787-799，2008

5）安達　潤，市川宏伸，井上雅彦，他：広汎性発達障害日本自閉症協会評定尺度，スペクトラム出版，東京，2008

6）Attwood T, Social Understanding and Friendship：The Complete Guide to Asperger's Syndrome, Jessica Kingsley Publishers, London, p57, 2007

7）Schopler E, Van Bourgondien ME, Wellman GJ, et al：Childhood Autism Rating Scale, 2nd ed（CARS2）manual, 2nd ed, Western Psychological Service, California, 2010

8）ショプラー E：自閉児・発達障害児教育診断検査―心理教育プロフィールの実際，川島書店，東京，2007

9）Lord C, Rutter M, DiLavore PC, et al：Autism Diagnostic Observation Schedule（ADOS）, Western Psychological Services, Los Angeles, CA, 1999

10）諏訪利明，安倍陽子編集，内山登紀夫監修：こんなとき，どうする？　発達障害のある子への支援　幼稚園・保育園，ミネルヴァ書房，東京，p99，2009

広汎性発達障害の心理社会的支援をめぐって

福島大学人間発達文化学類人間発達専攻
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KEY WORDS
●自閉症スペクトラム
●TEACCH
●行動分析

Psycho-social support for people with ASD.
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はじめに

1960年代，自閉症は母子関係の問題による心因性の障害であると考えられ，精神分析的心理療法の対象となっていたが，1970年代になり次第に脳器質障害・発達障害説が唱えられ，行動療法や治療教育が行われるようになった[3]。その後，自閉症の認知特性についての理解が進み，現在ではTEACCHプログラムやSPELLアプローチなどの心理社会的支援のシステムが開発され，行動分析学や認知行動療法を応用した介入法も行われている。

Ⅰ．自閉症スペクトラムへの支援システム

自閉症スペクトラム（Autism Spectrum Disorders：ASD）の人が，その人らしく自立した生活を送り，自尊心や自己効力感を育みながら，地域のなかで共生していくためには，生涯にわたる支援を要する。それを支える代表的なプログラムを紹介する。

1．TEACCHプログラム[1-3]

TEACCHとは，Treatment and Education of Autistic and related Communication handicapped CHildrenの略で，米国のノースカロライナ州全体を対象にする包括的プログラムのことであり，ASDの人たちと社会でともに暮らすための社会的支援システムである。TEACCHが提供するのはASDとその家族への援助，ASDの研究，スタッフの教育であり，特定の技法のみを指すものではない。その目的は，ASDの人が社会のなかで有意義に暮らし，できるだけ自立した行動をすることにある。方法論としては行動理論や認知理論，言語心理学，社会的学習理論，応用行動分析などの影響を受けているが，援助手段を考えるときには「ASD特性から考える」という視点を用いる。TEACCHには９つの基

本理念がある。

1）ASDの特性を理論よりも実際の子どもの観察から理解する

TEACCHは実証的なデータをもとに，家庭や学校や職場という「現実の世界」で，子どもと家族が安心して生活できる援助を目指している。理論から出発するのではなく，実際の子どもの行動を観察することから出発するのが基本的なスタンスである。

2）親と専門家の協力

TEACCHは親と専門家の関係のあり方として次の４つをあげている。すなわち，専門家が親を指導する関係，親からの情報や親の考え方を尊重して専門家が親から学ぶ関係，親と専門家が共同して気持ちを支え合う関係，親と専門家がコミュニティーで子どもの代弁者として活動する関係の４つである。親と専門家のコラボレーションを大切にし，親や子どものニーズがどこにあるかを把握し，支援の方法を考えていくのである。

3）治癒ではなく，適応能力を向上させる

ASDの原因は脳の機能障害であり，脳障害そのものを治癒させる方法は現時点ではない。TEACCHでは，ASDの人たちの適応能力を向上させ地域社会のなかで自分らしく生きていくことを目標にし，そのために必要な長期にわたる支援プログラムを提供することを重視する。

4）正確なアセスメント（評価）

ASDという診断は同じでも，特性は１人ひとり違っている。１人のASDの適応能力を向上させようとしたときには，得意なこと，苦手なこと，できること，できないこと，興味関心のあること，生活している環境などを考慮し，何を教えるべきか，苦手なことを環境調整によってどう補うことができるかを考えていかなければならない。そのためにさまざまな方法を用いてその人を評価し，得られた結果は，親や教師，支援者と共有して教育や生活支援に生かしていく。

5）構造化された指導法の利用

ASD認知特性の長所としてあげられるのは，視覚情報処理の強さ，特定のことに強い興味と関心を示す，それに関連した記憶がよいなどがある。短所としては，実行機能（計画すること，物事を開始し終結し次のことを新たに開始すること，行動を調整すること）の困難さ，中枢性統合（部分を全体のなかに意味づけること）の弱さ，聴覚情報処理の弱さ，気の散りやすさや本質的には重要でない情報に気を取られやすい傾向などがある[4]。

このような長所を生かし短所を補う方略が構造化である。構造化とは，ASDの人が理解しやすい環境を設定し，「１人で活動できること」を増やすための工夫である。構造化が適切に行えれば「どこで，いつ，何を，いつまで，どのようなやり方で，終わったら次に何をするか」をASDの人は理解しやすくなる。

6）認知理論を重視する

支援プログラムを考えるとき，認知理論による状況の理解と脳内で生じる認知過程を重視している。TEACCHの構造化された学習モデルにおいて，ASDの人にとって周囲の状況が意味のあることとして理解できる環境が学習能力に決定的な影響を与えるとしており，予期と有意味性を重視している。そのような環境のなかで，「自分は実行できる」という達成感への期待をもち，「達成できた」という経験を積むことで，「自己効力感」，「自己肯定感」を感じることができるようになる。

7）スキルを伸ばすと同時に弱点を受け入れる

ASDへの有効なアプローチは，現在の能力や興味・関心のあり方を認識し，そこから出発する姿勢から得られる。そのためには適切に評価をすることを重視するが，弱点を正確に把握し，受け止めることも必要である。評価に基づき達成可能な課題設定をし，成功体験や自立的経験のなかから自己肯定感を育むことを目指す。ここでいう課題とは机上での学習課題や身辺自立の課題だけでなく，問題行動のコントロールやコミュニケーションの理解，職業スキルや社会的場面での振る舞いなど広い意味で使われている。いわゆる報酬がなくとも，課題が「できた」という達成感が動機付けとなり，スキルが向上していくことが期待できる。

