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OPENING THE DOOR

A report on diagnosis and assessment of autism and Asperger syndrome based on personal experiences

THE NATIONAL AUTISTIC SOCIETY

This report has been compiled and written by Ann Stirling of The National Autistic Society and Aidan Prior of Aidan Prior Communications.

The National Autistic Society would like to acknowledge the contributions of the families and people with autistic spectrum disorders involved in this survey.

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OPENING THE DOOR

"It's a year since we first approached the educational psychologist. That day was like a door opening. Prior to that the school SENCO had insisted there was nothing wrong with him and barred our way to any outside help. ..... Since diagnosis, the outlook has changed dramatically – Jack is a different child from the depressed, angry, intimidated little boy he was last year."

Quote from parent of 11 year old boy

"As parents we were treated like idiots – we were ignored and left feeling we were being a nuisance by insisting something was wrong with our son."

Quote from parent of 14 year old boy

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INTRODUCTION

Reported problems around diagnosis and assessment of autistic spectrum disorders[1] are of great concern to The National Autistic Society (NAS). Getting a diagnosis and an assessment is a crucial first step in Opening the Door. There are many other challenges parents and people with autism have to face throughout their lives. Even with a diagnosis and assessment getting the right help is often still a struggle – but without them that door remains firmly shut and no amount of hammering on it by frustrated parents or families will make it open.

Problems relate not only to parents of young children but also to adults. Diagnosis in adulthood tends to happen particularly when the disability is at the subtle end of the autistic spectrum, including Asperger syndrome. These more subtle forms of autism are sometimes dismissed as shyness or a natural tendency towards not socialising – especially if the person concerned is of average or above average intelligence.

There is also an apparent reluctance to label children (in particular) with a medical definition of disability. Labelling has been seen in some quarters as demeaning to the person who is disabled and to unhelpfully emphasise the disability rather than the person. It is certainly true that this is a concern and as an organisation the NAS completely supports civil rights for people with disabilities and the need for society to regard people who are disabled as people first and foremost, whatever their abilities. However, in the case of autism, getting an accurate diagnosis is the key required to open the door to the specialised support families and people with autistic spectrum disorders need.

Due to the increasing awareness of autistic spectrum disorders amongst professionals and the general public, more adults are being diagnosed as having autism. Having an explanation for the problems that a person has been experiencing, possibly for many years, can bring a sense of relief for both the person themselves and their family. In particular, the partner of that person. People at the more subtle, more able end of the autistic spectrum do form long term relationships and there can be particular problems for them and their families both before and after diagnosis.

Without a diagnosis, parents, people with autism and their families are almost literally shut out and disempowered. Shut out not only by a society that all too often treats people with disabilities and their families as second class citizens but just as importantly, shut out from the services and support that could really improve their lives in tangible, practical ways. For instance, without an accurate diagnosis they may not be able to get the benefits they have a right to – including mobility allowances – or to specialised pre-school help and education, respite care or support in finding employment.

Getting an accurate diagnosis is the first challenge parents and people with autism have to face. Equally important is a full and accurate assessment of how the disability will affect the person and how it will affect the family. Without such an assessment, years can be wasted in trying out various treatments or approaches that may not be suitable. In addition, the brothers and sisters of a child with autism as well as the parents themselves may not get the help they need – caring for a person with autism can put a great strain on the family.

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[1] Footnote: For ease of understanding, the word autism has been used in this publication to refer to all conditions on the autistic spectrum. This includes Asperger syndrome.

Whatever age someone is when they receive a diagnosis – whether they are 2 years old or 40 years old – the right type of help can make a difference to not just them but also their families. However, this is especially true of children. The younger a child receives a diagnosis the more can be done to minimise the effects of the disability. For instance, parents can be shown how they can work with their child to give them essential life skills that are usually taken for granted – skills such as toilet training.

We hope this report will help to ensure that the voices of parents and people with autism are heard as well as providing positive action points that will show how central and local government, together with professionals can help put an end to at least one of the struggles parents and people with autism experience.

METHODOLOGY

A questionnaire was devised which was sent to a random sample of 600 UK members of The National Autistic Society. Excluded from the random sample were overseas members, professional and corporate members. The random sample was therefore drawn from a database of nearly 4700 households. The questionnaire was aimed at parents of people with autistic spectrum disorders/people with autistic spectrum disorders/partners of people with autistic spectrum disorders. It was checked by a group of parents, as well as a person with Asperger syndrome, for appropriateness and ease of answering. The questionnaire was sent out by first class post on 29th January 1999 with a reply paid envelope for returns; a deadline of 22nd February was given for the return of questionnaires. The questionnaires were accompanied by a covering letter from the NAS explaining the background and rationale of the study.

A response rate of nearly 50% was achieved within the deadline, with 294 questionnaires being returned. This is an average to good response rate for surveys of this kind. The main findings of this survey are presented in this report, which presents a 'snapshot' of personal experiences of diagnosis and assessment in the UK in early 1999.

The figures shown in this report have been rounded to the nearest percentage point. The cumulative effect of this rounding is that percentage figures will not always total exactly 100%. The symbol * is used for an amount of less than 0.5%.

