

研究成果の刊行に関する一覧表( 3 / 11 )

書籍

著者氏名	論文タイトル名	書籍全体の編集者名	書籍名	出版社名	出版地	出版年	ページ
杉山登志朗・ 辻井正次		監修 杉山 登志朗・辻 井正次, 協 力 NPO 法人アスペ ・エルデの 会	発達障害のある 子どもができる ことを伸ばす! 学童編	日東書院	東京	2011	
杉山登志朗・ 辻井正次		監修 杉山 登志朗・辻 井正次, 協 力 NPO 法人アスペ ・エルデの 会	発達障害のある 子どもができる ことを伸ばす! 幼児編	日東書院	東京	2011	
宇野洋太、 内山登紀夫	成人期の広汎性発 達障害の診断	青木省三	専門医のための 精神科臨床リュ ミエール 23 成 人期の広汎性発 達障害	中山書店	東京	2011	P28-36
宇野洋太、 内山登紀夫、 尾崎紀夫	診断によるかかわ り - 発達障害	うつ病リワ ーク研究会	うつ病リワーク プログラムの続 け方	南山堂	東京	2011	28-37
安達潤	支援が必要な子ど もへのトータルケ アを目指した取り 組み	辻井正次	特別支援教育 実践のコツ	金子書房	東京	2011	180-187
安達潤	発達障害の基礎知 識 2 (教育)	井上雅彦、 吉川徹、日 詰正文、加 藤香	ペアレントメン ター入門講座 発達障害の子ど もをもつ親が行 なう親支援	学苑社	東京	2011	34-35

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書籍

著者氏名	論文タイトル名	書籍全体の編集者名	書籍名	出版社名	出版地	出版年	ページ
安達潤	メンター活動の課題 3. 教育の立場から	井上雅彦、吉川徹、日詰正文、加藤香	ペアレントメンター入門講座 発達障害の子どもをもつ親が行なう親支援	学苑社	東京	2011	116-118

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発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
Tanaka, K, <u>Uchiyama, T</u> , Endo, F	Informing children about their sibling's diagnosis of autism spectrum disorder: An initial investigation into current practices	Research in Autism Spectrum Disorders	5(4)	1421-1429	2011
<u>Kuroda M</u> , Wakabayashi A, <u>Uchiyama T</u> , <u>Yoshida Y</u> , Koyama T, <u>Kamio Y</u>	Determining differences in social cognition between high-functioning autistic disorder and other pervasive developmental disorders using new advanced "mind-reading" tasks	Research in Autism Spectrum Disorders	5 (1)	554-561	2011
内山登紀夫	思春期から成人期の広汎性発達障害 思春期から成人期の自閉症スペクトラム	児童青年精神医学とその近接領域	52 巻 4 号	431-436	2011
Kuwano Y, <u>Kamio Y</u> , Kawai T, Katsuura S, <u>Inada N</u> , Takaki A, Rokutan K	Autism-Associated Gene Expression in Peripheral Leucocytes Commonly Observed between Subjects with Autism and Healthy Women Having Autistic Children.	PLoS ONE	6(9)	e24723	2011

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<u>Yoko Kamio</u> , Naoko Inada and Tomonori Koyama	A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders	Autism	Published online	doi:10.1177/1362361312436848	2012
神尾陽子	20年後を見据えた精神医学・心身医学研究の展望特集. 児童精神医学研究の将来展望.	学術の動向	7	15-19	2011
神尾陽子	教育講演 児童期から成人期へ：レジリエンスという視点.	児童青年精神医学とその近接領域	52(4)	379	2011
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神尾陽子	災害時に見えてくる、これからの子どものメンタルヘルス対策に必要なこと（巻頭言）.	精神医学	53	934-935	2011
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Marui T, Funatogawa I, Koishi S, Yamamoto K, Matsumoto H, Hashimoto O, Jinde S, Nishida H, <u>Sugiyama T</u> , Kasai K, Watanabe K, Kano Y, Kato N.	The NADH-ubiquinone oxidoreductase 1 alpha subcomplex 5 (NDUFA5) gene variants are associated with autism.	Acta Psychiatr Scand.	123(2)	118-124	2011
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杉山登志郎	【自閉症スペクトラムの生物学】自閉症スペクトラムとは	分子精神医学	11(4)	264-268	2011
杉山登志郎	【性的虐待】性的虐待の実態とケア	子どもの虐待とネグレクト	13(2)	209-215	2011
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杉山登志郎	子ども虐待と精神医学	児童青年精神医学とその近接領域	52(3)	250-263	2011
海野千畝子、小山内文、 <u>杉山登志郎</u>	心療科病棟における性的安全の文化の創造に関する研究,(その2) 性的虐待対応看護師チーム (SAR) による性的安全プログラム	小児の精神と神経	51(1)	51-58	2011
森本武、 <u>杉山登志郎</u> 、東誠	広汎性発達障害における双極性障害の臨床的検討	小児の精神と神経	52(1)	35-44	2012
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杉山登志郎	子ども虐待 子どもの命とこころを守る	心と社会	42(1)	12-15	2011

