

■ Back Cover

Foreword

Congratulations on the birth of your baby!

We wonder where you are reading this booklet “+Happy - The Seeds of Happiness” right now.

We bet it took a bit of courage for you to start reading it.

We are so happy and thankful that you decided to do so.

This booklet was created by those who have gone through similar experiences as you.

We would like you, the parent of a child with Down syndrome, to take your first steps forward with confidence.

If you are able to take the initial steps, you will find that moving forward isn't as difficult. We know that you are worried, but it will be ok. Children with Down syndrome grow up to be strong and kindhearted people.

Those of us who are raising children with Down syndrome are leading very happy lives.

Once again, it is going to be ok. Please try to enjoy parenting your new baby.

Life is a series of continuous miracles.

Please remember that your baby is here with you because of these miracles.

And again...

Congratulations on the birth of your baby!!

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*Cover picture: Moeko Inada

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What your baby was like when he or *she* was born

How you felt when you became a mom or dad

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For the Family

Raise your child as you would any of your children.

The precious life that was lovingly nurtured in your womb is now in your arms. You might feel anxious as you look at your small, fragile baby. However, although children with Down syndrome develop at a slower pace, they do grow and develop like other children. Raise your child the same way you would raise any of your children. Giving more care and attention to your child will lead to more growth and progress. You will mainly raise your baby at home and provide him/her with Ryouiku services when needed. (See p8 and 9 “What is Ryouiku?” for details.) Even if you feel unsure about how to raise your child, abandon the idea that your child cannot do certain things because he/she has Down syndrome. The best thing you can do for your baby while interacting with him/her is to think about what he/she needs and provide him/her with the best care that you can.

Health Management

Think of your child’s health first. Children with Down syndrome have vulnerable immune systems and catch colds easily during infancy. Some children with Down syndrome also have weak bronchi and can easily develop pneumonia. Try to find a family doctor in your neighborhood as well as an emergency clinic in your area that provides medical examinations and care at night. Create a support network for yourself (e.g., experienced moms, friends, grandmothers, etc.) so that you have a wide range of people you can contact when you are unable to decide whether or not to take your child to see the doctor. If your child has a medical issue and is hospitalized, make sure to talk to him/her a lot. Communicating with your child through talking and through physical contact (e.g. hugging or holding your child) should help to speed up his/her recovery. Also, make sure to talk to the doctor or nurse if you have any concerns at all. Keep asking questions until you are satisfied with the answers. It is important that you don’t bring your worries and fears home with you.

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For Mom and Dad

Mom, are you in good shape? Dad, is your work making you tired? Staying healthy is one of the most important things you can do while raising children. Take turns taking breaks in order to maintain your health. Do something relaxing from time to time for a change of pace. Raising children is hard work. Try not to do everything by yourself. Raise your children with support from those around you.

Taking Care of Siblings

How are the baby’s siblings doing? When a new baby is born, parents typically pay more attention to the baby than to the older children. Because they are now the “big brother” or the “big sister”, the older

children may push themselves unconsciously or feel pressure without realizing it. Remember to give lots of love and hugs to your older children too. Show that you appreciate them by saying, “Thank you,” “You are a big help,” and “I’m very happy that you are here with me.” I am sure that your baby’s siblings will help you out a lot in the future. Make sure to cherish your family members. Raise all of your children with lots of love.

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For Grandpas and Grandmas

Children with Down syndrome thrive on social interaction with many people. Smiles and kindness from other family members can really help encourage young parents who are raising children. Spend as much time with your grandchild as you possibly can. If you live far away and can’t visit frequently, then call frequently. Just hearing your voice can help new parents feel more at ease. We hope you will extend a helping hand to young parents.

Welfare Services

~Ryouiku Techou (e.g., Ai No Techou, etc.) ~

The Ryouiku Techou (Rehabilitation Certificate) system was established in 1973 to provide consistent guidance, consultation, and various benefits to individuals with Down syndrome throughout their lives. Because the Ryouiku Techou is a certificate issued by each prefecture, its name varies depending on the region. It is generally called the Ryouiku Techou or the Ai No Techou. The Ryouiku Techou can be issued to a person with disabilities at any age if it is deemed necessary. However, in some areas you can only apply for the Ryouiku Techou after your child has reached the age of one. The reason for this is that some areas find it difficult to determine the intellectual level of a child who is under one year old. The intellectual level of your child will be determined by the Child Consultation Center (Jidou Soudan Jo) in your area if your child is under 18 years old.

Obtaining a Ryouiku Techou will not put your child at a disadvantage when he/she, for example, enters school. On the contrary, you and your child gain access to various services. (The services offered differ depending on each prefecture.) Some familiar services that people of our child-raising generation use are as follows:

- Free admission to public zoos and aquariums for the child and, in most cases, for one of the accompanying parents as well
- Discounts for public transportation such as buses and taxis
- In some cases parking lots at certain facilities can be used free of charge

Individuals with Down syndrome and their families very much appreciate these services.

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In addition, you can receive the Tokubetsu Jidou Fuyou Teate (Special Childcare Allowance). This is an

allowance for parents raising a child with disabilities who is under 20 years old. However, you may not be eligible to receive the allowance if your income reaches a certain level. When your child turns 20, he/she will be eligible to receive the Shougai Kiso Nenkin (Disability Basic Pension) in his/her name.

Services and allowances offered vary depending on where you live. Please ask for details at the department in charge (e.g. welfare department) in your city, ward, town, or village office.

~Shintai Shougaisha Techou~

If your child has a medical issue such as heart disease, you can receive a Shintai Shougaisha Techou (Physical Disability Certificate) for your child. The Shintai Shougaisha Techou system is not the same as the Ryouiku Techou system; so, you can obtain both certificates if required. Ask a family doctor or nurse whether or not your child is eligible to apply.