The sample for tables in this report varies due to a small number of parents caring for more than one child. Sometimes the total figure for a table reflects the number of parents in the survey (294) and sometimes it reflects the number of people cared for (304). Not all parents answered all questions, which is shown in the tables where applicable. Percentages have been calculated on the number of answers to each question.

WHAT ARE AUTISTIC SPECTRUM DISORDERS?

Autistic spectrum disorders are now believed to be due to physical dysfunction of the brain and not, as was once thought, as a result of emotional abnormality. Autism is a pervasive developmental disorder of lifelong duration which affects the individual in varying degrees of severity. It is characterised by failures in social interaction, social communication and imagination. This has been referred to as the Triad of Impairments:

Impairment of Social Relationships

- Aloof – almost complete indifference to other people
- Passive
- Active but odd – integration with other people is odd, repetitive and often inappropriate

Impairment of Social Communication

- Absence of any desire to communicate with others
- Echolaic and repetitive speech
- Makes factual comments often irrelevant to social situation

Impairment of Imaginative Thought

- Inability to play imaginatively with objects or toys or with other children/adults
- Involvement in repetitive stereotyped activities
- A tendency to select for attention minor or trivial aspects of the environment eg. attending to an earring rather than the whole person; a wheel instead of the whole train

(Ref: L Wing 1992 – Autistic Spectrum Disorders – An Aid to Diagnosis)

Individuals with autism will also commonly have related problems which include:

- Language disorder (receptive and expressive)
- Panic attacks
- Temper tantrums
- Dread of change
- Obsessional or ritualistic behaviour
- High anxiety
- Lack of motivation
- Inability to transfer skills from one setting to another (generalisation)
- Vulnerability and susceptibility to exploitation
- Depression
- Low self esteem
- Self injury or mutilation

People with autism have difficulty in assessing mental states in others and in anticipating responses and events; this can be bewildering and confusing leading to anxiety. In children with autism who are of normal intelligence their social difficulties may be seen as wilful, leading to punitive or inappropriate sanctions.

People with autism are vulnerable in generic situations where their condition is not recognised. This may be particularly so in unsupported mainstream education or general special schools and during their transition to adult life.

ASPERGER SYNDROME

Autism is a "spectrum disorder", which includes people with a range of intellectual ability. Asperger syndrome (after German psychiatrist Hans Asperger) is a form of autism where people are often of average or above average intelligence. A person with Asperger syndrome may have a great interest in other people and wish to be sociable and yet find such interaction beyond them; they then may resort to gauche or inappropriate behaviour.

Contrary to the stereotype of the silent and withdrawn person with autism, the person with Asperger syndrome may have very fluent language to the point of talking on and on regardless of the listener's interest. They may be over-precise, over-literal and socially insensitive. Their good vocabularies have often led people to over-estimate their real level of understanding and conclude that their difficulties are wilful or due to psychological influences such as dysfunctional or disturbed family experiences.

HOW MANY PEOPLE ARE ON THE AUTISTIC SPECTRUM?

The fact that autism is a spectrum disorder covering people with a wide range of intellectual ability and presenting a huge range of behaviours which are complex and may be challenging, adds to the problems of recognition and understanding. Kanner's autism (classical autism – named after the American psychologist Leo Kanner) affects 5 children per 10,000. However, other forms of autistic spectrum disorders show prevalence rates of between 15 and 36 per 10,000 which includes Asperger syndrome. Classical autism affects four times more males than females and as many as nine times more males than females are affected in the case of Asperger syndrome. The estimated prevalence rate of autistic spectrum disorders including Asperger syndrome is 91 per 10,000 people in the UK.

Autism was not discovered until the mid 1940s and its arrival in the UK as a diagnostic entity did not occur until the late 1950s.

WHAT CAUSES AUTISTIC SPECTRUM DISORDERS?

The exact cause/s of autistic spectrum disorders is/are not known but research is showing that genetic factors are important. In some cases, autistic spectrum disorders may also be associated with conditions affecting brain development such as maternal rubella, tuberous sclerosis and encephalitis.

MAIN FINDINGS

ANALYSIS OF RESPONSES

All the 294 responses received were from parents. One of these parents was also the partner of someone with an autistic spectrum disorder. The vast majority of these parents care for one child with autism or Asperger syndrome. A small number were from parents caring for two children. No questionnaires were received from people with autism or Asperger syndrome.

As there was only one response from a partner it was impossible to analyse partners' experiences of diagnosis in any meaningful way for the purposes of this report.

Responses were received from all over the UK except for Northern Ireland (full breakdown is in the Appendix). However, the numbers per region were too small for any meaningful geographical analysis.

AGE AND GENDER OF PEOPLE CARED FOR

TABLE

How old is the son/daughter with autism/Asperger syndrome for whom you care?

