

# Inclusion and autism: is it working?

1,000 examples of inclusion in education and adult  
life from The National Autistic Society's members



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## Inclusion & Autism

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|  |    |
|--|----|
| <b>Introduction</b>  | 5  |
| <b>Part one: Summary findings with quotes and case studies</b> |    |
| Inclusion .....  | 6  |
| Experience of education.....                                   | 6  |
| Differences in Scotland and Wales.....                         | 9  |
| Into adulthood.....  | 10 |
| Costs and funding.....   | 12 |
| Conclusions.....   | 12 |
| Recommendations.....   | 13 |
| <b>Part two: Summary results of survey</b>                     |    |
| The sample and response rates.....                             | 15 |
| Key findings:  |    |
| Parents and carers of children under 20.....                   | 16 |
| Parents and carers of children over 20.....                    | 21 |
| Adults with autism.....  | 23 |
| <b>Appendices</b>  |    |
| 1. What are autistic spectrum disorders?.....                  | 25 |
| 2. Inclusion in education.....                                 | 26 |
| <b>References</b>  | 28 |

## Inclusion & Autism

# Introduction



We picked inclusion as the focus for a survey this year as it seems to be a prominent principle of government policy at a national and local level. But people are constantly questioning exactly what it means. Many people interpret it within a narrow educational context where it is often used to describe the integration of children with special educational needs into mainstream schools - sometimes linked with the closure of special schools. We wanted to look at the wider picture: inclusion in society - a broad concept of social inclusion - as it touches the lives of real families: our membership.

To that end we devised a questionnaire which was sent to 2,409 National Autistic Society (NAS) members across the UK. Over 1,100 were returned. The first 1,000 were analysed. The survey was divided into three sections: one for parents/carers of school-aged children; one for parents/carers of adult children; one for people with autism or Asperger syndrome. As the response rate to the third section was anticipated to be low (previous questionnaires had demonstrated this to be the case) a series of supplementary interviews with adults with autism or Asperger syndrome were carried out. Some adults within NAS services also completed the questionnaire with help from their support workers.

This report highlights the key findings from our survey and interviews and identifies a number of recommendations for the future. Differences in Scotland and Wales compared to the overall UK results have been identified separately. This report also features key findings from the latest research into the annual cost of autism and Asperger syndrome in the UK and the consequences of late diagnosis and intervention (see page 12). The NAS will work with policy and decision-makers in central and local government to ensure that these issues are addressed.

## Terminology

We have used the term 'autism or Asperger syndrome' throughout this report to refer to autistic spectrum disorders. Appendix 1 (page 25) gives a more detailed explanation of autistic spectrum disorders. Unless mentioned otherwise, all findings relate to both autism and Asperger syndrome.

The mid-point lines on diagrams (-----) indicate the middle point of agreement and disagreement in terms of response.

## Quotes from surveys

We have used quotes from surveys to illustrate key findings. The reference to low, medium or high functioning relates to a question asked of all respondents as to the ability of the child or adult with autism or Asperger syndrome. 'High functioning' or 'very high functioning' relates to the more able end of the autistic spectrum where the disability may not always be so obvious. 'Low functioning' relates to the less able end of the spectrum.

# Summary Findings

## Inclusion

Autism and Asperger syndrome are described as a 'hidden' disability - they are not easily recognised and as such do not attract the same attention from society as more obvious physical disabilities. As awareness of autism amongst most of the population is very low and the nature of the disability often extremely complex 'inclusion' is harder to achieve as it requires adjustments from others if people with autism and Asperger syndrome are to be able to participate fully in society.

The NAS report *Autism - The Invisible Children?* (Peacock, Forrest and Mills 1996) identified the difficulties faced by children and their families as a consequence of poor planning and co-ordination by local authorities and of inadequate support for students with autism in the mainstream. This survey demonstrates that many schools have improved in recent years. Parental satisfaction is increasing, but not for all age groups or for all types of provision yet.

*'Inclusion is not about everyone being the same but about having the choice to live where they feel most comfortable and having the opportunity to 'join in' with what they want to - and not what someone else thinks they ought to.'*

*'There should be an awareness by policy makers that inclusion should be about choice. Residential communities can be used to help create opportunities in the local community and should not be seen as 'excluding' people from 'the' community. Our son has far more access to the community through the activities and support provided by his residential community than ever he would if stuck in a house in a street relying totally on someone/carer being available to take him out.'*

Parent of a low functioning adult living in a therapeutic community

The policy of inclusion must ensure that appropriate learning or other positive experiences take place. It is not simply about where an individual is educated or receives services or support; it is about the quality of such a service or support. Inclusive education is a process involving the restructuring of the curriculum and classroom organisation. This distinguishes it from integration which focuses on the placement of an individual or group and that individual or group having to adapt to what the school is able to offer.

Inclusion should never replace sensitive, individual planning. This is particularly so in the case of a complex but relatively small number of individuals.

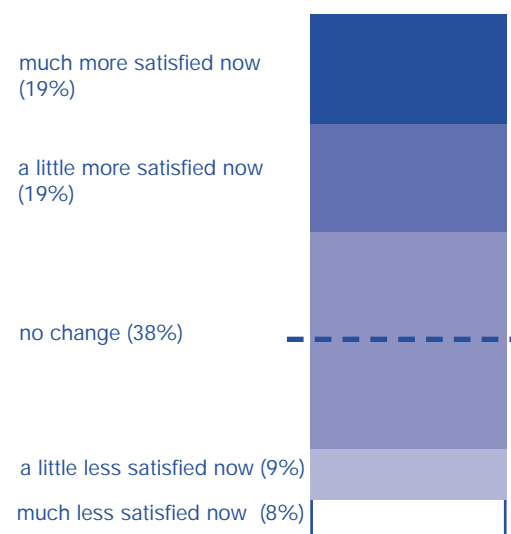
Autism is a spectrum condition requiring a range of individual and often highly sophisticated responses. The majority of these will hopefully occur within the mainstream of provision for all or most of the time. There are, however those individuals whose interests will be best served by discrete specialised services to provide the most appropriate and meaningful education and lifelong support.

## Experience of education

Roughly half the respondents to this part of the survey were in a mainstream environment and half in specialist provision away from the mainstream. A positive picture begins to emerge for early years provision which declines through the later school years.

Overall 73% of parents and carers are satisfied with the education their child is receiving (35% very satisfied, 38% quite satisfied). Where autism specific support was provided - whether in autism specific units attached to mainstream schools or special schools, or autism specific schools parents' satisfaction levels were at their highest. Those with a child in autism specific provision were twice as likely to be 'very satisfied' (54-70%) than those whose child was in a mainstream

### How has your view changed over the last two years?



Note: 7% not stated

# Summary Findings

setting (23-41%). Only 12% of parents with children in an unsupported mainstream primary school are very satisfied. The evidence therefore demonstrates that staff training and expertise in autism is key if the needs of each individual child with autism or Asperger syndrome are to be met; also that each child should have access to appropriate levels of support. The type of school may be important in some instances because the particular needs of a child may require a very specific setting. But the overall finding of this survey highlights the need for relevant training and expertise for staff and appropriate support for the child as being of paramount importance.

*'The best! The teachers and support staff in my son's autistic unit are highly trained professionals, truly experienced in autism and its management. As parents we are continually learning from them as our mentors - it's wonderful to have these professionals who can help us to understand and manage our autistic son. The classroom set-up and approach is appropriate. Staff:pupil ratio is very high. Structure is the essence of the unit. Social and independence skills development targets are included. All children are statemented and have individual education plans.'*

Parent of a high functioning child, in an autism specific unit attached to a mainstream primary school

*'The school has welcomed him and been open to understanding him and his problems. He has the example of a 'normal' peer group. He has virtually full-time support. He has an excellent speech therapist who he sees weekly with one or two different 'normal' children for social skills etc. He also sees a specialist teacher once a week who works in a similar way and who helps advise teachers and support workers on curriculum if necessary. It is a team. But it took a lot of fighting for!'*

Parent of a high functioning child in mainstream primary with support

Parents are no happier with generic special schools (without autism specific provision) than they are with mainstream provision with some learning support. Children with autism and Asperger syndrome have uneven abilities and it may not be appropriate for them to be in a setting for children with learning disabilities where it is assumed that abilities are equal across a range of subjects.

*'Stop babysitting and start teaching.'*

Parent of a low functioning child in a special needs primary school

*'Teachers and staff do not seem to have much knowledge about teaching children with autism at his special playgroup. They seem to be more concerned with the children with physical disabilities, and my son is left to play alone because he does not demand any attention.'*

Parent of a medium functioning child in a special needs playgroup

*'Strengths are not developed. Individual Education Plans have as 'aims' things he has been able to do for a considerable time - some of which, at least, the staff must be aware of as he has done them during school time. Boredom is a problem. There is no attempt to help interact - the unit is a communication disorders unit - the three (out of six) children with autism are often left out of activities the others are included in with the mainstream class.'*

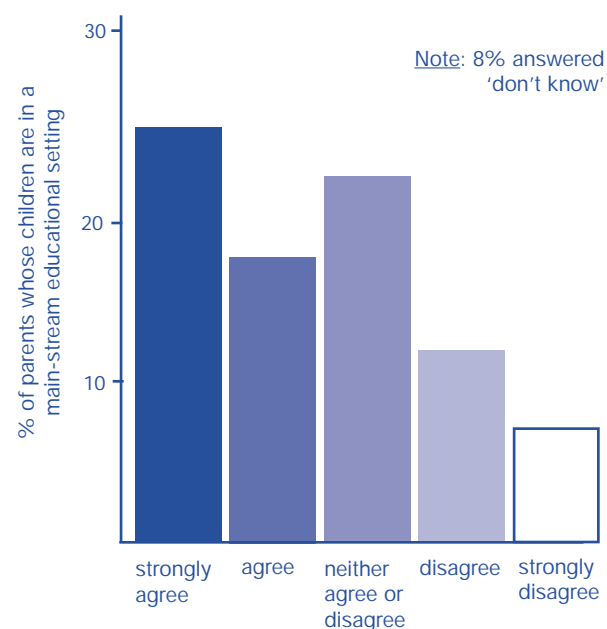
Parent of a medium functioning child in a special needs unit attached to a mainstream primary school

Parents need more choice - very few schools have staff who are adequately trained and can provide the right level of support for children with autism and Asperger syndrome, and autism specific provision is very limited. Some young children have to travel long distances.