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+Happy - The Seeds of Happiness

How to Raise Your Child 1

“What is Ryouiku in Japan?”

Experts say that it is necessary to make an effort to provide external stimulation to children with Down syndrome as they tend to develop at a slower pace. Ryouiku (Rehabilitation Services) can be started relatively early since Down syndrome can be diagnosed fairly quickly after birth.

Japan started offering Souki Ryouiku (Early Intervention Services) to children with Down syndrome on a professional level in 1980. Institutions such as Tsukuba University developed a number of programs at that time. Later, other programs such as “Baby Gymnastics for Children with Down Syndrome” (Akachan Taisou ©JSPCDDDS), the “Portage Early Intervention Program” (NPO Japan Portage Association), and the “Washington University Method” (Kodomo no Shiro General Incorporated Association) were introduced. All of these programs are recognized as effective in encouraging development in children with Down syndrome and in offering support to parents.

So what is the actual meaning of Ryouiku? Some people might mix up Ryouiku with “formal” Education. However, Ryouiku is not a strict method of teaching or training a child. Ryouiku takes a softer, calmer approach. Children learn little by little every day in a relaxed environment to build up their skills.

When you hear the term Souki Ryouiku, you also might think that your child needs to start right away. You might feel nervous or frustrated if you cannot find any facilities nearby that offer such services.

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Some people might misunderstand what Ryouiku really means. They might feel satisfied simply sending their child to a facility that offers Ryouiku services. However, what would you do if your child cried the whole time he/she was participating in these services? What would you do if going to this facility tired your child out so much that he/she did not have the energy to do anything at home? Would you or your child feel calm and at ease if this were the case?

Please understand that your child does not need to go to a facility for Ryouiku services. Simply reading to your child or playing him/her your favorite music while relaxing together is beneficial. Going for a walk on a nice day to get some fresh air while showing your child flowers along the way or just letting your child have fun spending with siblings or friends is also helpful. Sometimes just playing “horse” (i.e., having your child sit on Dad’s shoulders) can help build up your child’s sense of balance. Talking to your child while engaging in physical contact is also very important. (This is especially important while your child is still young.) In order to raise your child in a relaxed environment with a sense of ease, you just need to figure out what works best for your family. Being able to do this is an example of excellent parenting or, in other words, Ryouiku.

We have one request for you. Before you start thinking about Ryouiku, please make your child’s health a top priority. A healthy body is essential. You can start Ryouiku once your child is in good physical condition. Please don’t worry – it will not be too late to start.

Let’s be patient when raising our children. Let’s go at their pace and take it day by day.

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How to Raise Your Child 2

“I want to participate in my neighborhood’s Oya No Kai (Parent Support Group), but the thought of it makes me nervous...”

One of the first things a doctor at your hospital or a Hokenshi-san (Public Health Nurse) will tell you about are Parent Support Groups called Oya No Kai. Some people might feel hesitant to contact their local Oya No Kai when they first hear about it. So what is an Oya No Kai anyway?

To put it simply, an Oya No Kai is a place where you (parents) can cleanse your heart and mind. It is a place where you can talk about your painful feelings, worries about the future, health concerns about your child, schooling, siblings, etc., with others who have felt the same way and can empathize with you. Just talking about these things with others can really help.

In addition to the above, you can obtain whatever information you may need from your local Oya No Kai including information about welfare services or hospitals in your area. This is a strength of having community-based parent support groups. You can ask others in your group to let you know which ENT doctor they recommend, what the system for getting your child enrolled in a nursery school or a kindergarten is, etc. Please get any information you may need from your local Oya No Kai.

If you cannot find an Oya No Kai in your area, then you might want to consider connecting with people from all over the world via the Internet! You can read blogs or use SNS. You can even join the “21+Happy” group on mixi (SNS) which created this handbook.

Once you have received the friendly support from others that you might need and have come to the realization that you are not alone, please share what you have learned with others who might need your help in the future.

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Those who help you get through difficult times are lifelong treasures. Please always cherish them.

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How to Raise Your Child3

“Am I going to be able to work again? Is that even possible...?”

Yes - it is possible! There are lots of moms who go back to work! They have different types of jobs, and they lead different lifestyles. Let’s hear what some of these moms who have returned to work have to say.

Name: Masako Yamamoto

What kind of work do you do?

I am a Director in charge of planning, editing and ensuring that production is carried out.

How old was your child when you returned to work?

My child was one and a half years old. My job requires me to continue working even after returning home for the night, sometimes until very late. Since there are days I need to take my child to the doctor or to Ryouiku appointments, I had my company change my working hours to flex time.

Admission to Hoikuen (Nursery School)

When I was trying to find a nursery school for my child, public nursery schools required that a child with

special needs be at least 2 years old to be considered for admission. There also had to be a slot available in order for him/her to be admitted. Because of these requirements, I observed a private Ninka Hoikuen (a licensed nursery school that satisfies standards regulated by the government) instead. I spoke directly with the assistant principal of the school. After doing this, my child gained admission to that school. A number of other parents also felt that it wasn't right that they could not return to work in a more timely manner due to the fact that their children with special needs had to wait until they were two years old to be admitted to the public nursery school. These parents voiced their needs to their municipal office. As a result, public schools changed the entrance age requirement for children with special needs from age 2 to age 0.

Were there certain conditions that you had to meet in order to return to work?

I am very thankful because my workplace offered to support me as much as possible. I work full-time, but they were flexible in regard to my schedule. Even so, there are still times that my job requires me to take overnight business trips to gather materials. There are also times I need to work late at night. At these times, my husband helps take care of our child, or we make full use of all the services available that provide help in taking care of children with special needs when parents cannot. This is how we are able to make it work.