8）ホーリスティック（全体的）な見方を重視する

ASDの認知特性は生涯にわたり続くものであり，一貫性のある包括的な支援を必要としている。成長に伴いそれぞれの場面で，小児科医，精神科医，言語聴覚士，心理士，教師，ケースワーカー，作業療法士，ヘルパー，就労支援の専門家，余暇活動の支援者などが関わることになる。専門家がそれぞれの専門性をもって関わることは当然であるが，ASDへ関わる場合は，スペシャリストであると同時に，その人の全体を見渡し理解したうえで，取り組むべき優先順位や目標設定をするという視点をもったジェネラリストとしての姿勢が求められる。

9）生涯にわたるコミュニティーに基礎を置いたサービス

現在のところASDを治癒させる治療方法はなく，支援も生涯にわたって必要である。ASDの人たちが地域でできるだけ自立して生活していくために，コミュニティーに基盤をおいた支援サービスを充実させることが必要である。

TEACCHが日本に紹介されて30年近く経ち，幼児期から成人期のASDを支援するさまざまな機関で，支援モデルとして採用されている。その実践は「自閉症カンファランスNIPPON」(朝日新聞厚生文化事業団及び実行委員会主催)や「TEACCHコラボレーションセミナー」(TEACCH研究会主催)で報告されている。しかし一方で，絵カードや構造化によってASDの人たちの行動を修正したりロボットのように支配するといった誤った理解のまま，表面的に形だけを取り入れている支援機関がまだ存在するのも事実である。

それぞれの支援機関がそれぞれの立場でTEACCHの理念やアイデアを応用し，密接に連携しながらネットワークを構築していくことで，個々のASDの人に連続性・一貫性があり包括的な支援を提供していくことが望まれる。

2．SPELLアプローチ

英国自閉症協会(National Autistic Society：NAS)は７つのASD学校をはじめとして幼児から成人までを対象にした多くの支援機関を運営している。NASの運営する支援機関は，ASDにはASD特有の特性と支援ニーズがあるという認識から出発し，すべてSPELLという共通の理念に基づいて運営されている。

SPELLの理念とは，次の５つを指す。①Structure(構造：ASDの人の聴覚的理解より視覚的理解が優れていることや，順序についての関心が高いなどの長所を生かし，予測可能・理解可能で安心できる環境を提供する)，②Positive（肯定的に：ASDの特性の一つは不安感をもちやすいことであり，威圧的・強圧的な態度を支援者がとるとASDの人は不安になったり，本来もっている能力を発揮しづらくなるため，肯定的な雰囲気で支援を行う)，③Empathy（共感：ASDの人の目を通して外界を理解し，ASDの人の苦痛や楽しみに共感する。そのために，ASDの特性を意識した個別のアセスメントを行う)，④Low Arousal(穏やかな刺激：ASDの人は音や光，臭いなどの感覚刺激に過敏なことが多いため，その人の苦痛になるような刺激を最小限にする)，⑤Links(つながり：当事者，親，専門家が相互にオープンにコミュニケーションをとり情報を共有し，つながりを維持する)。このようなSPELLアプローチはTEACCHの理念とも非常に近い。SPELLはカナータイプのASDのみでなく，アスペルガー症候群の人にも共通して適用される。

Ⅱ．ASDへの具体的な介入方法

1．行動分析学の応用

応用行動分析学は，行動の生起・非生起を環境との相互作用から捉えようとする行動分析学の一分野であり，ASDの療育においては，コミュニケーション・身辺自立・余暇指導・社会的スキル・学習など広範囲に適用されている。

基本的な考え方として，ある行動が後続事象によって強化されるという「強化の原理」などを用いて望ましい行動を増やし望ましくない行動を減らすことを目指しており[5]，絵カード交換式コミュニケーションシステム(Picture Exchange Communication System：PECS)[6]，ペアレント・トレーニング[5]，社会生活技能訓練(Social Skills Training：SST)[7]などに応用されている。

2．認知行動療法の応用

認知行動療法とは，人間の気分や行動が認知(ものの考え方や受け取り方)のあり方の影響を受けることから，認知の偏りを修正し問題解決を手助けすることによって精神疾患を治療することを目的とした構造化された精神療法である[8]。

ASDへの応用としては，社会的対人的な場面を正確に説明し，その場面での上手な対応を明確にすることを目的に親や支援者が文章を書く「ソーシャル・ストーリー」[9]，２～３人でのコミュニケーションを線画によって示し状況理解を促す「コミック会話」[10]，目にみえない感情を目にみえる形で理解できるように工夫し感情の認識と不安や怒りのコントロールを目指す「The CAT(Cognitive Affective Training：認知的感情トレーニング) Kit」[11]などが開発されている。

おわりに

ASDの人たちにとっての「良好な社会生活」とは，どのような状態を指すのだろうか。さまざまな側面は考えられるが，日本において行われた調査結果がある[12]。それによると「就学前から中学校時代まで何らかの支援が継続して行われていたこと」，「母親が助けになっていたこと」が，親や支援者が「良好である」とする要因にあげられた。また，言語発達が良好な場合でも，「４歳前に発達に関する何らかの診断を受けていた」こともあげられた。

日本におけるASD支援において求められるものは，早期発見・早期支援，支援の個別化，支援機関の連携，各種専門職の配置と専門性の向上などがある。ASDに関わる親や支援者がその特性を正しく理解し，一貫性のある支援を提供できるよう社会システムを改善する必要がある。

文献

1) 佐々木正美：児童精神医学の臨床．東京，ぶどう社，1986
2) 佐々木正美 編：自閉症の療育者．神奈川県児童医療福祉財団，1990
3) 内山登紀夫：本当のTEACCH．東京，学習研究社，2006
4) ウタ・フリス 著，富田真紀，他 訳：新訂自閉症の謎を解き明かす．東京，東京書籍，2009
5) 井上雅彦，三田地真実，岡村章司：子育てに活かすABAハンドブック．東京，日本文化科学社，2009
6) アンディ・ボンディ，他 著，門眞一郎 監訳：絵カード交換式コミュニケーションシステム（PECS）トレーニングマニュアル第２版．福岡，ピラミッド教育コンサルタントオブジャパン，2005
7) モーリーン・アーロンズ 著，飯塚直美，他 訳：自閉症スペクトラムへのソーシャルスキルプログラム．東京，スペクトラム出版社，2005
8) 慶應義塾大学認知行動療法研究会：うつ病の認知療法・認知行動療法 治療者用マニュアル．東京，2－5，2010（http://www.mhlw.go.jp/bunya/shougaihoken/kokoro/dl/01.pdf）
9) キャロル・グレイ，他 著，安達 潤，他 訳：マイソーシャルストーリーブック．東京，スペクトラム出版社，2005
10) キャロル・グレイ 著，門眞一郎 訳：コミック会話．東京，明石書店，2005
11) Tony Attwood（http://www.tonyattwood.com.au/index.php）
12) 稲田尚子：長期予後の現状，ライフステージに応じた要因との関係：成人後の良好な社会参加の実現に向けて～全国調査の結果から～．神尾陽子 編，ライフステージに応じたASDスペクトラム者に対する支援のための手引き．東京，国立精神・神経センター精神保健研究所，15－18，2010

