

You can do anything if you have a strong will?!

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Mari Arai/Yutaro Arai

My only son, Yutaro, is 16 years old now. He is a freshman in upper secondary school. Although he can breathe spontaneously, he lives on an artificial ventilator. He is unable to cough, spit out sputum or swallow saliva and so he needs to have sputum suctioned frequently with an apparatus. Also he is unable to chew or swallow food, he has to take in nutrition from liquid food through a gastrostomy tube. He can hardly move his limbs and when he moves from a place to another he does so in a stretcher-type wheelchair. He needs other people's support as he cannot do almost anything including excretive care. Since he cannot talk with his voice, the only way for him to have communication with other people is blinking. Even though slowly, he can move his eyeballs and eyelids and when asked something, he blinks to indicate "Yes," and does not blink to indicate, "No."

1. Birth to life at home

When Yutaro was born, two weeks later than the expected delivery date, he was in a state of apparent death. Although no abnormality was found when he was in his mother body, it took too long for him to be born. When finally he was born via Caesarean section, he was not breathing. Immediately he was on artificial ventilation and was taken to another hospital's NICU (Neonatal Intensive Care Unit). For about 10 days from his birth, Yutaro did not move at all being unconscious. We were told that he might not gain consciousness again if he stayed like that. Later, however, he started moving little by little and opened his eyes. However, because enough oxygen was not supplied to the brain at the time of birth, he ended up in a condition where he could not move his body well, the breath was weak and it was difficult for him to take food or put out saliva and sputum through his mouth not being able to swallow or spit. He repeatedly caught pneumonia and had high fever, as the result, he had to get over the high wall between life and death again and again.



When four months passed from the birth at the hospital, he received a tracheotomy. We were a little reluctant about the operation as it was the first time for us to have him have such an operation. It was, however, what he had to

have as he needs to have an open airway so that suction could be done easily. The operation was also necessary to allow him live a life at home later. We decided to have the operation, by also considering it would make things easier for Yutaro, too. After the operation, I and my husband and other family members including Yutaro's grandmother started practicing the tracheal suction, which had only been done by healthcare workers at the hospital. We all learned and practiced how to handle the artificial ventilator and how to perform lifesaving treatment. We also practiced how to get him into a car and tried to let him stay at home with his family. When he reached the age of three, Yutaro was discharged from hospital and his life at home started.

2. From staying home to attending preschool and higher schools

Even after having been discharged from the hospital, Yutaro was unable to go out except for the monthly visit to hospital. We started practicing on going out to get used to it little by little and in the next spring, Yutaro and I together began to attend a therapeutic and educational school for infants and toddlers. We have to bring many tools with us, such as suction apparatus, oxygen cylinders and an artificial ventilator, which was not easy because Yutaro's health condition was not stable, too. Yutaro, however, began to look very different and much livelier when he went out, compared to the time he had been hospitalized. We noticed that his reaction improved and he became physically stronger as he was receiving various kinds of stimulation outside home. When he reached the school age after graduating from the preschool, we decided to enroll him in a school for special needs education, as we, as parents, assumed, "Our son would not be able to attend any regular school because he is hooked on an artificial ventilator. He often has high fever. In the first place, we are not sure even if he can commute to and from the school." When choosing a school for special needs education, we decided that my son should have a visiting student status* not an attending student status*. He started a new life attending the school two days weekly and studying at home with a teacher visiting him one day weekly.

We had an expectation that Yutaro, although he had a severe disability, could receive education in a more professional manner. We thought there should be a number of experts at such a school. In case of students like Yutaro who live on an artificial ventilator, parents had to perform medical care like suction of sputum and tube feeding. And Yutaro was not allowed to use the school bus*, too. For that reason, we, parents, had to take him to and from school.