*'We are in dispute with the school about its appropriateness for our son. His teachers believe that he should be moved to an SLD school [school for children with severe learning disabilities]. We believe that they base their judgement on his poor communication and lack of language rather than on his ability to learn through other means (ie. visual)... We feel that there is a lack of commitment towards our son and a prejudice against non-verbal children.'*

Parent of a quite low functioning child in an autism specific unit attached to special needs primary school

My son/daughter has been better served by being in a mainstream school but only because we have fought hard for what we want





## Summary Findings

*'The school seems to be pulling out all the stops to help my son. But there is not enough expertise on autism. County-wide not enough spaces in autism-specific units. Teaching aids etc. not geared to autism. More courses needed for teachers and LSAs - some are available but school cannot afford them.'*

Parent of a high functioning child in a mainstream primary school with considerable support

*'We would like our son to be able to be educated nearer to home. Having to be picked up in a taxi at 8 am is not fair on a six-year-old child.'*

Parent of a medium functioning child in an autism specific unit attached to mainstream primary school

*'They don't understand autism and how to reach or teach autistic children. They miss the point about social skills and communication and don't help at all with social skills, therefore my son hates school. They overestimate his skills and push him too hard. His memory is poor and they don't listen to anything we have to say about this which is putting him at risk. He now suffers psychologically.'*

Parent of a very high functioning child in mainstream primary with some support

Choice may mean greater co-operation and collaboration between mainstream providers and specialist autism providers. For some children a specialist environment is still the best to promote their own inclusion. Equality of opportunity will mean flexibility in rules, routines and curriculum - not that all pupils get the same. A range of provision is needed if individual needs are to be met.

*'My son is being taught at a special school that is a centre of excellence for autistic children. He has the chance to mix with non-autistic children, but has the advantage of being taught by specialist teachers right through his school life. An MLD school was the right choice for my son. Mainstream school would have been disastrous!'*

Parent of a quite low functioning child in a special needs school

*'I would like my son to have more opportunities to mix with 'normal' children through closer links with nearby mainstream schools. We have been told by the LEA that this was an aim but it has not been implemented.'*

Parent of a medium functioning child in a special needs primary school

Satisfaction is higher among parents of pre-school and primary aged children which indicates that nurseries and primary schools are responding quite well to the needs of children with autism and Asperger syndrome. What parents value most is the recognition of their child's individual needs and they are happiest when schools are recognising and meeting those needs.

*'The school has an excellent policy of treating all pupils as individuals. It prides itself as being a 'people place'. The school has worked with us to remove barriers by finding simple solutions. All direct teaching staff have been made aware of Asperger's symptoms and useful strategies. Ancillary support staff are aware but have less understanding. Sure problems occur but are resolved speedily. A knowledgeable proactive special needs co-ordinator helps. It was totally the opposite situation at his previous school.'*

Parent of a child with Asperger syndrome, in a mainstream primary school with no special support

Secondary schools and further education are less able to meet the needs of children with autism and Asperger syndrome and parental satisfaction levels decrease the older their child becomes.

*'He has been put in the 'lowest' class because he has Asperger's without looking at ability. There seems to be a tendency for him to be seen as just another one in the slow group rather than an individual with specific and different needs.'*

Parent of a high functioning child in an 11-16 mainstream school with some support

Parents' perceptions are that LEAs are driven by cost and resources, not by the needs of the child. Parents struggle to get the provision they believe is right for their child - 64% said that they only achieved satisfactory provision by fighting hard for it.

*'Each child should be educated according to their individual needs and what is best for them. Too often they are placed in unsuitable environments on the grounds of cost. If inclusion in mainstream school provides the best opportunity for an individual child then they should have the opportunity to attend with whatever support they need, regardless of cost. My child would not cope in mainstream because of her severe learning disabilities and her autism, therefore placement in a special school is better for her at the moment. This may change as she gets older.'*

Parent of a quite low functioning child in a special needs primary school

*'The local education authority clearly wanted the cheapest option for my son. They were not honest about the most appropriate provision for him.'*

Parent of a medium functioning child in an autism specific unit attached to special needs primary school

One in five children with autism or Asperger syndrome is excluded from school at some point, quite frequently because of a lack of staff with autism experience. Schools are unable to cope with a child's behaviour and will ask parents to remove the child at difficult times. Children at the more able end of the autistic



# Summary Findings

spectrum have more problems. Their behaviour can often be more challenging and they are more likely to be excluded from school.

*'Our son's educational needs are not being met. Our son is in crisis, on occasions we are being asked to withdraw him from school. He is being exposed to physical abuse within the school environment. He is not gaining education, social benefits from his placement. Our views as parents are not being properly listened to.'*

Parent of a high functioning child in mainstream secondary school with considerable support

Overall 84% have a Statement of Special Educational Need or a Record of Need (Scotland). And almost half those without are in the process of assessment. However, 31% of those at the higher end of the autistic spectrum fail to achieve a statement.



*'His statement of special needs was issued far too late. Some teachers are still unaware of how to meet his needs in lessons.'*

Parent of a medium functioning child in a mainstream secondary school with some support

Social skills training is often neglected by schools; greater weight is placed on academic achievement. This leads to children being excluded and often bullied at school. Positive inclusion policies need to encourage friendship and support among peers; schools should work proactively to encourage social integration, not just adopt measures such as 'anti-bullying' policies. Basic life skills are an important part of the development of any child - but even more so for children with autism. Inclusion will not work for these children if it is wholly academic in its focus. The preparation for an adult life - which is likely to be tougher than for the average child - is very important. Undertaking 'normal' tasks later in life such as shopping, managing to live independently, or for those higher up the spectrum, commuting to a job or

dealing with change at work can create many challenges and difficulties. Parents are not satisfied with the level of life and social skills training their children are receiving.

*'He needs more time for his social skills and help with his fine motor skills. The school is more interested in his academic side - he has very little time spent on life skills.'*

Parent of a high functioning child in a mainstream primary school with some support

*'SEN sympathetic, but very large, school and some teachers are dismissive of special needs which are only social and comprehension. Little training for teachers although they are sent factsheets and have had a nurse coming to school to explain his problems to them.'*

Parent of a very high functioning child in mainstream secondary school with no special support

*'My son is 13 years old and suffers from Asperger syndrome. The large secondary school he attends are well meaning but overwhelmed with other problems. He suffers badly from bullying which is largely ignored by the school in the hope that it will go away. When he objected to being bullied it was easier to exclude him than exclude 5-6 bullies.'*

Parent of a high functioning child in a mainstream secondary school with some support

## Differences in results in Scotland and Wales

Responses from NAS members in Scotland, (127) Wales, (77) and Northern Ireland (7) were logged carefully in analysing the results so that any significant differences from the overall UK findings from the sample of 1,000 could be analysed.

The element of the survey where a large enough response was obtained (818) to be able to draw some conclusions on regional differences in Scotland and Wales was the section for parents with children under the age of 20. Responses from Northern Ireland were too low to be able to draw any robust conclusions on differences from the overall UK results.

Respondents from Scotland were younger than the UK average with slightly younger children with autism or Asperger Syndrome than the UK average.

30% of children of parents in Scotland do not have a Record of Need compared to only 13% in the UK overall (this is partly explained by a larger number of parents who are in the middle of the assessment process now.).

# Summary Findings

There is a core of about 10% of the Scottish respondents who are 'very dissatisfied' with the education their child is receiving (this compares with 5% of parents in the UK as a whole).

As compared with the UK as a whole, almost twice the number of respondents from Scotland and Wales reported that their child did not have an Individual Education Plan (IEP).

Parents in Scotland with children with autism and Asperger Syndrome in mainstream education are more polarised in their views. Their overall rating of mainstream education is a little lower than for the UK as a whole. There appears to be a consistent number (albeit a minority) who are not happy with the provision their child is receiving. A further minority express greater satisfaction than for the UK as a whole.

Respondents in Wales are a little less happy (than the UK as a whole) in the way that educational options are described to them.

In Scotland educational psychologists are far more likely to be describing educational options to parents than in the UK as a whole, (55% as opposed to 35%). Child psychologists are also more involved in advice in Scotland than in the UK as a whole.

Twice as many respondents in Scotland compared with the UK as a whole still don't feel that they know what sort of education their child should be receiving, although this may be simply because their children are on average, younger.