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吉田友子	自閉症スペクトラムの子どもへの医学心理学教育(告知)	児童青年精神医学とその近接領域	51 巻 3 号	281-289	2010
Shimmura C, Suda S, Tsuchiya KJ, Hashimoto K, Ohno K, Matsuzaki H, Iwata K, Matsumoto K, Wakuda T, Kamenoy Y, Suzuki K, Tsujii M, Nakamura K, Takei N, Mori N	Alteration of plasma glutamate and glutamine levels in children with high-functioning autism.	PLoS One	2011; 6(10)	e25340	2011-10
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明翫光宜・飯田愛・森一晃・堀江奈央・稲生慧・中島俊思・辻井正次	広汎性発達障害児を対象とした「気分は変えられる」プログラム作成の試み	小児の精神と神経	51(4)	377-385	2011
川上ちひろ・辻井正次	思春期広汎性発達障害男児への性教育プログラムの検討：試行的実践からの分析	小児保健研究	70(3)	402-411	2011-05
辻井正次	子どもたちの「できること」を伸ばす-発達障害のある子どものスキル・トレーニング実践(12・最終回)楽しい生活のために必要なこと	こころの科学,	157	116-121	2011-05

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明翫光宜・望月知世・内田裕之・辻井正次	広汎性発達障害児の人物画研究(1)：DAM 項目による身体部位表現の分析	小児の精神と神経	51(2)	157-168	2011-06
原幸一・神谷美里・辻井正次	高機能広汎性発達障害児のバウムテストの発達特徴	発達障害研究	33(3)	314-321	2011-08
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辻井正次	発達障害のある子どもたちの家庭と学校(5)特別支援学級に在籍すること・通常学級に在籍すること	子どもの心と学校臨床	5	89-97	2011-08
宮地泰士・神谷美里・野村香代・吉橋由香・辻井正次	広汎性発達障害児本人への診断説明(告知)に関する親の意識と実態調査	精神科治療学	26(11)	1465-1472	2011-11
辻井正次	発達障害への支援～ライフステージに応じて～青年期の支援(生活・就労支援)	第 52 回日本児童青年精神医学会総会抄録集		121	2011-11
辻井正次	成人期アスペルガー症候群の社会適応支援—ライフプランニング・スキルに関連して	第 107 回日本精神神経学会総会プログラム・抄録集		S.338	2011-11
黒田美保・稲田尚子	Autism Diagnostic Observation Schedule (自閉症診断観察検査) 日本語版の開発状況と今後の課題	精神医学	54		2012
安達潤	地域での発達障害に対する一貫した支援のあり方について	児童青年精神医学とその近接領域	52(3)	280-288	2011



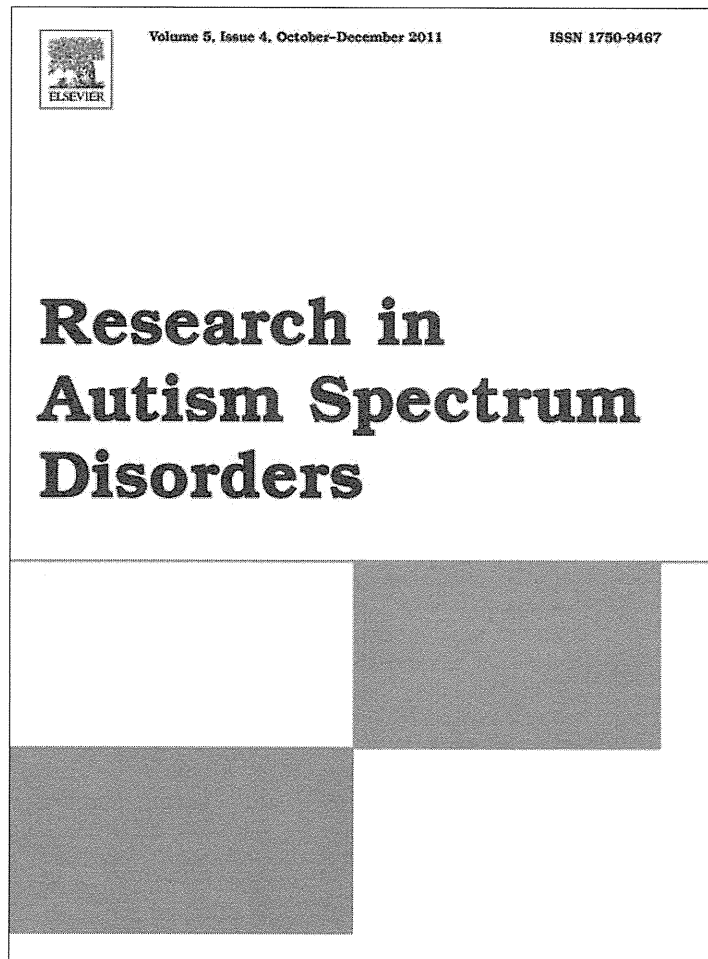
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発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
安達潤	P A R S 短縮版の作成と評 定における観点	乳幼児医学・心理 学研究	20(2)	83-88	2011

## IV. 研究成果の刊行物・別刷

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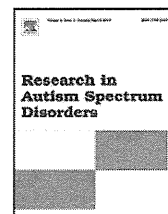
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# Research in Autism Spectrum Disorders

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## Informing children about their sibling's diagnosis of autism spectrum disorder: An initial investigation into current practices

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### ABSTRACT

The manner in which typically developing (TD) children were informed about their sibling's diagnosis of autism spectrum disorders (ASDs) was examined in Japan. Seventy-seven parents, each with a child with ASD and a TD child, participated in a questionnaire survey. From the data obtained, it was revealed that parents informed 66.7% (72/108) TD children about their sibling's diagnosis, and usually informed them when they were around 9 years of age. Birth order, age spacing and type of ASD affected the parents' decision about whether or not to inform them, and type of ASD, sex, age spacing and total number of children affected the timing of when parents informed them. TD children whose sibling had high-functioning ASD were informed less often and later. The most common question asked by TD children concerned communication problems, and parents often informed them of symptoms and difficulties of ASD as well as the diagnosis. Before receiving an explanation, 77.9% (53/68) of TD children had guessed the diagnosis or noticed something different about their sibling with ASD and 77.3% (51/66) of them reacted moderately to the parent's explanation. The influence of the parent's explanation on TD children's understanding of ASD warrants further research.