	Total	Age					
		1-5	6-10	11-15	16-20	21-30	31+
Males Base: all sons mentioned	244 100%	48 20%	89 36%	43 18%	21 9%	22 9%	21 9%
Females Base: all daughters mentioned	49 100%	14 29%	9 18%	12 24%	3 6%	6 12%	5 10%

55% of respondents care for someone under 10 years of age. Of the sample there are 5 times as many males (83%) as females (17%). Given that this is a sample of people from the whole spectrum of autistic disorders, this is roughly in line with the accepted female: male ratios of 1:4 for autism and 1:9 for Asperger syndrome.

FIRST CONCERNS

A large percentage (over 90%) of parents had concerns themselves that their son or daughter might have a disability and the majority of these parents (95%) first felt these concerns before their child was 5 years old.

41% of parents who were concerned thought that their son or daughter might have autism/Asperger syndrome. This relatively high percentage perhaps shows that public awareness of autistic spectrum disorders is growing.

In response to an open-ended question, the sort of behaviours parents mentioned that first gave them concern were commonly :

- lack of speech or slow to talk (mentioned by 111 parents /38% of sample)
- lack of eye contact (59 parents/20%)
- screaming/temper tantrums/shrieking (50 parents/17%)
- lack of response/lack of interest/lack of curiosity (47 parents /16%)

These behaviours all fit in with how autistic spectrum disorders manifest themselves (as described previously) and shows parents are well aware of signs that their children may be having problems.

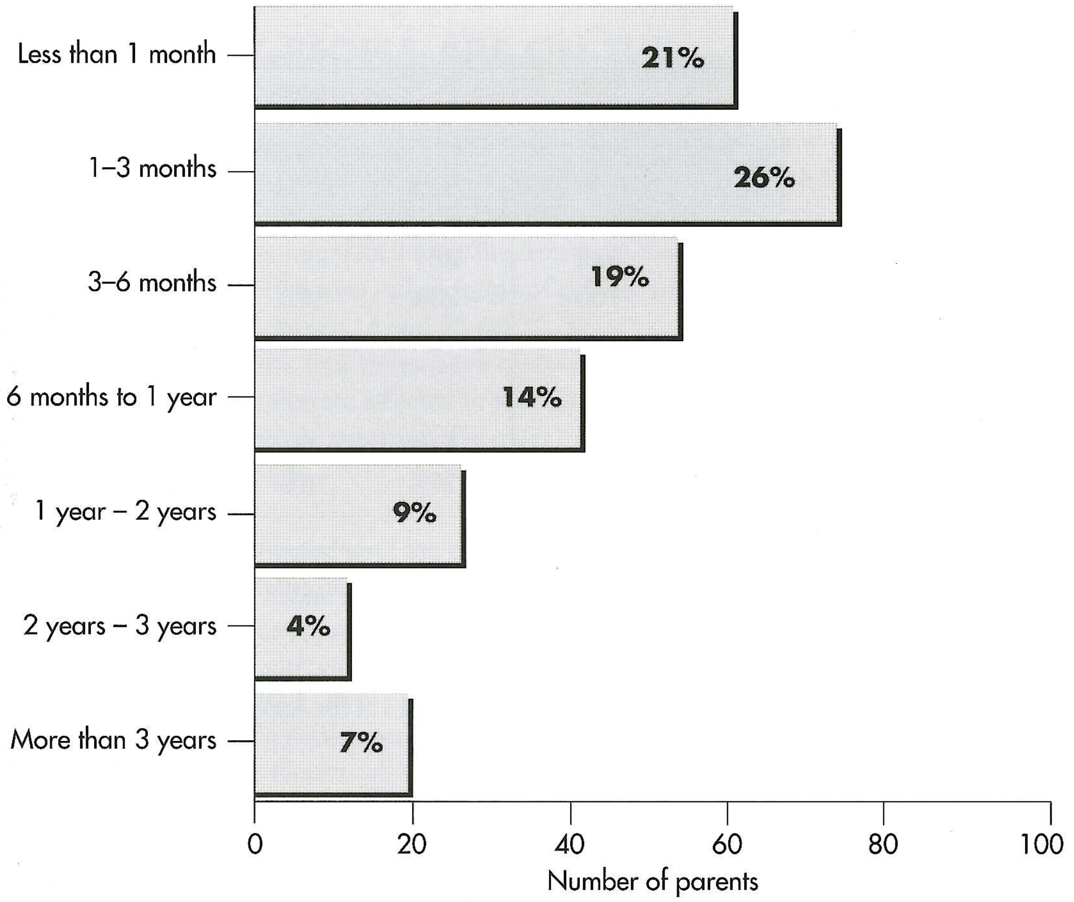
GETTING A DIAGNOSIS

TABLE

What gap in time was there between you first having suspicions and first seeking help?