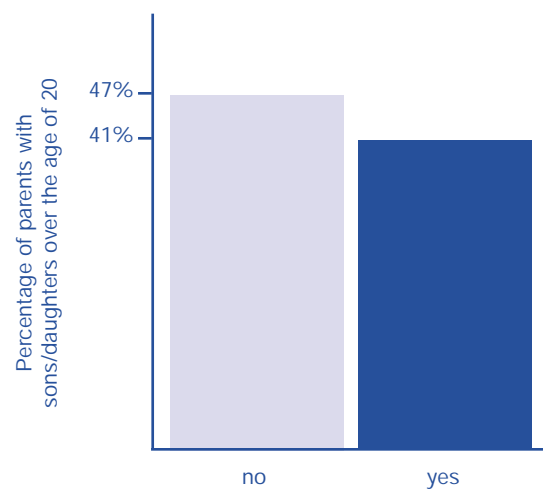
## Into adulthood

For adults a bleaker picture emerges. Inclusion becomes harder to achieve once the institutional world of education has been left behind. Most adults with autism or Asperger syndrome we spoke to have aspirations to be in a paid job but few actually manage to achieve that goal at present. Living independently, socialising, making friends and forming relationships are all challenges.

Parents described inclusion as being 'accepted by other people', 'part of society', 'taking part in community life', 'able to lead an independent life', 'able to lead as normal a life as possible', 'included in the workplace', 'included in social/recreational activities' and 'offered the same opportunities as others'.

Only 41% of parents feel that their son or daughter is included in society.

### Do you feel that your son/daughter is included in society?



Note: 12% not stated

*'The reason he is not included in society is because 'society' doesn't want him to be.'*

Parent of very high functioning adult living in rented accommodation with some support

*'Our son does not wish to participate wholly in society. He is happiest when alone... How do you include someone who doesn't want to be included?'*

Parent of an adult in residential care

*'He desperately wants to live in the community but is so gauche socially that he is laughed at, picked on and has even been attacked at a bus stop in daytime.'*

Parent of an adult living in a bedsit within a nursing home for people with mental health problems

Parents believe that the most important areas for their adult children to make progress in are relationships, socialising, educational opportunities and work. Yet half the parents said that their son or daughter has not been able to meet people and make friends outside their home as much as they would like, and only 11% have access to paid employment.

*'My son is well cared for, does work he enjoys, although he is not paid and continues with his education doing the same things he did ten years ago. He does not progress. We have very limited help but I am not sure that now, at the age of 27, he will ever be able to socialise, have relationships and live independently. Perhaps if his autism had been diagnosed earlier and his education had been more appropriate to his special needs [he would have been more prepared for an inclusive life in society].'*

Parent of a low functioning adult living at home

# Summary Findings

10% of adults have no access to services or other activities at all - they do not attend day services, have no employment opportunities, either paid or voluntary, no training, further education or leisure opportunities either.

*'Even a few hours of work, either paid or unpaid. He doesn't mind not earning the money but needs more structure to his day and more purpose in his life to be fulfilled. He has a qualification in advanced computer studies but at present is unable to get a job. He needs someone with him such as a job coach for support.'*

Parent of very high functioning adult living in rented accommodation with some support

Looking to the future 55% of parents think that opportunities for inclusion will be better, but only 21% think that their son or daughter will be living a more fulfilled life ten years from now.

*'[Inclusion means] that my son, though supported, should be able to mix with other members of society on equal terms and have equal access to leisure and other facilities. That he should not be treated as a second class citizen, but that his special needs should be acknowledged.'*

*'Thanks to the skill and imagination of the staff in the service where he lives, new ways of helping him blossom are constantly being devised. He is less bored, more communicative, more creative than he was ten years ago. I can only see, all things being equal, this process continuing.'*

Parent of a medium functioning adult living in an autism specific group home

What would be the one change now, (either in society or in your son/daughter), that would make most difference to your son's/daughter's inclusion in society?

|  | Percentage<br>(of those respondents who answered this question) |
|--|---|
| A more understanding and respectful public/better public awareness                     | 34  |
| Improved social skills/better and more stimulating social activities and opportunities | 20  |
| Suitable employment  | 10  |
| More friendships and/or relationships  | 8   |

While the education system is now meeting the needs of younger children with autism and Asperger syndrome far better, many of today's adults were not diagnosed when they were young and therefore did not benefit from early intervention. Some parents believe that it is too late for them to benefit now. We asked what would have prepared them better for an 'inclusive' life in society?

*'Being diagnosed at an early age and receiving appropriate education as well as care for her needs. It's too late now.'*

Parent of a low functioning adult in a day service for adults with special needs

*'Early diagnosis. A proper autistic primary school environment where she would be understood as she is now.'*

Parent of an adult in residential care

Adults with autism or Asperger syndrome have expressed their own views about inclusion. Their priorities are clear: the desire for a job, being able to make friends, and for some, having a relationship. Some have access to social skills groups where they can learn to socialise with other people. But not all want to socialise with people with autism or Asperger syndrome. Yet opportunities to make friends with other people are very limited.

*'There are a few things I would like to follow through within the next ten years. First of all, and most importantly, my work. Secondly, friendship: I would like to obtain a variety of different friends... I think later on I would like a relationship. That relationship will only be a meaningful relationship with the right person... that is the third, I guess least important, thing of the three.'*

A young woman with Asperger syndrome

*'I imagine that 'inclusion' means - to the extent that you want to be included - [dealing with] the things in society that are barriers to inclusion which might be: not being able to get a job, or other people's reactions to you, or finding it difficult to form friendships, as well as your own individual skills and your way of living in the world and trying to make yourself 'acceptable' to 'normal' people. So socially you don't say things that upset people. A code for socialising with people even if it is not your code for socialising with people.'*

A young man with Asperger syndrome

*'The friendships I generally have are through a youth club called LINKS which has a mixture of people with learning disabilities and other disabilities... they go on all sorts of outings which is good. I am not aware of any other groups which have ordinary people with Asperger's that can go on all these trips with me.'*

*'I would much rather have the practice in learning to socialise with ordinary people and people with Asperger'*

## Summary Findings

*syndrome because I would like to be respected in society and accepted in society and not be branded an outcast or thought of as an outcast by the ordinary person.'*

*'I need to change my habits in order to fit in with society, because the truth is obviously that society isn't going to conform to your ways: you have to conform to society in order to get on in life.'*

A young woman with Asperger syndrome

### Costs and funding: investing for the future

The Government needs to consider the longer term costs of meeting the needs of people with autism or Asperger syndrome. What this report demonstrates is the need for educators and carers to have adequate training and expertise to help people with autism and Asperger syndrome meet their potential. The parents of adults with autism and Asperger syndrome who were diagnosed later in life believe that earlier diagnosis and then intervention would have made a difference to their children's prospects in life: more chance of living independently, more chance of education and training.

A recent report summary published by the Mental Health Foundation *The Cost of Autistic Spectrum Disorder* (Knapp and Jarbrink 2000) identifies the annual total cost of autistic disorder in the UK to be at least £1 billion.

The greatest costs are for living support (70%) and day activities (14%). Much less is spent on education (7%). Evidence suggests that even moderate increases in educational provision could potentially result in major savings in later living costs. The economic consequences to parents of having a child with autism living at home include an annual loss of earnings estimated as at least one-sixth of the average disposable income.

Supported employment schemes such as the NAS Prospects scheme provide an extremely cost-effective way of helping adults at the more able end of the spectrum. With a small amount of support many are able to find stable and fulfilling employment - with the added benefit of contributing to the public purse and leading less dependent lives.



### Conclusions

If inclusion is not just an empty slogan it will require an effort. People with autism and Asperger syndrome have strengths and can make useful contributions to society. However, they also have special needs that require adjustments from those around them. Such individuals may function in the mainstream but only with careful attention to their needs. Some may be easily distracted, have poor concentration, be anxious or confused, suffer 'overload' of information or sensory stimulation or be unable to interpret subtle academic or social rules. It is here that environmental modification and training of professionals are an essential prerequisite for success.

Schools need to buy in wholesale to inclusion if it is to work. Inclusion cannot rely on the interest, commitment and enthusiasm of one or two individuals. Without a shift in the whole organisation's attitude and approach it will fail children with autism and Asperger syndrome - as witnessed by many schools' inability to cope when key staff are unavailable and the resultant exclusion of some children. There are also more difficulties at secondary school because of the greater peer pressure to conform. A study by Whitaker (1994) showed that a third of secondary aged pupils were concerned about ridicule or rejection by peers if they maintained contact with pupils with disabilities.

The National Curriculum does not adequately reflect the broader educational needs of children with autism and Asperger syndrome and often fails them and, in particular, the older children. If it is to work then it needs to be adapted imaginatively to meet the differing learning needs of these children. Evidence from a number of academics (Sebba and Sachdev 1997, Flack 1996, Myles and Simpson 1998) shows that this can provide a more stimulating curriculum for all children.



# Summary Findings

Equal emphasis needs to be given to social skills and life skills, especially for those who stand to benefit most from this input.

But there is a fundamental question: to what end is inclusion being promoted in education? Our evidence shows that post-19 there is very little for many adults to look forward to. Are we in danger of setting our children up for failure in adulthood? If we want to match the aspirations of an effective education following early intervention then far more must be done throughout society to change attitudes and raise awareness.

Whatever the provision or situation for a child or adult with autism or Asperger syndrome it is essential that their individual needs are met. It is vital that all people who come into contact with these children and adults should acknowledge their autism and recognise what impact it has on their lives and their ability to learn and to live within our society if they are to be fully included. Training and expertise for educators and health professionals is essential.