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### 1. Introduction

It is said that living with a sibling with a handicap greatly affects the lives of typically developing (TD) children in many ways (McHale & Gamble, 1989), although how the children experience their family situations and the quality of the relationships they develop with their affected sibling will differ individually. Several studies of TD children in families with a sibling with a handicap have identified one or more of the following factors that may influence the TD child's relationships within the family: sex, age, birth order, living in the same household, family size, type and severity of sibling disability, and socioeconomic status of the family (e.g., Breslau, 1982; Lobato, 1983; Orsmond & Seltzer, 2007; Simeonsson & McHale, 1981).

Sibling relationships, in particular, can become complicated when one or more child is experiencing difficulties acquiring the necessary social skills to develop age appropriate relationships. This is especially the case when one child has been diagnosed with an autism spectrum disorder (ASD) which, by definition, affects a child's ability to relate to others (American Psychiatric Association, 2000) (in this paper, the term ASD will be used to include all subtypes and related terms, including autism, Asperger's syndrome, and pervasive developmental disorders). Studies have reported that TD children of siblings

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with ASD experience resentment and confusion in response to their sibling's unusual behaviors, such as screaming, temper tantrums, and odd behaviors associated with preoccupations in public places (Howlin & Rutter, 1987), and have a higher level of stress compared to children of siblings with other disorders (Fisman et al., 1996; Rodrigue, Geffken, & Morgan, 1993).

Previous research on TD children of siblings with ASD tended to focus on TD children's adjustment to stress and behavioral problems. Meyer and Vadasy (1994) found that the manner in which TD children deal with the perplexing behaviors displayed by their siblings with ASD is influenced by whether TD children have information about the characteristics of ASD. Moreover, Royers and Mycke (1995) reported that there is an association between the children's knowledge of autism and the quality of the sibling relationship, and Howlin (1988) has pointed out that explaining autism to TD children will help in resolving sibling problems. While the importance of providing TD children with information about their sibling's disorder in a developmentally appropriate way has been stressed (Glasberg, 2000; Harris & Glasberg, 2003; Meyer & Vadasy, 1994), there are no clear guidelines for *what* type of information should be given to children at different ages (Glasberg, 2000). Further, there is little research that looks specifically at *how* parents typically inform their TD children of their sibling's diagnosis even though it greatly affects TD children's adjustment (Meyer & Vadasy, 1994).

Bagenholm and Gillberg (1991) reported that 55% of TD children aged 5–20 years old of siblings with autism could not explain their sibling's disorder. In Glasberg's (2000) study with 63 siblings ranging in age from 5 to 17 years, she found that 79.4% reported having been told the name of the disorder (e.g., "autism"), and that the proportion of siblings who knew of their sibling's disorder increased with age. However, she also indicated that TD children of siblings with ASD, compared to those of siblings with physical illnesses, need to be older in order to comprehend some of the more abstract concepts associated with ASD. She states that it is even more difficult for TD children of siblings with milder characteristics of autism to comprehend the disorder. To date, however, there have been few studies concerning TD children of siblings with so-called high functioning ASD (HFASD) such as Asperger's syndrome and high functioning autism (Verte, Roeters, & Buysse, 2003).

ASD is a life-long disability which requires long-term and multi-dimensional support. Within the family, TD children often have the greatest amount of involvement with the child with ASD, so it is essential that they possess accurate knowledge to support the child. Despite this need, there is a lack of research about informing TD children of the disorder and diagnosis.

The aim of this study was to explore current practices of how parents inform TD children about their sibling's diagnosis of ASD. Firstly, associations between the parents' decision of informing the TD child and the following four factors reported to affect adjustment of siblings of a child with a handicap were examined: sex (sex of TD child, sex of child with ASD, and agreement of sexes between TD child and child with ASD), age (birth order and whether age spacing between TD child and child with ASD is less than 2 years or more), the total number of children and type of handicap. For example, in previous studies on TD siblings of a child with a handicap, it was suggested that older TD children were less adversely affected than younger ones, that female TD children were poorly adjusted (e.g., Simeonsson & McHale, 1981), and that among younger male TD children overall level of psychological functioning and aggressive behavior were significantly worse for those where the age spacing between the siblings was less than 2 years compared to those where it was 2 or more years (Breslau, 1982). We hypothesized that some of these four factors would also affect the parents' decision of when and how to inform TD children. In regards to type of ASD, we decided to focus on the informing of two groups of TD children, those with siblings with intellectual disability and those with siblings without intellectual disability, as not much is known about the latter group. Because the characteristics of high functioning ASD are invisible and abstract, we examined the hypothesis that parents would inform their TD children of their sibling's diagnosis less often and at a later age.

Secondly, the explanation given to TD children by parents was investigated qualitatively. We explored what kind of information the parents provided about the sibling's ASD diagnosis. Regarding TD children's responses, we examined whether TD children had asked questions to parents before receiving the explanation, how TD children reacted initially at the time of being informed and whether they had guessed the diagnosis. Features specific to TD children with siblings with high functioning ASD were revealed by qualitative comparison.

