

# When a Precious Little Life Develops

To keep moving forward with your disabled child

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## Chapter 1. Everybody is Raising Their Children in Anxiety

### Section 1. Every Child is Growing

#### **Q. Child Born Prematurely (EGAWA)**

My child was born prematurely. I am worried whether he will be growing just fine. My child doesn't seem to be developing the way as written in child-rearing books.

**A.** With advances in medical science, more and more babies are growing well even if they were born preterm with pretty low weight. Still, it is only natural that you get nervous about the growth and development of your premature baby, especially if he/she is your first child.

Generally, child-rearing books refer to standard babies who were born full-term with average weight, and the process of their growth and development written in those books only shows the average. Even mothers with matured babies often find that their children are not growing as those books say.

In terms of motor development, it would be reasonable to evaluate preterm babies by their adjusted age. For example, if a baby was born 10 weeks earlier than the due date after spending only 30 weeks in the womb, you may take these 10 weeks (about 2 and a half months) off his age for adjustment, and think that his development only needs to reach the level of this adjusted age. If he had not turned over yet at age 6 months, you would be worried, but considering that his adjusted age is 3 and a half months, you will see there is no need to worry if only he can hold his head upright at that point.

Premature babies, especially if they were once hospitalized in NICU (neonatal intensive care unit), often become too sensitive to the changes in the environment and develop rather slowly. However, they would start developing rapidly once they get to sit up by themselves and stand up with support at around 11 months, and many of them are catching up with normal children. The same can be said for the growth of height and weight. Some children may still be behind at 18-24 months, but there are reports saying that the differences between premature and full-term babies are disappearing at around age 3.

You cannot draw a clear line between “normal” and “abnormal,” as there is wide gray area between them. Each child has their own development patterns and each has their own individual qualities. Keeping in mind that there is an individual variation, please wait and see how your child is growing.

**Q. Child Born with a Difficult Delivery (EGAWA)**

My child was born with a difficult delivery in an oxygen-deprived state, and I am worried how it would affect his future development.

What are the points I should keep in mind when bringing up my child?

**A.** If you are bringing up a child born with a difficult delivery, you may really worry whether your child will grow normally without developing any problems in the future. You would have an even larger concern, if your child had a serious case of “newborn asphyxia” and the doctor told you about the developmental problems that could arise in the future.

“Asphyxia” is a condition that occurs to newborns caused by a lack of oxygen and blood supply to their brains. It could make a serious impact on the development of the brain, leading to delays in motor and mental development. In what’s called a “stroke,” adults also suffer from failure of oxygen and blood supply to their brains. The difference is that a baby’s brain is very flexible compared with an adult’s. This is because role assignment among baby’s brain cells is not complete yet, and therefore the functions of a damaged part of the brain can be taken over by other normal cells. This is called “plasticity” of the brain.

To maximize this plasticity, early detection of abnormalities is essential. If a baby had any developmental problem with the brain, the symptoms would first appear in his/her appetite and cry; drinking milk and crying are the two important jobs for every baby. Does your child drink well and cry loudly? If you have any concern about these two things, go for consultation at hospitals, clinics or public health centers. Just to be on the safe side, I recommend you have at least one specialist check your baby regularly.

Even if your child has symptoms that are worrying you now, please stay hopeful and try creating an environment to encourage normal development of your child through exercise at home, training at facilities, and so on.

**Q. Child Born with Hand or Face Deformities (EGAWA)**

My child has deformity of part of her body.  
Will it affect her growth in the future?

**A.** Take a close look at the earlobes of people around you, and you will notice they are all slightly different from one another. Although we tend to think that shapes of human body parts are basically the same in anyone, they can vary quite a bit actually. And when the variation goes beyond a certain range, they call it “deformity.” It sounds uncomfortable, doesn’t it? You might as well take it as “distortion of shape.”

