

## What I learned from Yu

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My son, Yu, is a 10-year old boy with two older sisters, one in upper secondary school and one in lower secondary school. He suffered hypoglycemia 3 days after birth and was put into NICU, but luckily he grew up healthy after that.

During his infancy, he began having sensitivity to sounds and gradually began to show temper, cried at night and exhibited delayed language development.

### ○ **Early Childhood**

At the 18-month health-checkup, his delayed development was pointed out and so we contacted the health center and attended parent-child class. At about the time he turned three, it was recommended that he enroll in therapeutic care and education classes, where I took and stayed with him. Later, detailed examination at a medical institute resulted in the diagnosis of pervasive developmental disorder, autism, and intellectual disability.

At the same time, his selective eating habits and temper had grown worse, and I was tired out. Friends and teachers I met at the therapeutic care and education school provided me with emotional support.

Eighteen months later, we came to a point of deciding on his next path. We had decided to send him to public kindergarten, and we expressed our decision. Some teachers were worried about him graduating from the school while concerns of his condition still remain. But to be able to enroll in local elementary school, we thought he needed to spend 2 years at a local kindergarten, and we took the time to discuss this with the teachers of the kindergarten we wished our son to attend, requesting their acceptance.

My son's information was sent to the kindergarten and my son was enrolled. Other than concern for support for Yu, the real issue was my emotional state. Eighteen months at the therapeutic care and education class had been a good experience; however, during that time my involvement with the community had been somewhat estranged.

There was also my discriminatory thinking that "My son is different from other children." I had a hard time opening up, and days of struggle continued. While I was distressed, my son was accepted amicably by other children and enjoyed kindergarten in his own way.

Two years passed quickly, and the time came to decide on elementary school. My husband and I were determined to send our son to the local elementary school, but he still talked very little, and his selective eating habits and short temper had not changed. But more than anything, we wanted our son to go to the same elementary school with children he made friends with during his 2 years at kindergarten. We extensively discussed this with the elementary school, were given

an opportunity for a trial visit, and he was accepted at the elementary school.

## ○ School years

### **\*Change of our way to involve with our community\***

Entering elementary school.

Yu was registered for a class for special needs education in the elementary school. You may ask if I resisted registering him in a class for SNE, but I didn't. It's because our oldest daughter was also suspected of having a developmental disability when she was 5 years old and was enrolled in a class for SNE when she entered elementary school. Looking back, there may have been a lot to be said about the choice we made, but it was the decision we made after struggling to find the right path for him.

We had decided on him joining a neighborhood group to walk to school. We wanted him to develop relationships with the neighborhood children. At the time, my second daughter was in the fifth grade, so I asked her to include him in the group and I followed them as they walked to school.



Enrollment ceremony. He was very shy but tried his best.

When Yu was in the first grade, other children were not used to him and anxious about him, and Yu expressed his anxiety about the new environment and inability to communicate his feelings by crying and sprawling on the ground.

At times like these, there was a boy that always stood by him. He doesn't speak to my son, but he would go pick up the shoe Yu threw out and just looked at him. At another time, a teacher at the class for SNE told me that there was a girl who is always kind to Yu. I wanted to see the mother of that little girl, and I found the courage to talk to her on the sport festival.

Her mother told me why her daughter became friends with Yu. "One time when she was crying, everyone thought that it would be wiser to leave her alone; but Yu asked her if she was okay. She was happy that he asked and that's why she likes to stay with him." I was so happy when she told me.

He truly understood the kindness and

Sport festival at his first grade. He ran a race of 50 meters though he was surprised at the whistle.



consideration shown to him by others. And now, I think he is trying to return the kindness he felt.

This incident made our family see how much Yu had grown.

### **\*Involvement with friends\***

He became a second grader.

Study had become difficult for him, and we gave up having him use the same textbooks as his classmates. At the time he couldn't even read, so Japanese and Math were taught in the class for SNE.

Many of the boys in his second grade class were very active. And at that time, I had categorized our son into a group of disabled children, so I was concerned that he may be bullied. His second-grade teacher was a cheerful woman. When I went to pick him up at school, I was surprised to see Yu with a boy who was a part of so-called active children's group.

Until then, he usually hung around with caring little girls. But we didn't get any report of problem so we were thinking he was doing okay.