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A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders

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Abstract

The psychosocial outcomes of individuals with high-functioning autism spectrum disorder (HFASD) appear to be diverse and are often poor relative to their intellectual or language level. To identify predictive variables that are potentially ameliorable by therapeutic intervention, this study investigated self-reported psychosocial quality of life and associated factors for adults with HFASD. All participants (n = 154) had a diagnosis of autism spectrum disorder, were over 18 years of age, lived in the community, and had used one or more support services during the survey period. The results demonstrated that psychosocial quality of life was lower than that of the general Japanese adult population. Environmental factors, such as mother's support and early diagnosis, were associated with better quality of life, and aggressive behaviors were associated with poorer quality of life, while expressive language level at preschool years, a conventional outcome predictor, did not predict quality of life. These results emphasize that quality of life measures should be included as outcome indicators in treating individuals with HFASD.

Keywords

high-functioning autism spectrum disorder, quality of life, adult, outcome, early diagnosis

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Introduction

Because autism spectrum disorder (ASD) is a life-long developmental disorder characterized by social and communication impairments and repetitive/stereotyped behaviors, therapeutic intervention for individuals with ASD and their families should be planned for and provided throughout the life span. According to previous outcome studies of autism/ASD, long-term outcomes have repeatedly been shown to be relatively poor when measured by conventionally used indicators, such as employment or independent living, and IQ or expressive language levels during the preschool years, have been thought to be powerful predictors of long-term outcomes (Kobayashi et al., 1992; Howlin et al., 2004; Mawhood et al., 2000). A growing body of literature indicates that children with ASD can be reliably diagnosed in the second year of life (Johnson et al., 2007; Landa, 2008). Furthermore, there is accumulated evidence that early detection and intervention focusing on communication development can lead to substantially better prognosis (Landa, 2008).

Although individuals with high-functioning ASD (HFASD) usually have good intellectual or language development from a very early age, their long-term outcomes are not necessarily desirable and are rather diverse (Kamio et al., 2011). Recent studies have discovered an HFASD subgroup with comorbid psychiatric conditions, which may lead to poor long-term outcomes (Howlin et al., 2004; Tsatsanis, 2003). Counter-examples are also found; some who would have been predicted to do poorly as adults based on their modest intellectual or language development were found to be leading satisfactory lives (Persson, 2000; Ruble and Dalrymple, 1996). Given such diversity in the long-term outcomes of individuals with ASD, it is important to measure long-term outcomes more comprehensively, including subjective aspects such as quality of life (QoL) (Renty and Roeyers, 2006; Ruble and Dalrymple, 1996), and to identify predictive variables that can be changed by therapeutic intervention.

The QoL concept is increasingly being introduced into the health-related science field for children with psychiatric disorders (Bastiaansen et al., 2004). According to the World Health Organization (WHO; The WHOQOL Group, 1995), QoL is defined as 'the individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns', ranging from the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment.

Several studies have investigated QoL during adulthood for people with ASD. Most studies evaluated QoL by proxy (Gerber et al., 2008; Saldaña et al., 2009) or through indirect measures (Persson, 2000) for adults with both intellectual disabilities and ASD, and Renty and Roeyers (2006) investigated self-reported QoL of 58 adults with HFASD. These results showed that the QoL of HFASD populations largely depends on the nature of support services currently being received, suggesting that QoL can be improved by changing environmental factors. Furthermore, Renty and Roeyers (2006) demonstrated that although support characteristics were significantly related to QoL in adults with HFASD, disability characteristics such as IQ or severity of autism were not. This result emphasizes the importance of an available supportive social network, individual needs assessment, and effective professional support for adults with HFASD as well as for ASD adults with intellectual disabilities. However, in the study by Renty and Roeyers (2006) neither informal nor formal support was correlated with QoL, and perceived informal support was positively correlated with it.

In Japan, a new regulation took effect in April 2005 that aims to establish multidisciplinary service systems to improve the function and social participation of individuals with high-functioning autism, Asperger syndrome, and other developmental disorders. Currently, the majority of people with HFASD were not diagnosed as children and only a few people received adequate formal or informal support throughout childhood (Kamio and Inokuchi, 2009). Moreover, mental health professionals have become increasingly aware of undiagnosed adults with HFASD seeking psychiatric treatment for their comorbid psychiatric symptoms.

The first aim of the present study was to determine the QoL of adults with HFASD living in the community in Japan. The second aim was to identify factors associated with QoL, both in the present and the past. We predicted that ongoing support from early childhood to adulthood is associated with a better QoL in adulthood.

Methods

In January 2009, we conducted a nationwide survey by mailing questionnaires to 192 specialized facilities that provide consultation and daycare services for local residents with developmental disorders, and to prefectural centers that provide welfare and primary mental healthcare services for local residents. These facilities consisted of 61 Support Centers for Persons with Developmental Disorders, 65 Institutions for Persons with Autism, and 66 Centers for Mental Health and Welfare Services throughout Japan. Clinical staff at each facility helped identify and enroll study participants. Participants were eligible for the study if they had a diagnosis of ASD, were 18 years of age or older, and used any services provided by the facilities during the period 13 January to 13 February 2009. Among 1103 individuals who were identified as eligible, questionnaires were given to the 402 individuals who were willing to participate in the study and whose parents were also willing to participate. By the end of March 2009, 321 questionnaires had been collected from participants at 63 facilities (a response rate of 79.9%).

The protocol of this study was approved by the ethics committee of the National Center of Neurology and Psychiatry in Japan. Written informed consent to participate in our study was obtained from a parent or a guardian, and also from each participant where possible.

Participants

Out of 202 respondents who returned questionnaires with the self-report portions completed, the final study sample consisted of 154 respondents (123 males and 31 females) with complete information provided by the respondents themselves, their parents, and facility staff who knew the respondents well. For seven ASD participants, information was obtained not from parents but from facility staff who knew the respondents well. Because the self-report questionnaires were distributed only to ASD participants whom facility staff thought could understand and respond appropriately, these participants should be considered to be relatively high-functioning. Although we could not confirm their functioning levels with cognitive test data, this assignment appears to be supported by the fact that 136 of the 154 participants (88.3%) received mainstream education and completed higher education without any support, and that only four participants (2.6%) received special education throughout grades 1 to 12. The mean age of the 154 service user participants was 27.6 years (SD 6.5 years, range 18–49 years), and their characteristics based on the parent-supplied information are outlined in Table 1. In decreasing order of frequency, clinical ASD diagnoses ranged from Asperger syndrome, pervasive developmental disorders, high-functioning autism, autism, to pervasive developmental disorders not otherwise specified (PDD-NOS). Table 2 outlines the past history of the ASD service user participants as completed by the parents.