## 2. Methods

### 2.1. Participants

The data for this study were based upon parental reports and were solicited from a general mailing of all of the members of the Autism Society of Kumamoto which is a chapter of Autism Society of Japan. The current membership consists of parents or grandparents of children with ASD, as well as professionals (i.e., teachers and physicians) and agencies who support individuals on the autism spectrum. According to Autism Society's June 2008 records, there were a total of 384 active members, with parent members reporting a total of 379 children with ASD: 313 (82.6%) males and 66 females (17.4%) with a mean age of 15.4 years (range 3–44).

The protocol of this study was approved by the ethics committee of the Mashiki Hospital. Following approval from the Committee of the Autism Society of Kumamoto, members with at least one child diagnosed with ASD and one TD child were invited to participate anonymously in the study by completing and returning a questionnaire developed by the author (see Appendix A), which was attached to the bi-monthly newsletter. Returned questionnaires that identified a child with a developmental disorder other than ASD (e.g., attention-deficit/hyperactivity disorder or learning disorder) or chronic serious physical illness (e.g., congenital heart disease) were excluded from the study. In families with more than one child diagnosed

**Table 1**  
Characteristics of study samples.

<i>Typically developing child (n = 108)</i>	
Gender, n (%)	
Male	39 (36.1)
Female	69 (63.9)
Age in years, mean (SD <sup>a</sup> )	12.9 (7.9)
Age range (years old)	0.5–36
Birth order, n (%)	
Older brother	19 (17.6)
Older sister	35 (32.4)
Younger brother	20 (18.5)
Younger sister	34 (31.5)
<i>Child with ASD<sup>b</sup> (n = 77)</i>	
Gender, n (%)	
Male	66 (85.7)
Female	11 (14.3)
Age in years, mean (SD)	12.7 (7.2)
Age range	4–37
Diagnosis, n (%)	
Autism	47 (61.0)
High functioning autism	13 (16.9)
Asperger's syndrome	12 (15.6)
Pervasive developmental disorder	5 (6.5)
ASD with intellectual disability (LFASD <sup>c</sup> )	50 (64.9)
ASD without intellectual disability (HFASD <sup>d</sup> )	27 (35.1)
<sup>a</sup> Standard deviation.	
<sup>b</sup> Autism spectrum disorder.	
<sup>c</sup> Low functioning ASD.	
<sup>d</sup> High functioning ASD.	

with ASD, the parents were asked to respond to the questionnaire items based upon their experience with the oldest child with ASD.

Returned questionnaires that met study criterion totaled 77. Although the vast majority of the members of the Autism Society of Kumamoto are believed to be parents of a child with ASD, Society records do not indicate what percentage of these parents also have a TD child in the family; therefore, an accurate return rate could not be reliably calculated for the target population, but the overall return rate based upon the entire membership was 20.1% (77/384).

Of the 77 eligible questionnaires obtained, the total number of TD children was 108, with a mean age (years) of 12.9 (range 0–36, SD = 7.9) at the time of the study. There were 39 males (36.1%) and 69 (63.9%) females. The birth order and sex of the siblings in relation to the child with ASD were as follows: 19 older brothers (17.6), 35 older sisters (32.4%), 20 younger brothers (18.5%) and 34 younger sisters (31.5%). The mean age of the 77 children with ASD was 12.7 (range 4–37, SD = 7.2) at the time of the study. There were 66 males (85.7%) and 11 females (14.3%). Diagnoses reported by parents included autism ( $n = 47$ , 61.0%), Asperger's syndrome ( $n = 12$ , 15.6%), high functioning autism ( $n = 13$ , 16.9%), and pervasive developmental disorder ( $n = 5$ , 6.5%). Fifty of the 77 parents (64.9%) reported that professionals identified that their child had a co-morbid intellectual disability. The other 27 children were considered not to have an intellectual disability in this study (Table 1).

## 2.2. Procedure

Data for this study were collected using a questionnaire completed by parents (see Appendix A). All parents were asked to respond to a portion of the questionnaire containing 4 questions and, depending upon their answers, were instructed to complete the remaining items. The common questions (Q1–Q4) asked (a) the age and sex both their child with ASD and their TD child, (b) the diagnosis of their child with ASD and the health condition of their TD child (whether he or she had a serious medical condition such as developmental disorder other than ASD and serious physical illness), (c) whether parents (or someone else) had informed the TD child of his/her sibling's diagnosis, and (d) whether the TD child had asked questions about his/her sibling's unusual behavior or life with his/her sibling with ASD before parent's (or someone else) explanation and if so, the content of the questions.

Regarding diagnosis information, parents were asked to accurately describe the explanation they received from their doctors who were usually psychiatrists or pediatricians specializing in developmental disorders. In Japan, only physicians are permitted to diagnose these disorders, and diagnosis is generally made through interviewing and clinical behavioral observations based on international standards such as DSM-IV-TR or ICD-10. Those children reported to have intellectual disability by parents were classified into the low functioning ASD (LFASD) group and those without intellectual disability were classified into the high functioning ASD (HFASD) group. Typically in Japan, even though professionals do not go into detail in explaining IQ test scores to parents, diagnosing physicians do base their conclusions as to whether or not a child has an intellectual disability on IQ test scores and this diagnosis is communicated to parents.

For those parents who responded that they had already explained the ASD diagnosis of the affected sibling to the TD child, they were asked to describe the following: (a) age at time of explanation, (b) who explained the diagnosis, (c) expressions used in the explanation, (d) how the TD child reacted to the explanation, and (e) whether the TD child had already guessed the diagnosis (Sheet A).