A Message to Other Moms

It would be really difficult to try to do everything by yourself. When you need help, please go to the department in charge at your municipal office. Ask if there are any services available that might be helpful for you. If you just sit around and wait, your municipal government is not going to help you. However, if you consult them, there will always be someone there to listen. You might even find that there are services available that work for you. If the services you are looking for are not available, strongly voice your needs! Let's try to change the system! Don't worry. Everything is going to be OK. You will find that there are lots of people who will be willing to help.

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Name: Atsumi Yamada

What kind of work do you do?

I work as a nurse and a support counselor at a nursing facility.

How old was your child when you returned to work?

My child was one and a half years old.

Admission to Hoikuen (Nursery School)

I didn't have any issues.

Were there certain conditions that you had to meet in order to return to work?

My workplace told me not to hesitate to take off from work for my child. They were very understanding. That helped me out a lot. However, full-time employees are required to take on a great deal of responsibility. To reduce my workload, I requested that they make me a part-time employee.

A Message to Other Moms

I am sure you will experience many different emotions when deciding whether or not to go back to work. To be honest, it was something I really struggled with. However, I realized that I was very happy to have a place to work. Please try your best to enjoy yourself while working with others to get the help and support you need!

Name: Ayako Mori

What kind of work do you do?

I am a curator for art museums in charge of planning and managing the exhibitions.

How old was your child when you returned to work?

My child was three years and two months old.

Admission to Hoikuen (Nursery School)

My child started going to school for Narashi Hoiku (an adjustment period in which children are only kept at the school for short periods of time to allow them to get used to the new environment) when she was two years old. When I returned to work, she transitioned to full-time childcare. She started attending kindergarten in April. She attended kindergarten for the first part of the day. After that, she attended a nursery school from 2:00pm to 6:00pm. (A teacher from the kindergarten would bring her to the nursery school.) There were no special requirements we had to meet in order to get our child admitted to kindergarten or nursery school. Our child was treated the same as all other children.

A Message to Other Moms

Try to get along well with your child's teachers, his/her friends' parents, your colleagues at work, etc. so that you can lean on them when you need to. I am sure your child is going to be very well-liked by everyone at his/her school!

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Name: Miona Kanda

What kind of work do you do?

I do marketing and planning in the Distribution industry.

How old was your child when you returned to work?

I started working from home just four months after birth up until my child was one year old. (Nobody from my company had ever worked from home like this before, but my company was very nice about it.) After my child turned one, I returned to work full-time. Since I had to take my daughter to the hospital once a week, I adjusted my work schedule and received time off.

Admission to Hoikuen (Nursery School)

I went to the municipal office in our area to ask about entry into nursery school and elementary school. They assured me that municipal nursery schools, elementary schools, and middle schools could not deny admission to a child because of a disability. With the help of my parents, we enrolled my child in a 2-year municipal nursery school. A teacher was placed in my child's class to help take care of him/her.

A Message to Other Moms

I went back to work full-time after my 1st and 2nd children turned 4 months old. I had planned to do the same with my 3rd child, but now I wasn't sure whether I would be able to continue working at all. When I received the results that my child had Down syndrome, my attending physician (a woman) asked me if I had any questions. I asked her if I would be able to continue to work as a full-time employee. Since this is what I was worrying about the most at the time, I felt like I wasn't qualified to be the mother of my child, but it was something I just had to ask. My doctor listened carefully to my question. She responded that I should definitely continue working. She told me that there are lots of working moms who have children with Down syndrome. Even now, I still remember how incredibly reassuring her words were. Just hearing her say what she did made it clear in my mind that going back to work was more than a possibility. In addition to deciding whether or not to continue working, you will also need to balance all of your child's doctor's appointments and Ryouiku appointments. I am sure there will be other things you feel conflicted about as well. If you start to worry about what to do, just go ahead and try doing something! If you want to try something new, just go ahead and do it! While trying these different things, you might find all sorts of ways to get things done. If you feel that things aren't working out the way you want them to, then you can just stop doing them. Try not to make any decisions right away about how things should be. I think it would be good to have a flexible mindset so that you can deal with changing circumstances and environments. You will be ok no matter what decisions you make. Be confident and enjoy life!

■ P15

Messages from an Experienced Mom

Kaoru Tachibana

When individuals with Down syndrome are babies, you may wonder about their potential for growth and development. But don't worry! An experienced mom created a manga (comic book) which describes the

daily life and development of cheerful Yunta, who has Down syndrome. We are sure that life for your baby and family will be filled with daily joy. We hope you will get this message from her manga.

* Kaoru Tachibana *

Born in 1970. Made her debut as a manga artist after working as an editor for a fashion magazine. Her energetic personality is reflected in her manga. Every day she faces the challenges presented by her four boys including her husband and their eldest son Yunta, who has Down syndrome. Thanks to Yunta's easygoing nature, laughter is frequent and family ties are the strongest they have ever been.

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Messages from an Experienced Mom

I'm the mother of an elementary school kid Junta (called Yunta). He has Down syndrome.

"Hello!" "I'm Kaoru Tachibana."

"ello"

A little over 7 years ago, I was holding a little Yunta and felt overwhelmed with anxiety. "What is our life going to be like?" "Daddy too, of course."

"But I'm just fine now." Now I wonder where my worries from that time have gone. Of course, Daddy is fine too.

Kids with Down syndrome always do grow and develop.

* This was drawn and written in 2013.

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Yunta walks

runs

eats

cries

laughs

and he also reads between the lines

He isn't good at speaking

"ello!" (meaning "Hello")

"I'm Ta." (meaning "I'm Yunta.")

But he can have conversations and sometimes he makes silly jokes.

"I'm O-Cake!" (instead of "I'm OK!")

It's often said that individuals with Down syndrome have distinctive facial features, but they definitely take after their parents in appearance (and perhaps personality too!)