Meanwhile, Yutaro were getting more physically resistant from year to year as well as becoming more and more motivated to study. On the other hand, Yutaro started feeling unsatisfied with his school life, while as parents we came to question about our actual situation in which we send him to and from school and attend him all the time at school. We wondered how other users of artificial ventilator were commuting to and from school in other parts of Japan. By making searches, we found "the Baku Baku Club, Ventilator Users Parents Association Japan," and we were shocked to learn that, of members of the club, some were attending a regular school rather than a school for special needs education, without parents' attending them. We for the first time noticed there was an alternative and we could have been able to choose a regular school. Later, therefore, after considering this very hard, Yutaro proceeded to attend a regular lower secondary school.

3. Life at a regular lower secondary school

At the regular lower secondary school, the principal and other teachers for the first time had a student with an artificial ventilator. The way of thinking was quite different between the school and us and we had to have conflicts repeatedly. The then principal of the school even made a discriminatory remark, “Yutaro should not have come to a regular school but should stay at the hospital.” We had discussions again and again with the school and the Hirakata City Board of Education, asking, “Why is the school not trying to get involved in the care of Yutaro?” We also said to them, “The school has the nurse and teachers to help and take care of Yutaro. Why do you leave everything to us, parents?” Sometimes we felt really weary but never gave up and continued discussions. In the meantime, teachers began to gain some understanding and the relationship between us and the school was getting better every year. From the second semester of Yutaro’s second year of lower secondary school, our burden to attend



Gym meeting during the first year

Yutaro was reduced and in his third year at school, we were fully released from the burden of taking care of him at school, except taking him to and from school.

At school, Yutaro studied together with other classmates while being attended by an assisting teacher, separate from another teacher teaching the class. The assisting teacher helped him by showing him the textbook, taking notes from the blackboard for him or holding Yutaro’s hand when he needed to do some manual works. As we were told that Yutaro had to be enrolled in a class for special needs education if he wanted the regular school to provide him an assisting teacher, he needed to be enrolled in such a class. As the result, he was required to be away from the regular class to take a course at the class for special needs education. The regular lower secondary school had no elevator and quite naturally Yutaro had to use the stair lift. Right after he had been admitted into the school, the school was excessively worried about him and Yutaro sometimes had to give up to study at class because of this problem. As time passed and teachers got used to and started understanding what Yutaro needed, however, less and less unfavorable incidents occurred. Yutaro could attend all school events at lower secondary school and students sometimes helped him by pushing his wheelchair. They even exchanged greetings with him, too. They even made considerations and discussions for Yutaro about how to help him attend school events together with other students.



In the third year, Yutaro is with his lower secondary school friends visiting him at a musical recital of the class for special needs education.



In the third year, Yutaro participating in a table tennis tournament.

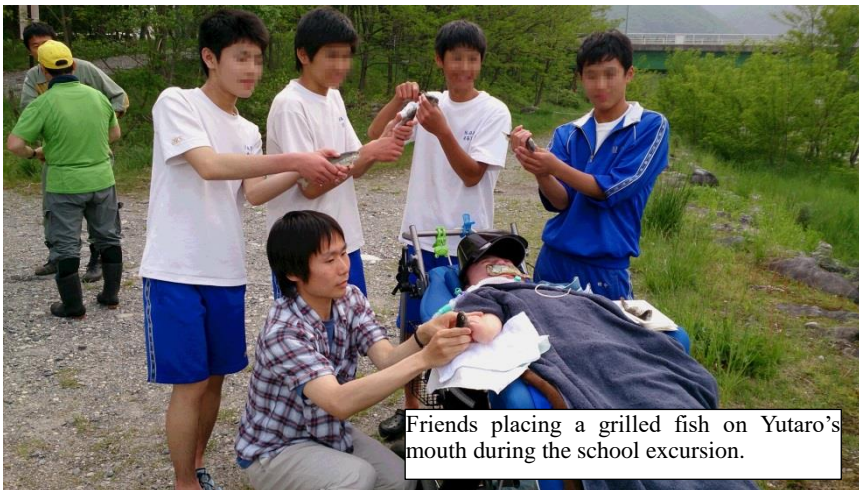
However, we had to discuss with the school or the board of education whenever there was a school event like an off-campus learning, overnight stay learning or school excursion. It was one of the large issues for us. Both Yutaro and we as parents requested that he should participate in such events along with his friends without family members attending him, which we thought very natural. Even after making discussions with the school and the board of education repeatedly and offering a range of possible ways while submitting his doctor's recommendation, the school did not change their position first and last and insisted that "the school could not allow Yutaro to participate if he insisted on going using the same transportation means as other students (bus)." Although such a problem remained at that time, retrospectively we can admit some improvements were made year after year, as shown in the fact that Yutaro was allowed to participate in the overnight stay learning using a special care taxi hired by us parents in his first year of lower secondary school and he attended the off-campus learning in his second year and the school excursion in his third year using a special care taxi arranged by the school (not at the expense of us, parents). At first, we parents had to be responsible for taking care of everything for Yutaro during such off-campus activities but it changed later and teachers began to take the responsibility for us.

