage occurred in the period before or during localization, the recovery of function can be possible. However, if localization is over, no recovery was expected. This sensitive period is defined as the "critical period". During this period, the organism needs inputs from external environment by which the neuronal circuits become complex and sophisticated. If deprivation of inputs occurs at this period, the neuronal circuits are in insufficient and inappropriate states.

According to the well-known findings of Hubel and Wiesel (1970), the principle of a "critical period" has the validity in the domain of sensory and associative sensory cortex. They reported that when one eye of a kitten was closed off for several weeks, the receiving cells in the visual cortex did not develop appropriately. Atkinson and Braddick (1988) also reported that the unused eye of the children with strabismus became weak sight, but when the used-eye was shut with an eye-patch, they began to use the previously unused eye. As a result, visual acuity of the unused eye increased. However, when the eye-patch was removed and the child use both eyes, the unused eye's acuity weakened again. In another words, the neuronal circuits which had been made in the critical period have better stability than those which were made after the critical period.

According to the definition of "the critical period", the environmental stimuli which were needed to make neuronal circuits for specific function, and the period when these stimuli were needed is determined innately. However, the complexity and sophistication of those circuits are operable through manipulating the quantity and quality of inputs. Disabled children have some difficulties in constructing neuronal circuits (i. e. difficulties in learning and difficulties in processing sensory input). These data regarding the "plasticity of the brain" indicate that there is a need to facilitate the development of neuronal circuits in disabled children.

For example, the sucking reflex of the infant, ordinarily, works only by stimulating mouth, lips or cheeks. Through exercise, he becomes good at sucking skills, and associates other stimuli that occurred contingently with a sucking, such as mother's face, smiling, and vocal sounds. This process is learning. There is a need to change from innate neuronal circuits to more adaptive circuits.

Children with disabilities also show some normal construction of the neuronal circuits along the above mentioned course. However, different from normal children, they have some problems. So, parents of children with disabilities need to intervene in the following two domains. Intervention is needed to repair the damaged reflex and to strengthen the reflex circuit (that is, repair of innate circuits). Intervention also needed to assist the infant to receive sensory stimuli correctly. Disabled children, especially autistic children have the tendency to avert overstimulation or affective stimuli. Parents should understand this is not an aversion of themselves but the results of the dysfunction of neuronal circuits for sensory information processing.

If they interpret the behavior of the child as aversion to them, parents will not interact with their infants. But understanding the behavior as resulting from overstimulation, they can strengthen sensory processing with interactions at the appropriate

level of stimulation.

According to the studies of development, various kinds of functions have critical periods within the first two years. Each function needs specific experimental stimuli to construct its own neuronal circuit. These needs cause difficulty in intervention. Along with understanding these needs, professionals, and parents too, must work to facilitate these children's development with effort and endurance.

### **Proposition 3 : Difficulty of Motivation**

The most difficult problem in rearing children with disabilities is to motivate them to do tasks. In most cases, although the caregivers give stimulation (tactile, auditory or visual) to their infant, he shows no interest or avoids the stimulation. However, stimulation is indispensable to the development of children with disabilities. In order to maintain sensory stimulation, the caregiver usually needs feedback from the child, such as smiling or getting his attention. Usually, if caregivers guess that the child has not an interest, they try to give another stimuli to motivate him. However, they often receive no feedback from the child with disabilities, so finally they feel that their devoted efforts are fruitless. As a result, they abandon giving sensory stimulation.

In addition to their lack of responsiveness to sensory stimulation, children with disabilities generally have a tendency to be unresponsive to any task. Consequently, there is doubt as to whether there is impairment in their mechanism of motivations.

Theoretically, "motivation" or "drive" means the mental condition in which an organism feels absence of something needed or desirable, and is searching for satisfaction (Hebb, 1972).

The mechanism of motivation consists of two subsystems. One is the arousal system and another is the limbic system. The arousal system supports the cortical process, like gas for a car. On the other hand, the limbic system is regarded as the centers of the motives (the center of hunger and satiation is in the hypothalamus, and the center of emotion such as fear and pleasure is in the limbic system).

Als(1982) recorded the infant-mother interaction with VCR and studied differences in the interaction among normal, severely mentally retarded, and blind infants.