"He looks like me!!"

"No, like me!!"

"I don't care either way."

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Of course, parents don't have to stop working.

Lots of moms work full-time. "I do, too!"

Some work for foreign-affiliated firms.

Others in mass communication.

Raising kids with Down syndrome isn't necessarily a financial burden. A Techou (Rehabilitation Certificate) actually provides many benefits...

They learn how to read and write.

We can travel abroad with them.

They can also make friends.

They have their own hobbies! Yunta likes to watch professional wrestling!!

■ P19

"If you are worried, just ask someone for help!"

Moms with experience

Local health centers

Oya No Kai (Parent Support Groups)

Japan Down Syndrome Society (JDS)

When we raise children, we often feel worried or distressed.

This is the case whether your child has Down syndrome or not.

Second son

Third son

At some point in the future you will wonder, "What was I so anxious about?"

Everything is definitely going to be "O-Cake!"

■ P20

A Comic about Yunta and his Growth and Development

Soon after Birth

Children with Down syndrome develop at a slower pace. It may seem like they sleep all the time for the first few months. They also tend to have a weak sucking reflex so it might take longer for them to breastfeed.

In Yunta's case, breastfeeding did take a long time. It took up so much time that I did almost everything, e.g., my work, the laundry, cooking and even yoga while breastfeeding him (haha).

Breastfeeding became easier when Yunta was 7 months old. At that time he learned how to roll over. In the next 2 months he learned how to sit up independently. Kids with Down syndrome have flexible bodies. Yunta could do splits!

When Yunta was 9 months old, he could roll over.
He raised his upper body
He did splits (I couldn't believe it!)
He sat up! Look at that beautiful middle splits pose. Yeah!

* It's not always recommended that children with Down syndrome do splits. Ask for advice from your child's physical therapist if you are concerned.

■ P21

The Pre-Walking Stage

After Yunta learned to sit up, it took him longer than expected to stand up and start walking.

We wanted him to start walking as soon as possible, so we bought him a toddler pushcart, a baby-walker, and a pair of high-cut sneakers from overseas that provided ankle support. We also had Yunta practice walking at a Ryouiku facility.

However, I understand now that no matter what we did he wasn't going to start walking until his muscles developed.

Try not to get worried or depressed. The quickest and most effective way to support your child's development is to be patient, give him/her lots of love, and all the time he/she needs.

Congrats! He stood up by himself at 2 years “He STOOD UP!!”
Congrats! He took his first step at 2 years and 1 month “He TOOK A STEP!!”
Congrats! He took more than 3 steps (42 steps) at 2 years and 5 months!!
“He W-A-L-K-E-D!!” (My husband and I were so excited.)

■ P22

About Diapers

Yunta started toilet training when he was 4 and a half years old. He was successful 90 % of the time after he turned 5.

We didn't actually encourage Yunta to give up diapers. He realized that he was the only one still wearing diapers in his class at nursery school. He decided on his own that it was time to stop wearing them.

Yunta wasn't potty-trained yet so this was not an easy task.

Potty training started with Yunta wetting his pants and wondering what it was that felt so cold. Potty training was by far one of my biggest accomplishments as a mother (haha).

Yunta tends to start things without thinking them over. I have to admit that he has inherited this from me.

When Yunta was 4 and a half “Diapers are for babies…”
“I'm old enough to wear underpants now.”
Pee…
“Cold!! What's this?” Hey!!

■ P23

The Joy of Raising a Child who Develops at a Slower Pace

Standing, walking, and speaking are the three biggest milestones in a child's development. However, children with Down syndrome tend to grow and develop at a slower pace. There are a number of variations for each milestone.

Standing while looking back, standing while clapping one's hands, standing while making a peace sign… There are about 100 variations in the category of standing. This means there are more milestones to celebrate.

As a result, we have more memories and photos of Yunta than we do of our second and third sons (haha).

It is taking Yunta two or three times (or maybe more?) longer to grow and develop, but we feel 10 times

more surprised, happy, and moved when he reaches his milestones.

Yunta 2 years and 1 month He drank juice with a straw for the first time
2 years and 2 months He drank fizzy drinks with a straw for the first time
“What is this? It tastes so good!”
2 years and 3 months He drank from a PET bottle with a straw for the first time
2 years and 4 months He drank with a straw at a restaurant for the first time
There are four variations in the category “Drinking with a straw.”

■ P24

You Can Work Too!

When we learned that Yunta had Down syndrome, the first thought that came to my mind was not about his health or his future but the idea that I might have to give up my career.

I used to think that parents who gave birth to children with disabilities would have to look after them for their entire lives. However, I did not need to quit my job or give up anything else after giving birth to Yunta.

There are usually various services and benefits available. Don't hesitate to consult with a government office or a local health center.

Yunta goes to Gakudou club (after school daycare).
A helper accompanies him on his way home from the club.
When his favorite helper goes to pick him up, he wants to spend more time with him/her and doesn't come straight home.
“Hi, Yunta. Let's go home!” “Yunta, let's go home?!” “Let's go home!?”

*You can consult with the welfare department in your city or a local health center about the benefits and services available for disabled children and their parents.

■ P25

The Characteristics of Down Syndrome

Down syndrome is a genetic condition in which a person is born with an extra chromosome. It is not an illness.

Even though Down syndrome itself is not an illness, it could have complications such as heart defects, intellectual disabilities, or poor muscle tone. (Individuals with Down syndrome are often said to have distinctive facial features, but they all look like their own parents.)

The disabilities associated with Down syndrome vary from child to child. Yunta had a speech delay and he rarely spoke real words until he was 3.

He gradually spoke more words after the age of 3. However, he only pronounced the last letter of each word, which was a mystery to us ...