“Distortion of shape” can cause cosmetic problems, as in phacomatosis (nevus or birthmarks) and microtia (small ears), when it occurs to the body parts like the face, hands, and legs which are not covered by clothes. Lately, these problems can mostly be solved by surgery at an appropriate age, backed by great advances in dermatology and plastic surgery. Surgeons have even developed methods to make scars much less noticeable, though their efforts are not always successful, depending on patients. Unlike cosmetic surgery, these procedures are considered medical treatments, so the costs are covered by health insurance. You may ask your child’s doctor for a referral to some specialists.

Distortion can also cause functional problems, as in cleft lip/palate, polydactylysm (extra fingers or toes) and syndactylysm (webbing of the fingers or toes). In these problems, you need to have an operation to improve your functions first as a stop-gap measure, then a second or more operations to improve appearance sometime later. You would probably have to go with plastic and orthopedic surgeons over a rather long time, but medical technology in these fields has been quite advanced, and many approaches are now available to take care of once untreatable diseases. Please ask for detailed explanation from specialists about the latest treatment.

Another concern related to “distortion of shape” is developmental problems. Generally, if your child has only one or two distorted parts in the body, he/she is less likely to have developmental delays. You would only need to take your child to a public health center for regular infant checkups.

However, if your child has more than three distorted parts in the body or has some internal problems such as heart deformity, he/she should be kept under careful observation, as chances of developmental delays become a little higher. First, try looking for a clinic or hospital with a developmental pediatrician. You may go to a local public health center, where you can talk to some experienced pediatricians. They will give you advice on raising children with developmental problems and may refer your child to specialists as needed. Public health nurses would also make good advisers, as they have been treating lots of children.

Growth and development are most important for children, and you should not

overlook it by focusing only on cosmetic or functional problems. If your child had a functional problem, you should try even harder to find a way for your child to get over it and grow. I suggest you start by getting professional staff who would join you in watching your child growing up.

**Q. Child Born with a Disease of the Heart or Other Internal Organs  
(EGAWA)**

The doctor told me that my child had a deformed organ.  
I am worried whether she will grow just fine.

**A.** The heart is the most fundamental organ to life, as well as the lungs. Starting from a simple tube-like structure, it develops gradually into a very complicated organ with four chambers and inlet/outlet valves. It takes a long process of formation starting from the early fetal stage until right after birth. Due to its complicated shape and functions, the heart takes far more time to form than any other organs, and that's why there are all types of hypoplasia (underdevelopment) of the heart recognized as congenital heart diseases.

If your child had such a heart disease, he/she would probably be under observation or treatment by a cardiologist. If the symptoms of heart failure started appearing from birth, the first thing to do is to stabilize heart function. Surgery may be necessary, depending on the type of disease. In some cases, only an essential operation is conducted first for survival and growth, then proceed to a major operation after the baby becomes strong enough to undergo it. Babies' first tasks are drinking milk well and crying loudly, and to do a good job, the heart should be kept in good condition. That is the top-priority thing, and cardiologists should help in that way.

Once the initial heart treatment is completed or the symptoms get to stabilize for the moment, you may start worrying about your child's development as well as physical growth. Of course, children born with a heart disease do not always have developmental problems. But if you were concerned about slow development of your child and assumed that it was due to his/her heart problem, you might miss the proper timing to take action if it was a real developmental problem. When a baby has hypoplasia in one organ, you really need to keep a close eye on his total development. A hospital big enough to have a cardiac outpatient department should have a developmental pediatric department as well, so discuss with your child's cardiologist about it. You may also use developmental counseling service at a public health center. Get your child checked regularly by as many specialists as possible; that is the best way to find an appropriate way to bring up your child.

Besides the heart, deformity is often found in digestive organs, such as the stomach, bowels and liver. Diseases of these organs should also be treated over a long time, mainly by pediatric surgeons, to help physical growth of the child. For hypoplasia of the kidney, treatments like dialysis may become necessary, depending on the child's kidney functions. If your child had a disease in any of these organs, I recommend you get at least one doctor who would check general development of the child on an outpatient basis, just like in the case of heart disease. No need for frequent visits but at least once every 3 to 6 months, you should have your child checked by the same doctor regularly.