Survey questionnaires

The survey questionnaires comprised the following: parent (or staff)-rated items of the ASD service user's demographic information (listed in Table 1), past history (listed in Table 2), and performance

Table 1. Characteristics of ASD participants (N = 154)

Characteristics	N (%)
Gender	
Male	123 (79.9)
Female	31 (20.1)
Age categories (years)	
18–24	61 (39.6)
25 +	93 (60.4)
Residential status	
Independent living	11 (7.1)
Living with family	142 (92.2)[e]
Supported living (group home)	1 (0.6)
Marital status	
Married/partnered	9 (5.8)
Unmarried	145 (94.2)
Education	
≤high school[a]	92 (59.7)
Further higher education[b]	62 (40.3)[f]
Employment	
Employed[c]	37 (24.0)
Unemployed[d]	115 (74.7)
Homemaker	2 (0.1)
Comorbid with other medical conditions	
Physical conditions	16 (10.4)
Psychiatric conditions (other than ASD)	58 (37.7)
Challenging behaviors	
Self-injurious behaviors	14 (9.1)
Aggressive behaviors	45 (29.2)

[a] The category '≤high school' includes secondary high school, high school, and special schools for handicapped children.
[b] The category 'further higher education' includes college, polytechnic junior college, and graduate school.
[c] The category 'employed' includes part-time job, full-time job, and self-employed.
[d] The category 'unemployed' includes no occupation, during vocational training, and during leave.
[e] A majority of unmarried Japanese men (70.3%) and women (76.4%) (18-34 years) live with parents according to National Institute of Population and Security Research (2009).
[f] 68.6% of new graduates from high school proceed to higher education according to Ministry of Education, Culture, Sports, Science and Technology (2009).

in his/her current environment (described below); self-rated QoL (nine items across two domains); and for staff only, several items concerning current family support.

Performance in the current environment. Parent participants were asked to rate the extent of difficulty that the ASD service user participant experienced when doing things related to general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions, and relationships in his/her current environment. Those questions were based on WHO's International Classification of Functioning, Disability, and Health (ICF), and the definition of 'current environment' includes assistive devices or personal assistance whenever the person actually uses them to perform actions or tasks. The parent participants answered questions using a 5-point rating scale (1 = complete difficulty; 2 = severe difficulty; 3 = moderate difficulty; 4 = mild difficulty; 5 = no difficulty).

Table 2. Past history of the ASD participants (N = 154)

Early developmental concerns	N (%)
Absent	29 (19.5)
Present	120 (80.5)
Age at first concern (median age)	30 months
Age at referral	48 months
Age at first diagnosis	123 months
Speech level at 6 years	
Words or two-word phrases	34 (24.8)
Sentences with more than three words	103 (75.2)
Early diagnoses before 4 years	
Diagnosed[a]	29 (18.8)
Service utilization[b]	
No utilization at any time	124 (80.5)
Continuous utilization through the entire life stages	22 (14.3)

[a] Includes diagnoses of ASD and other developmental disorders.

[b] Service refers to having professional advice regularly, participating in some therapeutic programs, receiving special educational aid.

Quality of life. Subjective QoL was measured using the WHOQOL-BREF, which is derived from the 100-item WHOQOL (The WHOQOL Group, 1995). The WHOQOL was developed to measure individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns, and is used widely and internationally. Its use has been validated for various populations, including psychiatric patients worldwide. Its shorter version, the WHOQOL-BREF, comprises 26 items on four domains of QoL: physical health, psychological health, social relationships, and environment. For the purpose of the present study, the six items of the 'psychological health' domain (bodily image and appearance, negative feelings, positive feelings, self-esteem, thinking, learning, and memory and concentration) and the three items of the 'social relationships' domain (personal relationships, social support, and sexual activity) of the Japanese version of the WHOQOL-BREF (WHOQOL 26) (Nakane et al., 1999; Tazaki and Nakane, 2007) were used. Each item is assessed by an individual diagnosed with ASD on a 5-point scale (1 = very poor/very dissatisfied/not at all; 2 = poor/dissatisfied/a little; 3 = neither poor nor good/a moderate amount; 4 = good/satisfied/very much; 5 = very good/very satisfied/extremely). The mean scores of these two domains were analysed.

Current family support. The family support situation was determined by responses to the question, 'Regarding the physical and psychological support provided by his/her family member, do you think it is actually helpful for him/her?' The facility staff who knew the person well answered using a 5-point rating scale (1 = very helpful; 2 = somewhat helpful; 3 = not helpful or unhelpful; 4 = not very helpful; 5 = not at all helpful) for the case of the father, mother, and sibling, respectively (Table 3).

Demographic characteristics. Demographic information was obtained through 17 items rated by parents, and included gender, age, residential status, marital status, education, employment, medical conditions, and challenging behaviors. In this study, we asked questions requiring yes or no answers regarding the presence or absence of self-injurious behaviors and aggressive behaviors. Self-injurious behaviors were defined as any kind of behaviors in which the ASD participants hurt themselves. Aggressive behaviors were defined as violent behaviors toward family members or

Table 3. Current family support to the ASD participants (N = 154)

	N (%)
Father	
Helpful	60 (39.0)
Not helpful	63 (40.9)
No father or unknown	31 (20.1)
Mother	
Helpful	119 (77.3)
Not helpful	15 (9.7)
No mother or unknown	20 (13.0)
Sibling	
Helpful	35 (22.7)
Not helpful	82 (53.3)
No sibling or unknown	37 (24.0)

other people, verbal aggression as statements such as 'Die' or 'I will kill you', and destructive behaviors as those causing serious material damage. The most important items are shown Table 1.

Past history. Developmental information was obtained through 19 items rated by the parents, and included age at parental concern, age at diagnosis, expressive language level at age 6, and service utilization. The most important items are shown in Table 2.

The self-rating part of the survey questionnaire was pilot tested in several clinical settings to confirm the ease of completion. It was confirmed that individuals with HFASD were able to understand and complete it satisfactorily, at levels similar to other psychiatric patients (Koyama et al., 2009).