It required a high level of analysis to understand Yunta who said “u-do-n” when he meant to say “Gyu-u-do-n” (haha).

Yunta’s first word was “Kippu.” He was 2 years and 11 months old.

“Kippu (train ticket)?” (Dad) “What’s Kippu?” (Mom)

No, no

“Kippu!!” “What are you trying to say!?”

The answer was “Tamagoyaki ni ketchup kakete (=Put ketchup on the rolled egg).”

■ P26

The Past 7 Years

Seven years have passed since Yunta was born. He currently goes to the special needs class in the public elementary school in our neighborhood. He has made slow but steady progress. He learned his route to school and how to read and write hiragana. He also plays with friends his own age.

He has a few hobbies and enjoys watching professional wrestling after he finishes his homework.

Yunta is small so when he wears his school backpack, he looks like a mountain climber from behind. We feel happy and grateful about the progress Yunta has made as we watch him walk to school every morning.

We really look forward to seeing Yunta continue to grow and develop.

He may have a special talent that will reveal itself later.

We want to continue to look after, encourage, and protect Yunta who is full of possibilities.

Yellow cover for child’s school backpack

Yellow cap

When he smiles,

we can see the four baby teeth he has lost. He is a typical first grader!!

* This comic was written and illustrated in 2013.

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When you find out your child has a disability you don't experience immediate acceptance.

You don't have to be a Major League baseball player.

You don't have to have to be as good looking as a movie star

You don't have to work at a first-class firm.

Living life happily with a smile on your face is enough.

If you feel this way from the bottom of your heart, you have taken the first step toward acceptance.

* Tachibana-san is the mother of the three boys including Yunta, and the author of the following essay comics which are full of laughter and tears.

“Memoirs of the slow development of Yunta – raising a child with Down Syndrome”(2013)

“Memoirs of the slow development of Yunta – the eldest son of the Tachibana family”(2014)

“Please hurry and grow up and become mature adults! To my first, second, and third son, as well as my husband” (2016)

The following essay explains the child-rearing of Tachibana-san, with illustrations.

“I am a mother of a kid with Down Syndrome! My daily life and the support I received are described within.” (2014)

■ P28/29

Messages from an Experienced Mom

「Welcome to Holland」 by Emily Perl Kingsley

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Translated by Yurie Sahashi

Translated with permission from “A Promising Future: A Guide to New and Expectant Parents” issued by
The American National Society for Down Syndrome

* Emily Perl Kingsley worked as a writer on the Sesame Street team for a long time. Ever since her son was born with Down syndrome in 1974, she has also been working hard to spread awareness about individuals with disabilities. She wrote “Welcome to Holland” in 1987. This piece of writing which provides emotional support and tips for new parents continues to be passed down from family to family.

■ P30

Messages from an Experienced Mom by Kan-chan

“A Brave Baby”

People say that babies with Down syndrome are only born into families that have the ability to raise them.

I was chosen.

I used to think like this, but these days I have a different story:

Out of 1000 babies who are about to be born,
one of them will be born with a disability.

All of the babies feel hesitant, but one brave baby raises his hand.

“If there are no volunteers, I will be born with a disability
because I know that having a disability does not mean I will be unhappy.”

God is touched by this baby,
and brings him into the world with a disability and lots of happiness

In the hopes that he will meet his family
who will love him very much.

This baby’s name is Moco, and he is my son.
Moco chose to be born with Down syndrome
because he is my brave son.

Your brave baby descended from heaven to be with you and your family.
Raise your baby with lots of love.

*From Kantaro’s Blog Kyuukei Sokushin Iinkai on July 30, 2007
Moco was 5 months old at the time this was written.

■ P31

Messages from Experienced Dads

Dad of 3-year old son, Sosuke

I naturally assumed that my child would be born healthy; so, I was very shocked to hear that Sosuke had Down syndrome and a medical issue. Looking back, I realize that I was worrying about minor issues.

Now, I just want lots of people to meet our boy Sosuke who was born with a “unique advantageous characteristic” called Down syndrome.

Sosuke is the center of attention in our family. His smile always makes me feel better when I return home after a hard day at work.

Sosuke has many obstacles to overcome, but he has helped me to realize that we will get through each of them together as a family. Our family has become much stronger since Sosuke was born. Thank you for coming to join our family, Sosuke.

Rika’s Dad

Rika, who was a long-awaited girl, was our third child. When I found out that she had Down syndrome, I did not know what the future would hold for her. I worried about many things, such as her schooling, her career, and what other people would think of her. However, looking back now I can say with no doubt that the days I spent making an effort to behave in a cheerful manner for Rika and her brothers were definitely happy days. Even now I don't know if I have accepted my four-year old daughter’s disability... I don’t really even understand the difference between accepting her and not accepting her. All I know is that the life I have with my five family members including my daughter is a treasure.

This is what I think. Every step that you take “now” will create your future. I hope that you will cherish the idea of “living happily” as opposed to wondering whether or not you “will be happy” when your child is born.

Please live happily with your family “now.”

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Messages from Experienced Dads

Hiro’s Dad (Hakken No Hiro-san)

It’s been 8 years since my son was born. I have had many experiences during these past 8 years. The most worrisome time for me was when my son was a newborn. At that time, I was informed by the doctor that my son not only had Down syndrome but was also hearing impaired. My wife and I cried many times after hearing this. Fortunately, those worries are no longer a part of our lives.

For many years I had to leave work quite often in order to bring my son to the hospital. Gaining understanding from my colleagues about why I had to leave work so often was essential. Since Hiro was born, I have been constantly busy with one thing or another. Looking back, I feel like I was always trying to figure out what I could do for my son and my family as a father.

I still feel like I am battling with my feelings of incompetence every day (and I lose in most cases), but my family is living happily together now. Sometimes I feel a lot of stress from work, but I hope that our families can find a way to get through the difficulties we face.