Getting treatment for internal organ diseases actually takes quite a lot of time and money. There are some public subsidy systems to help reduce medical cost burden, such as “Shoni Tokutei Shikkan” for designated diseases and “Ikusei Iryo” for reducing disability, so try to discuss with hospital social workers early. Once the disease develops into a chronic state, it is then designated as “Internal Disease” under the Physically Disabled Welfare Law, and the patient will be issued the Physical Disability Certificate which entitles him to many social services. This certificate will also help the patient’s family in their daily life, e.g. you can put your other children in a daycare center on a preferential basis. You might ask the doctor if this system is applicable to your child.

The word “Physical Disability Certificate” may make you feel hesitant, but it won’t hurt you to ask the welfare office what services are available for your child. And if you find them necessary and useful, I’d recommend you go ahead and apply for the certificate, thinking that it is just a means of making life easier.

**Q. Child Who Have Convulsions (EGAWA)**

My child has had repeated episodes of convulsions from a very young age. Won't it slow down his development?

**A.** One out of every 10 children experiences convulsions for some reason. In the past, a convulsion was considered to leave a scar in the brain, but this is refuted today.

One of the diseases that cause convulsions is epilepsy. In epilepsy, seizures occur when the normal activity of the brain stops due to abnormal excitement of brain nerve cells.

Most epileptic seizures can be controlled by one or two types of medicines, leaving no aftereffect on the development. However, seizures in “intractable epilepsy” are rather difficult to control and end up needing more types of medication. During the period when this type of epileptic seizures occur frequently, the patients are put in a state like listening to radio with noise interference every now and then. Naturally, they cannot fully receive and absorb stimuli from outside, and their development will slow down.

If your child had intractable epilepsy, it would not be easy to stimulate his/her development while treating the disease, but what we should do first is controlling seizures. During the period of frequent seizures, your child has to go to see a doctor quite often and may have to stop regular visits to physical therapy or some kind of lessons for a while. Yet, what is important here is to stabilize the child's condition so that he/she can fully absorb stimuli, then trying to make up for lost time. That is the shortest way after all, though it may look like the longest way round.

Once major seizure episodes are under control, stop for a while and look at your child. Watch how he/she is interested in things around and responding to stimuli. If your child looks more active than before and seems to show a sign of growth, consult the doctor about medication whether to increase the dose or not, or how to get rid of seizures while maintaining the child's activity. If you focus on the prevention of seizures all the time, you may succeed but your child will probably end up sleeping all day, which could take opportunities for growth away from him/her.

While seizures alone would be enough to worry you, it must be hard to accept and take care of the developmental problems your child might have, but please help him/her get over the disease, cashing in on the strength that only children can have – growth.



**Q. Child Yet to Start Walking (EGAWA)**

My child is already one year old and yet to start walking.  
I'm worried he might be slow in developing.

**A.** One of the parents' greatest concerns is that their children are yet to start walking. Once children start walking, they can go anywhere they like on their own without help. It is such a big change which may make you feel that start of walking is the very first step toward independence. So if your child is not yet walking, you may feel as if he/she were behind in independence and get anxious.

There are many aspects in child's development, which can be classified into the following 4 categories: One, interpersonal/social development, e.g., laughing at peek-a-boo and waving goodbye to someone; Two, language development, e.g., responding to their own names and babbling; Three, fine motor development, e.g., shaking a rattle and picking up tiny trash; Four, gross motor development such as holding their head upright and standing up with support.

Start of walking is one factor in the gross motor development. A child's development is a complex of all these factors, and the development rate varies from factor to factor in one child; these factors are not developing at the same rate but developing unevenly, so a child may be strong in some areas but still weak in others. Also, there are differences between individuals in the development rate of each factor. So every child has their own unique development patterns, no two are the same, even brothers and sisters.

The age at which children start walking differs greatly, ranging from 10 to 18 months. Early start of walking does not necessarily mean fast development. I would say if only they start walking by 18 months, they are generally normal in terms of motor development.

