

Live freely even with disabilities!

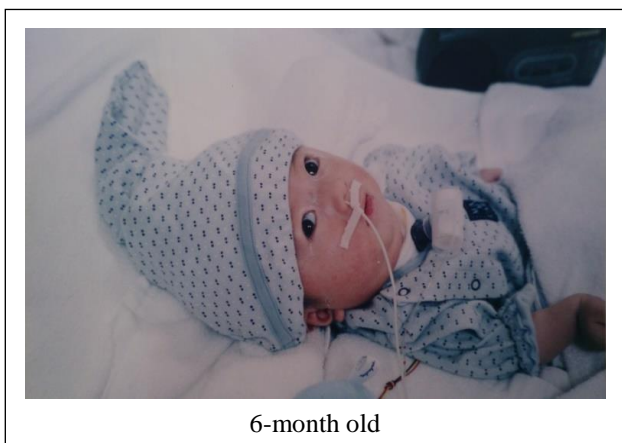
—Exploring a future course beyond example—

January 25, 2022

Mari Arai/ Yutaro Arai

My only son, Yutaro, is 22 years old and a university student. Although he can breathe naturally, he lives on an artificial ventilator. He is unable to cough or swallow saliva, and so he needs to have his sputum suctioned frequently with an apparatus. Also, he is unable to chew or swallow food, so he has to take in nutrition from liquid food through a gastrostomy tube. He can hardly move his limbs, and when he moves from one place to another he does so in a stretcher-type wheelchair. He needs other people's support as he cannot do almost anything alone, including excretive care. Since he cannot talk with his voice, the only way for him to communicate with other people is by blinking. When asked something, he blinks to indicate "yes," and keeps his eyes open to indicate "no."

1. Birth to life at home



6-month old

Yutaro was born two weeks later than his expected delivery date. When he was finally born via Caesarean section, he was not breathing. Immediately he was taken to another hospital's NICU (Neonatal Intensive Care Unit) and put on artificial ventilation. For about 10 days after his birth, Yutaro did not move at all and was unconscious. However, he started moving little by little and he opened his eyes. Because not enough oxygen was supplied to the brain at the time of birth, he could not move his body well and his breath was weak. Accordingly, he ended up in his current condition. He

repeatedly caught pneumonia and had high fevers, and as a result, he had to get over the high wall between life and death again and again.

At the hospital, he received a tracheotomy when he was 4 months old and next we worked to get ready to start taking care of him at home. We practiced mucus aspiration from the windpipe, studied how to use an artificial respirator, learned emergency responses, and had hands-on experience concerning how to get in and out of a car when leaving the hospital temporarily so he could sleep at home. Following this, right on his 3-year-old birthday, he was released from the hospital and started living at home.

2. From staying home to attending preschool and higher schools

After he was discharged from the hospital, we started practicing on going out to get used to it little by little, utilizing the opportunity of the monthly visit to the hospital. During the next spring, Yutaro and I together began to attend a center for the therapeutic care and education of infants and toddlers. When going out, we had to bring a range of equipment including an artificial respirator, a suction apparatus, and an oxygen cylinder.



Bowring at center of therapeutic care and education

Of course, he could not go out every day because he was not physically strong enough, and he was sometimes unstable. Compared with the time he was at the hospital, however, Yutaro's facial expression was unmistakably livelier when he was at home or went out. He started responding well to a variety of external stimuli that occurred around him, and he gradually gained physical strength. When he reached school age after graduating from preschool, we decided to enroll him in a school for special needs education, as we assumed, "Our son would not be able to attend a regular school because he is hooked on an artificial ventilator. He often gets sick and 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 status of receiving home-bound education rather than an attending student status. He started a new life attending the school two days a week and studying at home with a teacher visiting him one day each week. We enrolled him in a school for special needs education, expecting even a child with a severe disability like Yutaro would be able to receive suitable education, as the school had nurses and staff specialized in providing appropriate education. At the school for special needs education, however, there were not many children who were on a ventilator. In fact, we, the parents, had to accompany Yutaro to school to take care of mucus aspiration and nutritional support as well as take him to and from the school as he was not allowed to use the school bus service.