B's Dad (Susshii-san)

My daughter who has Down syndrome was born in 2008. I knew that people with Down syndrome have characteristic facial features. This is what I thought about the moment I saw my daughter's face after she was born.

Until receiving a definitive diagnosis, I would tell myself, "She looks like she has Down syndrome" one minute and then tell myself, "No, no. She looks like a typical child" the next. I did this over and over again.

Once I received her diagnosis, however, I decided I would be frank and open with everyone about my daughter. After doing so, I found that there was a person close to us who has Down syndrome, and I was able to obtain information from an unexpected source. I was very lucky because these experiences broadened my horizons.

People often say to me that having a child with Down syndrome must be "difficult." However, I believe parenting any child is difficult. My wife and I do our best to raise our child just like most other parents who work hard to raise their children.

■ P33

Messages from Siblings

My Treasure

Iori Otani (She was in the 2nd grade when she wrote this.)

My treasure is my 1-year-old brother

His name is Kotaro

Kotaro was born when I was in kindergarten

Kotaro is small but he cries loudly

When I hugged him soon after birth he smiled at me

He was so cute

I want to take good care of my brother

He was born with trisomy 21 and one more chromosome than others

So he grows slowly

But my brother is cute and I am very happy he was born

My Little Brother

Riko Ito (She was in the 2nd grade when she wrote this.)

A, I, U, E, Otouto (My brother is) very cute
KA, KI, KU, KE KOrokoro (Rolls) over in bed
SA, SI, SU, SE, SOrosoro (It is almost time) for milk
TA, TI, TU, TE, TOKidoki (Sometimes) he cries
NA, NI, NU, NE, NONbiri (Relaxing) nap time?
HA, HI, FU, HE, HONtouni (He is really) adorable
MA, MI, MU, ME, MOusugu (Soon) he will be able to sit up
YA, I, YU, E, YOshiyoshi He is a (good boy)
WA, I, U, E, Onamae (His name is) Yuto-kun

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Messages from Siblings

My Older Sister

Daichi Ito (He was in the 8th grade when he wrote this)

Have you ever heard of “Down syndrome?”

Shortly before I entered elementary school, I went out alone with my mother for the first time. I forgot where we went, but I remember that the last thing we did was to eat a meal together at a restaurant. At that time, she told me that my older sister has Down syndrome. It was difficult for me to understand at the time. I remember my mother telling me that once I started elementary school, I might feel offended by what some people say about my sister. She told me, however, that I should act openly and confidently about my sister because we didn't do anything wrong.

When my sister was younger, she was hospitalized a lot when she got sick. She has reduced muscle strength throughout her body. As a result, things that are easy for us to do are often difficult for her. Since I don't understand the difficulties she faces, I get annoyed by how long it takes her to do things. Her stubbornness also upsets me. However, I think any siblings I had, even if they didn't have a disability, would sometimes irritate or upset me. I am sure we would fight as well. My sister is persistent. She works hard to do the things she decides to do. She is very patient. She never speaks badly about others and she always finds good things to say about them. She is quick to forgive even if she gets bullied. She always has a positive mindset and has the courage to take risks. Every year on my birthday, she gives me handmade presents that she has put a lot of effort into making.

My sister doesn't have Down syndrome because she or my mother got sick. I heard that 1 in 1000 babies are born with Down syndrome. There is a chance that I could have been born with Down syndrome.

My sister was just born on behalf of 1000 babies, but many people do not understand that.

■P35

My father never gives special treatment to my sister. He scolds her when she does something wrong. He praises her when she does something good.

My mother was shocked when she found out about my sister's disability. She cried every day and rarely left the house for over a year. However, my father took my sister everywhere. I respect him for that.

Since I was born, I have never seen my mother cry. I heard that my mother decided since she had already cried a lot, she was never going to cry again no matter what happened.

I am lucky to have such parents. My parents did not choose to send my sister to a class for special needs. She spent her elementary and junior high school days in regular classes. She was very happy to be with her friends, worked hard on the things that she could do, and studied even harder than I did.

I knew my mother did research late into the night every night in an attempt to learn about laws and obtain information that might benefit my sister. However, I hated seeing my mother apologize to people who said rude things to my sister. I thought it was wrong that it was so difficult for my sister to be in a regular class with everyone else just because she had a disability. I was also frustrated by this. If my sister didn't spend time in the same class as everyone else, then I don't think her classmates would ever understand her. I think it is easy to understand how we can extend a helping hand to those who are in wheelchairs. However, people who have Down syndrome have individual differences just like we do. This means that they have different needs in regard to support as well. This is why I think it is important for people to gain an understanding about disabilities and actually get to know people who have disabilities. I don't think people with disabilities and people without disabilities should be put into separate categories because all of our lives are all equally important.

*This was taken from an essay that won first prize in the Junior High School Category (Kanagawa Governor's Prize) at the 40th Essay Contest on Welfare in Kanagawa Pref. (2016)

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Record of your Baby's Growth and Development

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Your Child's Name

Record of Birth

Date of Birth : YY/MM/DD

Time

Period of Pregnancy : Weeks / Days

Sex : Male · Female

Blood Type :
Height :
Weight :
Head Circumference :
Chest Circumference :
Place of Birth :
Name of the Doctor :
Name of the Midwife :

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Record of _____'s Height and Weight

YY/MM/DD	Height	Weight	Remarks (Age, Physical Condition, Place, etc.)
----------	--------	--------	--

■ P40

YY/MM/DD	Height	Weight	Remarks (Age, Physical Condition, Place, etc.)
----------	--------	--------	--

*References: You can download a form to record height and weight of children with DS from <http://www.jdss.or.jp/>. You can also download refill pages for each record contained in this handbook.