If your child did not start walking after 18 months, you need to get him/her checked and evaluated by professionals. Consult development counselors at public health centers or pediatric neurologists at hospitals. They may only recommend taking regular examinations, unable to find a clear cause at that point. But if things still didn't change, your child should be thoroughly examined at least by the time he/she becomes two years old. Also, you have to give your child a chance to get professional training or some sorts of therapy.

What are likely to happen to children with developmental problems is that they try growing without using their weak area. Those who are not good at walking would give up on moving farther than they can and end up growing in a small world. While other children about the same age are playing in the sandbox getting all muddy, what if your child always stays home? It would affect the development of other three factors as well. What you should do first is take your child out as frequently as possible and let him/her experience as much as other children do.

Walking is not the goal but the means of development. Please help your child grow and develop, keeping that in mind.

**Q. Child Yet to Start Speaking (EGAWA)**

My child is yet to start speaking.

I think he is slow in development compared with his sisters and other children about his age.

**A.** In development counseling, the most frequently-mentioned worries are about delayed speech, and 95% of them are from boys' parents. Speech and language development varies considerably from child to child, so your doctor may suggest just waiting to see for a while. In fact, most of those children start speaking in the meantime, but some may never be able to acquire a language without proper treatment, depending on the problems they might have.

Roughly speaking, a child can say single words like "mommy" at age 1, and say two-word sentences such as "No mommy." and point at things like "eye" and "nose" at age 2. Also note that a language is a tool for communication, so it is important to see whether your child can go with his/her peers on equal terms, rather than how many words he/she can speak. Take a look at your child from these points of view, and your child still seems to have a problem with speech development, then consult with a nearby public health center in the first place. Public health centers are working on a whole range of issues about children's health and development, and offering consultation and regular checkups by specialists. If they cannot make a definite diagnosis but suspect that your child might be delayed, then they may refer you to some voluntary groups which encourage children's development. You could also go directly to a "Ryoiku Center," a special institution for child development and rehabilitation, in your area for consultation.

Also, you could try a medium to large-scale hospital with the pediatric department. Ask at a reception which doctor to consult with; receptionists and nurses should know of each doctor's specialty and tell you which doctor(s) would be right for you. Such doctors may offer special consultation on a regular outpatient basis.

Do not put off consulting specialists when you begin worrying about delayed speech of your child. Even if your general physician suggests a wait-and-see stance, you should look for a specialist who would examine your child regularly. To stimulate your child's development, it is most important to detect his/her problem, if any, as early as possible.

**Q. Child with a Hearing Problem (CENTER)**

My daughter has delayed speech, and the doctor says there is a problem with her hearing. How am I going to teach her the language?

**A.** Hearing loss is one of the medical problems that can affect speech development. For hearing-impaired children, education has been developed and provided since a long time ago. These days highly upgraded hearing aids have also been available, which can transmit sounds adjusted to the nature of each person's hearing.

If you were told your child had a hearing problem, confirm first whether a hearing aid can be indicated for his/her problem. If they don't give you enough explanation, don't hesitate to go and ask other professionals in hospitals or counseling organizations. Once you know a hearing aid can help your child, ask them to make a prototype and see how your child will change by wearing it. Some children don't like wearing one. Do not force your child but wait and see for a while, then try again. If it still doesn't work, repeat the wait-and-try process several times. Acquiring as many words as possible is quite important not only for the immediate growth but the future social life of your child. There is no need to hesitate to rely on devices.

To help your child acquire language, you should also get him/her a place for training and education. It may be difficult to find a good place in your neighborhood as there are only limited numbers of special schools and training centers, but considering how education for hearing-impaired people has been helpful for a long time, I recommend you give your child regular training opportunities even if the place is a little far. While your child is getting training, you can learn how to teach and help him/her at home, which is also important.

Don't forget to help your child make friends in the neighborhood, either. If you are focusing too much on his/her language development, he or she may lose something childish and miss the timing to know how to fight with other children. Children can get along well even with limited verbal communication.

**Q. Child with a Vision Problem (CENTER)**

I was told by a professional that my child had an eye disease and would not be able to see well. I don't know how to care for him.

