High-Functioning Autistic Children
— From a physician's perspective —

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Introduction

In 1944, Hans Asperger has reported cases of children who are not intellectually impaired but who have difficulty continuing conversations, cannot follow instructions, have difficulty forming friendships, do not play well with others, and become intensely absorbed in something that interests them; however, his research was forgotten by the world until it was rediscovered in the 1970s by Lorna Wing. Since then, this condition has been referred to as "Asperger syndrome," but with changes to the concept of autism itself, today the term "high-functioning autism spectrum disorder (HFASD)" is frequently used ("high-functioning" means no intellectual disability or no clear intellectual disability—internationally, an IQ of 70 or above).

Autism overall is positioned as a developmental disability and was treated as a pervasive developmental disorder (PDD) in the past; however, because of the continuity of both symptoms and intellectual levels, the expression "autism spectrum disorder" (ASD) is often used. Currently the American Psychiatric Association's DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders) uses the term PDD, but the DSM-V to be published next year or the year after is expected to change the name from PDD to ASD.

It has become known both internationally and in Japan that HFASD is a common disorder, with reports estimating more than one in a hundred people affected. However, there is the problem that many children are dealing with these issues without ever actually being diagnosed, and there are children and adults who have been diagnosed but have been neglected with no appropriate treatment provided for them. Although there are also cases in which secondary disabilities and complications are treated with drug therapy, the fact that there is no effective medication to treat HFASD itself is creating such situations.

In HFASD, although patients have no intellectual problems, they have the characteristics of ASD. That is to say, high-functioning autistic people exhibit impaired social skills, impaired communication skills, and impaired imaginative skills (so-called the three autism groups), and these are associated with difficulties in their social lives.

In addition, with regard to communication, HFASD is also known to involve problems in non-verbal skills for conversation which can easily lead to difficulties in patients' social lives, including school lives. Communication through conversations comprises verbal skills (represented by the four areas of speaking, listening, reading, and writing) as well as non-verbal skills (i.e., looking at the other person's eyes, understanding gestures and body language, and under-

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standing the other person's emotions). Virtually all cases of HFASD exhibit impaired verbal communication skills and are poor at making conversation as a consequence.

With regard to the timing of diagnosis, although children may be diagnosed in early childhood based on difficulty with interpersonal relationships such as poor eye contact and inability to make friends, in the majority of cases children are diagnosed after entering elementary school after being examined by a physician for behavioral and/or communication problems. During puberty children may develop secondary disorders and problems such as non-attendance at school, withdrawal from social contact, depression, panic disorders, and obsessive-compulsive disorder (OCD), and the underlying HFASD may be diagnosed then, but it is thought that not a few cases go undiagnosed even into adulthood.

As an outlook for the future, although people with HFASD have low communication skills they also exhibit such strengths as honesty, earnestness, frankness and a strong sense of justice. Thus, unsuitable occupations for people with HFASD include marketing and sales, as well as public servants and bank employees whose main work involves dealing with members of the public, while suitable occupations include engineers, musicians, artists, Go or Shogi chess players, and computer-related system engineers and instructors.

I have been asked whether or not HFASD can only be diagnosed by a specialist physician, but in many cases it can be identified in general examinations if the examining physician understands the diagnostic standards and characteristics of the condition. However, in the case that the patient also has secondary disorders or complications, it is recommended that a specialist physician be consulted.

The basis of treatment is not drug therapy but social skills training (SST) and counseling. Although I will not go into detail here, undergoing appropriate SST and counseling can improve the quality of life for HFASD children as well as adults. Furthermore, when undergoing examination at medical facilities, despite the fact that in many cases the patient is experiencing some kind of difficulty with social life, it can happen that the only treatment provided is follow-up or the condition is treated as a personality trait, and time is unnecessarily wasted. If patients do not receive appropriate treatment, in many cases they develop secondary disorders and their condition deteriorates with time.

Coordination Amongst Medical Institutions, Schools, and Families

Many HFASD children without intellectual disabilities attend regular school classes. However, these children, who exhibit the characteristics of autism mentioned above, are dealing with social issues within a group environment, so coordination is imperative.