Statistical analysis

First, to compare the QoL domain scores for our ASD participants with those for a healthy Japanese population obtained using stratified sampling methods (N = 828; 410 males; aged 20–49) (Nakane et al., 1999; Tazaki and Nakane, 2007), the raw domain scores were converted to z scores using the mean and standard deviation of the Japanese standardization sample by gender and by age group (20–29, 30–39, 40–49) (Tazaki and Nakane, 2007). To obtain the z scores of participants 18–19 years of age, we applied the mean and standard deviation for the age range of 20–29 years to their raw QoL domain scores. Second, Pearson correlations were calculated to assess associations between performance in the current environment and QoL in both the psychological health and social relationships domains. Third, using two sample *t*-tests, z scores of the QoL domain scores were compared between subgroups of the following demographic characteristics: gender (male vs. female), age (≤ 24, 25+), residential status (independent living vs. other), marital status (unmarried vs. other), education (≤high school vs. additional higher education), employment (unemployed vs. other), medical conditions and challenging behaviors (present vs. absent), sentence level at 6 years of age (present vs. absent), diagnosis before 4 years of age (present vs. absent), and service utilization (none vs. continuous). For current family support, the responses were classified into two categories of 'helpful' (1, 2) and 'not helpful' (3, 4, 5). Finally, a stepwise multiple regression analysis was used to identify the most important characteristics in predicting QoL domain scores. As independent

Table 4. Means and SD for raw scores on psychological and social domains of WHOQOL 26 rated by ASD participants themselves (N = 154), and z scores converted from the raw scores of the ASD participants (N = 154)

QOL domain[a]	Mean (SD)	*t*	*p*	95% confidential interval
Psychological health				
Raw score	2.78 (0.74)			
Z score	–.80 (1.24)	–8.0	.0001	–1.0 to –.60
Social relationships				
Raw score	2.71 (0.82)			
Z score	–.63 (1.25)	–6.2	.0001	–.83 to –.43

[a] Psychological domain contains six items (1–5) and social domain contains three items (1–5). The mean raw domain scores of the ASD participants were converted to z scores using the mean and standard deviation of the Japanese standardization sample by gender and by age range (20–29, 30–39, 40–49) (Tazaki and Nakane, 2007).

variables, characteristics that were found to be significant on *t*-tests and all the demographic characteristics were used. A p-value < .05 was considered to indicate statistical significance. Statistical analysis was performed using SPSS version 18.0 (SPSS Inc., Chicago, USA).

Results

Psychological and social aspects of QoL in the ASD participants

The raw score means of the 'psychological health' and 'social relationships' domains of the WHOQOL 26 as rated by the ASD participants were 2.78 and 2.71, respectively (Table 4), whereas those of the Japanese standardization sample aged 20–49 ranged from 3.26 to 3.32 for the psychological health domain and from 3.19 to 3.25 for the social relationships domain, varying slightly by gender and age (Tazaki and Nakane, 2007). The differences in mean z scores of the ASD participants from those of the Japanese standardization sample were –0.80 for the psychological domain and -0.63 for the social domain, indicating that psychological and social aspects of QoL of the ASD participants were significantly lower (worse) than those of the healthy Japanese population ($p < .000$ for both).

Associations between psychological and social QoL and performance in the current environment in the ASD participants

Pearson correlations revealed that the QoL scores in both psychological and social domains for the ASD participants were not significantly correlated (r = 0.06 and r = 0.01, respectively, n.s.) with everyday performance in the current environment. This may be interpreted to suggest that the psychological and social domains of QoL capture more of the subjective aspects of QoL, and not objective function or capacity.

Factors related to psychological and social QoL in the ASD participants

As shown in Table 5, *t*-tests revealed that higher QoL was significantly associated with being male ($p < .05$ for psychological domain, $p < .01$ for social domain), having received a diagnosis before 4 years of age ($p < .05$ for psychological domain), and mother's support being helpful (p < .001 for both psychological and social domains). Lower QoL was significantly associated with suffering

Table 5. Comparison between two ASD subgroups by demographic characteristics, medical conditions past history, and current family support (N = 154)

	Psychological health domain QoL			Social relationships domain QoL		
	Mean score		*t*	Mean score		*t*
Demographic characteristics						
Gender (male/female)	2.83	2.56	2.35*	2.73	2.60	2.68**
Age (18–24/25+)	2.76	2.79	0.34	2.80	2.64	0.77
Residential status (living with family/independent living)	2.78	2.73	0.49	2.74	2.27	1.73
Marital status (unmarried/married or partnered)	2.78	2.74	0.37	2.72	2.46	1.37
Education (≤ high school/further higher education)	2.69	2.90	−1.51	2.64	2.80	−1.14
Employment (unemployed/employed)	2.76	2.85	−0.48	2.69	2.80	−0.40
Medical conditions						
Comorbid psychiatric conditions (absent/present)	2.91	2.58	2.76**	2.85	2.43	3.14**
Comorbid physical conditions (absent/present)	2.76	2.89	−0.38	2.71	2.60	0.42
Self-injurious behaviors (absent/present)	2.81	2.50	1.68	2.74	2.52	1.30
Aggressive behaviors (absent/present)	2.85	2.44	2.58*	2.80	2.36	2.38*
Past history						
Sentence level at 6 years (word or two-word phrases/ sentence with more than three words)	3.05	2.71	2.32*	2.93	2.65	1.64
Early diagnoses before 4 years (not diagnosed/diagnosed)	2.71	3.04	−2.02*	2.69	2.86	−1.18
Service utilization (no use at any time/continuous use through all life stages)	2.77	3.04	−1.63	2.71	2.73	−0.13
Current family support						
Father (not helpful/helpful)	2.73	2.81	−0.73	2.66	2.85	−1.25
Mother (not helpful/helpful)	2.14	2.84	−4.01***	1.91	2.84	−4.50***
Sibling (not helpful/helpful)	2.71	2.72	0.00	2.61	2.83	−0.92

**p<.05, **p<.01, ***p<.001.

Table 6. Summary of a stepwise multiple regression analysis investigating the predictive variables of demographic characteristics, medical conditions, past history, and current family support on QoL 'psychological health' domain scores of the ASD participants (N = 154)

Variables entered	Standardized coefficients (β)	*t*	*p*-value
Early diagnosis before 4 years	0.22	2.22	.05
Mother's support being helpful	0.32	3.24	.01

Adjusted R^2=0.16. Excluded variables by a stepwise procedure were gender, age, residential status, marital status, education, employment, comorbid psychiatric conditions, aggressive behaviors, speech level at 6 years.

from comorbid psychiatric conditions ($p < .01$ for both psychological and social domains), behaving aggressively ($p < .01$ for psychological domain, $p < .05$ for social domain), and having spoken sentences at 6 years of age ($p < .05$ for psychological domain).