**A.** There are diseases affecting vision right after birth, such as retinopathy of premature babies and congenital cataract. Vision is a key element in child's development, so we have to give full consideration to vision problems in young children.

When the problem is only with one eye, it is difficult to see things in three dimensions due to the difference in visual acuity between both eyes, which would affect the person's walking and other things. Ask an eye doctor whether your child will be able to see things with both eyes by wearing glasses, by the time he/she starts walking. Needless to say, your child should have regular checkups of underlying eye disease.

If at least one eye functions, enabling the child to see things at all, then he/she can receive general stimuli necessary for development, although perspective problems should remain. Allow them enough time to exercise or do some fine work. Keep in mind that, when they just start walking, they would feel uneasy going down the stairs since it is hard for them to know exactly what it is like at their feet.

If your child has a problem with both eyes, the first thing to do is improve vision as much as possible through surgery or the use of glasses. If that still doesn't work enough, he/she needs to use other senses, such as hearing and touch, to get enough stimuli for development. Go to a developmental counseling or educational counseling center in your area at least once, so that your child can get training appropriate for his/her growth stage. If possible, try to get your child regular training opportunities before entering elementary school.

In vision problems, amblyopia or weak eyesight is more common than complete blindness. With amblyopia, vision does not usually improve significantly with glasses, but these days stronger contact lenses and intraocular lenses have become available. There are also many books or picture books published with enlarged font size, and now you can easily enlarge the font size yourself by using a personal computer. Try gathering information on those useful products and devices from regional welfare centers and associations of parents with vision-impaired children.

The absolute number of vision-impaired children is not large, so a fine-tuned service system has not been completed yet in each region. We hope you will go ahead and create the most appropriate environment for your child.

**Q. Child Hard to Make Eye Contact with (EGAWA)**

My son won't turn when I call out his name. He doesn't really look at me even when we are face to face. I was told he was autistic.

**A.** Among the children taken to our hospital due to delayed speech, I see some showing these signs. Language is a means of satisfying our demands when we want to communicate with others. So if they are not interested in communicating or not good at making eye contact with other people, they will be slow to develop speech and unable to use words properly. This is what we call an "autistic" condition, and the typical disorder with this autistic tendency is called "autism." Autism has become well-known through the movie "Rain Man."

Being "autistic" or not is pretty much a subjective concept, so a diagnosis of autism should be made carefully by pediatric psychiatrists who specialize in child psychology. Recent diagnostic criteria include as many as 61 behavioral patterns to be checked, and someone is diagnosed with autism only when they show some of those patterns.

Most parents worry about intellectual development of their autistic children. Since language is a means of communication, people with autism have a problem with proper use of language. Children are developing mentally mainly through relationships they have with others at school and other places, so autistic children are likely to be slow in intellectual development. Yet, some of them show tremendous interest in characters or numbers, while others excel in realizing situations. In fact, we are often surprised how accurately they can sense even the slightest changes in environment.

Thus, autism is a rather characteristic disorder, and if you feel your child has some autistic tendency, we recommend you go and see a child psychiatrist soon. The earlier the diagnosis, the earlier your child can get appropriate education.

Autism has been known in the medical world for many years, and a lot of educational and training methods have been tried so far. I believe some of them are worth letting your child try, although there is no decisive approach established yet.

Now watch carefully how your child will respond to any of the methods. If you think your child isn't adjusting to one, don't hesitate to try another. You are the one to bring up your child, and it's important to find a method you are convinced of.

**Q. Child with Attention Problems (FUKUNAGA)**

My child is restless all the time and just can't focus on one thing.  
I'm worried about whether he will be able to adjust to school life.

**A.** Many parents must be thinking of their children as restless. In fact, that's the way children should be, with their interests are constantly shifting from one to the next. There will always be at least one child in a class who is so restless and has interest in everything around; we could call such a character "Totto-chan syndrome" (SUGIYAMA) from the main character in a book "Totto-chan, the Little Girl at the Window" written by TV personality Tetsuko KUROYANAGI.