### 2.3. Coding of qualitative data

Parents responded freely to the following three open-ended questions: “Has your typically developing child asked questions about the unusualness of his/her sibling’s behavior or life with his/her sibling with autism spectrum disorder before your (or anyone else’s) explanation? If so, what did he/she ask?”, “What did you (or anyone else) say about the diagnosis to your typically developing child?” and “How did your typically developing child react to the explanation?” Regarding the expression of explanation, we categorized by topic according to Aikawa and Nihei’s categorization system (2002, 2005) developed during their investigation of how teachers and parents explained developmental disorders to unaffected peers. As far as we know, this is the only available categorization system regarding such explanations of developmental disorders to children. Aikawa and Nihei specify 12 categories regarding the nature of the explanation provided: diagnosis or having a disability (e.g., the child has autism), cause (e.g., the cause is a dysfunction of the brain), symptoms and difficulties (e.g., the child can not talk), feelings of the disabled child (e.g., the child is happy to play with you), similarities of the disabled child to their peers (e.g., everybody has weaknesses), negative responses that peer children are likely to produce (e.g., we can’t excuse teasing the child), how to treat the disabled child (e.g., let’s talk to the child slowly), positive aspects (e.g., the child has strengths), future goals (e.g., the child practices this in order to live independently), how to support (e.g., let’s help if the child is in trouble), reason for special education (e.g., the child needs a quiet place to concentrate) and prognosis (e.g., the child’s difficulty can’t be cured. Regarding the content of questions asked by TD children and their initial reaction to the explanation, categories were newly created by the two of the authors (K.T. and T.U., two experienced child psychiatrists) according to the content of the parents’ responses because there were no existing categories. The primary evaluator (K.T.) read all of the parents’ responses and classified them into categories first, and then the second evaluator (T.U.) reviewed them. Different opinions of the evaluators were resolved by discussion and the final categories were agreed by consensus.

### 2.4. Statistical analysis

Statistical analysis was performed using SPSS 18.0J for Windows, and the level of significance was set at 5% (two-tailed).

## 3. Results

### 3.1. Informing TD children of sibling with ASD

#### 3.1.1. Age of TD children at the time of being informed and informing person

Of the 108 TD children, 72 TD children had been informed (Informed group, 66.7%) and 36 had not been informed (Uninformed group, 33.3%). The mean age at the time of study was significantly higher in the Informed group at 15.8 (range 6–36, SD = 6.6) than in the Uninformed group at 6.9 (range 0–32, SD = 7.0) ( $t = -6.45$ ,  $p < .001$ ,  $t$ -test).

From a total of 65 responses, the mean age of the Informed group at the time of being informed was 8.6 (range 2–24, SD = 4.2). Forty-five of these 65 TD children (69.2%) were informed between the age 6 and 12 (i.e., while elementary school students in Japan).

The mean ages of the TD children by birth order relationship and by sex at the time of being informed were 10.5 for older brothers (5–24), 8.3 for older sisters (2–22), 10.2 for younger brothers 10.2 (5–16) and 7.1 for younger sisters (3–17); there was no significance between them.

From a total of 67 responses, the person who informed the TD children was most commonly the mother (61.2%), followed by both parents (31.1%).

#### 3.1.2. Factors associated with parents’ decision to inform TD children of ASD diagnosis

As for whether parents informed siblings, differences in the number of children informed for each variable shown in Table 2 were tested (Chi-square test). Compared to children with ASD, there were significant differences in the number of younger and older TD children: parents informed older TD children significantly more than younger children ( $p < .001$ ), and significantly more parents informed siblings if the age spacing between the TD child and the child with ASD was more than 2 years ( $p < .05$ ). In addition, when the type of ASD was HFASD, significantly fewer parents informed the siblings ( $p < .05$ ). There was no significant difference in the sex of the TD children, the sex of those with ASD, when the sex of the TD children matched that of the children with ASD, or for the total number of siblings.

#### 3.1.3. Factors associated with the age of TD children at the time of being informed

Differences in mean age at the time of being informing for the Informed group were tested for the variables described in Table 3 ( $t$ -test). Siblings were informed at significantly young ages when the siblings were TD girls, when the age spacing was less than 2 years between the TD child and the child with ASD, and when the total number of siblings was two ( $p < .05$  for all

**Table 2**  
Factors associated with parents' decision to inform typically developing (TD) children of sibling's diagnosis of ASD.

		Informed group (n = 72)	Uninformed group (n = 36)	$\chi^2$
Sex of TD child	Male	23	16	1.625
	Female	49	20	
Sex of child with ASD	Male	62	33	0.700
	Female	10	3	
Agreement of sexes between TD child and child with ASD	Same	26	16	0.701
	Opposite	46	20	
TD child is older/younger than child with ASD	Older	48	6	24.000**
	Younger	24	30	
Age spacing between TD child and child with ASD	<2	6	8	4.103*
	2+	66	28	
Total number of children	2	37	14	1.505
	3+	35	22	
Type of ASD	LFASD <sup>a</sup>	53	19	4.688*
	HFASD <sup>b</sup>	19	17	

\*  $p < .05$ .

\*\*  $p < .001$ .

<sup>a</sup> Low functioning ASD.

<sup>b</sup> High functioning ASD.

**Table 3**  
Factors associated with when parents inform typically developing (TD) children of sibling's diagnosis of ASD.