Inclusion should never replace sensitive individual planning, particularly in the case of a relatively small number of complex individuals who, without very skilled support, are a source of severe disruption to their families, schools or other placements or who simply go on to lead unhappy, unfulfilled and vulnerable lives. This group will include the most severely disabled but will also apply to those of good academic potential but with severe social impairments.

The positive lead established by pre-school and primary educators shows that it is possible to obtain inclusive environments. As children grow older so their environments become more complex. Nevertheless, the adjustments needed to make life more manageable for people with autism and Asperger syndrome and to enable their inclusion are not onerous. There are simple steps to take, for example, being clear in the use of language, providing structure and avoiding uncertainty. To work fully there will need to be an awareness of these needs among all those in contact with a person with autism or Asperger syndrome.

Educators can promote such a sympathetic environment by positive policies such as 'buddy' or mentoring schemes, 'circle of friends' or peer tutoring. Employers can also tap into the strengths of people with autism and Asperger syndrome via the use of support workers, such as those provided by the NAS supported employment service, Prospects, and by ensuring that staff are made aware of the specific needs of their fellow workers.

There is more that Government can do to promote inclusion, particularly for adults. There is still a huge burden on ageing parents. Although their children might have had assessments of needs, their own needs as carers are often overlooked. Adults themselves need much greater support in obtaining work, for example, support in preparing job applications and at interviews. Employment staff need just as much understanding of the needs of this group as do educators. If it fails here any good work that has gone before will be reduced in value. Adults need more support and guidance in finding opportunities to make friends (some of them structured) if they are to achieve their stated goals: to increase their circle of friendships, and in some cases, to form relationships.



## Recommendations

1. That autism awareness should be a mandatory part of Continuing Professional Development for a range of professionals in health, social services, education and employment.
2. That earlier diagnosis, identification and intervention should be promoted to give all people with autism a better chance in life. This should include:
  - In education: initial teacher training, of SENCOs and practising teachers in the identification of autistic spectrum disorders, particularly Asperger syndrome, at reception and in key stage 1. This would be facilitated by a refinement of baseline assessment to monitor social and communication skills.
  - In health: the development of a national diagnostic consensus, to disseminate best practice, and to encourage the use of universal diagnostic labels.

## Summary Findings

3. Local education authorities should develop and make available autism specific expertise for mainstream schools whilst maintaining choice of autism-specific schools. This could take the form of autism-specialist consultant teachers as part of a local education authority's central teaching support services.

4. That positive policies in schools should be promoted to encourage the social integration of children with autism and Asperger syndrome; there are a host of practical initiatives which have been successful and which require wider dissemination. These include: how to build on strengths and self esteem; classroom organisation; pictorial or visual timetables; work organisation; structuring of teaching and leisure; friendship support networks; prevention of teasing and bullying; planned transitions; student and staff preparation; phased positive implementation of new experiences and so on.

5. Address the educational needs of those at the more able end of the autistic spectrum and improve their access to statementing.

6. Provide social and life skills training and social time support e.g. breaks and lunchtimes, for children with autism in schools to stand them in good stead when they leave educational provision. Also give greater emphasis to disability discrimination in personal health and social education and citizenship curricula for all children in order to address issues such as bullying.

7. Staff in secondary and further educational provision to be trained to respond more appropriately to the educational needs of students with autism or Asperger syndrome. For example, by reducing the number of changes the student will experience and ensuring that communication and organisation issues are responded to consistently and are relevant to the student's level of comprehension and functioning.

8. Establish a positive incentive for schools to include children with special needs by building into local education authority, and/or OFSTED performance indicator frameworks, the index of inclusion developed by CSIE/University of Manchester (1997).

9. Central Government should advocate the business case for employing and serving people with autism and Asperger syndrome, and encourage employers to make 'reasonable adjustments' so that this group can work if they want to. Employment services for people with autism and Asperger syndrome, such as the National Autistic Society's Prospects scheme, should be established in all major cities to match employers with potential employees.

10. Transition planning has rightly been afforded a high priority within children's services plans. The importance of this process should be restated as not all authorities respond adequately and those students who do not have a statement of special educational needs may be overlooked completely. Transition planning is a dynamic process which must begin early to ensure adequate preparation and appropriate provision for school leavers.

11. Further and higher education institutions should be encouraged to recognise the social needs of students with autism and Asperger syndrome who may form part of their student populations.

12. Care standards should be specific in supporting the needs of people with autism and Asperger syndrome.

13. Work with employers to achieve a better understanding of the needs of people at the more able end of the autistic spectrum and push for more 'reasonable adjustments' to be made in the workplace so that people with autism and Asperger syndrome can be employed.

14. That social services, health and education agencies should take into account the lifelong learning needs of adults when designing their care packages so that education and training continues beyond school and student age.

15. That further and higher education funding bodies recognise that people with autism or Asperger syndrome often achieve educational milestones at a different pace from their peers and have lifelong educational and training needs, so that funding should not be time limited.

16. Above all, it should be recognised that meeting individual needs should be fundamental when providing any service, support or education to people with autism or Asperger syndrome. Their rights as individuals must be recognised.

**The National Autistic Society pledges to work with central and local government and its agencies to achieve these aims to benefit all people with autism and Asperger syndrome.**

# Summary Results

## The Sample and Response Rates

### Response

1,110 (46%) of the 2049 surveys mailed were completed and returned to the NAS. The first 1000 surveys received were analysed.

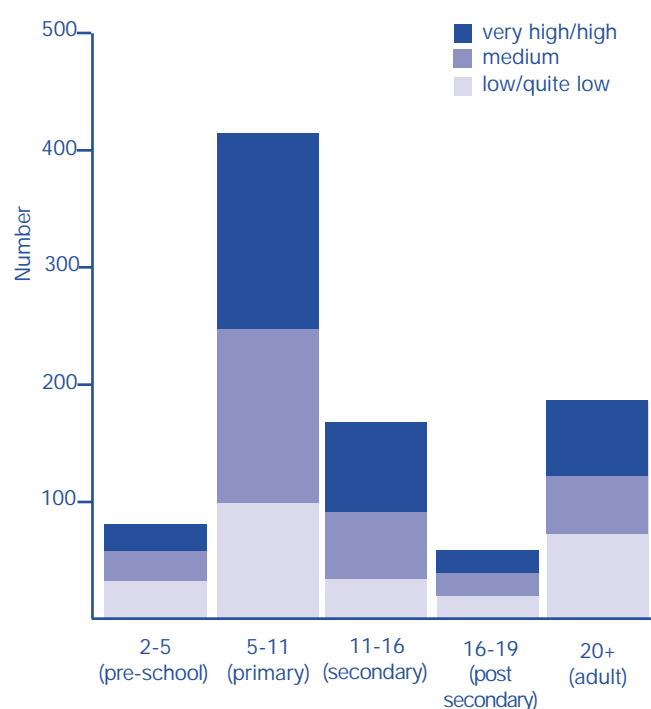
818 of the 1000 replies were from parents with sons or daughters under the age of 20.

- 11% replied 'very high' functioning
- 28% 'high' functioning
- 33% 'medium' functioning
- 18% 'quite low' functioning
- 10% 'low' functioning

94% of respondents answered a question on how high or low functioning their children are on the autistic spectrum.

19 adults with autism or Asperger syndrome replied, some sons or daughters filling out this section of the survey after their parents had answered an earlier

Age and level on autistic spectrum



section. (In addition, a further 20 surveys were completed by adults with autism with some support from their keyworkers or employment advisers).

34 adults with autism answered the question 'how high functioning or low functioning would you say you are on the autistic spectrum as follows. (The interviewees from Prospects were not asked this question in their one-to-one interviews.)

- 4 (12%) replied 'very high' functioning
- 9 (26%) 'high' functioning
- 14 (41%) 'medium' functioning
- 3 (9%) 'quite low' functioning
- 4 (12%) 'low' functioning'

### Methodology

Responses were needed from a large number of members for us to be confident in the findings. This was especially important if certain premises were to be tested which required analysis of sub-sets of the whole sample. (For example, are parents of high functioning children with autism or Asperger syndrome happier with the education their children are receiving in mainstream schools than parents of children lower down the spectrum?) IDA, the data-processing company used, included 95% confidence indicators in their results tables which made light of the task of considering whether any variations in the findings between sub-sets were significant or not.

Current academic thinking on inclusion was considered before the survey was drafted. The first two sections of the survey were then tested with a small but representative group of parents. Their feedback was invaluable in fine-tuning the structure of the survey and in re-wording questions that were considered unclear.

The structure and wording of the questions for adults with autism or Asperger syndrome were discussed and revised after discussion with Prospects. The five one-to-one discussions and one group discussion were also conducted with adults with autism or Asperger syndrome who are current clients of Prospects.

It was anticipated that only a handful of 'high functioning' adults with autism or Asperger syndrome (who were also NAS members), would be able to answer the survey without support. Therefore, in order to broaden the sample, responses were also sought from adults who weren't members of the NAS (some



# Summary Results

of whom were known to be less high up the autistic spectrum). Most of these respondents were in day or employment support services and most needed some support and assistance to complete the survey. Some questions needed to be reworded by support workers so that they could be more easily understood.

It should be remembered that, even with support, many adults at the lower end of the spectrum would not be able to answer the survey and therefore the sample is still only indicative of adults at the medium and higher end of the autistic spectrum.