Meanwhile, Yutaro was growing more physically resilient after a few years of attendance 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 the actual situation in which we sent him to and from school and attended him all the time at school. We wondered how other users of artificial ventilators were commuting to and from school in other parts of Japan. When we searched for information, we were shocked to learn that there were some people who attended a local regular school rather than a school for special needs education, without parents' having to be present. For the first time, we realized 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

Although Yutaro was admitted to a local lower secondary school as we had decided, the school principal and other teaching staff had never received a student on a ventilator, and we were even given discriminatory remarks and responses by the then-principal of the school. The school tried to get us, as Yutaro's parents, to take care of him and actually left him alone, considering that students on a ventilator should not attend a local school. What we asked was just that the school would receive him as one of the students and not depend on his parents to accompany him when he commuted to school. There was a very large gap between the two sides (the school and us), and we repeatedly had conflicts. Whenever such a conflict arose, we discussed it with the board of education. Sometimes we felt very weary, but we never gave up, and we 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 following year, our burden to attend Yutaro was reduced and in his third year at school, we were fully released from the duty of accompanying him to school.

At his lower secondary school, Yutaro had to enroll in a class for special needs education. We requested that he take regular classes together with other students for as many hours as possible. In the classroom, an assistant teacher who was there to take care of Yutaro helped him by showing him textbooks and printed materials, copying what was written on the blackboard for him and holding his hand to do some work. Since the school had no elevator, Yutaro had to move from one room to another using a stair lift. Right after Yutaro entered the school, teachers and other school staff overreacted and worried, and there were times when Yutaro could not attend the class and was sent off home early. As time passed and teachers got used to and started understanding what Yutaro needed, less and less unfortunate incidents occurred.

However extensively we held discussions, Yutaro could not be allowed to have lunchtime in classrooms when he was supposed to receive nutrition injections, and he also could not share a bus with other students on school excursions.

The discussions were made through consultations between us and the board of education concerning issues from the overnight stay study in his first year at the school to the school excursion prior to graduation. Even now, after his graduation, we are still discussing with the board to make things easier for students like Yutaro to enter the local school later.



School excursion of lower secondary school

about 7 hours by car). These events offered valuable experiences for both sides, giving teachers a chance to realize what they had not known before and bringing us more together by being in very close physical proximity to each other and spending a long time with each other. These events also reduced the distance between the two sides.



With friend who visited his music recital of the class for special needs education

Teachers who depended on us as parents to take care of Yutaro refused to ride together with him in the special care taxi. However, their attitude changed gradually, and later they started riding in the taxi together with Yutaro or taking care of Yutaro during the nighttime on overnight-stay study events. Yutaro participated in such an event near the Biwako Lake in Shiga Prefecture when he was in his first year, on a day trip to Kyoto in his second year, and during a two-night trip to Nagano in his third year (It took

In classes, students sometimes helped Yutaro by pushing his wheelchair. The exchanged greetings with him, too. They even considered and held discussions about how to help Yutaro attend school events together with other students. Yutaro was able to attend all school events at the lower secondary school.

We encountered both the good and the bad. Right after he entered the school (during the time when there were many uncomformable experiences), if asked what he thought about having entered the lower secondary school, he would reply that "he had to overcome many

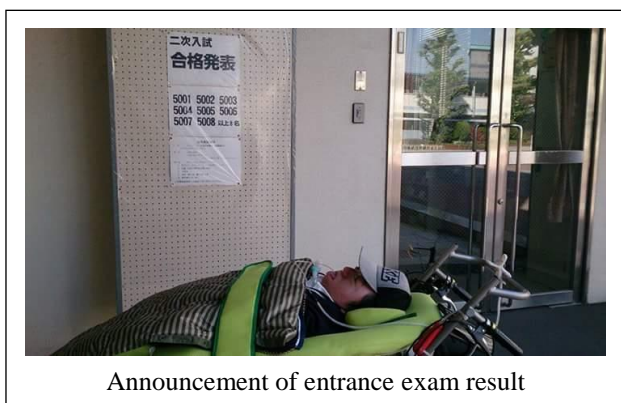
hurdles, but the life in the local lower secondary school was more joyful than that in the school for special needs education." And he expressed his intention to "enter a regular upper secondary school together with other students."

4. Entrance exam for upper secondary school

During his lower secondary school days, we participated in several study meetings to exchange information on school life or entrance exams for upper secondary school for students with disabilities, where we could have more chances to tell other people about Yutaro and consult about 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 for him to take regular exams at lower secondary school so that he would be given a grade even if the grade was not sufficiently high. So, we requested the lower secondary school to "give him exams and a grade not only in writing but using quantitative scores." Probably, everyone considered it impossible for a student with an artificial ventilator to take the entrance exam for upper secondary school.

Yutaro is unable to talk with his voice or write. 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 in a separate room. 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.