The results of multiple regression analysis are summarized in Tables 6 and 7. Mother's support being helpful emerged as significantly predictive of higher QoL for both the psychological and social domains ($\beta = 0.32, p < .01$; $\beta = 0.32, p < .001$, respectively). In addition, having received early diagnosis before 4 years of age was also significantly associated with higher psychological

Table 7. Summary of a stepwise multiple regression analysis investigating the predictive variables of demographic characteristics, medical conditions, past history, and current family support on QOL 'social relationships' domain scores of the ASD participants (N = 154)

Variables entered	Standardized coefficients (β)	*t*	*p*-value
Aggressive behaviors: absent	0.18	2.15	.05
Mother's support being helpful	0.32	3.69	.001

Adjusted $R^2=0.14$. Excluded variables by a stepwise procedure were gender, age, residential status, marital status, education, employment, comorbid psychiatric conditions.

QoL ($\beta = 0.22, p < .05$), and not having aggressive behaviors was significantly associated with higher social QoL ($\beta = 0.18, p < .05$).

Discussion

The present study investigated long-term outcomes for adults with HFASD living in the community in Japan, focusing on subjective aspects such as QoL, and also identified past and current environmental factors that had (pseudo) predictive value. Our major findings are the following.

First, as expected, the self-reported QoL in the psychosocial domain of our sample with HFASD over 18 years of age was found to be significantly lower than the gender- and age-matched healthy Japanese population. The QoL was not found to be related to parent-reported performance level, age, or conventionally used outcome indicators such as residential, marital, educational, and employment status. Although these conventional indicators are certainly important to consider as long-term outcomes, psychosocial QoL in our adults with HFASD appeared not to be related to them. Thus, our findings suggest that the QoL reported by adults with HFASD might be measuring an additional independent aspect that should be considered in judging long-term outcomes in populations with HFASD, which is in line with Renty and Roeyers (2006) and Ruble and Dalrymple (1996).

Second, receiving diagnosis before 4 years of age and mother's support that met current needs were determined to be factors associated with better psychological QoL for adults with HFASD. This finding supports our prediction and is partially consistent with Renty and Roeyers (2006) in that support variables had significant impact on long-term outcomes in HFASD. In Renty and Roeyers (2006), perceived informal support indicative of availability, but not received formal or informal support indicative of actual transfer of advice, aid, and affect, was found to have predictive value; both support characteristics were measured using validated scales. On the other hand, family support characteristics in the current study were not measured using such standard scales, and were instead judged by the facility staff who knew the person well and therefore knew to what degree the family support was actually helpful to the person. This is different from subjectively perceived availability or objectively measured actual transfer of family support. The question was intended to ask how family support met the participant's actual needs from an objective viewpoint. However, validation of this is required.

To our knowledge, the present study is the first to associate early diagnosis with better psychological QoL in adults with HFASD. Only 29 cases out of our sample (18.8%) were diagnosed before 4 years of age, and 22 cases among them used some services during childhood. On the other hand, parental concerns about development were reported for a majority of the sample (66.9%). Why parental concerns did not lead to early diagnosis may be explained by a lack of healthcare or educational professionals with accurate knowledge and wide experience with HFASD at that time in Japan. Moreover, socioeconomic status (SES) could be associated with age of diagnosis: according to birth cohort data from individuals with autism born in California between 1992 and 2001, children of high SES parents were diagnosed earlier (Fountain et al., 2011). The role of SES in our Japanese participants with HFASD is unknown and this remains a topic for future study.

The finding that mother's support was the best predictor of psychosocial QoL of individuals with HFASD has to be interpreted with caution, because it suggests a bidirectional but not causal association. However, the obvious significance of mother's support but not father's in our study may be related to the Japanese socio-cultural environment in relation to child rearing. For example, Japanese mothers have traditionally been viewed as overprotective and overindulgent toward their children (Doi, 1973). Although it is not clear how such a cultural bias in childrearing practices influences familial attitudes toward a child with HFASD, future intervention must target parenting behavior and assist mothers with formal and informal social support after an early diagnosis of ASD.

Third, our results suggest that adults with aggressive behaviors might experience lower psychosocial QoL. This could be attributable to satisfactory social relationships being disrupted by violent behavior toward others or anger being reflected on others or self, although the causal relationship is not clear.

Study limitations. There are several methodological limitations in the present study. First, our sample (N = 154) who returned a complete set of self-, parent-, and facility staff-report questionnaires were not representative of all persons with HFASD, although the male:female ratio was 4:1, which is similar to the epidemiological data in Japan (Honda et al., 2005). In regard to the 48 individuals not included in the analyses because of incomplete data, although they were older and more educated than our sample of 154, we confirmed, based on the information that was available, that they did not differ from our sample in psychological and social QoL scores. Moreover, being male, absence of comorbid psychiatric conditions, and mother's support being helpful were significantly associated with higher QoLs, as in our sample. However, whether early diagnosis before 4 years or having aggressive behaviors was similarly predictive of QoL in the 48 individuals not included could not be confirmed. Second, diagnostic status and IQ level of our sample was based on reports by parents and facility staff and was not confirmed using standard procedures. Third, we chose to focus on the domains of 'social relationships' and 'psychological health' because we considered that they best reflected psychosocial QoL, although the 'physical health' and 'environment' domains also reflect psychosocial functioning in everyday life to some degree. We based this decision on the findings of previous studies. Health-related QoL studies on ASD found that individuals with ASD scored lower in most domains than healthy populations (Jennes-Coussens et al., 2006; Kamp-Becker et al., 2010; Kuhlthau et al., 2010), but children with ASD had significantly lower scores for psychosocial health but not physical health than other clinical populations with chronic conditions (Kuhlthau et al., 2010), and adolescents and young adults with HFASD had higher scores than patients with schizophrenia-spectrum disorders except for the 'social relationship' domain (Kamp-Becker et al., 2010). Future research should aim to clarify the relationships between the various QoL domains in ASD. Fourth, past history was retrospectively obtained only from parents and was not based on a review of the clinical records, so there is a chance that the history has been influenced by parents' recall or memory bias.

Clinical implications. Despite these methodological limitations, this study points to some important clinical issues. First, clinicians can help children maximize their chances for high long-term QoL by changing environmental factors and treating comorbid psychiatric conditions related to aggressive behaviors, both of which may affect psychosocial well-being and QoL, even if the autistic core symptoms are largely not changeable. Bastiaansen et al. (2005) demonstrated that the QoL of a subgroup of child psychiatric patients improved although the level of psychopathology remained high during a 1-year follow-up period. Therefore, improving QoL should be included as one of the goals in treating individuals with HFASD.

Second, the present study provides evidence for the long-term significance of early detection and intervention for children with HFASD. Although there has been controversy about the positive and negative effects of early diagnosis for parents (Johnson et al., 2007), it may be important for clinicians to convey to parents – and empower them – that prognosis is not deterministic and may be changed by appropriate treatment and family support (Tantam, 2000).

