

How to Understand Children With High-Functioning Autism Attending Mainstream Schools: From the parental standpoint

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Introduction to “Tsubomi no Kai (The Buds Association)”

“Tsubomi no Kai (The Buds Association)” is a common name for the Autism Society of Aichi. This association had a 44-year history as of 2011. The secretariat of this association was set up in the Department of Psychiatry of Nagoya University Hospital in 1967, when the name of the disorder now known as autism was not familiar to the public, and there were no definite treatment and educational approaches for autistic children in Japan. Currently, the members of the association total about 900, and the total number of members of the Autism Society nationwide is approximately 16,000. About 40% of the members of this association have a child with high-functioning autism. School age children have recently become more common among newly joining members. It is often the case that the child comes to our association after he or she starts school and then encounters difficulties.

Autism is not a curable disease, instead being a disorder that requires continuous medical care after establishment of the diagnosis in most cases. It is not rare for autistic patients to also have epilepsy and to require continuous maintenance therapy with antiepileptic or antipsychotic drugs, which puts a heavy financial burden on many

patients and their families. Our association submitted a paper to the Aichi prefectural government requesting that a public expenditure system for the medical expenses of autistic patients be established. Then, in 1973, a new public expenditure system by which all the co-payments for patients who had been diagnosed with autism syndrome were to be paid by public funds was set up in Aichi Prefecture, and has been in effect to date. This system, which also covers autistic patients without intellectual retardation, is only found in this prefecture; there are no others anywhere in Japan.

Figure 1 shows the age distribution of the children of current members of this association. Parents who have children ranging in age from 8–17 years are most common among our members. During this school-age period, autistic children—and these include many patients with high-functioning autism—often have difficulties at school.

Projects of the association and activities of the high-functioning autism division

Our association provides support for families, patients and supporters through the activities of the support, high-functioning autism, father’s, planning and general affairs divisions.

The high-functioning autism division has

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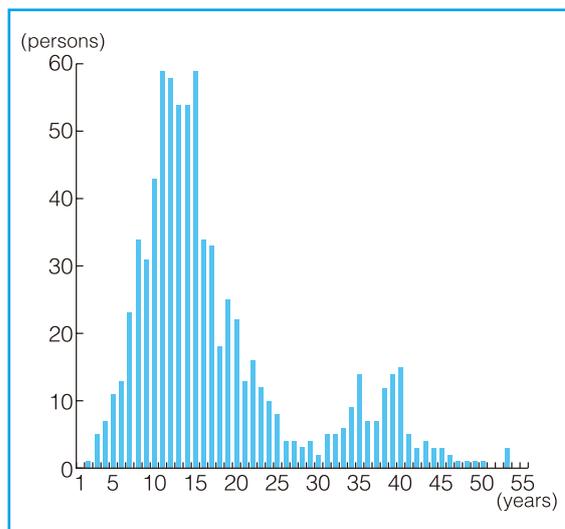


Fig. 1 Age distribution of children in the Tsubomi no Kai (as of February 2011)

been operating for 14 years. The initiation of the activities of this division was relatively early in this nation. The activities of the high-functioning autism division are carried out as Tsubomi no Kai, not under the name of the Autism Society of Aichi, considering the presence of patients or surrounding people who are not told of the disorder. The major activities for parents include semiannual group counseling with child psychiatrists and a monthly tea party with parent mentors. Tea parties for school age children, adult patients, and girls are also organized with the support of teachers or experts such as clinical psychotherapists. In addition, we also hold day camps covering patients and their families and sleep-away camps targeting elementary school third-graders to high school students (age 8 to 18). The latter were named “Happy Camps” by the children participating in the first camp. Sleep-away camps, having a history of 11 years, provide opportunities for children to have fun away from their parents with friends and college student volunteers, and many participants return every year. Other activities include events such as bowling games, figurative art and cooking classes during summer vacation, Christmas parties, and social skill training (SST) programs. All of these activities are supported by many experts and volunteers.