Base: All answering

Total 298 (100%)

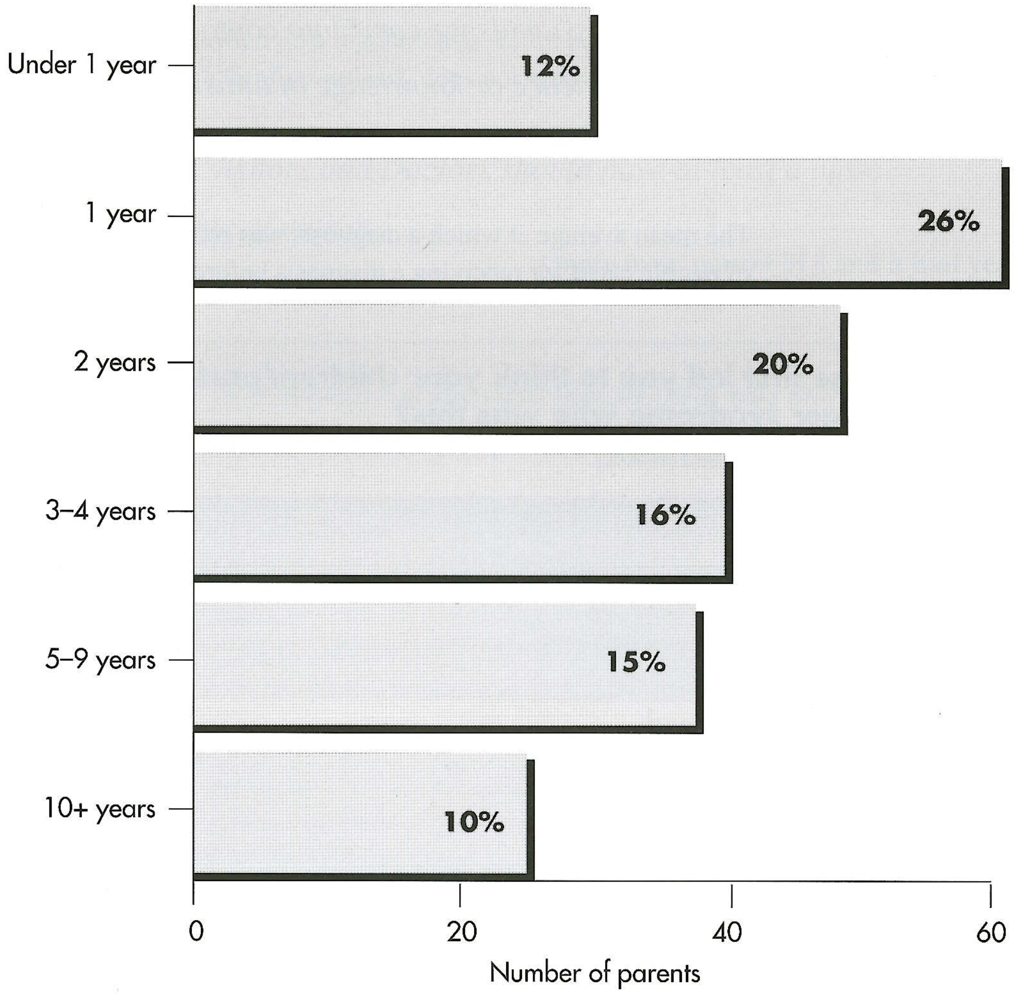


The majority of parents (66%) sought help within 6 months of first feeling concerned about their son or daughter. Of these parents 47% waited up to 3 months and a further 19% waited another 3 months before seeking help. On average, parents waited between 3 and 6 months before first seeking help.

TABLE

Time between first concerns and getting a diagnosis Base: All answering

Total 237 (100%)



More than 40% of parents had to wait over 3 years to get a diagnosis. 15 % had to wait between 5 and 9 years and it took 10% more than 10 years. The mean average time that it took to get a diagnosis was approximately 2 and a half years.

Waiting so long to get a diagnosis represents a huge amount of time wasted as well as frustration and strain on the family. Time and energy which could have been used to give effective help to these children and young people, their brothers and sisters, parents and grandparents.

If there was greater professional awareness of autism then perhaps the disability could be diagnosed without relying on parents seeking help in the first place – this would greatly assist in reducing the amount of time children with autism have to wait before getting help.

> *"I would like to see... diagnosis made a lot earlier. This would probably be done a lot quicker if GPs, Health Visitors etc listened to parents – sent children for assessment 'just in case' there may be a problem. After all, we parents are not qualified doctors, but we do know if our children have problems."*

Quote from parent of $4\frac{1}{2}$ year old

> *"The period leading up to diagnosis and receiving a diagnosis was a traumatic experience for all the family. It was a long drawn out process and we found that a number of professionals we came into contact with did not have sufficient experience or knowledge of autistic spectrum disorders."*

Quote from parent of 5 year old

The mean average at which a diagnosis was received was around 6 years of age with 63% of people cared for receiving a diagnosis before they were 5 years old.

TABLE

If someone else first led you to think your children/partner/you might have autism/Asperger syndrome who was this?

Base: All answering

	TOTAL	
	218	(100%)
Friend	22	10%
Family member	20	9%
GP	8	4%
Teacher	20	9%
Health Visitor	19	9%
Nursery Worker	6	3%
Child Minder/Nanny	2	1%
Paediatrician	31	14%
Educational Psychologist	20	9%
Clinical Psychologist	8	4%
Speech Therapist	19	9%
Psychiatrist	16	7%
Child Psychologist	15	7%
Child Development Centre	17	8%
Magazine article	6	3%
TV programme	9	4%
NAS literature	2	1%
Book/Reading	6	3%
Nursery	3	1%
Other	9	4%

A variety of sources from friends to professionals to the media were mentioned as being the way in which parents first suspected autism or Asperger syndrome. What was particularly interesting was how rarely frontline health professionals – ie GPs and Health Visitors – were mentioned. This suggests a worrying lack of awareness of autistic spectrum disorders by GPs and Health Visitors, who are the professionals parents of young children see most often on a regular basis. From parents comments it is of concern that this situation, for some families at least, does not seem to have changed over the years.