		Informed group (n = 72) Mean and range	T
Sex of TD child	Male (n = 23)	10.4 ± 5.0	2.20*
	Female (n = 49)	8.0 ± 3.7	
Sex of child with ASD	Male (n = 62)	8.8 ± 4.4	0.96
	Female (n = 10)	7.8 ± 2.6	
Agreement of sexes between TD child and child with ASD	Same (n = 26)	10.1 ± 4.7	-1.91
	Opposite (n = 46)	7.9 ± 3.1	
TD child is older/younger than child with ASD	Older (n = 48)	8.9 ± 4.4	-0.87
	Younger (n = 24)	8.0 ± 3.8	
Age spacing between TD child and child with ASD	<2 (n = 6)	6.2 ± 2.5	-2.35*
	2+ (n = 66)	8.9 ± 4.3	
Total number of children	2 (n = 37)	7.6 ± 2.7	-2.19*
	3+ (n = 35)	9.8 ± 5.3	
Type of ASD	LFASD <sup>a</sup> (n = 53)	7.3 ± 3.1	-4.41**
	HFASD <sup>b</sup> (n = 19)	11.8 ± 5.0	

\*  $p < .05$ .

\*\*  $p < .001$ .

<sup>a</sup> Low functioning ASD.

<sup>b</sup> High functioning ASD.

conditions). When the type of ASD was HFASD, the siblings were informed at significantly older ages. There were no significant differences in ages at the time of being informed in the sex of the children with ASD, when the sex of the TD children matched that of the children with ASD and for whether the siblings were older or younger.

### 3.2. Explanations and responses

#### 3.2.1. Expression of explanation

At the same time the TD children were told of their sibling's diagnosis, other kinds of information were provided. For example, the explanation, "Your brother has autism (diagnosis). He is not good at talking (difficulty), so would you talk to him slowly (how to support)?" encompassed three topics. In the total 65 responses, there were a total of 100 topics covered and they were assigned to 10 of Aikawa and Nihei's (2002, 2005) 12 categories (see Table 4).

The most common other information provided concerned "symptoms and difficulties" (61.5%), followed by "having a disability" (29.2%), "cause of disability" (27.7%), "reason for special education" (10.8%), "how to support" (6.2%), "feelings of the child with ASD" (4.6%), "positive aspects of ASD" (4.6%), "how to deal with a child with ASD" (3.1%), "prognosis" (3.1%) and "similarity" (1.5%). As the cause of ASD is not easy for children to understand, the word "disease" was the most commonly used expression (e.g., "Autism is a disease of the brain"). Some parents used a metaphor such as "A screw in his/her brain is loose".

The most common style of expression used with siblings of children in the LFASD group was simple expressions such as "It is a brain disease called autism." In the HFASD group, on the other hand, the parents reported explanations that are complex and difficult for TD children to understand such as "You can't see it, but he/she has a disability" and "He/she can't



**Table 4**  
Information given to typically developing children by parents.

Category	Examples of explanation (reported by parents)	LFASD <sup>a</sup>	HFASD <sup>b</sup>	Total (%)
1. Symptoms and difficulties	He/she can't talk He/she is not good at making friends	26	14	40 (40.0)
2. Having a disability	He/she has a disability called autism He/she has had a disability since birth	12	8	20 (20.0)
3. Cause of disability	Autism is a disease of the brain A screw in his/her brain is loose	17	1	18 (18.0)
4. Reason for special education and treatment	He/she needs to study slowly He/she goes to the hospital to be treated	6	1	7 (7.0)
5. How to support	We should support him/her as a family Please help him/her	3	1	4 (4.0)
6. Feelings of children with ASD	He/she means no harm He/she feels anxious easily	1	2	3 (3.0)
7. Positive aspects of ASD	He/she has strengths He/she is honest and pretty	2	1	3 (3.0)
8. How to deal with child with ASD	Please speak to him/her slowly We should wait when he/she is confused	1	1	2 (2.0)
9. Prognosis	Autism is not curable	2	0	2 (2.0)
10. Similarity	Everybody has difficulties	1	0	1 (1.0)
		71	29	100 (100.0)

<sup>a</sup> Low functioning ASD.

<sup>b</sup> High functioning ASD.

**Table 5**  
Questions asked by typically developing children.

Category	Examples of question (reported by parents)	LFASD <sup>a</sup>	HFASD <sup>b</sup>	Total (%)
1. Communication problems	Why can't he/she talk? Why does he/she say strange things?	10	4	14 (24.6)
2. Difference of parents' attitude to each child	Why don't you scold him/her? Why are you kind only to him/her?	7	4	11 (19.3)
3. Odd behaviors	Why does he/she jump so often? Why does he/she bite himself/herself?	7	3	10 (17.5)
4. Difference of educational setting	Why does he/she go to a different school? Why is he/she in the special class?	7	0	7 (12.3)
5. Developmental delay	Why can't he/she do this on his/her own? Why does he/she need help to do this?	5	0	5 (8.8)
6. Difference from others	Why is he/she so different from others? Why does he/she behave differently?	3	2	5 (8.8)
7. Need for treatment/therapy	What does he/she do at the hospital? Why does he/she go to this center?	1	3	4 (7.0)
8. Obsessive behaviors	Why does he/she obsessive about this?	0	1	1 (1.8)
		40	17	57 (100.0)

<sup>a</sup> Low functioning ASD.

<sup>b</sup> High functioning ASD.

understand other people's feelings because he/she was born with a disorder, and it might be difficult for him/her to have interpersonal relationships." Six parents also reported using brochures and books to explain. Moreover, characteristic of the explanations seen in only the HFASD group were that parents did not use the expression "disease" and they explained the feelings lying behind the child's challenging behaviors such as "He/she means no harm" (see Table 4).