In the school excursion, Yutaro was taken care of by a nurse and assisting teachers when he needed to get in the taxi during daytime activities and we parents moved along with them in a separate car. Teachers even helped Yutaro during the nighttime including care Yutaro needed when taking the bath. By deepening interactions with each other, some kind of attachment to or a sense of togetherness might have been born between Yutaro and teachers. One teacher even commented

happily later, "I have never had a school excursion like this one." The long trip to Hakuba, Nagano was not easy and tiresome but it was one precious experience. Yutaro had an experience of being lifted with a wire while sitting in his wheelchair in an attraction called EX Adventure, while other classmates were cheering (and worried a little). In a game to



Yutaro in a wheelchair about to be lifted with a wire in an attraction of the school excursion.



Friends placing a grilled fish on Yutaro's mouth during the school excursion.

catch fish with hands, some classmates caught a fish for Yutaro and handed it to him, because he could not go near the river. They also placed a grilled fish on his mouth.

Yutaro appeared like he did not like that but his classmates were enjoying how Yutaro responded to the fish, barking a laugh and

being surprised with his reaction. All the experience was probably new and interesting to those students, too. Yutaro even could go and see a nearby skiing jump ramp which otherwise he might not have seen. Both Yutaro and his classmates had great experiences, eating together, finding who each other was and shrinking the distance between them. I was realizing that even a student with severe disability could see, feel and experience the same thing as other normal students do, if only efforts are made to overcome barriers.

4. Future course after graduating from lower secondary school – Taking entrance exam for upper secondary school

Before and after entering lower secondary school, we encountered both the good and the bad. Still, Yutaro and we had often talked about “going to regular school would be (and was) better.” Yutaro expressed his wish to attend upper secondary school even right when he entered lower secondary school. In his lower secondary school days, we participated in several study meetings to exchange information on school life or entrance exam for upper secondary school for students with disability and where we could have more chances to tell other people about Yutaro and consult on problems we encountered in relation to Yutaro. At one such meeting, we heard that if Yutaro wanted to take the entrance exam for upper secondary school, it would be better he took regular exams at lower secondary school to be given a grade even if the grade was not high enough. So, we requested the lower secondary school to “give him exams and a grade not only in writing but in quantitative scores.” Probably, everyone considered it impossible that a student with an artificial ventilator was going to take the entrance exam for upper secondary school.

Yutaro is unable to talk with his voice. He only can express his intentions with blinks. When taking an exam, he needs one teacher who reads questions for him and another teacher who decodes his blinks to write answers for him. At the beginning, we requested teachers at lower secondary school to give him multiple-choice questions but in the third year he started taking the same exams as other classmates took so that he could get prepared for the future entrance exam.