> *"Health visitors and Doctors should have at least a basic knowledge of autism."*

Quote from parent of 8 and a half year old

> *"We felt very strongly at the time that so little was known about autism. That so many professionals, including GPs, hospital doctors and health visitors had no idea of what we as parents had to deal with."*

Quote from parent of 37 year old man

TABLE

Who did you go to for help first?

Base: All answering

	TOTAL	
	294	100%
Health Visitor	90	31%
GP	80	27%
Paediatrician	26	9%
Speech Therapist	15	5%
Educational Psychologist	14	5%
Health Visitor and GP	13	4%
Child Development Centre	10	3%
Teacher	6	2%
Child Psychiatrist	6	2%
Clinic/Child Clinic	5	2%
Psychiatrist	4	1%
Community Paediatrician	4	1%
Friend	3	1%
Clinical Psychologist	3	1%
NAS	3	1%
School MO/MO	3	1%
Social Services	1	*
Other	8	3%
Don't know/not stated	7	2%

This lack of awareness is of even greater concern when one looks at where parents went for help first. Almost two-thirds of them went to their GP or to a Health Visitor. These results explain, in part, why it seems so hard for parents to have their concerns taken seriously.

> *"I feel we were very 'unfortunate' with our GP. But once we managed to get past him things moved quickly and I found that the label 'autism' opens doors to senior people."*
>
> **Quote from parent of 11 year old girl**

> *"Diagnosis had to be pushed for. My GP was reluctant to refer me and said I was worrying about nothing. I saw him at least six separate times to express my concerns about my son before he would refer me."*
>
> **Quote from parent of 7 year old boy**

79% of parents reported that the first person they saw did not give them a diagnosis. Although it must be borne in mind that around 7% may not have initially gone to a health professional that could have made a diagnosis (eg friend, teacher, social worker).

It is encouraging that, of those parents who did not get a diagnosis from the first person they saw, only 5% (14 parents) stated that they were not referred on to another professional. This still, of course, represents 14 families who were left to their own resources without any apparent guidance about what to do next.

The professionals that parents were most frequently referred on to were:

- Paediatrician or Community Paediatrician 79 (27%)
- Child Development Centre/Unit 32 (11%)
- Speech Therapist 31 (11%)
- Psychiatrist/Child Psychiatrist 27 (9%)
- Clinical Psychologist 23 (8%)
- Educational Psychologist 18 (6%)
- Child Psychologist 14 (5%)
- Hospital specialist (unspecified) 11 (4%)
- Doctor (unspecified) 11 (4%)

TABLE

How many different professionals were you referred to before a diagnosis was made?

Total	**268[1]**	**100%**
No. of professionals		
1	41	15%
2	53	20%
3	50	19%
4	30	11%
5	25	9%
6	16	6%
7	11	4%
8	3	1%
9	1	*
10	1	*
11	4	1%
Several (3 or more)	33	12%

[1] 26 people did not know or did not answer question

As previous research has found, parents have to see a number of professionals before they can get a firm diagnosis. 65% (174) parents who answered this question saw 3 or more professionals before they got a diagnosis and 23% saw 5 professionals or more. This is another reason why so much time is wasted in the struggle to get a diagnosis.

Parents also mentioned in their general comments that they felt professionals often left them in the dark – sometimes deliberately.

> *"The main problem was the fact that when problems were pinpointed we were not told the true diagnosis and only found the real diagnosis by looking at letters written by other professionals."*
>
> **Quote from parent of 6 year old**

> *"...we found it not to be so much a problem of difficulty of getting a professional to recognise autism as their willingness to ADMIT autism due to a 'conspiracy of silence' which appeared to preclude that admission. The speech therapist who had worked with our son for 2 or 3 years reacted when we asked if she thought he could be autistic by saying 'yes – she always had but it was more than her job was worth to tell us'."*
>
> **Quote from parent of 16 year old**