## Key Findings

### Parents and carers of sons/daughters under 20 (818 respondents)

Just over half of these children are taught in a mainstream setting. The remainder are in some form of specialist provision away from the mainstream.

Overall, 84% of children have a statement of Special Educational Need (SEN) or Record of Need in Scotland.

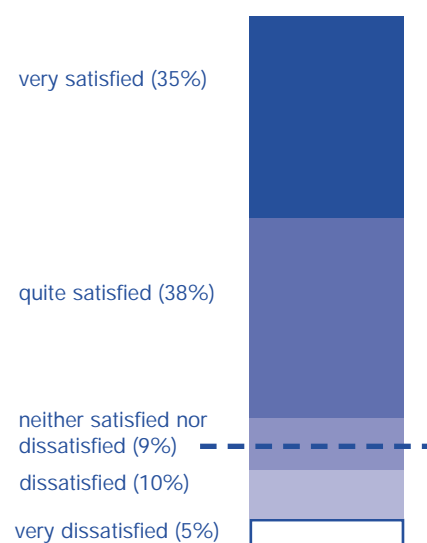
Overall, 73% of parents are 'very satisfied' or 'quite satisfied' with the education and support their children are receiving.

The reasons for their satisfaction most commonly mentioned are in order:

- Good support/help
- Excellent/trained staff
- Caring/understanding staff
- Child making good progress
- Good communication
- Child is happy
- Good teacher/pupil ratio
- Meets child's needs
- Good knowledge/experience
- Child benefits socially

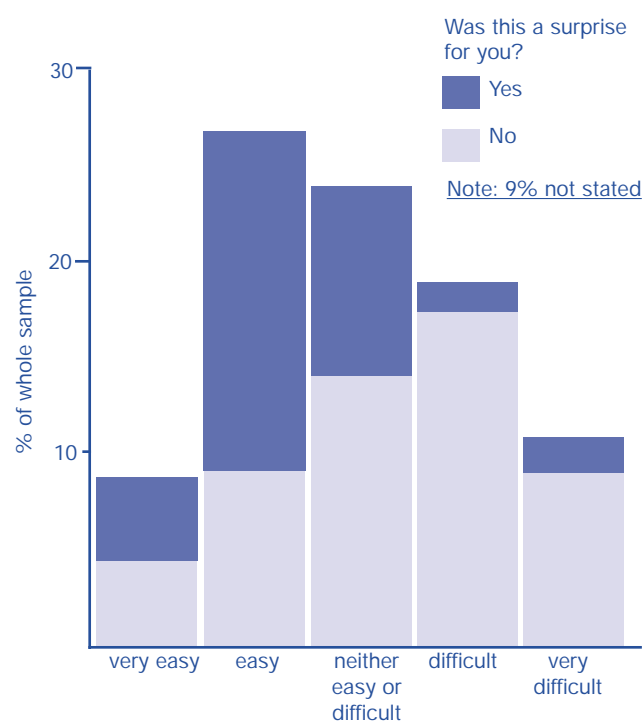
Only 57% of parents who judge their children to be very high functioning are very or quite satisfied and 29%, (twice the average response), are quite dissatisfied or very dissatisfied.

How satisfied are you with the education and support your son/daughter is currently receiving?



Note: 3% not stated

How easy or difficult was the transition (from their previous educational establishment) for your son or daughter? (Was this a surprise for you?)



Was this a surprise for you?

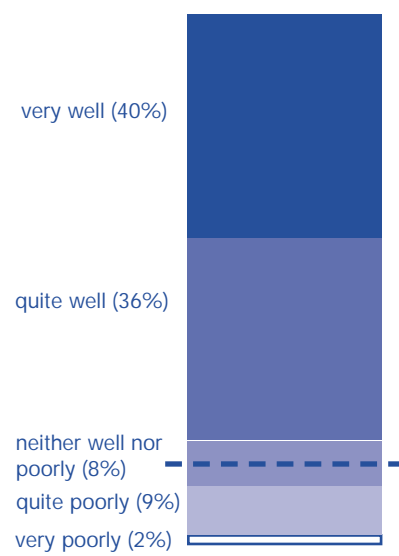
Yes

No

Note: 9% not stated

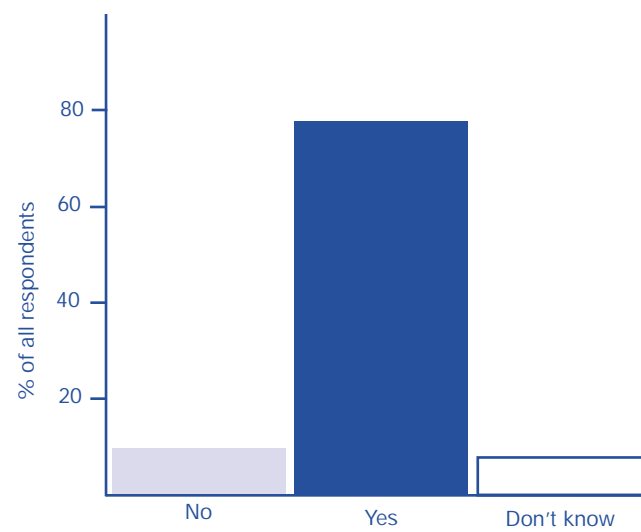
# Summary Results

How well does their present educational establishment inform you on the progress that your son/daughter has been making



Note: 4% not stated

Does your son/daughter have an individual education plan (IEP) ?



Note: 3% not stated

Open question: If one single change was to be made to teaching and support of your son/daughter to improve their learning or experience what would it be?'

| Comment   | Number | Percentage (of all respondents) | Notes  |
|---|--------|---------------------------------|--|
| More knowledge about autism/more training/expertise | 124    | 15                              | Especially respondents with sons/daughters of 2-5 years old and those with higher functioning children                             |
| More one-to-one support                             | 85     | 10                              | 17% of respondents with 'low-functioning' sons/daughters, 15% of 2-5 year olds   |
| More speech therapy                                 | 57     | 7                               | 12% of 2-5 year olds   |
| Address social needs                                | 50     | 6                               | 17% of respondents who consider their sons/daughters 'very high functioning' and 10% of those who consider them 'high functioning' |
| More integration                                    | 41     | 5                               | Even weighting   |
| More understanding/acceptance                       | 34     | 4                               | 17% of respondents with sons/daughters who they consider 'high functioning', 8% of 11-16 year olds                                 |
| Better communications                               | 33     | 4                               |  |
| Special autistic units                              | 27     | 3                               |  |

# Summary Results

Parents of children who are in autism specific schools at primary level (89%) and at autism specific schools at secondary level (94%), score higher on satisfaction as do parents whose children are in autism units within mainstream schools.

Interestingly, special needs schools and special needs units within mainstream schools score no higher than mainstream schools where support is provided.

The majority of the 15% of parents who say they are dissatisfied mention a 'lack of knowledge/commitment of teaching staff' or poor teaching. Many others mention 'insufficient help or support' or that their 'child's needs are not being addressed'.

38% of parents are 'much more satisfied now' or 'a little more satisfied now' than they were 2 years ago, more than twice as many as the 17% who are 'a little less' or 'much less satisfied now'.

For 23% of parents, their child's last educational establishment was just a temporary solution, (a higher percentage for younger children).

30% of parents say their child's transition to their current school was difficult or very difficult with the percentage finding it difficult increasing with age.

However, one-third of parents are surprised by the ease with which their child handles the transition.

76% of parents say they are 'quite well' or 'very well' informed of their child's progress (autism units in mainstream schools and autism specific schools score higher still).

79% of parents say their children have an individual education plan (IEP) and only 10% of them said they didn't find this helpful. (IEP figures are significantly lower, 64%, in mainstream secondary schools.)

15% of parents, and particularly those with young or high-functioning children, call for more knowledge about autism reflected in better training and expertise.

10% of parents would like more one-to-one support, (particularly those parents with children who they consider 'low functioning' and younger children.)

7% overall but 12% of parents of 2-5 year olds call for more speech therapy.

6% overall but 17% of respondents who consider their children high-functioning ask for their social needs to be addressed better.

## Detailed responses on mainstream experience

Only 16% disagree with the statement that their child has been better served by being in a mainstream school than they would have been at a special school or autism specific school, but almost a half think this is only because they have fought hard for the provision they want.

76% consider their children to be happy.

59% agree or agree strongly that their children are making good academic progress.

64% agree or agree strongly that they have made good improvements to their social skills.

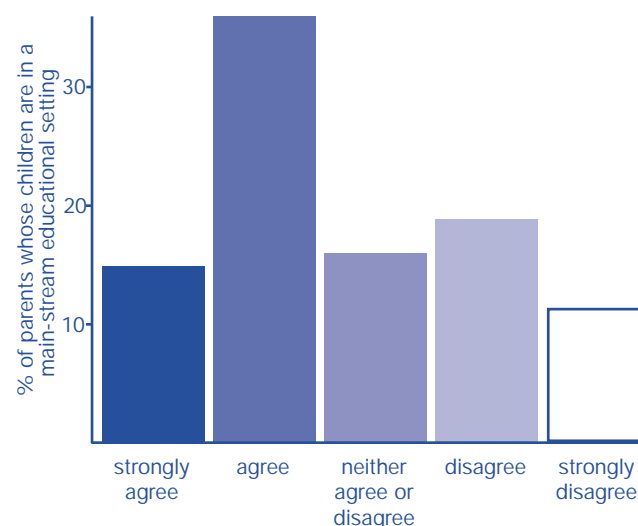
68% think Learning Support Assistants are doing a very good job.