### 3.2.2. Questions asked by TD children before parent's explanation

From a total of 73 responses, 45 (61.6%) parents reported that they were asked the questions by their TD children. There were 57 questions reported by parents, with the TD children sometimes asking more than one question. On the basis of the content, their questions could be divided into eight categories (see Table 5): communication problems (24.6%), difference of parents' attitude to each child (19.3%), odd behaviors (17.5%), difference of educational setting (12.3%), developmental delay (8.8%), difference from others (8.8%), need for treatment/therapy (7.0%) and obsessive behaviors (1.8%). TD children recognized and asked about difference of parents' attitude to each child or educational setting sensitively in addition to the characteristics of ASD.

Although the most common question asked by TD children concerned communication problems in both the LFASD and HFASD groups, most of the questions asked in the LFASD group were related to speech and language delay ("Why can't he/she talk?"), whereas in the HFASD group TD children asked most about peculiar conversation ("Why does he/she say strange things?"). In the HFASD group, the equally common question concerned difference of parents' attitude to each child, such as

“Why don’t you scold him/her?” followed by questions about odd behavior and reasons for going to the hospital or rehabilitation center. The questions about differences in the educational environment and developmental delay were not reported by parents of children in the HFASD groups.

### 3.2.3. Reactions among the TD children

Parents described various reactions seen in TD children at the time they spoke to them about the diagnosis. Among the 66 responses obtained from parents, the most common was “They showed no particular reaction” (44.6%), followed by “They displayed a more accepting attitude than expected” (13.8%), “They showed understanding” (13.8%), “They expressed sadness” (10.8%), “They wanted to learn more” (6.2%), “They expressed surprise” (3.1%), “They seemed not to understand” (1.5%) and other responses (6.2%).

Regarding whether the TD children had noticed anything prior to the explanation, the 68 responses from parents were “They appeared to have noticed something” (70.6%), followed by “They had not noticed anything at all” (22.1%) and “They already guessed at the diagnosis” (7.4%).

## 4. Discussion

When TD children learn that their sibling has a disability, the experience is quite different from that of their parents learning this information. Since they are likely to find out about the disability during childhood, they do not necessarily receive explanations from specialists. They are still undergoing development, are not sufficiently equipped to understand many issues and relationships with siblings are not fully formed. The way children acquire knowledge of their sibling’s disability may influence their future relationships and lives. Knowing of a sibling’s disability is meaningful for children because it will allow them to meet other children in similar situations and learn how to deal with future prognosis.

In this study, we explored the current situation of informing TD children and attempted to derive factors that may affect parents’ decision of when and how to inform them. We are not aware of any other reports that have examined how, and to what extent, the TD children of siblings with Asperger’s syndrome or high functioning autism have received explanations about diagnosis, and the present study is therefore valuable as the first of its kind to closely examine this topic in ASD.

We found that parents informed roughly two-thirds of TD children of the diagnosis (up until 36 years of age), and mothers typically informed their TD child at around 9 years old. This finding accords well with that of Harris and Glasberg (2003) who found that generally children in middle childhood (9–12 years old) receive information about ASD, and understand complex topics such as the need for special education and that children with some disorders have a problem in the brain. Thus, it appears that the timing of informing TD children found among the present population was appropriate.

Parents informed their TD child significantly more often when he or she was older than their sibling with ASD, when the age spacing was more than 2 years between them and the type of disability was LFASD. Stoneman, Brody, Davis, and Crapps (1987) suggested that older TD children more often have a responsibility of care taking than younger TD children. Parents might therefore expect an older TD child to take care of the child with ASD, especially when the age spacing is more than 2 years. More research is needed to clarify where there is association between the parents informing the TD child of his/her sibling’s diagnosis and entrusting a role of caregiver to the TD child.

Parents informed their TD child significantly earlier when the TD child was female, age spacing was less than 2 years, the total number of children was 2 and the type of disability was LFASD. It is known that female TD children tend to be expected to take on the role of caregivers of siblings with disabilities (e.g., Stoneman, Brody, Davis & Crapps, 1988), and this might be a reason for parents informing female TD children earlier, in order to encourage their cooperation with parents. When age spacing is close between the TD child and child with ASD, the timing of the child being informed might come earlier because the children often share experiences in daily life, such as at school, and thus have the opportunity to recognize the difference in the sibling earlier. When the total number of children in the family is 2, the TD child cannot share the responsibility of caregiver with anybody as he or she gets older and thus his or her burden tends to be heavier (Simeonsson & McHale, 1981), but the parents might want the TD child to know of their sibling’s disability earlier because they expect the TD child to support their sibling in the future as the only other immediate family member.

The current situation of parents informing their TD children about their sibling’s diagnosis of HFASD was examined. Parents informed them of the diagnosis less often and did not inform them until they were older. There are some reports that TD children who have a sibling with ambiguous and undefined disability tend to show poorer adjustment when the sibling has autism than when he or she has other disabilities such as Down’s syndrome (Howlin, 1988; Simeonsson & McHale, 1981). According to Verte et al. (2003), TD children aged 6–16 years of siblings with HFA were significantly more likely to have internal and external behavior problems compared to children with TD siblings. Because the characteristics of HFASD are fuzziier and more invisible compared to typical autism, the informational needs for TD children of siblings with HFASD might be higher than the parents expect. Information on the sibling’s condition can promote understanding and lighten the burden (Meyer & Vadasy, 1994), so a better way to inform TD children of siblings with HFASD should be comprehensively researched.