You should not jump into a conclusion that such a character is associated with some medical problems or diseases, but if someone is extremely active and restless, so much so that it could even put themselves in danger or put the people around them under unbearable stress, then you might call it "attention deficit/hyperactivity disorder" or ADHD. The diagnosis of this disorder is difficult for general physicians; it should be made by specialists called child psychiatrists.

When their symptoms exceed certain limits, medications are sometimes used to treat them, but the basic idea is to create an environment where those children can develop their good points. This is an important role of adults around them.

Restless children are often seen as troublemakers by adults, especially after they enter elementary schools. Once they get nervous about it, their character may get twisted. You need to talk well with your child's teacher in kindergarten or school and create an environment that suits him/her.

If problems seem to arise, you'd better take your child to a specialist soon. Besides a public health center and a university hospital, you can ask a developmental counseling center in your area.

**Q. Child with Learning Difficulty (FUKUNAGA)**

My child is falling far behind in his studies at the elementary school. Does he have a learning disability?

**A.** Children who do extremely poorly in elementary/primary schools often just don't know how to learn properly, but sometimes there are hidden medical problems. Some may have mild intellectual disability or autism which went unnoticed at a nursery or kindergarten. Others have trouble adjusting to school life due to attention deficit disorder. Or it could be "learning disorder," which has been written about in newspapers quite often lately.

There are 3 main types of learning disorders: mathematics disorder, disorder of written expression, and reading disorder. In other words, only certain functions are affected and other intellectual abilities are generally OK. That's what learning disorders are like.

However, most of the children with poor academic performance do not meet this definition in the strict sense. So we first need to make sure what causes such poor performance of each child. Depending on the cause(s), we should take different approaches at school and home.

You can have your child examined at an educational counseling center, child consultation office, or pediatric neurology/child psychiatric department in a hospital. If you feel a bit uneasy about being known to your child's school, it would be safer to go to a child consultation office or a hospital. It is important that the parents get a satisfactory explanation, so I recommend you visit specialists, even if they are a bit far from your place.

In any case, what is most important is to find the most appropriate way to bring up your child, based on a full understanding of his/her strong points and weak points.



## Section 2. Questions difficult to ask doctors

### Q. Developmental delays

We were told that our child could have developmental delays.  
What should we try to do about it at home?

A. Who told you that your child might have developmental delays? If it was a health professional in general pediatrics or a public health center, you should definitely consult a specialist in pediatric neurology. And try to establish a good relationship with the specialist on a long-term basis, talking with that doctor about everything regarding diagnosis, treatment and rehabilitation for your child.

Developmental delays can occur due to various causes, sometimes with complications in the body. To identify what has caused the problem and whether a child has any complications, we have to do all kinds of examinations, some of which may be painful and require hospitalization. This is where we need your understanding and cooperation, since your child's disease could be treatable. Once we know how things will possibly go in the future, let's discuss and think over together how to bring up your child. In this kind of important discussion, we hope both parents will be able to join from the beginning.

Now what is your child's condition like? Were you told by a professional that your child were behind normal children in such and such?

What's called "intelligence scale" cannot evaluate every ability. As we all have strong and weak points, children with developmental delays might be good at something that can't be evaluated numerically. So, please seek out the good in your child with heart and soul. No need to rush, just think of the way to help your child develop, starting with what he/she can do.

Every child develops their own way even if they have developmental problems. If you love plants and flowers, you would grow them with loving care by giving them good fertilizers and water. Likewise, children need deep attention and good stimuli to grow. Please take time and bring up your child step by step, keeping that in mind.

If the doctor says your child needs to get some training, you should take him/her to a special training facility on a regular basis. The earlier the training starts, the more effective it will be. Once a child learns to do activities of daily living (eating, toileting, etc) without difficulty at home and a training center, it would make a big difference in the development of other abilities. Also, help your child establish a regular routine about sleep, toileting and hygiene. Keeping regular sleep hours is especially important for the child to create energy for tomorrow, as well as for you to rest enough and take better care of the child.