Activities of parent mentors

The activities of the support division include parent mentor training sessions. Parent mentors are parents trained to serve as reliable advisers who listen to other parents experiencing trouble or who are at a loss after receiving the diagnosis of their children’s impairments. Parent mentors provide information and advice based on their own experience. They should not impose their own ideas about how to rear children, instead always providing other parents with attentive listening and sympathy. Many parents have stated their good impressions about talking with parent mentors, reporting that they were relieved or encouraged about rearing children in a positive manner because they were able to share their distress and anxieties with other parents. In particular, parents who have autistic children who are attending regular school classes are sometimes isolated from the parents of their children’s classmates because there may be a misunderstanding that their children are troublemakers in the class or are badly brought up. Some parents shed tears, finding that so many people are in the same situation. We, parent mentors, are delighted when newly attending parents smile while listening to mentors and ask if they could come to the meeting again.

The training program to nurture parent mentors started in 2005 as an activity of the Autism Society of Japan, and became a measure of the Japanese Ministry of Health Labor and Welfare in 2010. In Aichi Prefecture, 46 parents completed basic training and proceeded with skill upgrading through follow-up training, application training, case studies, etc. Many of the parents who completed training now cover a broad range of activities including serving as instructors for training in support book preparation and simulated experiences of autism by the caravan.

Purpose of the Social Skill Training activity

Although many autistic children who are free of intellectual retardation attend regular classes, it is not rare for them to be unable to understand the feelings of others and have trouble with classmates. As it became more common for autistic children around age 9 to 10 years who had troubles in school to join our association, we started a SST program to allow them to master the skills necessary to live and cope with life in school or society, such as control of emotions and under-

standing of the feelings of others. Participating staff members consist of specialists such as school teachers and clinical psychotherapists, and graduate or undergraduate students who want to become teachers or clinical psychotherapists under the overall supervision of Masayoshi Ogura at Naruto University of Education. The SST program is provided to children divided into three groups by age: groups of 10 elementary school children (age 6 to 12), 8 junior high school students (age 12 to 15), and 5 senior high school (age 15 to 18) or college students (about age 18 to 22). The program is carried out once per month for elementary school children, and once every two months for the other two groups.

Support for families of Social Skill Training program participants

SST programs have been attracting attention nationwide, and have been introduced into programs for the treatment and education of autistic children, special needs classes or special support services at school, and special needs schools. Our association, as an association of patients' parents, provides support for patient families. In the SST program of this association, basically, not only children but also parents attend each session. At the beginning of each fiscal year, the instructor carries out a questionnaire survey of parents, and inquiries are made about the needs of patients by group interview. Debriefing sessions are held individually and by group during six-month intervals and at the end of the fiscal year. Each time the child is participating in the session, his or her parent takes peer counseling with a parent mentor. Parent mentors participate in each debriefing session to convey various concerns parents have about issues at home or in school, and the reported issues are used as references for future activities.

Although not many SST sessions are held each year, participating parents have responded positively when asked to answer the questionnaire about these sessions. The predominant impression is that "children enjoyed attending the sessions," and other impressions include "this was an opportunity for children to express themselves, unlike in school," "children were able to build up a sense of fellowship during the SST sessions," and "we were delighted to see that children used what they had learned in the SST

sessions in school and at home." As for parent meetings, many positive impressions were obtained, as follows: "I felt empathy with the stories of success and failure shared by participating parents, and was always encouraged by a sense of fellowship," "I felt that I am not alone because parents have daily worries and other issues in common," "I was emotionally supported to a great extent by receiving advice given from more experienced parents when we had troubles at school," etc.