More negatively:

31% of respondents, (rising to 40% for those with secondary aged children), don't think that adequate resourcing and staffing are in place to provide the care needed for their child.

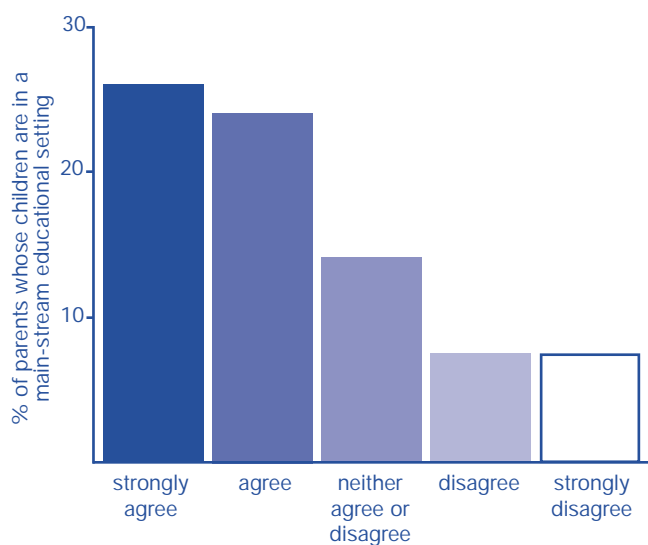
31% of parents don't think that the teachers have received the professional training they need to adapt to the special requirements of pupils with special needs, again worse at secondary level.

Adequate resourcing and staffing are in place to provide the care needed for my son/daughter



# Summary Results

My son/daughter has been better served by being in a mainstream school than at a special school.

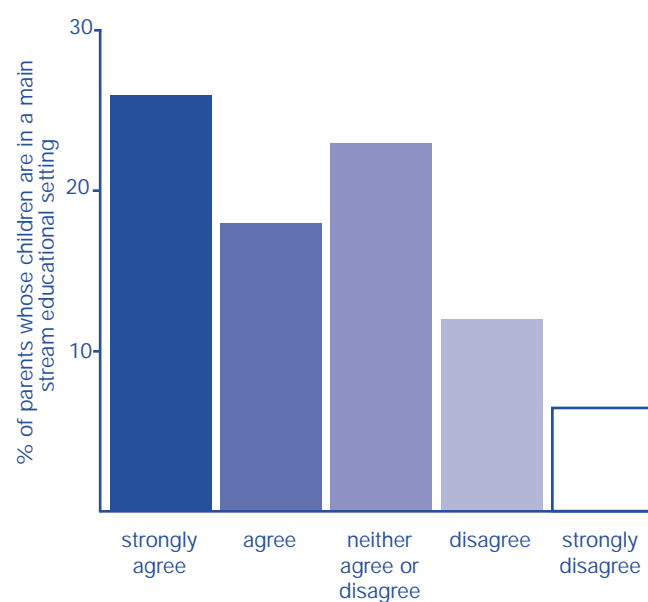


Note: 17% responded 'don't know'.

What were the reasons given for exclusion?

| Comment  | Number | Percentage |
|--|--------|------------|
| Unable to cope with child                      | 41     | 5          |
| No support/support teacher away/ short staffed | 36     | 4          |
| Child was disruptive/noisy                     | 27     | 3          |
| Unacceptable behaviour                         | 19     | 2          |
| Violent behaviour                              | 19     | 2          |
| Aggression towards teacher                     | 17     | 2          |
| Child no coping/not settling                   | 17     | 2          |
| Staff were not adequately trained              | 16     | 2          |
| Aggression towards other children              | 15     | 2          |
| Inappropriate behaviour                        | 12     | 1          |

My son/daughter has been better served by being in a mainstream school but only because we have fought hard for what we want



Note: 17% responded 'don't know'.

## Exclusion and SEN tribunals

21% of respondents said their child had been excluded at some time (17% of these more than six times), the most common reason given being that the school was unable to cope with the child (usually because specialist staff were absent or not available).

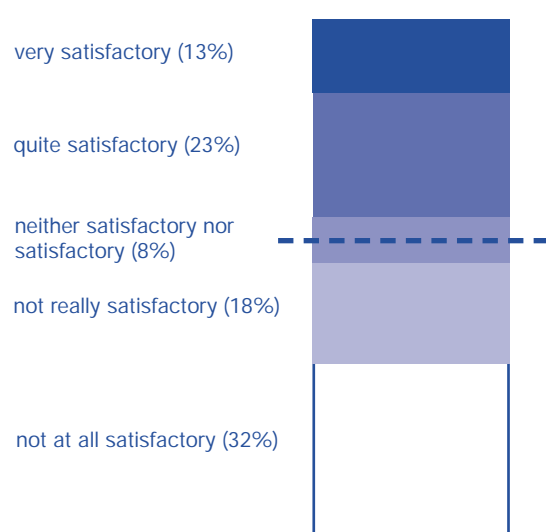
Although they understand the reasons given, 54% of respondents did not agree with those reasons.

8% of respondents had taken a concern to an SEN tribunal and most either won the case or the LEA gave ground before the tribunal. 50% found the process unsatisfactory.

Exclusion was a greater problem for higher functioning children - 29% of 'very high functioning' children had been excluded from school.

# Summary Results

## How satisfactory did you find the SEN tribunal process?



## Choosing a school and obtaining a place

24% of parents did not think they understood the educational options before choosing a place for their child. 21% found the information they were able to obtain inadequate, and 40% found choosing a school hard.

16% of respondents did not manage to obtain a place for their child at their first choice school and few parents received any advice on where to go for help or support once their child had been refused a place.

64% of respondents thought that arguing their case made a significant difference to the services that were provided.

Worryingly, 9% of parents still feel they do not know what sort of education their child should be getting, (this figure is 19% in Scotland).

The most common source of support for explaining options was an educational psychologist (35%) followed by a 'teacher from a previous school' (19%) and LEA special needs co-ordinators (17%).

## Open question: What would most have improved the whole process of educational selection and obtaining a place?

| Comment  | Number | Percentage |
|--|--------|------------|
| More schools in my area/more choice of schools/more options                                      | 137    | 29         |
| LEA to consider needs rather than finance/more supportive LEA                                    | 84     | 18         |
| More support/(independent) advice/guidance   | 67     | 14         |
| More accurate information/clearer information/ list of schools/information on what was available | 52     | 11         |
| Earlier diagnosis  | 49     | 10         |
| More informed/trained professionals  | 49     | 10         |
| Less need to fight/battle  | 39     | 8          |
| Earlier provision of statement   | 34     | 7          |
| Less delays/whole process speeded up   | 25     | 5          |
| Professionals who listen   | 24     | 5          |
| More openness/honesty  | 22     | 5          |
| Less stress  | 21     | 4          |
| More understanding   | 20     | 4          |
| More inclusion of parents in decision  | 19     | 4          |
| Better communication between professionals   | 19     | 4          |
| More time  | 16     | 3          |
| More provision for sending out of Borough  | 16     | 3          |
| Not a blanket policy on inclusion/less pressure to move to a main stream school                  | 14     | 3          |

# Summary Results

## Parents/carers of sons/daughters over 20 (177 respondents)

Overall, a far less encouraging picture emerges. Only 41% of parents feel their son/daughter is involved in society.

55% of respondents think that the opportunities for inclusion are better than they were a few years ago.

But, only 21% think that their son/daughter will be living a more fulfilled life in 10 years time.

Common reasons for pessimism are the lack of understanding that leads to their son or daughter's abilities not being developed and a perception of a lack of appropriate services and care. Those who are optimistic see their son or daughter progressing, developing and fulfilling their potential.

Most parents think their son or daughter is happy where they live.

Most think that their support workers do a good job.

Parents are pessimistic about their son or daughter's progress in being able to live independently.

**Open question: What would have prepared your son/daughter better for an 'inclusive' life in society?**

One-third of respondents said 'earlier diagnosis'. Other common answers:

- Better and more appropriate educational opportunities
- More understanding staff
- Specialist autistic provision
- More emphasis on social skills

**What would be the one change now that would make the most difference to your son's/daughter's inclusion in society?**

|  | Percentage<br>(of those respondents who answered this question) |
|--|---|
| A more understanding and respectful public/better public awareness                     | 34  |
| Improved social skills/better and more stimulating social activities and opportunities | 20  |
| Suitable employment  | 10  |
| More friendships and/or relationships  | 8   |

Respondents were asked to rank a series of options as the 'most' and 'least' important for their son/daughter to make progress in, to feel 'included' in society.

|                                       | Percentage<br>(of those who answered who think it 'most important') |
|---------------------------------------|---|
| Relationships                         | 40  |
| Socialising                           | 25  |
| Educational opportunities             | 15  |
| Work                                  | 10  |
| Living independently in the community | 4   |
| Support                               | 4   |
| Dealing with money                    | 1   |

**Open question: What is your understanding of the term inclusion?**

| Comment  | Number | Percentage<br>(of all respondents) |
|--|--------|------------------------------------|
| To take part in community life/take part in as many activities as possible | 42     | 24                                 |
| To be accepted by other people [see note one]                              | 30     | 17                                 |
| To be part of society [see note two]                                       | 28     | 16                                 |
| Support as needed  | 21     | 12                                 |
| To be able to lead as 'independent' and 'normal' a life as possible        | 21     | 12                                 |
| To be included in social/recreational activities                           | 20     | 11                                 |
| Being encouraged to reach full potential/given opportunity to use skills   | 13     | 7                                  |
| Included in the work place   | 12     | 7                                  |
| Understanding special needs  | 12     | 7                                  |
| Offered same opportunities   | 10     | 6                                  |
| Treated as equal   | 10     | 6                                  |
| Going into a mainstream school   | 8      | 5                                  |
| To have access to education  | 8      | 5                                  |
| Treated with respect   | 8      | 5                                  |
| Integrated   | 6      | 3                                  |

Notes:

1- A much higher percentage of respondents with sons/daughters who they consider to be 'quite low' (29%) or 'low' functioning (40%)

2- As opposed to 'apart' from society

# Summary Results

## Living and working

14% of respondents' sons/daughters are in paid work.

