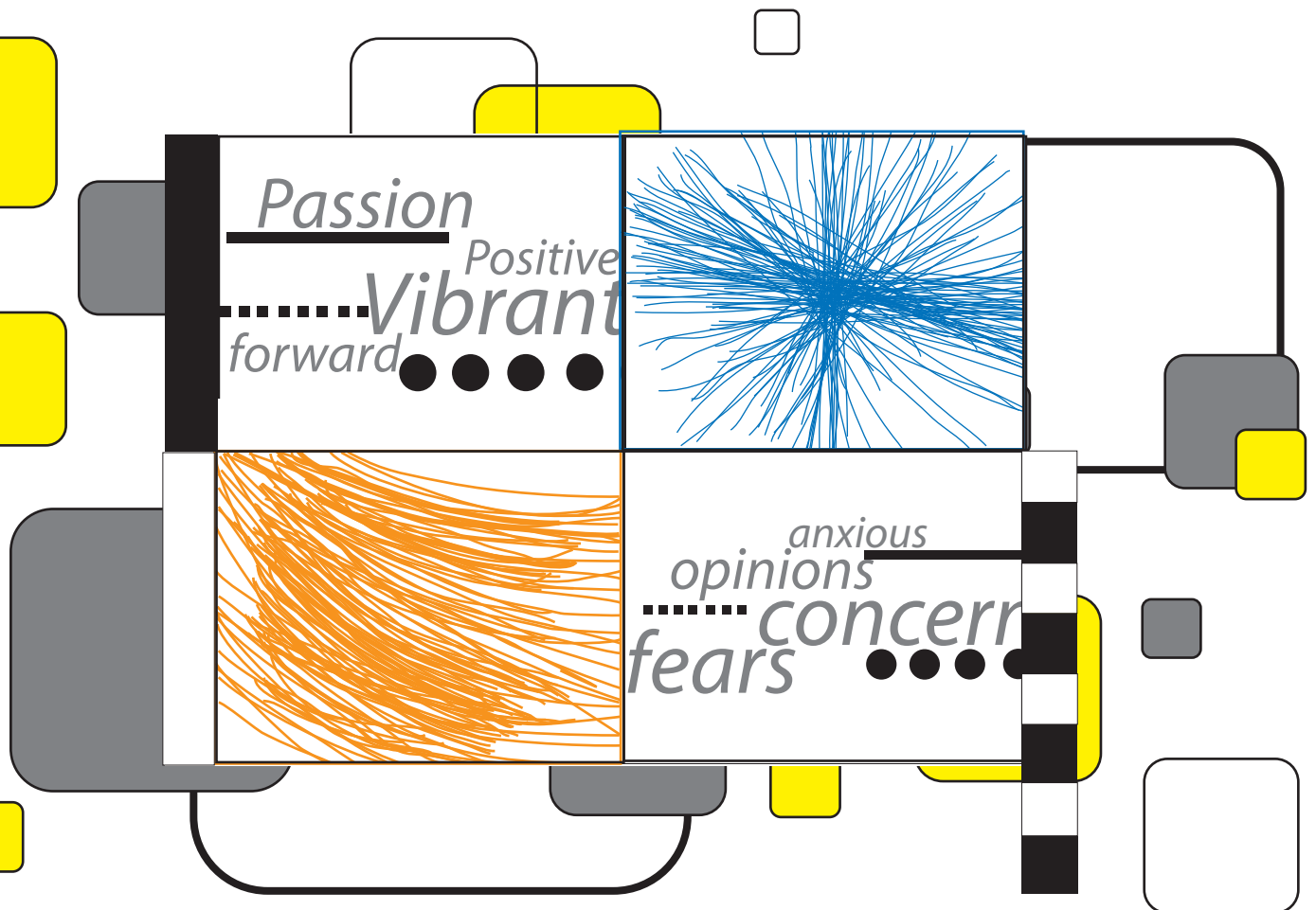




autism challenge



The
Asperger Syndrome
Survey Report

National edition



*Support
network*

*difficulty
subjects*

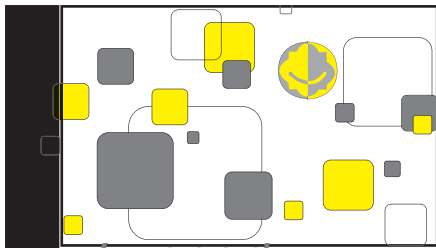


Debate
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*Support
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Debate
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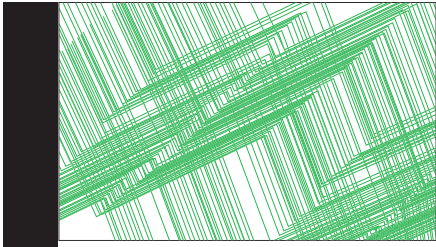


This survey is dedicated to the following people:

Andrea Macloed who was my first point of contact at autism.west midlands after I was diagnosed and has been very supportive during her role at ASSET (formally Outreach Service). When I wanted to create this survey Andrea was also very supportive of the idea. She offered guidance and assisted me in getting the survey started. I am very grateful for all the support from her. She now works at University of Birmingham teaching autism to higher education students.

One year after I was diagnosed Nicky Campbell hosted a phone-in to do with Asperger Syndrome. This was the first time I had heard any broadcast related to this. Then in 2002 BBC Radio Five Live wanted to do another phone-in on Asperger Syndrome and I was asked to take part in this show. It was my part in this phone in that created my idea to develop this survey.

Thank you.