One day, I asked his teacher if he was getting along okay with the group of active boys, and the teacher replied, "Those boys find ways to be near Yu. Yu also finds ways to go near them. They make unwanted comments at times, but when Yu is crying, he goes to them to be consoled. They have very unique friendship. One time, Yu had scratched a boy's face. When the school contacted the parent, the parent asked if we played favorites and didn't scold him. But I said that I always scold my students for wrongdoing, and Yu is no different. The father said, 'Then that's okay. My kid is a boy, and boys always get hurt.'"

We were truly grateful for the friends he made that I didn't know about, teachers who mediated whatever problem that arose, friends and their families that accepted Yu. There were times boys had fist fights, but these experiences slowly changed the image I had of my son.

### **\*Changing feelings toward our son and involvement with others\***

Yu became a third grader.

This was the year of significant change for Yu, with the construction of a new school building and the change in the route to school. He was finally getting used to school life and becoming calmer, but this change took a toll on him. He began taking his frustrations out on his classmates. Every day, the special support teacher and I took bawling Yu out of the classroom. I was tired out by this repetition.

When I was consulting with the people of the Kitakawachi Liaison Group, they asked me "Do you



Family trip during summer vacation.

really understand Yu not as a child with disabilities but as one human being?" It opened my eyes.

I was able to explain Yu's conditions and characteristics, but I wasn't able to explain Yu as one individual. After thinking about this for a week, I decided to pull Yu out of the class for SNE.

The teacher of the SNE class was surprised and worried, "What are you going to do if Yu gets crushed by other children?" I knew that the teacher was very good to Yu and understood her concern. But I wanted everyone to understand Yu by spending more time with him, and I wanted to know more about him too. My mind was made up.

Next, I needed to consult with the third grade class teacher. The teacher was new and young, and amazingly okayed my request without hesitation. She said, "I don't know how much I can do, but let's try. If it doesn't work out, then we'll think of another way. I don't like to give up before trying."

My heart felt lighter.

I ask that Yu be given the same textbooks as everyone else. This is because I saw Yu enviously looking at the Kanji drill book of the student sitting next to him at open school day. I felt like I had been robbing something important to him without realizing it. This talk of putting Yu in a regular classroom came about in June of the first term, and Yu was still unstable.

By the end of the third grade, a mother of Yu's classmate said to me. "My daughter wants to be a kindergarten teacher or special support teacher. I think knowing Yu had lot to do with it." I was so happy I wanted to cry. Other parents encourage me by saying "Let's send our children to local lower secondary school together."

### **\*Yu's growth and struggle\***

This year he became fourth grader.

I requested that the teacher give Yu the same work and homework, but the difficulty and the volume had took a toll on my emotions. I was stuck in a dilemma between the joy and burden of "letting Yu do the same work as other children."

I consulted with the school teacher about my feelings and the teacher said, "You probably want Yu to have the same experience, not to acquire the same knowledge, right? Then, there's no need for him to do the same amount of work as other students. It's okay. Why don't we think about the amount of work that is comfortable for Yu." This opened my eyes. I thought I still hadn't really understood Yu.

**\*Future issues\***

The current issue is the sense of distance. This issue is not just for Yu, but for me too. When Yu sees someone he likes, he would call out, run to that person and grabs his or her arm. Some children are scared and don't like it.

This is the issue on the part of Yu that shows he doesn't have the sense of distance with others. Other children's reactions are natural, but seeing it happen makes me uneasy.

From this, dealing with this issue is a good opportunity to have Yu learn the sense of distance, and for me to re-think the distance between Yu and I.

It would be difficult for children to build true relationships if parents are always by their sides supervising and intervening. Parents also need to think of their lives after raising their children.

And so we need to gradually let our children go. I'm just realizing this fact. This will be my huge issue from now on.

Our family feels that we were given a huge opportunity to think about the true meaning of independence through Yu. In these past 10 years, thinking of involvement with and support for individuals with disabilities, we began to think that we shouldn't categorize or to only provide individual training, but to think together about how each person with or without disabilities should live, being themselves provided with minimal support.

We intend to think and experience with Yu, as we cry and laugh through our lives.



Third grade. Experiencing shopping at day service program, buying his snack.