46% of respondents' sons/daughters attend either autism specific or special needs day care services.

24% are in further/continuing education.

10% of respondents' sons/daughters have no access to services of any kind.

### My son/daughter lives:

|   | Number | Percentage (of all respondents) |
|---|--------|---------------------------------|
| In a residential setting                        | 59     | 33                              |
| At home with me                                 | 39     | 22                              |
| In a group home                                 | 24     | 19                              |
| At home with other family members               | 10     | 6                               |
| In a therapeutic community                      | 10     | 6                               |
| In rented accommodation with some support       | 8      | 5                               |
| In their own home with some support             | 5      | 3                               |
| Independently in rented accommodation           | 6      | 3                               |
| In a National Autistic Society residential home | 4      | 2                               |
| In a further education or residential college   | 3      | 2                               |
| In a nursing home                               | 3      | 2                               |
| Independently in their own home                 | 2      | 1                               |
| In a hostel                                     | 2      | 1                               |
| In a hospital                                   | 1      | -                               |

*Note:* 50% of sons/daughters of respondents who say they are 'quite low' functioning live in a residential setting

## Assessment of needs and obtaining appropriate services as a result

64% of respondents found obtaining an assessment of the needs of their son/daughter 'quite hard' or 'very hard'.

Only half of the respondents have a copy of their son's/daughter's care plan.

21% of respondents said that the services identified as being appropriate in the assessment had not been made available to their son/daughter.

## Quality of residential care

Parents are generally happy with the quality of care and the encouragement provided in the development of independent living skills.

However, 16% of respondents don't think that the health and social services staff adapt their practices adequately to take account of their son's/daughter's autism or Asperger Syndrome.

A half of parents don't think that their son/daughter has been able to meet people and make friends outside their home as much as they would like.

## Care from parents (and support in their role as carers)

14% of parents care for their son/daughter more or less full-time.

7% of parents care for their son/daughter part-time.

A quarter care for their son/daughter only on those occasions when they return from a structured care setting, (weekends or holidays).

16% of parents spend no time caring for their sons/daughters, (either because they live independently or because they need full-time support from experts).

About half of regular carers have not had an assessment of their own needs as a carer.

A half of regular carers feel that they have not had adequate support in caring for their son/daughter.

12% of regular carers have received training in behavioural management.



# Summary Results

## How many hours a week do you care for your son/daughter, (if at all)?

| Hours               | Number | Percentage |
|---------------------|--------|------------|
| None                | 28     | 28 (16%)   |
| 1-6                 | 15     | 15 (8%)    |
| 7-15                | 12     | 12 (7%)    |
| 16-25               | 2      | 2 (2%)     |
| 26-100              | 6      | 6 (3%)     |
| 101-150 (full time) | 19     | 19 (11%)   |
| Weekends            | 7      | 7 (4%)     |
| Every other weekend | 5      | 5 (3%)     |
| One weekend a month | 15     | 15 (8%)    |
| Holidays            | 20     | 20 (11%)   |

Note:  
 12% of regular carers have received training in behavioral management  
 About one-half of regular carers have not had an assessment of their own needs as carers  
 About half of regular carers feel that they have not had adequate support in caring for their son/daughter

## Adults with autism

(19 respondents plus 20 replies from adults who had support in answering the survey. In addition, eight one-to-one interviews were conducted.)

29 responses were from men with autism or Asperger Syndrome and 10 from women.

Almost a third of those responding, were not diagnosed until over 20 years of age.

### Home and independent living

69% of respondents say they are happy with where they live.

71% think they have made progress in being able to live independently.

28% find it difficult to shop for what they need.

## Where do you live?

|   | Total |
|---|-------|
| At home with my parents (see Note 1)      | 21    |
| In a group home(14% of total sample)      | 7     |
| In a residential setting                  | 4     |
| Independently in my own home              | 3     |
| Independently in rented accommodation     | 2     |
| At home with other family members         | 1     |
| In my own home sharing with friends       | 1     |
| In my own home with some support          | 1     |
| Independently in a council home           | 1     |
| In rented accommodation with some support | 1     |

Note 1: 50% of those answering. However, over-represented as all 9 of one set of 'supported' respondents live at home with their parents.

## Questions about employment

|   | Percentage (of total sample responding yes or no) |    | Percentage (of total sample not answering) |
|---|---|----|--|
|   | Yes   | No |  |
| Are you in paid employment? (full or part time)           | 20  | 72 | 8  |
| If you are <u>not</u> in paid work, would you like to be? | 59  | 13 | 28   |
| Have you had access to employment advice?                 | 46  | 33 | 21   |
| Do you have an employment support worker?                 | 31  | 56 | 13   |

Note: People with autism and Asperger syndrome find questionnaires difficult to complete. As a result, the number not answering questions is quite high. The percentage not answering has been indicated next to each question.

### Work

20% are in paid work, (either full or part-time), 30% are in voluntary or unpaid work.

The majority who are not in paid work would like to be and about half the sample have had access to employment advice. The biggest barriers to working in a job are: concerns about the social aspect of working,

# Summary Results

## What do you see as the biggest barriers to you working in a job?

(Respondents were asked to rank these factors in order of their importance. Here they are ranked in order of the overall importance given to them by those respondents who answered the question.)

|   |  |
|---|--|
| 1 | Don't think I could cope with the social side of working |
| 2 | Not sure what I could do                                 |
| 3 | Lack of support worker                                   |
| 4 | Negative perceptions of employers                        |
| 5 | Worry about benefits                                     |
| 6 | Don't know where to go for advice                        |
| 7 | Bad experience in previous jobs                          |

followed by lack of a support worker, negative perceptions of employers and worry about benefits.

## Help and support

Three quarters of respondents think they know how to get help if they need it and three quarters think the help they receive is good.

However, almost a third of the respondents don't know how to complain if things go wrong.

## Which of these do you use/take part in your local community?

|                              | Total/percentage<br>(of those answering) |
|------------------------------|--|
| Libraries                    | 22/56%                                   |
| Continuing/further education | 22/56%                                   |
| Leisure/sport activities     | 19/46%                                   |
| Pub                          | 17/44%                                   |
| Cinema                       | 16/41%                                   |
| Discos/night clubs           | 4/10%                                    |
| Community centre             | 3/8%                                     |
| Youth club                   | 2/-                                      |
| Self advocacy group          | 1/-                                      |
| Church                       | 1/-                                      |

## Social life and relationships

One-third of the sample are not happy with the number of friends they have.

Only 19% of the sample say they are not comfortable socialising with other people with autism or Asperger Syndrome.

26% are not comfortable socialising with people who aren't on the spectrum.

54% agree or agree strongly that a long-term (sexual) relationship with one person is important to them.

But, only three of the respondents (8%) are in a long-term sexual relationship.

## What would most improve your life and make most difference to you being included in society?

Anecdotally from the one-to-one interviews, one could place in order three priorities:

- Finding an appropriate job.
- Making more friends (and building a wider variety of friends).
- Building a long-term (sexual) relationship.

While important for most of those interviewed, the last two points (and especially the latter), are not at all important for a few. Interestingly, these are the same priorities which parents identified, but they weighted them in reverse order of importance: relationships, socialising then work.

Note on education: most of those interviewed mentioned bullying at school during the discussions.

# Appendix One

## What are autistic spectrum disorders?

Autistic spectrum disorders are now known to be developmental disorders due to physical dysfunction of the brain and not, as was once thought, the result of emotional disturbance. Complex genetic factors are involved in most cases but other conditions, such as viral encephalitis before birth or in early childhood may sometimes be implicated. The brain functions affected are those concerned with the drive to interact with other human beings that is inborn in people who do not have autistic disorders. This results in what is often referred to as the 'triad of impairments' (Wing 1992) affecting social interaction, communication and imagination.

Autistic disorders can occur in widely varying degrees of severity. Each aspect of the triad can be manifested in different ways, in different individuals and at different ages in the same individuals, as follows:

### The range of impairments in

#### Social interaction

- Aloof and indifferent to other people
- Passively accepting social approaches from others
- Active but odd, repetitive and inappropriate approaches to others

#### Social communication

- Absence of desire to communicate with others
- Echolalia and repetitive speech
- Good grammar and vocabulary but speech used only or mainly to talk about special interests

#### Imaginative thought

- Inability to attribute thoughts, beliefs or actions to others
- Inability to play imaginatively with toys or with other children
- Repetitive stereotyped play with objects
- Imaginative ideas pursued in isolation from other people

The triad of impairments can occur on its own but, in most cases, it is accompanied by other problems. These can include one or any number of the following:

- Generalised learning disability of any level of severity from profound to mild

- Language disorders (receptive and/or expressive)
- Reading difficulties
- Difficulties with number work
- Poor motor co-ordination
- Unusual responses to sensory stimuli
- Problems with posture and movement
- Problems with sleeping, eating, drinking
- Poor attention and hyperactivity
- Any kind of physical disability including epilepsy, hearing impairment, etc
- Psychiatric problems, especially anxiety and depression

Autism and Asperger syndrome are the clinical pictures described respectively by Kanner and Asperger. It also includes other pictures showing the impairments described both of which do not fit precisely in the named syndromes.