The basic roles of schools are group living and learning; the basic roles of medical institutions are diagnosis and treatment; and the basic roles of families are establishing living practices and making future plans. Despite the fact that in HFASD, the treatments necessary are medical and educational, such as counseling and SST rather than drug therapy, this is not well-known. How, where, and by whom these educational and medical treatments are to be provided is an important point and an ongoing issue.

In cooperation between schools and families, when the school is having difficulty in handling a HFASD child, it is sometimes recommended that the child be examined at a medical institution and be prescribed medication. There are also cases in which a developmental examination is requested, and if the child's scores are low, it is recommended that the child be transferred to a special-education class. Cases have been observed in which, during all of this, the relationship between the child's family and school breaks down and worsens, with the child's guardians even becoming so-called "monsters" over time in extreme cases.

In cooperation between schools and medical institutions, it is not easy for the two institutions to exchange information as they are both required to protect personal information. Even if schools and medical institutions are cooperating, requests from the school to the medical institution and vice versa are regarded unreasonable in not a few cases because the two institutions do not have a good understanding of the other's situation or because of the issue of protecting personal information.

With regard to the cooperation between families and medical institutions, some guardians actively take the child to be examined when they feel that something is amiss. But in many cases

they also fear being told that the condition is somehow their fault if the child is diagnosed with the disorder. Consequently, there are cases in which the child is not examined when there is a reason for them to be. There are often also problems with the medical institutions, such as not being able to properly diagnose or treat the children, or simply observing them or prescribing drugs.

As shown here, even though there is a clear need for cooperation, in reality it is not easy to achieve common awareness, and there are many cases in which children are not being provided with educational and medical treatment. The special educational assistance program was implemented nationwide in 2007, making it possible for HFASD children enrolled in regular classes to receive educational support once or twice a week by attending special classes. However, currently schools with such classes are grappling individually with questions such as whether the goal of these special classes should be educational guidance or helping children acquire living practices.

Problems That Arise During Puberty

Puberty is a time when huge fluctuations can be observed in children even without having HFASD. But in the case of HFASD children an issue is how to maintain self-esteem. I will touch on this in the "Basis for Treatment" section below.

First of all, non-attendance at school: the rate of becoming truant amongst HFASD children is high, and consequently their rate of withdrawal from social contact is also assumed to be high. Medical institutions are frequently observed to tolerate non-attendance at school by HFASD children, but since these truant children do not themselves feel that not going to school is good, tolerating non-attendance has the effect of prolonging it. For example, for a child that becomes truant due to bullying, not only is non-attendance unavoidable, but the state of being truant is also directly linked to a decline in academic ability. When the child returns to school, if there is a disparity between their academic ability and that of their classmates, the child may easily become truant again, and so backup for learning is imperative. Furthermore, in the case of non-attendance at school it is necessary to clearly identify the problems the child is encountering in the school life and think of measures to deal with these problems. But since school may not necessarily understand HFASD correctly, adjusting the school environment is not easy.

With regard to bullying, approximately 70% of HFASD children encounter bullying while at elementary or junior high school. In many instances bullying takes place unwitnessed and it is difficult to ascertain the actual situation. In the case of HFASD children, the people around them recognize "teasing" but frequently do not recognize bullying. However, since children are hurt by bullying, measures are also necessary from the standpoint of maintaining their self-esteem.

Bullying is a crime and should be stamped out decisively; however, HFASD children also need SST to make it more difficult for them to be bullied. For example, when it is determined that the child's inability to look at a person's face and speak clearly is related to their being bullied, the risk of their being bullied can be reduced simply by their learning to raise their face and say, "Good morning" while looking at the other person's face. Acquiring this kind of responsive ability takes place as a part of SST. Furthermore, since people with HFASD have difficulty comprehending situations, if they become bullies themselves, the bullying can become severe because they do not understand the degrees of bullying.