Conclusions

This study demonstrated that self-reported QoL by adults with HFASD can be an important subjective aspect of long-term outcomes. Environmental factors, such as mother's support being helpful and early diagnosis, were associated with better QoL, and aggressive behaviors were associated with poorer QoL in adulthood, whereas expressive language level in preschool years, a conventional outcome indicator, did not predict QoL levels. To improve long-term QoL, professionals need to detect autistic symptoms in the early years, evaluate the needs of the child and family, provide consistent support, and comprehensively monitor all aspects of mental health. Future outcome studies should be conducted prospectively to determine predictive factors at each developmental stage and at the same time try to determine the mediators and moderators that modify the developmental trajectories for children with ASD.

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References

Bastiaansen D, Koot HM, Ferdinand RF and Verhulst FC (2004) Quality of life in children with psychiatric disorders: self-, parent, and clinician report. *Journal of the American Academy of Child and Adolescent Psychiatry* 43(2): 221–230.

Bastiaansen D, Koot HM and Ferdinand RF (2005) Psychopathology in children: improvement of quality of life without psychiatric symptom reduction? *European Child and Adolescent Psychiatry* 14(7): 364–370.

Doi T (1973) *The anatomy of dependence.* Tokyo: Kodansya International.

Fountain C, King MD and Bearman PS (2011) Age of diagnosis for autism: individual and community factors across 10 birth cohorts. *Journal of Epidemiological Community Health* 65: 503–510.

Gerber F, Baud MA, Giroud M and Carminati GG (2008) Quality of life of adults with pervasive developmental disorders and intellectual disabilities. *Journal of Autism and Developmental Disorders* 38: 1654–1665.

Honda H, Shimizu Y, Imai M and Nitto Y (2005) Cumulative incidence of childhood autism: a total population study of better accuracy and precision. *Developmental Medicine and Child Neurology* 47: 10–18.

Howlin P, Goode S, Hutton J and Rutter M (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* 45: 212–229.

Jennes-Coussens M, Magill-Evans J and Koning C (2006) The quality of life of young men with Asperger syndrome: a brief report. *Autism* 10: 403–414.

Johnson C, Myers S and the Council on Children with Disabilities of the American Academy of Pediatrics (2007) Identification and evaluation of children with autism spectrum disorders. *Pediatrics* 120: 1183–1215.

Kamio Y and Inokuchi E (2009) Psychiatric practice's role for individuals with developmental disorders: Current trend and future issues. *Journal of Japanese Association of Psychiatric Hospitals* 28: 14–20.

Kamio Y, Tobimatsu S and Fukui H (2011) Developmental disorders. In: Decety J and Cacioppo J (eds) *The Oxford Handbook of Social Neuroscience*. Oxford: Oxford University Press, 848–858.

Kamp-Becker I, Schröder J, Remschmidt H and Bachmann CJ (2010) Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *GMS Psycho-Social-Medicine* Aug 31; 7. pii: Doc03.

Kobayashi R, Murata T and Yoshinaga K (1992) A follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. *Journal of Autism and Developmental Disorders* 22: 395–411.

Koyama T, Kamio Y, Inada N, Adachi J, Uno Y and Kasahara M (2009) Laifusutêji ni okeru syujyunoyoin to chokiyogo tono kannren nikansuru kenkyu: Chokiyogo ni kansuru zenkokuchosa wo motoni [Examinations on the association between long-term outcome and related factors across life stage]. In: Kamio Y (ed) [*Annual Report of Research Supported by Health and Labour Sciences Research Grants*]. Tokyo: National Center of Neurology and Psychiatry.

Kuhlthau K, Orlich F, Hall TA, Sikora D, Kovacs EA, Delahaye J et al. (2010) Health-related quality of life in children with autism spectrum disorders: Results from the Autism Treatment Network. *Journal of Autism Developmental Disorders* 40: 721–729.

Landa RJ (2008) Diagnosis of autism spectrum disorders in the first 3 years of life. *Nature Clinical Practice Neurology* 4: 138–147.

Mawhood L, Howlin P and Rutter M (2000) Autism and developmental receptive language disorder-a comparative follow-up in early adult life. I: Cognitive and language outcomes. *The Journal of Child Psychology and Psychiatry* 41: 547–559.

Ministry of Education, Culture, Sports, Science and Technology (2009) *School Basic Survey 2009*. Nikkei Insatu. Available at: http://www.mext.go.jp/b_menu/toukei/001/08121201/1282588.htm.

Nakane Y, Tazaki M and Miyaoka E (1999) WHOQOL-BREF survey of general population. *Iryo To Shakai (Journal of Health Care and Society)* 9: 123–131.

National Institute of Population and Social Security Research (2007) Report on the thirteenth Japanese National Fertility Survey in 2005. Volume II: Attitudes towards marriage and the family among Japanese singles, March 2007. Available at: http://www.ipss.go.jp/syoushika/bumken/DATA/pdf/132542.pdf.

Persson B (2000) Brief report: A longitudinal study of quality of life and independence among adult men with autism. *Journal of Autism and Developmental Disorders* 30: 61–66.

Renty J and Roeyers H (2006) Quality of life in high-functioning adults with autism spectrum disorder. *Autism* 10: 511–524.

Ruble L and Dalrymple N (1996) An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities* 11: 3–14.

Saldaña D, Álvarez RM, Lobatón S, Lopez AM, Moreno M and Rojamo M (2009) Objective and subjective quality of life in adults with autism spectrum disorder in southern Spain. *Autism* 13: 303–316.

Tantam D (2000) Adolescence and adulthood of individuals with Asperger syndrome. In: Klin A, Volkmar FR and Sparrow SS (eds) *Asperger Syndrome*. New York: Guilford, 367–399.

Tazaki M and Nakane Y (2007) *WHOQOL26 Tebiki Kaiteiban*. Tokyo: Kaneko Shobo.

Tsatsanis K (2003) Outcome research in Asperger syndrome and autism. *Child and Adolescent Psychiatric Clinics of North America* 12: 47–63.

The WHOQOL Group (1995) World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine* 41: 1403–1409.

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Quantitative autistic traits ascertained in a national survey of 22,529 Japanese school children

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Abstract

Objective—Recent epidemiologic studies worldwide have documented a rise in prevalence rates for autism spectrum disorders (ASD). Broadening of diagnostic criteria for ASD may be a major contributor to the rise in prevalence, particularly if superimposed on an underlying continuous distribution of autistic traits. This study sought to determine the nature of the population distribution of autistic traits using a quantitative trait measure in a large national population sample of children.

Method—The Japanese version of the Social Responsiveness Scale (SRS) was completed by parents on a nationally-representative sample of 22,529 children, age 6–15.