As he wanted to go to upper secondary school as other students do, we visited several fairs to consult about the entrance exam for higher schools and actually visited the schools (on open campus day) to directly see the atmosphere, teachers and the school's physical structures (to learn

whether there is an elevator or how he could move from a place to another), etc. to decide which school he should choose. Prior to actually taking the entrance exam, we submitted a request to the Osaka Prefectural Board of Education to make accommodations and appoint teachers who read for him and confirm his blinks' intention as well as a nurse to stand by. As we know such accommodations could be made differently from student to student, we thought it important to make such a request in the first place, regardless of whether our request would be met or not. Also, we asked the board to come to the lower secondary school to see how Yutaro took regular exams at school. There were a lot of discussions and conflicts about accommodations to be made until the last minute, Yutaro ended up in taking the entrance exam for the same upper secondary school twice, the first round (3 subjects) and the second round (5 subjects).

Yutaro could not pass both of the rounds and he took the entrance exam in the secondary selection procedure, which was the last chance for him. In this procedure, applicants have a chance to apply for schools that could not fill the predetermined student quota even after the second round of the entrance exam ended. There is no written test but only an interview. In the procedure, Yutaro was required to take the exam on his own. The problem was how he could be interviewed not being able to talk using voice. I told him to “respond with blinks to any question,” and let him bring with him a written ambition and intention why he wanted to enter upper secondary school along with photos of his life at lower secondary school. We asked the interviewer to read what Yutaro brought with him.

5. He passed the exam to enter Osaka Prefecture's part-time upper secondary school

We were informed that if an applicant takes the entrance exam in the secondary selection procedure, “any applicant can pass if the number of applicants are less than those needed to fill the gap between the quota.”* At the same time, however, we were worried that Yutaro would possibly be rejected if the upper secondary school determined that they “could not accept him.” We hoped “third time lucky” would happen to us. And finally, we could find his No. 5001 on the board announcing successful applicants.

“Getting closer to the board,” I told him, “there is No. 5001 on the board. Take a look at it,” but

he would not look at it immediately. He seemed very calm. When we were happily taking photos and calling people to tell the result, teachers of the upper secondary school asked us to “come inside as they needed to ask something. They wanted to



Result announcement, Yutaro succeeded to pass the exam to enter the school

get prepared to accept Yutaro at school. They asked us several questions. What was the name of his disability actually? What kind of care should be provided for him? What was his life at lower secondary school? How would he take lessons at class and what kind of tools should the school provide?

And the day of the upper secondary school's entrance ceremony arrived. There were a total of just three classes with a small number of students. The upper secondary school is very small in size, quite different from the lower secondary school he attended which was composed of 8 classes per year. At both the entrance and the school term opening ceremonies held in the gymnasium of the upper secondary school, students introduced themselves to the school. It was one of the school customs. Just as I had heard, the students of this school were very diverse. I could see many different hair colors and clothes they were wearing. They might have come to this school for diverse reasons but they were all very kind, irrespective of their appearance.

The class was totally quiet at first because students were on guard to each other but soon they started talking. At the upper secondary school, where there is no class for special needs education, Yutaro studies together with other students and during lunchtime he takes liquid food through the gastrostomy tube and has suction. Every one of his classmates treats him naturally. At the lower secondary school, we had many frustrating experiences when our request had not been heard no matter how we discussed earnestly with the municipal board of education and the principal and other teachers. Even when our request was accepted, it was not realized soon. However, at the upper secondary school, all such requests are quickly accepted as if they have been supposed to be accepted from the first. Why do things proceed like this? I even wonder sometimes. We had once been told, "Students have to be enrolled in a class for special needs education if they want to have an assistant at class" and Yutaro was taken care of in a separate room "devotedly" (!) Now I wonder again what all that was about. Students with disabilities do not need to be separated from other students. It will not be a problem if necessary care can be given in an appropriate environment. Rather, I think, separating students based on disability can cause problems.



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In a week from the entrance ceremony, the staff who assist Yutaro at classes were appointed and in May a nurse started to attend him. As early as in June, we parents were not required to attend Yutaro all the time and could leave him at the hands of the upper secondary school. I have a feeling that part-time upper secondary schools are very cautiously and thoughtfully taking care of students who are very different from each other in terms of academic achievement, background and environment and those schools readily accept students as they are not rejecting, resenting or resisting which is common in other schools. These kinds of school seem not to be defensive and they are relaxed in a good way, which I think wonderful. I hope Yutaro can have chances to learn

everything over from the basics under the instruction of the school's teachers as well as to experience various activities he could not do at lower secondary school such as having many friends and enjoying club activities.