Even when children have no intellectual disabilities, how they are treated within the group can easily lead to poor academic performance. In the case of HFASD children in particular, since they have difficulty with parallel processing such as taking notes while listening to the teacher talking, it can be effective to separate "listening" and "writing notes" time-wise. Rather than attempting to resolve every issue, it is frequently the case that focusing on one area of study can lead to improvements in others. For example, focusing first of all on improving the child's arithmetic, if this is their strong area, can lead to their tackling verbal problems—their weak area—with the result that the child has better results in the Japanese language class.

Entering puberty, many sexually-related problems also arise. When junior high school boys see a girl, in many cases they feel a desire to directly touch the girl—hold her hand, or kiss her—where in the case of teenage boys with HFASD, the period of emotional puberty gener-

ally tends to be prolonged. For example, just their emotional feelings of vaguely liking or admiring a girl may last.

However, if HFASD children have sexual problems, measures need to be taken that are appropriate for each individual case. For example, a commonly observed symptom is touching the genitals, but telling a boy who wants to touch his penis to stop doing it in many cases results in the boy—unconscious of his actions—putting his hand in his pocket and touching himself through the pockets, regardless of whether or not his actions can be seen by others from the outside. In such cases, training to take an alternative behavior is recommended, such as the boy hanging a key around his neck and grabbing the key each time he wants to touch his penis.

Girls with HFASD may become frightened of males. They may be misunderstood due to sexualized behavior and in some cases may be deceived and/or become the victim of a sex crime.

Notification

The purpose of notification is to assist the children with HFASD in understanding how and why they are different from other children based on the diagnosis. Notification usually takes place when the children are beginning to notice the differences between themselves and others, at a point when not notifying them would decrease their self-esteem whereas notifying them would increase their self-esteem. In many cases this is when they are in their third year of junior high school. Notification does not simply involve telling the child, "You have HFASD." Meetings are held with the child's guardians in advance, a list of the child's strong and weak points is prepared, and notification materials are prepared. Notification involves telling the child not only the name of the disease or disorder but also their strengths and weaknesses, taking time to discuss how to cover for one's weaknesses. After notification, it goes without saying that follow-up needs to be carried out regularly and any questions or problems that arise must be addressed.

Basis for Treatment

SST is regarded as the basic treatment for HFASD, and many HFASD children are able to lessen the difficulties they encounter in their social lives through SST. Of course, secondary disorders and epilepsy are treated with drug therapy in some cases. But the basic treatment is definitely SST, which involves building the foundation for interpersonal relationships and everyday living practices that children need to know and be able to put into practice in order to live in society, and most importantly, praising the children when they respond to requests and perform something well. This act of praising is regarded as the most important aspect of SST and is also a way to enhance their self-esteem.

Accordingly, in addressing only problem points that invite difficulties in children's social lives, the only available methods are to either focus on the problem or scold the child, and so treatment is carried out while considering how best to praise the child in order to avoid the need to scold them. Never take for granted what the child can do. It is imperative to praise the child for being able to line up correctly if the child would be admonished or scolded for not lining up properly. Sparing the effort involved in giving praise reduces the improvement in the child's behavior. Similarly, if the child is admonished for not listening in classes, the child should be praised when they do listen. During medical examinations, too, if the child sits properly in the chair, first of all the physician should praise them.

The ultimate goal of the treatment is to nurture HFASD children so as to be able to live in society with confidence. This means not only acquiring social practices and customs but also creating images in the children's minds of how they will earn and make a living for themselves. All treatments and therapies are aimed towards this end. Although this can be said for all children—including children who do not have HFASD—but in the case of HFASD children it is necessary to continue monitoring with even greater care. Nurturing self-esteem means ensuring that the child does not lose one's self-confidence, as well as that the nurturer ensures that the child comes to be able to do things without coming to dislike the child or becoming angry when the child cannot do things just yet. In order to achieve this, praising skills and experience are essential.

From the standpoint of healthcare, I would like to endeavor to work hard together with others in the future so that as many HFASD children and adults as possible can become healthier and happier.

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