Walking with my Daughter-Inclusive Education

Mother: Misuzu Arata Daughter: Machiko Arata

10-year challenge to pass upper secondary school entrance exam

My daughter took 14 years to obtain a upper secondary school diploma from an Osaka prefectural upper secondary school after graduating from lower secondary school. She took the entrance exam of the "N" Upper Secondary School 10 times in total. The school was located 10 minutes from our place by foot. Every day she was watching students going to and from the school from our window, while she could not attend the school.

The 10-year period when my daughter failed to enter upper secondary school saw significant changes in the "system of upper secondary school entrance examination." For example, the "Social Independence Course for Students with Intellectual Disabilities" was newly introduced (though my daughter was never recognized as qualified to take the exam) and the entrance examination system itself was changed during this time. During those 10 years, both my daughter and I shed tears many times. There were three chances for my daughter to enter upper secondary school. The first one was when she took entrance exam of the part-time course of "S" Upper Secondary School for the first time. The second chance was when she tried to attend "N" Upper Secondary School a year after. The third time, she tried again to enter the part-time course of "S" Upper secondary School. Every time, however, my daughter failed in the exam, even though the number of students who passed the exam did not reach the limit, a predefined enrollment capacity.

We were let down and suffered very much. "Why can't my daughter become an upper secondary school student while her friends all enrolled in upper secondary school without problem? What is wrong with my daughter? How can we remedy her disability in order for her to be able to get enough score for entrance examination? Can't students with intellectual disability go to upper secondary school? What is the difference between my daughter with disability and other students who are so called able-bodied persons? Is it just a parent's ego to let her continue trying to enter upper secondary school?"

I, however, had second thoughts and started again and tried to let her enter upper secondary school. Because my daughter did not give up after being rejected again and again and I thought it would be insulting to my daughter who kept trying if her parent got beaten and gave up. At first, we were excited to see the result of the entrance exam. We would look at the announcement board several times to see if there was her number in the numbers of students who had passed the exam. Later, we came to think she would be rejected again this time and stopped looking for her number seriously. The more we were forced to see the reality, the more we were overwhelmed, expecting another rejection. Every time, we were devastated and went home. There is no harder experience than seeing an announcement board without my daughter's number on it again and again.

Every year, we wanted to make her pass the exam, although we had no idea concerning what we could do. We always felt anger, sadness and strong frustration whenever we found the thick wall of the

student selection system. Both of us, mother and daughter, kept on wrestling with these hard feelings for 10 years.

When she was finally admitted to the part-time course of "O" Upper Secondary School, we were delighted several tens of times more than the tears we had shed for the past 10 years.

Attending local nursery, elementary and lower secondary schools

In next September, my daughter born with intellectual disability will become 29 years old.

We did not want her to study under the inclusive education system from the beginning. Her doctor we had been seeing for her training told us, "Your child will not grow up in the same way as other children. She has both severe intellectual disability and difficulty in walking. I recommend you to make her attend a special school for children like her." The doctor's comment made me act repulsively. I challenged the doctor with outrage. I said to the doctor, "Why do you think you have understood everything about my daughter by just giving her a brief examination? As her parent, I know her better than anyone else." With a belief that "children grow up well when they are raised among other children," I enrolled her in a local nursery school when she was 3 years old after having waited for 2 years. At first, the administration rejected my daughter because they wouldn't accept children with disabilities aged 3. I responded to that saying, "She should be taken care of in a nursery school not as a child with disability but as one child." And after having visited the relevant administrative office and made extensive negotiations with them again and again, I finally succeeded to enroll her in the local nursery school. Although my daughter, Machiko, had difficulty in walking when she was enrolled in the nursery school, she came to be able to walk after having her heart operated when she was 4. Machiko grew up stably being with other children in the nursery school.

Next, she went on to a local elementary school. We did not agree, however, to a suggestion that she should enroll in the class for special needs education of the school. It was because we did not want to deem her as a child different from others by making her enrolled in such a class. We had a hard time at the elementary school as the school did not understand how I think and feel. For example, when my daughter was in the 1st grade, the classroom teacher complained saying, "I took the post of the teacher for the 1st grade because I thought she would be enrolled in class for special needs education. You broke a promise." The teacher also said to my daughter in front of other children, "I did not become a teacher to take care of your wet pants." My daughter often wet her pants back in those days.

On the other hand, I think it was great for her to grow up together with classmates. In her second semester of the 1st grade, other students started helping my daughter. They started volunteering to replace the teacher in taking care of her accident, wiping the floor with cleaning cloth. Some of her classmates took her to the bathroom at breaks and my daughter came to be able to do what she needed to do in the bathroom.

Every year for six years in the elementary school, whenever she went on to the next grade, the school told us that they had difficulty to find a classroom teacher for her class because my daughter did not enroll in the class for special needs education. When she was at the 6th grade, Machiko was bullied by classmates. The classroom teacher explained about the bullying during a meeting of teacher and parents, saying "Bullying could not be avoided because your daughter had been an obstacle to

classroom lesson as she cried out loud." This comment surprised even other parents. Not all classmates, however, did bully my daughter. Some students watched over her in the classroom. I heard that one student got home from school and said, "The teacher is probably taking it out on Machiko."