Results—SRS scores exhibited a skewed normal distribution in the Japanese population with a single factor structure, and no significant relation to IQ within the normal intellectual range. There was no evidence of a natural "cutoff" that would differentiate populations of categorically affected children from unaffected children.

Conclusion—This study provides evidence of the continuous nature of autistic symptoms measured by the SRS, a validated quantitative trait measure. The findings reveal how paradigms for diagnosis which rest on arbitrarily-imposed categorical cutoffs can result in substantial variation in prevalence estimation, especially when measurements used for case assignment are not standardized for a given population.

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Declaration of Interest

Dr. Constantino receives royalties for commercial distribution of the Social Responsiveness Scale, which is published by Western Psychological Services. No royalties were generated from use of the scale for this research study, and the study was exclusively designed to address scientific questions in the domains of epidemiology and public health.

The authors have no conflicts of interest to declare with respect to this article.

Keywords

autism; questionnaire; prevalence; classification; diagnosis

INTRODUCTION

Although to date the designation of pervasive developmental disorders in children—and the services to which affected children are entitled—rest on categorical case definitions, the concept of an autistic *spectrum*, along which the number and intensity of autistic features vary continuously from mild to severe, dates back to early epidemiological research by Wing and Gould.[1] Wing[2] subsequently developed the concept of the autistic continuum, broadening the case designation beyond classic autism to encompass the mildest (but most prevalent) of the autism spectrum disorders (ASD), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) assigned by DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders: Text Revision).[3] Several lines of subsequent research[4–7] now strongly suggest that the autism spectrum extends beyond this PDD-NOS subcategory to include subclinical levels of symptomatology which are known to aggregate in the undiagnosed members of families with multiple-incidence autism. Very recently, Lord et al[8] observed that diagnostic assignments of Autistic Disorder, Asperger Disorder, and PDD-NOS made by expert clinicians varied considerably across sites, despite the fact that distributions of scores on validated measures were similar. They concluded that current taxonomies should be revised to place priority on characterizing the dimensions of ASD while controlling for IQ and language level.

Clarifying the nature of the population distribution of autistic traits and symptoms across cultures has substantial implications for understanding a rise in prevalence over time[9] and for establishing the "boundaries" of clinical affectation. A recent Korean study[10] suggested the highest ever reported prevalence for categorically defined ASD in a total population sample; in that study, symptom counts were found to be continuously distributed in the population.

Aims of the study

This study determined whether autistic traits would be continuously distributed in a population-based sample in order to establish the appropriate epidemiologic framework for interpreting the rise in estimated ASD prevalence over time.

Material and methods

Participants—The participants comprised a normative sample (n=22,529) of schoolchildren, a child psychiatric clinical sample (n=417), and typically developing children (n=61). The normative sample was exclusively assessed using the Japanese version of the Social Responsiveness Scale (SRS)[11]. The latter two samples were more extensively assessed using standard diagnostic batteries for the purpose of validation and calibration of the Japanese version of the SRS.

In regard to the normative sample, questionnaires were distributed by mail to the caregivers of all students attending mainstream classes at primary or secondary schools in the 10 geographical areas making up Japan in 2010 (n=87,548 caregivers). One hundred forty-eight primary schools and 71 secondary schools participated in this study. All of them were community schools where >93% of children living in the community attend, according to the annual report of Japan's Ministry of Education, Culture, Sports, Science and Technology, 2010.[12] Questionnaires were returned for 25,779 children aged 6–15 years (response rate 29.4%). Questionnaires with missing answers were excluded so that all analysis was based on a complete dataset, leaving a final normative sample of 22,529 participants (11,455 boys) with SRS data provided by their mothers (n=20,430), fathers (n=1,728), both parents (n=166), other caregivers (n=119), or unspecified (n=86). Each of the 9 grade levels comprised a minimum of 754 participants of each sex, and both sexes were proportionally represented (Table 1).

The clinical sample consisted of 257 children diagnosed with ASD (ASD group) and 157 children with psychiatric diagnoses other than ASD (non-ASD group) (Table 2). They were patients who visited one of 10 child psychiatric clinics during 2008–2010 and whose caregivers gave informed consent to participate in this study. Their existing clinical diagnoses were confirmed according to DSM-IV-TR criteria[3] based on all of the clinical information available to our research team, which included experienced child psychiatrists and licensed clinical psychologists. Among the 257 children of the ASD group, 229 were subcategorized with 100% diagnostic agreement; 96 with autistic disorder, 65 with Asperger's disorder, 68 with PDD-NOS, and 28 were unspecified. Children in the non-ASD group were diagnosed with adjustment disorder, attention-deficit hyperactivity disorder, anxiety disorder, eating disorder, schizophrenia, somatoform disorder, conduct disorder, mood disorder, or mental retardation. Moreover, 61 children recruited from local communities comprised a typically developing (TD) group and were confirmed in diagnostic interviews with the children and their parents to have no history of neuropsychiatric conditions.

The intellectual levels of the children in the clinical sample ranged from normal intelligence to severe mental retardation based on cognitive testing carried out at clinics (various versions of the Wechsler Intelligence Scale and the Revised Kyoto Scale of Psychological Development[13]) or educational/administrative records. The proportions of children with normal intelligence in the ASD and non-ASD groups were not significantly different (χ^2=1.42, n.s.).

Measures

The Social Responsiveness Scale (SRS): The SRS[11] is a 65-item questionnaire of autistic traits for use with 4- to 18-year-olds that can be completed in 15 minutes by any adult who has observed the child over time in naturalistic social settings. The SRS was developed to assess autistic symptoms or quantitative traits and has subsequently undergone extensive validation in U.S. samples for use in subclinical and clinical child populations[14–17] as well as in general child populations for behavioral genetic research.[18–20] It also demonstrated satisfactory internal consistency (Cronbach's $\alpha > .95$), inter-rater reliability between parents and teachers($r = .78, p < .01$) and concurrent validity with an interview-based instrument[21] ($r = .86, p < .05$ for preschoolers; $r = .48, p < .05$ for children aged 7–12; $r = .77, p < .001$ for adolescents aged 13–18) for Japanese children[22,23], as for German children[24]. The Japanese version was used in the present study. Higher scores on the SRS indicate higher degrees of social impairment. The 65 SRS items were further categorized into five Treatment Subscales (social awareness, social cognition, social communication, social motivation, autistic mannerisms).[11] The SRS total scores are generally unrelated to IQ in the normal range, and distinguish children with ASD from those with other types of psychopathology.[16]

The Autism Diagnostic Interview-Revised: The Autism Diagnostic Interview-Revised (ADI-R)[25] is a parent-report interview and is a research standard for establishing a diagnosis of autism. To meet the ADI-R criteria for autism, the cut-off must be reached in each domain of reciprocal social interaction, communication, and restricted, repetitive, and