TABLE

Final diagnosis as compared with previous diagnosis

	Final % = % of 298: (302 = all answered minus 4 with 'no diagnosis')	Other before final % = % of 173: (211 = all answered minus the 38 who said, 'no diagnosis')	Difference
Autism	120 (40%)	16 (9%)	
Kanner autism	5 (2%)	1 *	
Classic autism	17 (6%)	1 *	
Autism and Asperger syndrome	10 (3%)	2 (1%)	
Asperger syndrome	69 (23%)	11 (6%)	
Autistic tendencies/traits/features	42 (14%)	49 (28%)	
Autism + another disorder	9 (3%)	1 *	
Asperger syndrome + another disorder	10 (3%)	1 *	
Autistic tendencies + another disorder	8 (3%)	11 (6%)	
Language disorder/delays	26 (9%)	67 (39%)	41
Learning disabilities	32 (11%)	65 (38%)	33
Conduct disorder	2 (1%)	21 (12%)	19
Developmental delay	14 (5%)	79 (46%)	65
Attention Deficit Disorder	7 (2%)	13 (8%)	5
Obsessive Compulsive Disorder	1 *	9 (5%)	8
Psychiatric disorder (eg schizophrenia/manic depression)	3 (1%)	17 (10%)	14
Autistic spectrum disorder/infantile autistic spectrum disorder	7 (2%)	1 *	
Dyspraxia	1 *	6 (3%)	5
Semantic Pragmatic Disorder	3 (1%)	5 (3%)	2
Other	4 (1%)	13 (8%)	9
Retarded/subnormal		5 (3%)	5
No diagnosis	4	38	34

Around 100 parents were given more than one final diagnosis for their son or daughter as in total 390 diagnoses were given. As can be seen from the table, 40% of the final diagnoses were 'autism' and 23% were 'Asperger syndrome'. 76% (297) of the final diagnoses (390) can be grouped within the autistic spectrum.

One of the main problems this table highlights is the variety of terms used. Parents quickly have to become experts in this complex field in order to try and understand the professional terminology – and, more importantly perhaps, the implications of these terms.

An interesting finding from the above table is how, over time, diagnoses change. Parents have reported a reluctance by professionals to give a specific diagnosis of autism or Asperger syndrome, preferring to give a more general, but incomplete, diagnosis such as learning disability. A diagnosis that does not recognise the autism does not ensure, in fact it may prevent, the disabled person from getting access to the support that can change their lives.

Indeed, some parents believe the reluctance to diagnose autism is due to a lack of appropriate services locally and a desire to save money.

> *"The consultant did not want to diagnose autism as suitable education would have been supplied and this was not available."*
>
> **Quote from parent of 17 year old**

> *"We were passed from one professional to another never wanting to give a diagnosis. We believe this (was) to spare the parents feelings and to save money and hide the lack of resources available after diagnosis."*
>
> **Quote from parent of 7 and a half year old girl**

Parents report that they have had to pressurise professionals into giving a more accurate diagnosis or that over time the child's problems become more severe (due perhaps to not being given the right support) which results in a changed diagnosis. This explains why, over time, there is a shift from a general diagnosis such as developmental delay or learning disability towards a more specific diagnosis of autism or Asperger syndrome.[2]

Nearly 30% of the 500,000 people estimated to be on the autistic spectrum have an IQ under 70 and are therefore learning disabled. This is part of their autism and has to be recognised as such. In order to help them, it is the autism that must be addressed first and foremost.

In addition, the fact that parents have also been given multiple diagnoses makes the task of identifying the right course of action to help their child even more problematic.

> *"I feel I still don't have a definite diagnosis for my daughter. One doctor says Asperger syndrome or Semantic Pragmatic Disorder – another says it's a language problem with no autistic tendencies. Because they don't agree I don't know who to believe. This makes everything more difficult especially as we are now becoming involved with the LEA over her education. How do we know where she should be placed when we can't say exactly what her problem is?"*
>
> **Quote from parent of 5 year old daughter**

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[2] Footnote: For example, 37% of those who were given other diagnoses before the final diagnosis (sample size: 173) mentioned 'learning disability ' and only 9% mentioned a diagnosis of 'autism' but on the final diagnosis (sample size: 298) this figure had reduced to 11% who mentioned 'learning disability' and increased to 40% who mentioned 'autism'. Even taking into account the different sample sizes there are marked differences in the frequency with which general diagnoses are mentioned compared with specific ones.

A range of professionals made the final diagnosis:

- Paediatricians 74 (24%)
- Combination of professionals 68 (22%)
- Child Development Centre/Unit 54 (18%)
- Educational Psychologist 19 (6%)
- Child Psychiatrist 54 (18%)
- Child Psychologist 44 (15%)
- Neurologist 5 (2%)
- Speech Therapist/Audiologist 14 (5%)
- Clinical Psychologist 7 (2%)
- Psychiatrist 6 (2%)
- Elliot House 6 (2%)

The fact that it is mainly paediatricians who made the final diagnosis probably reflects the fact that most of the people cared for in this survey are children under the age of 10.

ASSESSMENT

Realising your child, your partner, someone in your family or you yourself may have a disability can be a worrying time. To have your worries confirmed can be a traumatic experience. Not only is it a struggle to get a diagnosis but all too frequently, as previous research has shown, parents are not told of the diagnosis in a sensitive manner.

In addition, autistic spectrum disorders are complex and vary from person to person. For this reason, it is crucial that at the time of diagnosis some idea is given of how – in practical, day to day terms – the person is going to be affected and what action can be taken to help the person lead as fulfilling a life as possible.

It is encouraging that quite a lot of positive comments were made in this survey about how the assessment was handled. However, 18% made negative comments ranging from 'unfriendly' to 'lack of expertise/training'. Clearly things are improving although there is still some way to go.