This study clarified the type of information that parents had given TD children about their sibling’s diagnosis. Similarly to Aikawa and Nihei’s (2005) findings, parents usually informed them of the diagnosis accompanied with other information, often concerning “symptoms and difficulties”, “having a disability” and “cause of disability” because they seemed to want the TD children to understand their siblings. On the other hand, “how to support” and “prognosis” were not so commonly

explained, although TD children might want such information. As TD children get older, they should be told more information and told in a way that matches the child's comprehension. The use of metaphors or brochures to supplement the explanation might help their TD child to better understanding the difficult nature of ASD.

Around 60% of parents were asked questions by their TD child before their explanations in the present study. It is notable that questions about difference of the parents' attitude to each child were the second most common group of questions overall and the most common in the HFASD group. McHale and Gamble (1989) reported that TD children's satisfaction with the parents' differential treatment of self compared with a sibling with disability were associated with the TD children's adjustment. TD children may misread contexts (e.g., mistakenly thinking the parents' attitude to each child is different because parents have different affection for each child) and may become angry, resentful and conflicted if insufficient information is given to them. TD children who did not ask questions may have refrained from doing so because of concern for their parents or a sense of guilt. Therefore, parents and specialists should be sensitive to the feelings of TD children (Meyer & Vadasy, 1994) and answer their questions in an appropriate and sufficient manner.

Parents reported that around 80% of TD children seemed to react moderately (they showed no particular reaction, they displayed a more accepting attitude than expected, they showed understanding, they wanted to learn more) to their explanation. However, around 15% of the children showed sadness, surprise and a lack of understanding. In a previous study, TD children reported experiencing various complex feelings when informed of their sibling's diagnosis (Feiges & Weiss, 2004), so there might be a gap between the actual TD children's feeling and the parents' perception. More research is needed to determine the real feelings of TD children and the relationship between the explanation they receive and these feelings. Also, not surprisingly, parents reported that around 70% of TD children felt there was something different about their sibling with ASD before receiving the parent's explanation and around 10% of TD children guessed the diagnosis probably because they had heard words such as 'autism' in family conversation or activities. It is essential for parents and specialists to recognize that TD children do not fully comprehend what ASD means even though they may have heard such words (Bagenholm & Gillberg, 1991; Glasberg, 2000). Inaccurate information and misunderstanding may make TD children even more confused (e.g., Feiges & Weiss, 2004).

There are several limitations to the present study. The first involves the recovery rate of the questionnaire and participants. The questionnaire was distributed to all 384 members of the organization. However, we cannot ascertain family make-up of the participants from the questionnaire. In addition, the 77 families who completed the questionnaire were likely to have been cooperative and highly interested in supporting siblings of children with ASD. Second, the diagnosis used in the study was reported by guardians who participated in the study. They may not necessarily understand the diagnosis and therefore their reported diagnosis may not be accurate. In addition, the presence of intellectual disability was also determined from the parents' reports, and thus it is that the reports do not accurately represent the condition of the child with the disability. The third limitation is that cultural influence needs to be taken into account when interpreting the present findings. Fourth, this study did not examine other factors such as the psychological state of the parents or TD children, support provided to the family, economic conditions and education levels. Whether these variables are related to the decision to inform siblings of the diagnosis should be examined in future studies. Despite these limitations, the current findings provide meaningful information regarding parents' decision to inform their TD children of the diagnosis, and are important when considering education and support for siblings of children with disorders.

Since information was based on parental reports, the level of comprehension and feelings of the TD children may actually be different from what was reported. Parents tend to overestimate their child's comprehension abilities: although parents may believe that they have explained thoroughly, children may not fully understand, causing a gap between the children's understanding and the evaluation of the children's understanding by his/her mother (Lobato, Barbour, Hall, & Miller, 1987). ASD is an abstract concept that children have difficulty understanding, and is not something that can be completely covered in a single explanation. An explanation involves more than simply telling TD children the name of the disorder. It is crucial that the explanation is given in such a way that TD children can fully comprehend what the diagnosis means. Information needs to be repeatedly conveyed as the siblings mature. Future studies should examine how understanding of their siblings' disorders and the sibling relationship of informed TD children change over time, and what constitutes good ways of informing TD children.

In conclusion, the present study revealed that many elementary school-aged TD children in Japan had been informed of their sibling's diagnosis of ASD. Some factors affected the parents' decision about if and when to inform them. In the case of siblings with high-functioning ASD, TD children were informed less often and later. It is important to develop better ways to inform TD children because they will later provide the main support for their siblings with ASD as their parents get older.

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## Appendix A

### Questionnaire

#### Common question

Q1. The age and sex of both your child with autism spectrum disorder and your typically developing child.

If your typically developing child has another developmental disorder (e.g., attention-deficit/hyperactivity disorder or learning disorder) or chronic physical illness (e.g., heart disease), please write here.

Q2. What is the diagnosis of your child with a disability?

Q3. Have you (or anyone else) informed your typically developing child of the diagnosis of his/her sibling with autism spectrum disorder?

Yes/No

Q4. Has your typically developing child asked questions about the unusualness of his/her sibling's behavior or life with his/her sibling with autism spectrum disorder before your (or anyone else's) explanation? If so, what did he/she ask?

Yes ( )/No.

#### Sheet A

(a) Age of your typically developing child when the explanation about his/her sibling's diagnosis was given

(b) Who explained the diagnosis?

(c) What did you (or anyone else) say about the diagnosis to your typically developing child?

(d) How did your typically developing child react to the explanation?

(e) Had your typically developing child already guessed the diagnosis?

- They had already guessed at the diagnosis
- They appeared to have noticed something
- They had not noticed anything at all.

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