Requests From Parents to School Physicians

Parents who have a child who speaks normally and has no intellectual retardation, but shows problem behaviors, want to regard the behavior as being part of the child's personality rather than accepting it as an impairment. Even if a school teacher or a physician has recognized the child's impairment, a sudden reference to the diagnosis, i.e. actually calling it autism, may cause parents to close their minds, suspecting that the teacher or physician dislikes their child because he or she is disobedient. Although it may vary among individuals, acceptance of the impairment of one's own child is very painful. It is a task requiring a long period of time. It is important, rather than giving them the medical label of the diagnosis, to focus on what troubles the child and surrounding people are experiencing. It is very hard for parents to hear about what their children are incapable of doing or learning, even if they understand the situation. If the teacher also highlights good features of the child, parents may feel more at ease and inclined to trust and take advice from the teacher.

It may happen that the mother alone has noticed the impairment of her child and thus has felt increasingly isolated from the father and grandparents, who do not acknowledge it. Some members request that the association not send mails with the name Autism Society of Aichi on the envelope because the child's impairment is being kept secret from the grandparents, with whom they are living, and the neighborhood. Therefore, bulletins and all other mailings from the association are sent under the name "Tsubomi no Kai." Even if the mother has noticed that her child is somehow different from other children, she may be told by other family

members or relatives that she is uptight and too worried. It is also possible that the mother is blamed for a poor upbringing or for spoiling the child, and she herself may become depressed or even abuse the child, hastily providing strict discipline. In some communities, parents may hide the child's impairment from others, due to concerns about damage to the family's reputation.

It is often the case that suspected hazard characteristics are attributable to the original personality or rearing environment of the child. Some children showing an autistic demeanor at a younger age may become minimally different from other children when they grow older. Some parents have developmental disorders and raise children in their own way, which may be the cause of, or at least contribute to, the problem behaviors of their children. How children are raised and the rearing environment may exacerbate the features of this spectrum of disorders, whereas children may become well-adapted if raised in a way suited to their characteristic features.

Even if parents are aware of the disorder their children suffer, they may not know where to go for advice. Some parents are so afraid of it being noticed that their children have impairments and they cannot go for advice or show up at public health check-ups for 18-month-old and 3-year-old infants. Parents may not be able to speak openly to the teacher in charge or the school authority because of the discrepancies among opinions. Some of them do not visit the school, in order to avoid hearing about the problems of their children. They may become defiant and aggressive when their children are regarded by parents of other classmates as problem children and they are blamed for the perceived bad behavior of their children. Some parents may become depressed, blaming themselves for giving birth to children with impairments or for having failed to raise their children properly.

School physicians are often primary care physicians in the local community and are accessible for consultation, even if they are not child psychiatrists. Primary care physicians who have been seeing the children from a very young age are aware of the characteristic features and patterns of behavior of these children and can provide examination and treatment with good continuity. Therefore, these primary care physicians are often trusted by parents. In recent years, some pediatricians or internists have come to acquire

a good knowledge of developmental disorders. It is desirable that dentists or otolaryngologists, though these disorders are outside of their areas of specialty, spend time truly listening to what parents say when they ask for advice. If physicians, on whom parents rely, introduce them to a special hospital or support center for persons with developmental disorders, stressed parents may accept the advice and visit the referred institution with little or no hesitation.

Requests From Parents to Healthcare Providers

Some autistic children who have hyperkinesia and utter strange sounds cannot sit still in the waiting room when they visit a hospital. Autistic children without intellectual retardation may speak loudly about their favorite things without paying attention to surroundings or repeat the same question over and over again.

Many patients with autism do not like to hear a baby's cry, even after they reach adulthood. One day in a hospital, my son was not able to stand the naughty behavior of a young child scolded by a parent, and he shouted loudly at the fretful child, "Are you going to behave like that all day?," which frightened the child. Although I had repeatedly told my son since he was a little child that we should be quiet in a hospital, I was surprised at this act of his, and apologized to surrounding people. Because he wants to go to the hospital by himself these days, I worry that he might cause a similar situation again, when he is alone.