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Medical History

Keeping a medical history for your child will help you when your child gets older.

We recommend that you record the names of the hospitals where your child had treatment, any symptoms you are concerned about, etc.

Diagnosis

Heart Disease

Details :

Pulmonary Hypertension

(+, -)

Digestive Disease

Details :

Blood Disease

Details :

Neurological Disease

Details :

Thyroid Disease

Details :

Eye Disease

Details : Hyperopia (Farsightedness)/Myopia (Nearsightedness)/Astigmatism/
Strabismus (Cross-eyed)/Other

ENT Disease

Details : Hearing Loss (Right Ear db/Left Ear db) /Other

Orthopedic Disease

Cervical Subluxation (+, -) /Pes Planovalgus (Splayfoot) (+, -)
Scoliosis (Curvature of the Spine) (+, -) /Hip Joint Dislocation (+, -)

Other

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Name of Disease / Date of Onset / Hospitalization

Measles/ Year Month Day / YES (Days) NO

Mumps/ Year Month Day / YES (Days) NO

Rubella (German Measles)/ Year Month Day / YES (Days) NO

Chickenpox/ Year Month Day / YES (Days) NO

Febrile Convulsion/ Year Month Day / YES (Days) NO

Exanthem Subitum (Sudden Rash)

Year Month Day / YES (Days) NO

Pneumonia Year Month Day / YES (Days) NO

HFMD (Hand, Foot and Mouth Disease)

Year Month Day / YES (Days) NO

Erythema Infectiosum Year Month Day / YES (Days) NO

Please list food and/or medication allergies below:

Important Events in Your Child's Health Care

Vaccination is one of the most effective methods to protect children from contagious diseases. Make sure to get your child vaccinations. In order to protect your child's health, however, it is important to understand the purpose of the vaccinations and their potential side effects. If your child has any underlying medical conditions or if you have any other concerns, please consult your child's doctor. Please record all vaccinations your child has received in the "Mother and Child Handbook." This information will be necessary when your child gets medical checkups at his/her elementary school. These records are also used when your child travels abroad.

Having information available about your child's medical history will be extremely helpful when you apply for your child's disability pension in the future. Therefore, we recommend that you keep the information you record in this booklet as well as the information you record in your "Mother and Child Handbook" available for future reference.

*References ◆ Please visit the website below to check the vaccination schedules recommended by the Japan Pediatric Society.

http://www.jpeds.or.jp/uploads/files/vaccine_schedule.pdf (Japanese)

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Name of Disease	/	Date of Onset	/	Remarks
	/	<u>YY/MM/DD</u>	/	
	/	<u>YY/MM/DD</u>	/	
	/	<u>YY/MM/DD</u>	/	
	/	<u>YY/MM/DD</u>	/	
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	/	<u>YY/MM/DD</u>	/	
	/	<u>YY/MM/DD</u>	/	

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Record of Growth and Development

Developmental Milestones

Made my Child Laugh YY/MM/DD

Held a Toy YY/MM/DD

Okuizome (First meal) YY/MM/DD

Held up own Head YY/MM/DD

YY/MM/DD

Rolled over YY/MM/DD

Started Eating Baby Food YY/MM/DD

Displayed Stranger Anxiety YY/MM/DD

YY/MM/DD

Started Creeping YY/MM/DD

YY/MM/DD

Got Down on All Fours YY/MM/DD

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Started Crawling YY/MM/DD

YY/MM/DD

Sat up Independently Using Hands YY/MM/DD

YY/MM/DD

Sat up Independently YY/MM/DD

YY/MM/DD

Pulled Himself/Herself up to Stand YY/MM/DD

Started Cruising YY/MM/DD

_____ YY/MM/DD

_____ YY/MM/DD

_____ YY/MM/DD

Stood up By Himself/Herself YY/MM/DD

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Took his/her First Steps YY/MM/DD

_____ YY/MM/DD

Took More than 10 steps YY/MM/DD

_____ YY/MM/DD

Jumped YY/MM/DD

_____ YY/MM/DD

Climbed Stairs YY/MM/DD

_____ YY/MM/DD

_____ YY/MM/DD

_____ YY/MM/DD

Jumped from a Height of 20 cm YY/MM/DD

_____ YY/MM/DD

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Omiyamairi (First Shrine Visit) YY/MM/DD

Hatsuzekku (First Annual Festival) YY/MM/DD

First Christmas YY/MM/DD

First New Year's Day YY/MM/DD

First Day Out YY/MM/DD

First Birthday YY/MM/DD

■ P49/50/51

Things That Made Me Happy / Words That Left an Impression

■ P52/53/54/55

Questions and Concerns

YY/MM/DD :

Person you talked to:

Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

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Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

YY/MM/DD :

Person you talked to:

Answer to your question:

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Record of Certifications and School History

Let's record your child's developmental milestones in this handbook. This information will definitely be useful in the future.

Record of Certifications Obtained

Name of Certification :

Issuer :

Date of Issue / Date of Renewal :

Certification Number :

Level :

Remarks :

* Example) Name of Certification : Ai No Techou

Issuer : Tokyo

Date of Issue / Date of Renewal : 20XX/XX/XX

Certification Number : No.1234567

Level : Level 3

Remarks : Class II

Record of Schools Attended / After-School Activities

Name of School :

e.g.) Happy Nursery School / Swimming / ※※ Municipal Daisan Elementary School

Type :

e.g.) Nursery School / After School Activities / Elementary School

Grade / Class :

e.g.) Hiyoko Class / Star Class / 1st Grade, Class 2

Start :

e.g.) 20XX/1/23 / 20XX/2/12 20XX/4/05

End :

e.g.) 20XX/3/31 20XX/3/15 20XX/3/31

Classroom Teacher :

e.g.) Harumi Sensei (Ms. Harumi) / Sato Sensei (Mr. or Ms. Sato) / Suzuki Sensei (Mr. or Ms. Suzuki)