Finally, I would like to ask you to fully accept your child, although it may take quite a long time. No one is to blame for the disease of your child. Every child wants to live and be

loved, and it is the love from parents that they need most.

## **Q. Paralysis**

There is something stiff and awkward when my son moves his legs and arms. The doctor says it could be paralysis. I don't know how to care for him.

**A.** When you see, hear or feel something and then act, your brain is working. When you try to walk or pick up something, your brain cells give an order, which travels through nerve fibers to your legs and hands and move them. Such an order is issued from the cerebral cortex, where intricate networks are formed of 14 billion nerve cells. The neuron networks, still immature at birth, are supposed to be completed by around age 7.

Sometimes brain orders cannot be transmitted due to partial destruction of brain nerve cells or poor communication between nerve fibers. Then, when you try to do something, your body may become stiff or move involuntarily, or you may become unable to move your arms and legs smoothly. This is what the doctor meant by saying "It could be paralysis."

There are a lot of causes of paralysis, such as asphyxia (a lack of oxygen in the body at birth), bleeding within the brain and deformity. Every child has different causes, so ask your child's doctor to explain the details; they would conduct examinations to identify what is causing your child's problem.

However, causes are often unknown even with thorough examination. Even if they didn't find any abnormalities in the first test, your child should see the doctor regularly and continue necessary examinations. Now, whatever cause it might be, it is not the father's or mother's fault, of course. Needless to say, it is never the child's fault. The purpose of the examinations is to look ahead and consider the way of training of the child.

When the brain is injured and some kind of disability is likely to remain, can't we do anything about it? Is it helpless? No, it isn't. Destroyed brain cells never recover, but remaining cells get to form a new network or spare cells start functioning. This is called "brain plasticity." Young children's brains have great plasticity and flexibility.

Therefore, you should not think of disability as being fixed, but do something to maximize brain plasticity. This is where training comes in. The main purposes of the training are maintaining and improving functions by taking full advantage of the remaining functions and giving good stimuli to disabled parts. It is also aimed at helping children fully develop their potential.

There are various training methods. You need to incorporate them into daily life at home under the guidance of training specialists and keep at them with patience. Yet, if you only look at things like disability and functional training, you might miss mental development of your child. With or without disability, a child will be growing as a human being, a process requiring mental development and stable emotions. Disability is visible so you may be easily obsessed with training of your child, but doesn't it get to affect your relationship with the child? Do you have enough room in your heart to pick up on what

your child is really feeling? A child will go out into the world someday so he needs to learn how to stand up for himself. It really takes holistic development --- not just physically but mentally and emotionally. This is what I'd like you to keep in mind in particular.

All the family should work together to bring up the child. Do not compare your child with other children, but compare the present condition and the condition a few months later of your child. I'm sure you will find some changes and hope in there.

## Section 5. When a Precious Little Life Develops (EGAWA)

A five-year-old child was found in a baby bed at home. The child weighed six kilograms and was eighty-five centimeters in height, looked nothing but just like a baby. When the child was one and a half years old, he was hospitalized due to a traffic accident, and the parents stopped expecting the baby's further growth and consequently the baby stopped developing since then. It is called, "Emotional (or Maternal) Deprivation Syndrome". Quite a few cases of this kind of disorder have been reported in Japan as well.

Often people think that the growth of mind and body are separate matters but in reality, they are mutually indispensable to one another. A mother would try hard to talk to her newborn baby. Baby's smiles would delight the mother and baby's cries would upset her. Such an apparently simple relationship between them is essential for a baby's development.

By making the same facial expression repeatedly, a baby learns to smile trying to bring out the mother's joy. The baby also realizes that the best way to call his or her distant mother is to send a signal by crying and make the mother feel restless. With such, the baby acquires how to communicate through her or his relationship with the mother.

In other words, a baby would stop developing the brain without the communication with the parent(s) in the hope of "wishing my baby fast growth", as there is nothing for the baby to depend on for judgment or know how to develop. Furthermore, not only the mental development, but also physical development, would brake off as the secretion of growth hormone gets restrained. That is said to be the condition of "Emotional (or Maternal) Deprivation Syndrome".