Some autism sufferers have hypersensitivity to taste or touch, and many of these patients cannot take medicine, particularly when they are very young. My son was also unable to ingest syrup or powdered medicines, and we had a hard time when he took such medicines. Although I added sugar or mixed the medicine with juice or other beverages, it was always very hard for him to take it. When he reached age 6 and the medicines were changed to tablets or capsules, he had no difficulty taking them. When he was at age 10 or 11 years, he also became able to tolerate powdered medicines. Some members of this association say that their children cannot take medicines or receive injections, under any circumstances, so they must wait until illnesses resolve spontaneously.

Some autistic patients are sensitive to pain, while others are not. My son was susceptible to pain from a very young age, and he was particularly frightened of blood. He required an adhesive plaster for a scrape and I was often anxiously concerned about the possibility of bone fracture with even a slight bruise, and I brought him to a surgeon in each case. Because the surgeon knew the characteristic features of my son, he disinfected the wound and applied an adhesive plaster or bandage, saying "It is a tiny wound that requires nothing but licking, but I am going to treat it because you are sensitive."

On audiologic assessment, autistic children may always answer "yes" to the examiner when asked whether they can hear a tone, even when they cannot hear the test tone, and this is because they can hear the examiner's voice. This was also the case for my son. On the vision test with Landolt rings, my son was not able to point in the observed direction with a finger, and I told him to answer verbally right, left, top, or bottom because he understood such directions. If a physician says about a treatment that, "It doesn't hurt. It's going to be really quick.," even though it is actually a painful treatment requiring a certain amount of time, the child may feel that the physician told a lie. Then, the child may well become anxious next time, and be unable or unwilling to go to the hospital. Specific explanations are helpful, e.g., "There will be a stinging sensation, but you can endure it." or "It will be over once you have counted to ten."

It is difficult for many autistic patients to deal with injections. My son was not able to tolerate injections until he became at age 15 years. When he was very young, he had to be restrained while being injected. When he was between age 12 and 15 years, he could not receive an injection of tuberculin. He strived to extend his arm to receive the injection because he knew it necessary, but he could not hold still because of fear. Later, he underwent chest roentgenography as a substitute for the tuberculin test, but this was an incident that made me nervous about future injections. When he was at age 15 years, he caught a gastrointestinal infection and suffered severe diarrhea. This time, he resigned himself to accept-

ing drip infusion, with the words of his personal internist "Intravenous drip is all it takes, and you will be cured." After receiving the drip infusion in an intensive manner, i.e., in the morning and evening of that day and the following day, he overcame his fear of injections. Currently, he can receive preventive vaccinations against influenza without an attendant.

A characteristic feature of autism is impairment of imagination. Patients feel alarmed at unforeseeable things or when they have no idea what sort of medical procedure is going to be performed on them. Patients are relieved if they are informed, as thoroughly as possible, by the healthcare provider about the instruments used for treatment, how the treatment is to be performed, how long it will take, etc. When my son was in a dental office and could not receive treatment smoothly, the dentist showed him the treatment procedure, saying "I will treat your mother first. Watch what is done." He explained specifically, "the carious part of the tooth will be drilled out using this and that. It will make some noise, but will not hurt." Thus, he was able to receive the treatment without anxiety.

The "Consultation Support Card" and "Consultation Support Notebook," in which considerations required for healthcare providers in the treatment of the patient can be written, help convey information about the characteristics of the impairments of individual patients to healthcare providers. These have recently been issued by various prefectural or city governments, as well as by our association. Healthcare providers are encouraged to read them, if submitted by patients or their families.

In my son's case, he was able to receive medical treatment without anxiety because physicians and nurses treated him with a gentle and caring attitude when I told them about his impairment. Characteristic features of autism vary among individual patients, and they each have their own behavioral problems that require particular considerations. Although this may be challenging for healthcare institutions when providing care for autistic patients, these institutions are asked to treat such patients with due considerations of their impairments.