TABLE

How well was the autism or Asperger syndrome described to you at the time of diagnosis?

Base : All answering

	TOTAL	
	281	100%
Very well	50	18%
Adequately	104	37%
Not adequately	78	28%
Not at all	49	17%

TABLE

At the time of diagnosis were you given an assessment of the severity of autism or Asperger syndrome and the likely effects of this?

Base : All answering

	TOTAL	
	296	100%
Yes a good assessment	52	18%
A vague assessment	119	40%
No assessment of severity at all	120	41%
Yet to be decided	5	2%

As can be seen from the above tables, 45% of parents stated that the disability was described inadequately or not at all. In addition, 81% stated that there was either no assessment of severity given at all or a vague assessment.

It is at the time of diagnosis that parents most need positive, practical support and to be given some guidance on how they can help their child. As has been stated before, early intervention is crucial for children with autism. The earlier they can be given appropriate help the greater the chances are that the anxiety and confusion common to children with autism can be lessened, which helps them to learn skills usually taken for granted.

> *"If GPs and social workers had paid more attention to my very real – and well founded – concerns regarding our son he could have received the help he required much earlier and therefore perhaps have developed less entrenched behaviour patterns."*

Quote from parent of 26 year old man

One of the most prevalent feelings that parents felt at the time of diagnosis was relief (56%). This may seem at first a strange reaction but given that it has taken many parents years to get their concerns taken seriously and that diagnosis is the key to getting help, a feeling of relief is hardly surprising. Other strongly felt reactions were anxiety, extreme distress and shock.

> *"Diagnosis is a very lonely process. It can leave you in a state of despair, shock and bewilderment. There is no one on the diagnostic side to direct you after you have received a diagnosis. What happens now ? Where do we go for help and advice ?"*

Quote from parent

In their general comments, many parents also spontaneously referred to the dismissive or patronising way they were treated by professionals through the diagnostic process.

> *"I was very angry that the so called experts (psychologist, paediatrician) were so condescending – and so ready to put the 'blame' on my shoulders."*
>
> **Quote from parent**

VIEW OF DIAGNOSTIC PROCESS

TABLE

Overall what was your view of the diagnostic process ?

Base : All answering

		Assessment of severity and likely effects of this			
Satisfaction with process	**TOTAL**	**Yes a good assessment**	**A vague assessment**	**No assessment of severity at all**	**Yet to be decided**
Total	**285 100%**	**49 100%**	**116 100%**	**116 100%**	**5 100%**
Very satisfied	24 8%	7 14%	9 8%	8 7%	- -
Satisfied	41 14%	12 24%	20 17%	7 6%	1 20%
Quite satisfied	52 18%	10 20%	23 20%	18 16%	- -
Not satisfied or dissatisfied	43 15%	3 6%	20 17%	18 16%	- -
Quite dissatisfied	23 8%	3 6%	12 10%	7 6%	- -
Dissatisfied	38 13%	3 6%	14 12%	20 17%	- -
Very dissatisfied	64 22%	9 18%	17 15%	33 28%	4 80%

Not surprisingly, 43% of parents were dissatisfied to some degree with the diagnostic process with 22% being very dissatisfied. In addition, 52% of those parents who were given no assessment of severity were dissatisfied to some degree.

EFFECT ON FAMILY

Respondents were asked "What was the effect on any siblings/extended family of the diagnostic process ?"

In response to this open ended question, a range of reactions and feelings were reported. Many respondents reported more than one feeling or reaction. Not surprisingly perhaps, more negative than positive feelings were reported – including stress, upset, anger, anxiety, worry and confusion. Some parents reported a positive response with the rest of the family being supportive (23 people) and siblings being very loving (12). 33 parents reported that siblings felt left out or that they didn't receive attention.

SUPPORT RECEIVED

43% of respondents reported they were not given any advice about where to go for help/support/counselling or further explanation. This once again supports the anecdotal finding that parents are often left to cope on their own after the diagnosis has been given.

TABLE

How would you rate the overall help received around the time of diagnosis?

Base : All answering

	TOTAL	
	285	**100%**
Very good	23	8%
Good	43	15%
Quite Good	39	14%
Not good or bad	40	14%
Not very good	55	19%
Poor	36	13%
Very poor	49	17%

As can be seen from the above table, 49% of those who answered this question reported that the support they received at the time of diagnosis was inadequate.

TABLE

What support would you have liked?

	Mentioned by no. of people
Practical advice/how to help child	45
Contact other parents	38
Educational help/help choosing schools	35
Someone to come to talk/support/visit at home	30
More support	28
More information	25
Professionals (GPs/HVs) should have better understanding of autism	24
Local Support Group	24
Counselling	21
Advice on behavioural management	21
Explain autism	20

The responses to this open-ended question highlighted the need for more practical advice, contact with other parents, general support and that professionals should have more understanding of autism. GPs and Health visitors were spontaneously mentioned in this respect, reinforcing the problems discussed earlier in relation to who parents go to for help.

In spite of all the problems highlighted by this report, this final comment underlines what a difference professionals can make to what is clearly a traumatic process for parents.