Machiko could not understand lessons at all. She went on to lower secondary school together with children she grew up in the same elementary school. The lower secondary school understood how I think, because I told my feelings and thoughts in advance. So, Machiko spent her lower secondary school life not being enrolled in the class for special needs education. And any extra teacher who was available at that time took care of Machiko in the classroom on a shift basis.

In the lower secondary school, where students need to move from classroom to classroom, Machiko was escorted by her classmate when moving to other classroom. Even male students were there to lead her by hand. Back in those days, Machiko easily got nervous and frequently cried out loud during class when the classroom was noisy and other students did not concentrate on lesson.

In her 2nd year in the lower secondary school, an increasing number of students understood Machiko and her disability and they told other students to be quiet during class. Teachers told me that it was easy to teach the class of Machiko because students were quieter than in other classes. There was one student in her class who took care of Machiko well even though the student got injured on the hand as Machiko sometimes dug her nails into the hand when the student came close to her to take care of her. The student went on to an upper secondary school specialized in welfare and now he is working in a welfare facility.

While her compulsory education life filled with ups and downs, I believe, Machiko got very much stimulated by her classmates and learned how to live a life with strong nerves. I also believe that other students also understood that persons with disabilities were not different from them by being near and interacting with my daughter.

When Machiko was 20, prior to the coming-of-age ceremony held by the local government, I told the 3rd-year classroom teacher of the lower secondary school that Machiko was going to attend the ceremony. The teacher called up her classmates of lower secondary school days and asked them to sit close to Machiko to take care of her during the ceremony. It was a wonderful ceremony, as most of her classmates got together to take care of her. Machiko herself looked very prim wearing kimono, which made her ex-classmates surprised and happy. Seeing her behaving well, one of them said, "Machiko really grew up." I believe this comment was made because they grew up together with my daughter.

I thought it would be a waste if she lost such a great friendship after graduating from the lower secondary school. So, we kept on trying to enroll her in a local upper secondary school, "N" Upper Secondary School, even though she had disability. She took the entrance exam 10 times but the wall of the student selection system was very thick for a student who could not get a sufficient mark to enter. She could not pass the exam to enter "N" Upper Secondary School.

Upper Secondary School Life

Finally in the 10th year, she could get in the part-time course of "O" Upper Secondary School. It, however, opened up another school life with ups and downs.

The upper secondary school had no experience in receiving a student with severe intellectual disabilities and did not know what kind of student Machiko was and how to deal with a student with severe disabilities like Machiko. They had totally no knowledge. The school tried to get information on persons with severe intellectual disabilities, visiting and consulting with upper secondary departments of schools for special needs education.

Meanwhile, Machiko had not been in the classroom for 10 years after graduating from lower secondary school. There was a range of concerns including whether she could fit in school life to attend every day or whether she could manage to get to and come back from school. It was expected to take one and a half hours for her to go to school. She needed to take a 30-minute bus ride from home and next she had to take Keihan Railway train from Kuzuha to Tenmabashi. It would be around 11 in the evening when she got back home, due to an inconvenient bus operation. It was really a rocky start because both the school and I had to grope around about everything.

As expected, she could not fit in the school life well at the beginning and she often cried with a loud voice thundering all around the school. When she was not crying, she escaped to bathroom. Of course, she could not stay in the classroom to study. On the way to and from school, she caused diverse incidents. For example, she cried very often on the bus and train, tore her commuter pass and pulled other passengers in front of her when she got off.

At school, when struck by a major panic, she stayed in the hallway. Teachers at "O" Upper Secondary School were also seized by panic. As time went by and as she went on from the 1st semester to 2nd and 3rd semesters, however, she started getting calmer and became able to stay in the classroom.

She probably was influenced by other students' behavior, staying in the classroom when studying. One day when she was crying in the hallway, 2 students of the same year as Machiko said to her, "You'd better stay in the classroom." Hearing which, Machiko entered the classroom without difficulty. The two of them were also students who often didn't stay in the classroom. And when I encouraged them to go back to the classroom saying, "It would be unfair if you do not do what my daughter did." Hearing this, they returned to their classroom, saying, "That's true. She is back to the classroom to study. So, we will do the same." The two students were infamous for not going into the classroom easily. The teacher was surprised to see them going back without any fuss.

When the school festival was held at her 1st year, students decided to play drums in front of audience. Drum performance was chosen following one student's suggestion. The student said to the class, "Machiko might be able to play the drum. If she can't, she probably would move as if she is playing the drum." A male student volunteered to help my daughter practice drumming. Until the day of the school festival came, several classmates had stood by my daughter to teach her how to play. On the stage of the school festival, she played the drum happily. (I heard that some teachers at the school said, "I would be sorry for her if we let her appear on the stage because she has a disability.")

My daughter, however, gained confidence after she played the drum on the stage and I think she started being motivated in many things in her own way after the festival.