In the case of normal infants, the interaction occurred appropriately. For example, when the mother did something, the baby gazed at the mother, and also, when the baby vocalized, moved or did something, the mother stayed still to receive feedback information from her baby. Sometimes they laughed together.

The blind infant and his mother, they could not interact appropriately for the first few weeks, however with intervention to the mother on how to give auditory stimulation instead of visual stimulation. Their interaction became better after one month or so. In this case, in spite of knowing her infant's blindness, the mother needed more than one month to change her parenting behaviors.

On the other hand, the interaction between the mother and infant with severe disabilities was inappropriate from the first time and the mother soon stopped the interaction, saying that she could not endure any more. The disabled infant showed over-

excitement (crying) with a little stimulation from the mother or he couldn't shift his level of arousal or activation appropriately to the mother's stimulation. Usually, when infants show over-excitation, mothers need to soothe them. However this mother did not know how to soothe her infant. His range of activation was so limited that even a little stimulation became out of range.

Stern (1985) said that infants before two months old need to learn "physiological regulation" with the help of their caregivers. The disabled infant also needs to acquire this ability. In order to acquire this regulation, the caregiver must learn how to stimulate and how to soothe her baby, specifically.

The method of maintaining appropriate level of arousal is as follows: when the infant with disability has a tendency of over-activation, there is a need to give brief stimulation and stop before over-activation. Even if he averts and withdraws from the stimulation for the first time, we must repeat stimulation and make him endure it. Finally he comes to anticipate stimulation.

On the other hand, when he shows no response, there is a need to increase the level of intensity and find the appropriate intensity, then maintain it. After the expectation of stimulation is confirmed, the caregivers can decrease or increase the level of intensity of the stimulations to extend the range of appropriate level of activation. After acquiring stability of activation-level, the infant is given an interactive task. For example, in playing "peek-a-boo", the caregivers initiate the play, and wait for the infant's response. Even if they receive no response, they must repeat this over ten times everyday. In order to understand what happens and what result is obtained, the disabled infant usually needs several sessions of exercises. After the experience of the whole process of the play, he starts to respond with smiles and cooing. Having understood the play, he likes the tremendous repetitions.

However, the caregivers usually express dissatisfaction about these tremendous repetitions. Since the disabled infant is making the neuronal circuits of this task through exercise, the caregivers need to endure the inexhaustible repetitions and wait for habituation to occur. When the infant expects or anticipates the desired result and he has the will to acquire the desire, it is said that he is now in a state of being motivated. It is important to understand that learning leads to motivation.

Especially in caregiving for infants with disabilities, caregivers should have the attitudes to make their infant to learn motivations, rather than they search for their infant's motives (interests), when their interactions are not appropriate.

#### **Proposition 4 : Intervention Program for Children With Disabilities**

The child with disabilities is ready to challenge tasks which facilitate his cognitive development when he is around two years old.

Usually he responds to the cognitive tasks in the following manner: (a) He can not understand the situation and how to respond, so he seems to be inattentive or to act on the objects with already acquired skills; (b) his attention is easy to distract by other stimuli, including reinforcing stimuli; (c) he can not focus attention on the task-relevant features of the stimuli; or (d) he can not imagine what happened when the results are obtained. Namely, he can not understand the meaning of reinforcement.

In spite of these behaviors, he must acquire the attitude to solve the problems. In order to achieve this attitude, a 5 minute lesson by caregivers is developed and presented once a day at a certain time. It is important to do it only for five minutes. Also it is important that the infant has a right to stop the lesson less than five-minutes if he wants. Usually, he is able to endure for 5 minutes, after several repetitions of the lesson.

The strategies of this lesson are as follows; the caregiver repeatedly shows a whole process of a task by modeling procedures. At first, it is important not to use reinforcement. Since the stimulus on the reinforcement distracts his attention. The best way is to use a peer as a task-solver model. After seeing the whole process repeatedly, he is able to understand the process as a whole, especially what happens when the problem is solved.

As the disabled infant becomes interested (or motivated) in this situation, he starts solving the task by himself. At this stage, any activity needs to be reinforced. Also, the method of "shaping" should be introduced. It is important that he succeeds with 100% probability in order to keep his motivation. By decreasing the "shaping", the caregivers assure that the infant is able to perform the task thoroughly by himself. Then, the caregivers start to delay the presentation of stimulus or their response, in order to facilitate his expectancy and demanding behavior.