Starting six months prior to the entrance exams, we visited several fairs to consult about the entrance exams for upper secondary schools and actually visited the schools (on open campus day) to directly experience the atmosphere, teachers, students and the school's physical structures (i.e., to learn whether there would be an elevator and how he would be able to 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 provide reasonable accommodations including appointment of teachers who read for him, write answers for him, and confirm his intention through his blinks, as well as a nurse to stand by. Also, we asked the board to come to the lower secondary school to see how Yutaro took regular exams at school. There were many discussions and conflicts about reasonable 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. The test was only given in the form of an interview. Although we were concerned about the fact that Yutaro, who could not speak with his voice, had to take the exam on his own, he wanted to try the interview. We let him bring photos showing his strong desire to enter a regular upper secondary school and how he had been spending the lower secondary school life.



Announcement of entrance exam result

In Osaka Prefecture, we heard, in recent times no new students would be denied if there were fewer applicants than the limit. Still, we were worried that Yutaro might be rejected based on the upper secondary school side's judgment. On the contrary, it went as the saying goes, "the third time is a charm!" We saw his examinee's number, 5001, on the board announcing the exam results! Soon after the announcement was made, we were called in by the teacher of the upper secondary school because the school "wanted to hear what we had to prepare before Yutaro would enter the

upper secondary school," and we were asked about his disabilities, how he lived his lower secondary school life, and what the school should prepare for him.

5. Life at an upper secondary school

The day of the upper secondary school's entrance ceremony arrived. As it was a part-time upper secondary school, there were significantly fewer students than had been in the lower secondary school. As we knew by hearsay, all the students attending the entrance ceremony looked different from each other, in terms of color of hair, appearance, and age. And every student seemed to have some kind of problem (some students has been non-attending students at lower secondary school). Despite their appearances,



Regular exam at upper secondary school

they were generally kind people. Students even in their senior year gave Yutaro greetings, helped him when he moved from class to class, or let him use the elevator first.

At the upper secondary school, where there is no class for special needs education, Yutaro studies together with other students, and he takes liquid food through a gastrostomy tube and undergoes suction at his classroom. Every one of his classmates treats him naturally. Yutaro had once been taken care of in a separate room "with devotion". Now I wonder again what all that was about. Students with disabilities do not need to be separated from other students, if necessary care is given.

At the upper secondary school, Yutaro can get the help of a caretaker, a nurse, and an assistant teacher who takes notes for him. When two or three months passed after he entered the school, we were able to leave his care to those staff members at the school. We were very grateful about it, and at the same time very surprised. The part-time upper secondary school is able to pay close attention to needs of students who have a wide range of backgrounds and academic skills. At this upper secondary school, we were even able to find students who had been unable to attend lower secondary school regularly but were then enjoying the part-time upper secondary school. The upper secondary school does not show rejection, an attitude of repulsion, or reluctance. It looks as if the school accepts students as they are. Some students are even married and have children. There are also a number of students who have a daytime job but they are also enjoying making friends, participating in extracurricular activities, and learning lessons from the ground up at this school. Many students look happy attending the school as if they are reliving days they had lost at lower secondary school.

6. Experience leads to future and once-in-a-life-time encounters



Participating in a Science Conference as a member of the club



Overnight activity of Science Club (upper secondary school) with students in various age group

Thanks to one teacher who earnestly invited Yutaro, he became a member of a Science Club and participated in a workshop held every other Saturday. Students in the Science Club propose their own ideas, repeat experiments to get data, and present the results at a Science Conference. They have received many prizes. When the time for the conference approaches, students get together to practice how to make a presentation. Yutaro joined other students standing on stage to make a presentation at the conference on several occasions. In addition to this, fun events are held one after another, such as Christmas and birthday parties and opportunities to go out with friends. His friends help Yutaro to move in his wheelchair or to ride in a car, and they enjoy long discussions. Yutaro enjoys such valuable moments with his friends.

It was the first time for Yutaro to go to a training camp and the Science Conference as a member of the club. He enjoyed his first experience taking a bath together with his friends who did not have any experience in assisting persons with disabilities. And now he is experiencing many things he could not have done at the lower secondary school or the school for

special needs education. He joined other students in off-campus activities taking a lift-equipped bus or public transportation without being accompanied by a parent. It was what he had never been allowed to do at other

schools. To see him participating in such activities is quite moving for us and makes us truly happy. In his second year, he went on an overnight-stay study tour and in the third year, he went on a school excursion prior to graduation. We were amazed with the way the upper secondary school prepared for such events. The upper secondary school did not expect us to go with him from the beginning and made efforts to organize the events one step at a time, such as by making plans from an early phase and consulting us if they needed to and reporting the result to us.