Remarks :

e.g.) Every Saturday

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Name of School

Type

Grade / Class

Start Date

End Date

Classroom Teacher

Remarks

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Record of Agencies Contacted / Contact Information

Ryouiku (Rehabilitation) Service 1

Name:

Phone:

Person in Charge:

Mail:

URL:

Ryouiku (Rehabilitation) Service 2

Name:

Phone:

Person in Charge:

Mail:

URL:

Ryouiku (Rehabilitation) Service 3

Name:

Phone:

Person in Charge:

Mail:

URL:

Consultation Service in Your Area

Name:

Phone:

Person in Charge:

Mail:

URL:

Oya No Kai (Parent Support Group)

Name:

Phone:

Person in Charge:

Mail:

URL:

Father

Name of Workplace:

Phone:

Emergency Contact:

Mail:

Mother

Name of Workplace:

Phone:

Emergency Contact:

Mail:

Grandparents / Relatives

Name :

Emergency Contact :

The Japan Down Syndrome Society (JDS) consists of family members who have raised children with Down syndrome. They can give you advice by phone or FAX at no cost.

Contact Information of JDS

TEL 03-6907-1824

FAX 03-6907-1825

Phone Consultation Available

Mon - Fri 10:00~ 15:00

Mail: info@jdss.or.jp

URL: <http://www.jdss.or.jp>

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Afterword

When I had a baby with Down syndrome, I personally felt that I needed useful information right away. I wondered how my baby would grow and develop and what I needed to do. This booklet was created from my desire to prevent other new moms who have children with Down syndrome from going through the same painful experiences that I did.

The extra 21st chromosome that most children with Down syndrome have is an important gift to you from your baby. The “+” sign in the title “+Happy” means the “extra happiness” that your baby has brought to you.

The subtitle “The Seeds of Happiness” was taken from the title of a CD album by Tomoko Arakawa, a recorder player with Down syndrome. With lots of love from family members, “The Seeds of Happiness” will grow quickly and the biggest flowers you have ever seen will bloom.

In order to fulfill my sincere wish for every family who obtains “+Happy - The Seeds of Happiness” to be able to raise their children with lots of smiles, I am including some calligraphy for you by Shoko

Kanazawa, a calligraphy artist with Down syndrome. Last, but certainly not least, I would like to thank each and every one of you who contributed to the creation of this booklet by submitting articles and answering questionnaires.

Yurie Sahashi, 21+Happy

* “21+Happy” is a community (circle) on the Internet for families who have children with Down syndrome or disabilities due to other chromosomal differences and for people who offer support to these families. The people in this community all live in or have connections to one of the three Tokai prefectures (Aichi, Gifu and Mie). Since 2010 we have continued to actively promote awareness by holding photo exhibitions and creating photobooks throughout Japan which show families leading fun and happy lives.

About the cover picture

“Untitled” (2008)

Water-color painting and paper collage 34.8 x 24.8cm

Created by Moeko Inada

Belongs to craft atelier, La Mano

Photo and profile credit provided by the office of Yukiko Koide

*** Profile**

In 1985 Moeko Inada was born with Down syndrome in Kyoto. After graduating from high school, she participated in the craft atelier “La Mano,” in Machida, Tokyo, where she started creating works of art. Moeko uses various techniques and materials, but her work with torn paper is especially remarkable. Tearing painted Japanese Washi paper, putting it in water, then pasting it on a sheet of paper has a certain rhythm to it. It shows Moeko’s gentleness and strength as well as her unique color sense.

Planning & Production: 21+Happy (Yurie Sahashi and Yuko Otani)

Binding & Design: Mayumi Sawachi

Title Calligraphy: Saku Matsuda (Born in 2009 / 4 years old when she wrote this)

Editing: Masako Yamamoto and Kimiko Uehara

Corporation: Prof. Satoko Nakagome (Shinshu University School of Medicine, Health Department) and Hiroshi Tamai (Osaka Dental University)

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Children Fund.”

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Calligraphy by Shoko Kanazawa - “Smile” (2012)

* Profile

Shoko Kanazawa

A visiting associate professor at Nihon Fukushi University (Japan Welfare University)

She was born in 1985 in Meguro, Tokyo. She started learning calligraphy from her mother Yasuko in 1990 when she was 5 years old. She held her first solo exhibition at Ginza Shoro Gallery in 2005 when she was 20 years old. She also held solo exhibitions in the following areas: (1) Kenchouji in Kamakura, (2) Kenninji in Kyoto, (3) Toudaiji in Nara, (4) the Fukuoka Prefectural Museum of Art, and (5) the Ehime Prefectural Museum of Art. She has been involved in a wide range of activities. (1) She wrote the title in calligraphy for Taira no Kiyomori, a TV historical drama series broadcasted on NHK in 2012. (2) She did dedicatory writing for Kumano Taisha Shrine, Itsukushima Shrine, and Miwa Omiwa Shrine. (3) She wrote Gyousei (Emperor’s Poetry) in calligraphy as well. (4) She made a speech at the United Nation Headquarters in New York at an anniversary meeting held by Down Syndrome International <DSi> in March 2015. (5) She held her first solo overseas exhibition in New York in that same year and went on to hold solo exhibitions in Prague, Singapore, and Dubai as well.

Message from Shoko

Congratulations on the birth of your baby.

It has been 30 years since I was a newborn “baby.”

Thanks to my generous mother, I reached 30 years even though I was scolded and cried many times.

“Mother, thank you for always staying by my side.”

(Note: Shoko, who reached the age of 30 in 2015, has fulfilled her cherished dream of living alone.)