Thanks to one teacher who earnestly invited Yutaro, he now is a member of a club (science) and participates in a workshop held every other Saturday. Members of the science club present ideas and perform experiments on those ideas all the time. I hear they are planning to develop a way to help Yutaro communicate with others when the current project is completed! At present, Yutaro can only interact with other members when they help Yutaro pushing his wheelchair or when Yutaro offers greetings to them. In the future, I hope that he can express his own thoughts and communicate with other members to have an enjoyable and meaningful experience at the club.

Yutaro's cycle of daily life has changed completely. Now he goes to school in late afternoon and twice a week he attends the science club after class. He comes home late in the evening but has not had health problems and is always well. Previously he got up early and went to bed early. But he now can be awake even late into the night. I am impressed that children have more energy than parents and they have better adaptability. I consider that Yutaro has become who he is now all because he has had 3 years' experience in lower secondary school. In addition, it is because the current upper secondary school accepted him warmly and hospitably. Another reason for this is Yutaro himself has gotten stronger physically and mentally as he has been through various experiences and he now lives his life peacefully. At home we still have a large issue to solve. We have to take him to and from school. It is not easy to find helping hands who can provide Yutaro medical care or take care of him during the night at home. I strongly feel that we need to have respect for his wishes as a young upper secondary school student and want to continue to help him move forward to become self-independent.

6. We will never give up thinking we will make it. We will take on a challenge for many things

I think we have had many good and rare experiences at the school for special needs education, regular lower secondary school (day school) and part-time upper secondary school (night school). I find these experiences valuable and interesting. In Osaka, there are not many cases in which students on an artificial ventilator took the entrance exam with blinks of eyelids and perhaps there is not one case that such a student went on to part-time upper secondary school in Japan (or even in the world?). In an attempt to reject, people often say "there is no such a precedent." Of course there is no precedent if the challenge is not made for the first time and I think the world will become a more friendly and interesting place if we create precedents on our own without hesitation. Even a child with a severe disability can make it if he or she never gives up by not deeming it "impossible" and makes efforts in contriving ways. Being passionate and persistent and not being hesitant is important and there is always some way to solve problems. We will go on to achieve success and I want people to think the same way. We will be happy if other people in a similar position can learn that they also are able to do this. I hope such attitude and movement will expand further.

* Note (Tsuguo Kataoka)

[Schools for special needs education]

In general, they are called “tokubetsu shien gakko” in Japanese. But in Osaka, they are named “shien gakko.” (It is specified that schools for special needs education shall be established by and under the control of prefectures, while elementary and lower secondary schools shall be established by and under the control of municipalities. The “major contradiction” is left unsolved.)

[Status of attending student]

The student attends school from home or a dormitory attached to the school for special needs education.

[Status of visiting student]

In principle, the student stays home and teachers from the school visit to teach. (Aside from this, “classes in hospitals” are established at hospitals.)

[School bus]

In urban areas like Osaka and Kanagawa Prefectures, a school bus system has been in place at schools for special needs education. No such a system has been established for elementary and lower secondary schools.

[The Baku Baku Club]

The club’s name originates from a manual artificial ventilator (so called Ambu bag) because the bag makes the “baku baku” sound when operated with hand to send air.

[Entrance into upper secondary school]

Upper secondary schools are supposed to be schools which only students “with a certain level of capability” can attend. It is general in Japan that schools select successful candidates from applicants even when the number of applicants is less than the predetermined number of students (quota) the school wants to accept. This is called unmet quota. In Osaka, since the entrance exam in 2003 was given, applicants have not been rejected if the quota exceeds the number of applicants. At part-time upper secondary schools, the number of applicants has been less than quota for seven years in a row and all applicants are accepted.