Participating the training camp without parents

no choice but to use different public transportation from that his other friends used. He had use separate trains from his friends using a bus since there was no one that could manage to bear the cost for a different kneeling bus. Because of this, he missed some recreation and lunches with other friends. I think that it is important for all the students to share the same experience, including those with troubles as well as with joy. Therefore, I would like to ask the school to consider an appropriate plan including reasonable accommodation for transportation so Yutaro would be able to spend all of the time together with his friends.

For the training camp in his second year and the school excursion in his third year, the school obtained a budget for two nurses so we (his parents) did not need to accompany him. Two nurses and the teachers were brave enough to take care of his bathing and help him with overnight stays at unfamiliar places. During his school excursion, Yutaro experienced a stay at a guest house and enjoyed Disneyland and a Tokyo tour with his friends.

However, during some parts of the program, he had



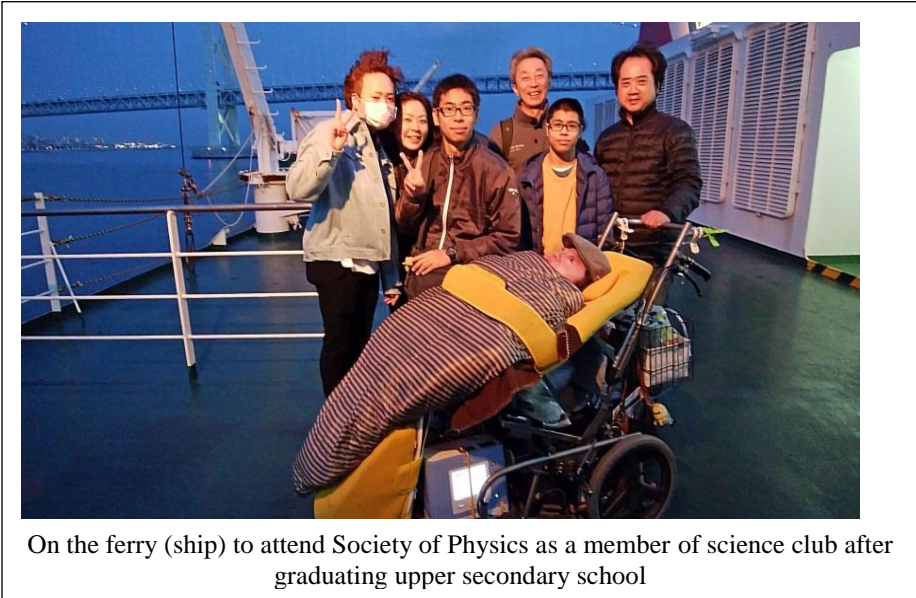
Dinner at the guest house during the school excursion



At Disneyland



Graduation ceremony of upper secondary school



On the ferry (ship) to attend Society of Physics as a member of science club after graduating upper secondary school

7. A future course with a freer selection after graduation



Open campus

Yutaro was in his final year of upper secondary school, and his classmates had been taking action to discover their future courses since before the summer. In the regular upper secondary schools, there are many students who pursue further educational paths. However, part-time upper secondary schools can be said to be characterized by the fact that there are many students who start to work after graduation. Yutaro lives with severe and multiple disabilities, but as a matter of course, he started to think about his future and take action like everybody else. It would be difficult for him to get a job with a company, so he thought that he would rather have

a chance to pursue further education. In June, he started visiting open college campuses, and he has been

consulting with some of colleges. We imagine college staff and students in open campuses were surprised by the sight of the only student with an artificial respirator on the campus. There are few students in wheelchairs on the campus. Even at colleges with departments in the field of disabilities and social welfare, there are few who show an understanding of or interest in us. They only recommend that students without disabilities acquire qualifications while at school and then get to work. They lack the open-mindedness to prepare for classes other than those for qualification acquisition, or to start a business. We wonder a bit whether this is the state of the highest institutions of education in Japan, and we thought that they should provide education with freer minds in many more fields. Yutaro is unable to do the same things as people without disabilities, but he likes to listen to lectures and go to see others to learn. We do not want those who eager to really study and make friends to be deprived of rights and opportunities without reason.

Until now, there had been almost nobody who had provided medical care to take care of Yutaro, but now we have gotten several helpers who have received training in medical care to provide the necessary care for Yutaro. Nevertheless, there are still very few care givers other than his parents, so he cannot go out except with his parents. Even though he is living with severe disabilities, he is an ordinary human being like everybody else. Being a grownup, he wants to work and live independently from his parents, but he cannot do so. That worries him most now. So, he wants to launch and operate a business that helps people in need of medical care and people with disabilities for the sake of himself, and for those in the same situation like himself. For that purpose, he wants to enter a college to study social welfare that is most deeply concerned with him and its management, expand his network with teachers and students, and increase the number of people to cooperate with.