At the end of her 1st year in the upper secondary school, during the extracurricular activity time, in front of other students, I talked about why Machiko was now attending the part-time course of "O"

Upper secondary School and asked how they thought about her. Almost no complaints were made about my daughter and her existence in the classroom and no one said that my daughter was bothering them and should not be there. Their comments included: "It is just great of her that she comes to school every day despite of her disability;" "She is doing her best;" and "She is not giving up although she raises a loud voice." To tell the truth, I was very nervous since I was expecting to hear something uncomfortable. When the classroom teacher asked students, "Would it be okay if Machiko is your classmate again?" Most students answered, "It would be okay to be in the same class with Machiko," which rather surprised the teacher.

In this way, Machiko gradually gained her own place in the class as its member. As if it was not true that Machiko often got panicked and cried out loud when she was in the 1st year, my daughter studied quietly in the classroom for the last half of her 2nd year and later. She was so quiet that it almost felt as if she was not there. I think it worked that way because, during her 2nd year, the support teacher did not stick close to her but watched over her from a short distance away.

Probably, my daughter learned gradually by watching other students' behavior. It is true she could not understand lessons offered in the class but no doubt she started considering little by little how she should behave as she watched other students' attitude.

For example, she did not seem to want to be in a different place separately from other students. One day, her English teacher suggested that she practices English pronunciation in a separate room for half the time during the class. I, however, replied to her, "I could not accept such a suggestion to let my daughter study in a separate room as a parent." The teacher suggested again that my daughter practices pronunciation separately for the last 5 minutes during the lesson. Giving in after seeing the teacher's passion, I agreed to the suggestion to give her 5-minute pronunciation practice in a separate room. When it came to time to have that lesson for the last 5 minutes of the class, the teacher encouraged my daughter to go to a separate room but she never did as told, saying "No." Maybe, she thought it odd if she went out of the room while others stayed. As this incident indicates, my daughter came to watch other people and make her own decision.

In the 3rd year at the upper secondary school, students were supposed to have a school excursion. Going out of the classroom on a school excursion probably provoked plenty of concerns to both the school and my daughter. The upper secondary school requested me to go on the trip to escort her. My daughter had already gone on a school excursion without my escort when she was attending elementary and lower secondary schools. I always thought it would not be good if a parent went along for taking care of the child so I refrained from going this time as well.

In the end, my daughter went on the trip together with other students without my escort. She had traveled on a plane in a family trip to Hokkaido when she was a lower secondary school student, however, it had been a long time since she had taken a plane. Later, I heard she had cried all the time on the plane on her way to, probably because she was scared. Even when she arrived at Chitose Airport, she was crying. She became quiet, however, when it was time to get on a tour bus.

She came home safely, completing the itinerary along with other students. She did not make a fuss on the plane back and I found her smiling when she arrived at Itami Airport. I once again have to say it is

great to let your child spend time not being watched over by a parent. For quite a long time, she kept on saying the snow was falling, falling, as if she remembered the time in Hokkaido. She might have said the same, looking at snow falling together with her friends (or, there might be teachers, too). I could tell she had had a very good time.

In her 4th year at the upper secondary school, she could stay in the classroom relatively calmly. She could participate in all school events during the year. It was a huge difference from her 1st year. For example, she visited the Nara Park from school when she was in her 4th year. On the field trip in the 1st to 3rd year, she always was with her teacher. But at the Nara Park, her classroom teacher asked other students to walk with her and she walked in the park with several students including male students. I was told she had been smiling walking with them. She even got used to the school festival at upper secondary school and caused no trouble. She appeared on the stage together with other

students and performed a dance, which she liked very much.

The graduation ceremony is one of the most exciting events at school. I discussed with the school many times and thanks to the school's warm considerations, Machiko came to the stage on her own and received her diploma firmly. Her face was glowing with triumph. I learned from her face that she was satisfied that she studied and completed her upper secondary school life together with other students.



Future course after graduation from upper secondary school

When the 4th year started, we had to consider how she should move on after graduation. The upper secondary school helped us when we were considering my daughter's future course but we could not have clear prospects easily. We just decided to visit universities during the campus visit season in summer and fall. We made some research to see when we could make campus visits for each university and asked the upper secondary school to, in advance, contact the universities we decided to visit. Again, the student selection system of those universities stood in the way for my daughter who had intellectual disabilities and could not get enough mark for entrance. When we visited Ryukoku University, we were told they had a program called "*Fureai Daigaku*" (open college for persons with intellectual disabilities). After having met with a professor in charge of "*Fureai Daigaku*" of the university, we decided to submit an application in March. In April, a letter of admittance arrived and now my daughter is attending the university twice a month.

She obtained the student ID number from the university, which enables her to become a member of the university cooperative. She now can enjoy lunch at the university cafeteria together with other students when she goes to the university. She now manages to sit and study all through a 90-minute class.

Only because she did complete her upper secondary school life, can she enjoy learning at the university now. My daughter has opened up a new life with full of new experiences.