It is not surprising that the triad, especially in combination with any of the other problems listed above, leads to all kinds of difficulties in emotional responses and behaviour. Children and adults with autistic disorders find the world, especially other people, very difficult to understand. They find it easier to cope if people, objects, events and their own activities remain exactly the same all the time. They are repetitive and stereotyped in their actions and dread change. They find it hard to generalise from one situation to another. Those who are more disabled and have severe learning disability can have very disturbed behaviour in response to change, including temper tantrums, aggression to others, or self-injury. Very often, their differences from other non-autistic children or adults with severe learning disability are not understood, leading to even more difficult behaviour. Those who are more able tend to have low self esteem and are very sensitive to any criticism. They have difficulty in assessing mental states in others and in anticipating responses and events. In everyday social situations they can become bewildered and highly anxious. Their social naivety makes them vulnerable to exploitation. If children with autistic disorders who are of average or high intelligence are not diagnosed, their social difficulties may be interpreted as wilful, resulting in punitive or other inappropriate responses that exacerbate their difficulties.

In general, people with autistic disorders are vulnerable in any situation where their condition is not recognised. This is particularly evident in unsupported mainstream education, or in special schools that do not specialise in autistic disorders, and during the transition from school to adult life.

## Inclusion in education

### Paradigms

This paper is a summary of the thinking surrounding inclusion taken from a review of recent academic and educational literature. The views do not necessarily reflect those of the NAS. Indeed, the survey's findings indicate that the situation has improved for some pupils with autism and Asperger syndrome within mainstream settings.

### Models

Commentators have widely differing views on the ways in which pupils with special educational needs should be educated. Here are some of the main models proposed:

- Separate provision for pupils with certain defined levels of disability ie specialist schools for children with autism. These might be only for children with autism or might have a wider remit covering children with severe learning disabilities. There is little justification now for separate schools for children with moderate learning disabilities.
- Integration by links between special and mainstream schools for defined areas e.g. social (level one), less academic curriculum areas such as art, music and drama (level two) etc.
- Integration with special units within mainstream schools with mainstream curriculum as above e.g. start in reception with Learning Support Assistant and then move to a specialist unit and integrate within mainstream classes as much as possible and as appropriate.
- Mainstream education with support e.g mixture of classroom support, some without support and some withdrawal for special tuition still within school. Social time support might be offered for pupils with autism or Asperger syndrome, for example breaks, lunchtimes.

There is a powerful lobby for inclusion philosophically and practically. However, there is also no doubt that achieving inclusive practice is both difficult and requires significant restructuring of provision and ideological commitment to implement. Jolliffe (1992) is clear that the mainstream schooling she received was entirely inappropriate for her particular needs as a pupil with autism. This could have been due to a lack of adequate support. Whilst she was an able pupil and managed to move on to university, others may not be so strong or fortunate. Whilst there are groups of 'special school survivors' Jolliffe and others see themselves as 'mainstream school survivors'.

Many parents have become very unsatisfied with current educational provision and have sought alternative provision for their children. e.g. Hillingdon Manor, Jigsaw and Treehouse schools have all been set up by parents for children with autism since 1998. Jordan, Jones and Murray (1998) review the various programmes specifically targeted

towards children with autistic spectrum disorders. To use the phrase embedded in the USA legislation, the 'least restrictive environment' for pupils with autism may be special, segregated provision. On the other hand, Alderson and Goodey (1998, 1999) provide evidence to suggest that children with severe autism can be included in the mainstream setting with benefits for all.

Howlin (1994) points out that all forms of education have their benefits and drawbacks. And all are variable in terms of the curriculum and quality of teaching and support offered. Certainly if education is to be inclusive for all it has to take account of individual needs and monitor them continually. This will probably mean an individualised programme. All children could benefit from such an approach. Whether it is realistic to expect it for all, however, is debatable. However, much can be done to develop classroom structure and strategies which enable all pupils to participate and learn for as much of time as possible e.g. through peer teaching or team teaching with learning support (Sebba and Sachdev 1997).

The nature of autism makes it very challenging to provide suitable education with their peers for some, but not all, children with autistic spectrum disorders. The social and communication difficulties faced by children with autism and Asperger syndrome and their often stereotyped or ritualistic behaviour patterns can be a challenge within an inclusive setting. Many parents have favoured obtaining specialist provision in order to ameliorate these problems and optimise learning in their children.

There are a number of specialist schools provided for children with autistic spectrum disorders in the UK, including six run by the National Autistic Society and several more run by local autism societies. The advantage of a centre of specialist expertise lies in being able to address the specific needs of children with autism in developing their social and communication skills, reducing their ritualistic behaviour and optimising the environment for them to learn. However, it may not provide the more intellectually able children with the opportunities for development they need.

The right expertise can be provided in the mainstream so long as teachers and support staff are adequately trained and resourced to meet the individual needs of every child on the autistic spectrum. Specialist units may also be provided for this population within mainstream or other settings. These enable students to be able to draw on wider facilities and a greater teaching curriculum. They help to move away from the rather isolated nature of segregated provision, which is often exacerbated by geographical distance from family and social networks. Even so there is evidence that separate units within a mainstream setting confirm a sense of separateness between those attending and their peers wholly included within the mainstream setting. This does not allow the benefits seen in fully inclusive settings to be shown, e.g. Jupp (1992) found that when five students with severe disabilities were placed in mainstream primary settings they were accepted and offered friendship, support and encouragement by pupils, with social relationships continuing outside school in the local setting, (though not for

# Appendix Two

the one child who was not placed in a local school). This is far more difficult to achieve in secondary settings due to the sheer scale of the environment and the complexity of peer relationships and the increased need to conform.

Schools for children with autism are understandably expensive and few in number. There are more schools for a wider range of pupils with severe disabilities and this, at least, allows pupils to be educated nearer to home. However, pupils with autism have an unusual profile of skills and disabilities and this can lead to some problems (Howlin 1998). The other pupils with learning disabilities will tend to be globally delayed and therefore teaching strategies may be easily adapted to their cognitive level. With autism, children's developmental profiles are uneven and this can be very difficult for teaching, especially with a varied group of children involved.

One compromise is the establishment of partnerships between special and mainstream schools, either through pupil 'sharing' or where special school staff act as outreach support. The more successful links involve the sharing of complementary expertise and resources, offering professional development on both sides (Ainscow *et al.* 1999). Crowther *et al.* (1998) suggest that this dual institution provision incurs significant additional costs.

Many children with autism depend on one-to-one teaching, at least for part of the day, and find it impossible to work co-operatively with other pupils. Impairments in imagination and imitative skills make play and other joint activities very difficult. These difficulties also apply to children educated at schools for mild learning disabilities or emotional and behavioural difficulties. Whereas the cognitive development of children with autism in this range may be more advanced than those with other disabilities, their social and communicative deficits will lead to teaching difficulties. They will also require a more directive input from teachers if they are to make progress whereas other students may need more stress to be given to independence and self-motivation. In some settings which combine the more socially competent with children with autism, the latter may be bullied. With attention these problems can be overcome and a sound educational environment created but sometimes this setting would not be at all appropriate for a pupil with autism.

Some inclusion studies have indicated that the presence of a learning support teacher appeared to limit the contact the class teacher made with certain pupils (Allan 1995, Thomas and Webb 1997). The use of learning support teachers in this way may not be an appropriate use of inclusive practice but it does illustrate a further dilemma. Is it reasonable to expect the class teacher to interact with all class pupils? Might the provision of classroom support be an impediment to social interaction and might it also hinder risk-taking, which can contribute towards learning?

Social inclusion conflicts with school improvement as measured by National Curriculum tests and GCSE results (Parsons 1999). Parsons argues cogently that there is a need for exclusion from education not to be possible as is



the case in other European countries. Equality of outcome, rather than of opportunity, is the key.

A further dilemma expressed by Hornby (1999) in his review of policy is that between maintaining the need for a continuum of provision whilst supporting the principle of inclusion. The reviews of research in Hornby's earlier article (Hornby 1992) found little evidence that the goals of inclusion were being met. It appeared that the benefits of greater educational attainment, increased social skills, reduced stigma, increased self-esteem, greater racial integration, improved parent involvement and individualisation of instruction did not necessarily result from including children with special educational needs in mainstream settings. Manset and Semmel (1997) in their review of eight different models of inclusion for pupils with mild disabilities concluded that a model of wholesale inclusive programming that is superior to more traditional special education service delivery models does not exist at present. Both Farrell (1997) and Salend and Duhaney (1999) found inconclusive results on the impact of inclusion on pupils with special educational needs. Hornby's review (1999) finds a continuing lack of research evidence for the effectiveness of inclusive practices, more particularly a lack of studies demonstrating that the outcomes of inclusive programmes significantly improve the lives of those young people with special educational needs.



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