Regular test at the Open University

So then, as his last trial to enter college, he took the National Center Test for University Admissions. The National Center provided him with the maximum reasonable accommodations; however, his score was low, and he decided not to apply for college. While he had given up on college, we remembered the club supervisor saying what a good college the Open University of Japan was, and we looked it up. We found that it is a legitimate school. There are no entrance exams, but there is an interview before a

prospective student sends in the application. And so we began preparing for it. At the interview, the university did not respond passively and treated Yutaro like any other applicants. He was accepted by the university. Yutaro graduated from upper secondary school and became a university freshman. He normally takes classes via TV, the radio, and the Internet, and he goes to the campus to take exams and attend on-campus classes to study space science, a subject that he loves, as well as other subjects that may be useful to him in the future. In addition, his days are filled with visits to doctors, rehabilitation, fun with friends, medical care workshops, giving lectures, and going to group meetings. He had enjoyed every day being busy with study, work, and having fun with his friends—until COVID-19 spread.



Reunion with friends at the coming-of age ceremony

Immediately before spread of COVID-19, the lower secondary school that Yutaro had attended held a coming-of-age ceremony. In this region, regardless of whether or not students have disabilities, graduates get together in local lower secondary schools for the coming-of-age ceremony. If Yutaro had gone to a lower secondary department of a school for special needs education, he would not have had any

acquaintances, even if he had attended the ceremony, and he would not had been eager to attend it. He was able to see friends and teachers from his lower secondary school after several years, made his recent reports, and was celebrated by local acquaintances. He was very pleased. It was such a fortunate experience that he was able to go to the local school.

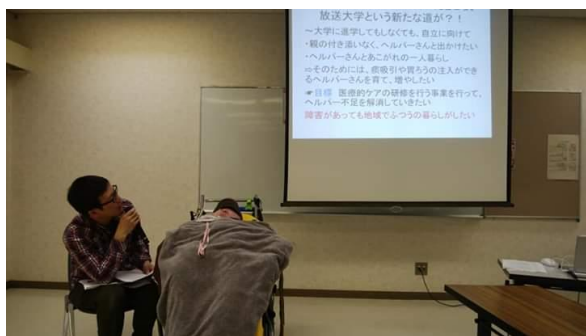
Right after that, COVID-19 began to spread. Yutaro was not able to go out, except when he visited the hospital and or went for rehabilitation. He takes university tests at home. Local functions and events as well as request for lectures have drastically decreased. He stays longer at home and has started to feel stressed out. While taking measures depending upon infection status gradually, it has become possible to go out, through use of online functions, he has been able to attend nationwide assemblies and live events that he had not been able to participate until then. Moreover, he was able to easily use take-away shops, which are increasing in number. This is the bright side.

Helpers and centers that are involved with Yutaro are gradually increasing. Some centers asked if Yutaro would be interested in working with them. Tapping into his feelings, Yutaro started to dispatch his ideas via twitter with helpers through use of an iPad. There is a movement that some parties would like to engage in the job that Yutaro can only together. Moreover, around the time at which he graduated from the upper secondary school, his acquaintances from his hometown, Hirakata City, were increasing, and he participated in various local events. While enjoying a project with local people, he would like to engage in a job for supporting the enrollment of children who need constant medical care in local schools for his hometown.

Since several years ago, in order to increase the number of caregivers, his hometown, Hirakata, provided medical care training several times a year. Yutaro engages in a part-time job. That is, he makes lectures for a curriculum called "Community life for persons with severe disabilities." Moreover, he demonstrates actual medical equipment and care sites and explains them. We are very much looking forward to seeing him work as a responsible member of society so that he can be independent.

Even after graduation from upper secondary school, Yutaro has been in contact with club members and

teachers. The other day, he joined a training camp as an alumnus and visited the observatory. At night, members helped him take a bath in a big tub, bonding by bathing together with him. The teacher who saw it was profoundly moved. One of his classmates who he had not seen for a long time said that research on an intention communication apparatus for Yutaro would be the topic of his graduation research at his university. We were very happy to see such a dependable, promising classmate. Good relationships still continue.



Training for medical care: Lecture through a helper reading on his behalf



The classmate explains about his research at a training camp

8. Closing

Children with disabilities only move along a path to a school for special needs education or a relevant facility, which is not very interesting. They would like to enjoy their lives in the society normally. With or without disabilities, we are all humans, so with necessary support provided where needed, people in need of support should be able to select a way of living more freely and comfortably. For that purpose, we would like all people to think about what they can

do.