Based on our experiences in this intervention, this method seems to be effective. Theoretically, there are three principles to support this method: contingency, development sequence, and self-esteem.

#### (1) Contingency as a Base of Learning.

Watson and Ramey (1969) reported that when two month old infants experience the contingency in the some activity (moving head) with the stimulus (display movements), they showed an interest on this association and responded with emotional behavior (such as smiling and cooing). Consequently, they understand the contingency of their behavior and stimulation. Many researchers think this understanding of contingency as the base of learning. The understanding of contingency begins with between motor activity and stimulus, between two external objects, and finally, between internal representations. It is called as "the association of ideas". At the middle of the second year, the normal children usually begin to imagine or represent things in their minds, and they can use signs and symbols. As a result symbolic play and language usage become possible for them.

Although disabled infants understand this contingency, they need external stimuli in constructing contingency. They usually have the weakness in representing things in mind. In order to overcome this deficits, the technique of delayed response is introduced. The disabled children showed still difficulty to make representation and to keep it in their minds for a long time.

This is the restriction of the disabled children. However, "they can feel happy when they understand the contingency".

## (2) The Problems to Sequencing the Tasks for Facilitation of Development

The children with disabilities begin to enjoy the solutions of cognitive tasks. Next stage is to determine the sequence of tasks which are most effective to facilitate their development specifically.

This method is called "developmental milestones hypotheses". According to experiences in this intervention program, there is no evidence about what kinds of tasks is needed to arrive at the next milestone. As discussed in proposition 2, the children must learn many kinds of tasks simultaneously.

Hunt (1987) reviewed the effects of early experience on development. His conclusion is as follows.

*"The effects of experience on the rate of early psychological development and the specific relationships between kinds of experience and kinds of developmental advance has been confirmed."* Hunt, 1987 p. 44).

He selected 6 subscales from Uzgiris-Hunt ordinary scale (the OBJECT-PERMANENCE, MEANS-ENDS, GESTURAL IMITATION, AND VOCAL IMITATION SCALES). The specific experiences which correspond to each subscale facilitate specific development but no general development. Also, Wachs(1987) presented the "BEAM MODEL". He noted ;

*"A few environmental factors (i. e. contingency) have global effects on most development patterns for most children at most ages. The great majority of environmental factors are highly specific in their action patterns. They have the three components, such as environmental, age, and organismic (individual difference) specificities".*

In general, it is very difficult to develop an intervention program for specific individual children who are over two years old, since they each have different environmental, age, and organismic specificity. Probably, there is a need to develop programs which have multiple tasks.

At this stage, it is better to present "the menu" of tasks for disabled children, so they have a right to choice what kind of task to facilitate their own development at this moment.

## (3) High Self-Esteem

Most studies reported that disabled children have low self-esteem and also low self-confidence. Koegel and Mentis(1985) have reported that some autistic children displayed low motivation and apathy, they also suggested that these may be the indicative of learned helplessness. It has been said that children who frequently fail to accomplish the demands may develop a sense of learned helplessness.

Since the start of the RCCCD program of intervention, one of the most important propositions is that the children with disabilities should keep high self-esteem, even if they fail to accomplish their demands. One solution is to provide them experiences which are adjusted to their developmental level. Through the insurance of 100% suc-

cess, they develop a sense of contingency and a sense of control. Thus they come to have confidence of their ability. The other solution in keeping high self-confidence is that caregivers do not attempt to keep the child trying to cope, if the child can not cope with the demand. Hunt (1987) said:

*“When the child encounters situations with demands beyond his/her ability, these demands do not even exist as challenges. When the challenge is appreciated but the child cannot cope, he/she will, if free to do so, leave the field without damage; but if adults attempt (by means of either reward or punishment) to keep the child trying the child suffers both stress and distress and damage to his/her confidence.”*

According to Hunt, we can say that failure in any task does not of itself cause lowering of self-esteem, but when caregivers' demands for tasks that children cannot cope with, does do damage to their self-confidence.

There is another solution to keep self-confidence high. The child with disabilities, as well as every human being, needs support from another person (attachment person, family, or teacher) and also a supportive atmosphere in their family and society, even if there is no hope in life. This is a difficult problem to treat. However, after participation in our program we can see that children with disabilities and also their parents recover their spirits and feel happy in spite of their difficult lives.

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