The case mentioned above teaches us how important the feelings of those around are, for a child's development that they should be happy to see the child's growth. This is especially true for children with physical or mental development problems, but actually quite a few parents cannot afford to notice their child's development and share the pleasure of it.

Those parents have to take a long time, perhaps months or years to calm down from the moment that the doctor informs them the name of their child's disease or disorder. Hatred toward the illness or anxiety about the child's growth, they could easily forget to find pleasure without realizing it. Also mistakenly, they might compare their child with books on child-rearing or other children of the same age, to check if their child is growing okay. That would make them turn only to the child's aspects that are falling behind, even if the child shows other aspects that are certainly growing.

"Kaa-kun" is a third grader of a special needs class. He is standing in front of the blackboard, as it is his class duty day, today. "Well, what is the date today?" asks the teacher and Kaa-kun tries to answer by writing it on the blackboard holding a piece of chalk.

First, he draws a horizontal line and another, down from the left end then his chalk stops. For 5 seconds, 10 seconds ..., Kaa-kun is hesitating over which way to continue the line, to the right way or the left way. There are about 10 pupils in class and a few of them who knew how to write it right try to help him saying, "Right, go to the right way" eagerly and loudly. The others also make cheering voices, "this way!" or "that way!" in their own ways. 30 seconds and then 40 seconds pass by.... Two teachers in charge of the class and one practice teacher in an intern, keep a very close watch on what is happening and Kaa-kun, as if they were praying. 50 seconds already passes ..., Kaa-kun still looks hard at the blackboard. 60 seconds and then 70 seconds go by... now the whole classroom is filled with the chorus of cheering him, "Go, Kaa-kun, go! Go, Kaa-kun, go!" The next moment as Kaa-kun moves his hand to draw the right arc, a storm of applause and hurrah for him fill the classroom.

It is just a minute incident, just a moment of development to write '5' on the blackboard, yet all of Kaa-kun's classmates, his two teachers and practice teacher in the classroom share the moment of such a little development of life praying. Naturally, Kaa-kun is in the heart of their prayer circle. Something that Kaa-kun was not sure about until yesterday makes him happy today because he surely knows it now. Kaa-kun also knows now that so many friends of his and his teachers are supporting him all together which he can feel all over his body!

Can you notice that your child begins to be able to do the things today that they could not three months or even a month ago? If so, then can you rejoice at it sincerely? On top of that, can you let your child know what you are rejoicing? Is there any uneasy feeling about the future standing in your way of finding tiny developments of little life? Is any kind of anger for something interrupting you from being delighted? When was the last time that you let your child know of your joy, giving a hug?

It is important to prepare for your child's future and it is rather hard to forget about your uneasy feeling about your child's future. However, it is true that your child will have to stand on her or his own feet in the future. Therefore, you should make your child understand your messages; what you wish for your child to be and what kind of value your child should possess while her or his brain is still flexible. That is for sure. By doing so, you must also guide and energize your child in order to prepare the course of the child's life well. Because that is the only way life could and should develop.

Perhaps reminding yourself of these words may help you, "Being; easygoing, patient, and vigorous": First, you have to be strong enough to get through this long journey of parenting—being vigorous. At the same time, keeping your mental health is as equally important as your physical strength, for being able to rejoice at little developments of your child's.

Understanding is valuable, too—being patient. You need a supportive partner or two, or even more to keep up with your will. Your spouse, family, other families, friends and teachers, or anyone else could be the supportive partners. You should be able to share your

thoughts with them freely.

Now do not forget to have calmness in your life to let your intentions last long—being easygoing. Sometimes it might be necessary to let go of your feelings and make your own time or devote yourself to things you enjoy. Those actions surely would refresh you mentally and physically for gaining more room in your heart and mind. That way, you are able to provide your child with peace of mind, and he or she can stay by your side free from fear whenever your heart becomes capable of wrapping around your child with warmth. Thus, you enable your child to keep growing mentally and physically.