> *"I felt we were treated with great respect from the minute we walked through the door at the Child Development Unit. We were met by the speech therapist and offered unlimited tea and coffee. They were running late, but this was explained to us. We were treated during the diagnosis with kindness, caring, understanding and we were believed. No-one laughed at us or contradicted us. Basically, we were treated with an excellent professional approach."*
>
> **Quote from parent of 14 year old**

KEY ACTION POINTS

- The Checklist for Autism in Toddlers (CHAT) should be administered to all children at the 18 month check. It is designed for GPs and Health visitors and can be completed in 5 minutes.
- Central government should issue national quality standards to be used in the provision of diagnosis and assessment and establish a co-ordinated approach amongst all agencies involved.
- A clear assessment of the degree of disability and information on practical ways of addressing the disability should be supplied at or within 2 months of diagnosis.
- Local authorities should establish a register of diagnostic facilities within their area and publicise this register widely.
- Diagnostic facilities should be available within reasonable travelling distance of the individual's or family's home.
- Local authorities are encouraged to develop early intervention programmes for children with autism.
- Particular attention needs to be paid by professionals from all disciplines to the recognition of Asperger syndrome, which due to its nature may be more prone to be overlooked as a diagnosis.
- Professionals and service providers working in the areas of Health, Social Services and Education should receive appropriate training in the recognition, awareness and management of children and adults with autistic spectrum disorders.
- Professional, accredited in-service training needs to be developed for staff working in the field. Training in recognition and awareness of autistic spectrum disorders should also be included in qualifying and post qualifying courses for relevant professionals.
- The particular needs of people who receive a diagnosis of an autistic spectrum disorder in adulthood as well as the needs of their families should be considered and addressed within all professional and service contexts.
- Evaluations should be undertaken to ensure that the views of parents, children, and adults with disabilities are taken into account in the provision of services.

The National Autistic Society would be pleased to work with professionals, central and local government and professional bodies to achieve these aims.

REFERENCES:

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AUTISM AWARENESS WEEK

Autism Awareness Week, organised by The National Autistic Society, takes place in May. This year the theme for the week is diagnosis and assessment. This report has been compiled with the intention of bringing greater focus to bear on these issues. The National Autistic Society has produced a range of publications which it is hoped will be of help to professionals, people with autism and their families. These are a new booklet aimed at health professionals; a leaflet specially for GPs; a leaflet for adults who have recently received a diagnosis of an autistic spectrum disorder and a special edition of the NAS Parents Pack for parents with recently diagnosed children, which has been sponsored by Railtrack.

The NAS is keen to work with professionals through providing them with such information and also through its other activities, such as training, to help them understand the nature of autistic spectrum disorders.

ABOUT THE NATIONAL AUTISTIC SOCIETY

The National Autistic Society (NAS) was formed in 1962 on the initiative of a group of parents who were later joined by professionally interested people. Today, the Society has grown into the UK's foremost charity for people with autism and those who care for them, spearheading national and international initiatives and providing a strong voice for autism. The organisation works in many areas to help people with autism live their lives with as much independence as possible.

THE NAS:

- runs education and adult centres
- supports local authorities in the development of their own specialist services
- publishes a range of books and leaflets
- has a library that parents and researchers can use by appointment
- runs an autism helpline for parents and carers and people with autistic spectrum disorders
- organises conferences and training programmes
- offers specialist diagnosis and assessment services
- encourages research into the causes of autism
- supports local groups and families around the country
- raises awareness and creates a better understanding of autism
- provides consultancy to professionals and organisations working in the field of autism
- offers an accreditation programme for autism-specific education and care services
- runs Prospects, a supported employment service for adults with autistic spectrum disorders

APPENDIX

GEOGRAPHICAL SPREAD OF RESPONDENTS

TABLE

Area of residence

Base: All respondents

	TOTAL	
	294	100%
Yorks	27	9%
Scotland	21	7%
London	20	7%
Surrey	19	6%
Essex	13	4%
Kent	13	4%
Herts	11	4%
Middx	11	4%
Sussex	11	4%
Avon	9	3%
Somerset	9	3%
Suffolk	9	3%
Wales	9	3%
West Midlands	8	3%
Lancs	7	2%
Cambridge	6	2%
Dorset	6	2%
Wilts	6	2%
Cheshire	5	2%
Devon	5	2%
Hants	5	2%
Lincs	5	2%
Oxon	5	2%
Staffs	5	2%
Gloucester	4	1%
Beds	3	1%
Berks	3	1%
Bucks	3	1%
Derbyshire	3	1%
Durham	3	1%
Leics	3	1%
Merseyside	3	1%
Channel Islands	2	1%
Isle of Man	2	1%
Tyne & Wear	2	1%
Worcs	2	1%
Norfolk	2	1%
Warwick	2	1%
Cleveland	1	*
Cornwall	1	*
Herefordshire	1	*
Isle of Wight	1	*
Rutland	1	*
Northants	1	*
Not stated	6	2%

* too small to give percentage

The numbers in any one geographical area are too small to draw conclusions on a geographical basis. There is a representative spread across the UK bearing in mind the relative smallness of the sample.