The Author

Keith Mckenzie



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Debate

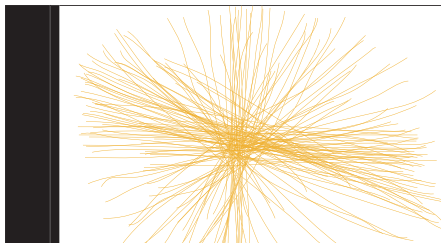
Key Services



My Name is Keith Mckenzie I live in the Worcestershire town of Redditch. I was diagnosed with Asperger Syndrome in 1999 when I was 27. This was after an endless struggle to find appropriate support to overcome my difficulties. I am a qualified Graphic Designer. I studied at Herefordshire College of Art and Design and University College Northampton.

I have been involved in various design tasks for the community. I have a strong interest in Art and Design overall and Information design is my specialist area. My other interests are related to transport issues.

In my freetime I like to go to Salsa dance class and clubbing. Also I like to visit Art Galleries and Museums.



Support
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Debate

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Acknowledgements



Thanks to everyone who participated in the survey questionnaire and the organisations who supported this survey.

Asperger Norfolk
Autism London
autism.west midlands
Leicestershire Autistic Society
Nottingham Society for Autistic Adults and Children
Scottish Society for Autism
Strathclyde Autistic Society
Wessex Autistic Society

I would like to thank the team of people at autism.west midlands that have provided me advice and support in putting this project together.

Thank you to Claire Craven (ASpire Employment Service), Morag Taylor (ASpire Employment Service), Caroline Lear (ASpire Employment Service) and Claire Fennell (ASpire Employment Service).

I would like to thank the volunteers at autism.west midlands that helped me input data regarding the survey.

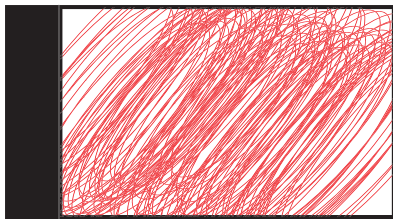
Thank you to Alison Gray and John Steele.

I would like to thank Andrea Macleod for being instrumental in the early stages of the project and Danielle Roper for researching contacts for the survey.

Thank you both.

Lastly, I would like to give a special thanks to Lawrence Brewer, Richard Woolrich and Jill Aylott for their encouragement.

Executive Summary



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Debate



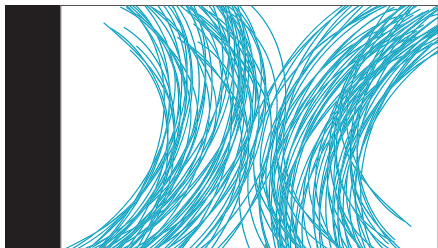
y Services

This is a survey completed mainly by adults with Asperger Syndrome. This survey ask various questions about the services they receive and their experiences of their difficulties. From the findings of this survey recommendations are proposed.

These recommendations emphasise the importance of service user involvement at every level.

Background & Rational

Section 1



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The idea of the survey came about after I appeared on a radio debate, talking about my personal experience as a person with Asperger Syndrome. This was transmitted on BBC Radio Five Live with Nicky Campbell in January 2002. On the programme few people with Asperger Syndrome took part and have a say. I felt, other than Asperger United, that there is little opportunity for people with AS, like myself to have a voice.

Any voice or opinions tend to come from professionals, academics and parents. So I designed this survey to gather the opinions and expressions from people with Asperger Syndrome. I felt that it is important that people like myself have a say on what affect our lives. This is essential as many people still don't know or understand Autism and Asperger syndrome.

The Study Process

Section 2



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Debate

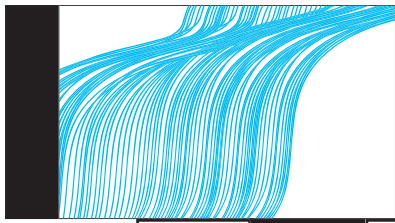


by Services



I planned the subjects which forms the survey. Then I asked the team at autism.west midlands to distribute the survey to people with Asperger Syndrome. This survey was delivered with autism west midlands newsletter. I then thought to extend this survey to people outside the West Midlands region. So I sent the survey via post to selected organisations with services for Autism and Asperger Syndrome. After a while I then received replies from many places, including East and West Midlands, parts of Central Scotland, Norfolk, London and the South Coast.

The team at autism.west midlands assisted me in gathering, processing and analysing the replied surveys. With my graphic design talent I created the presentation templates, then combined the presentation and content together as you see it now.

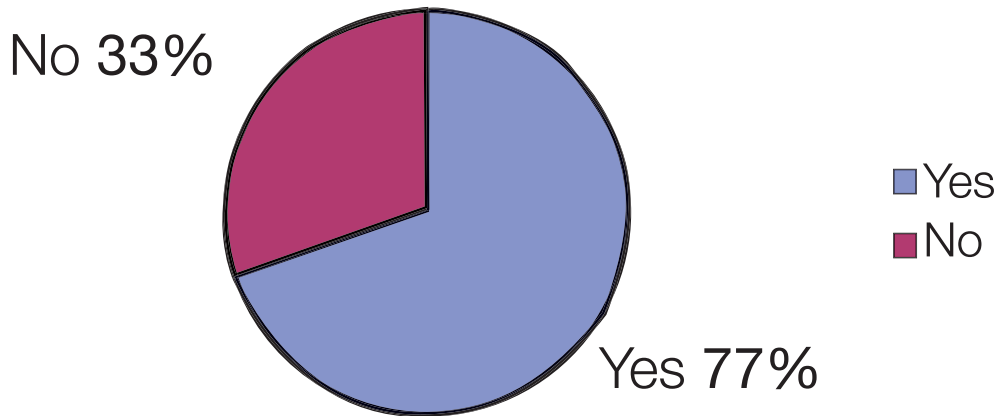


The Findings

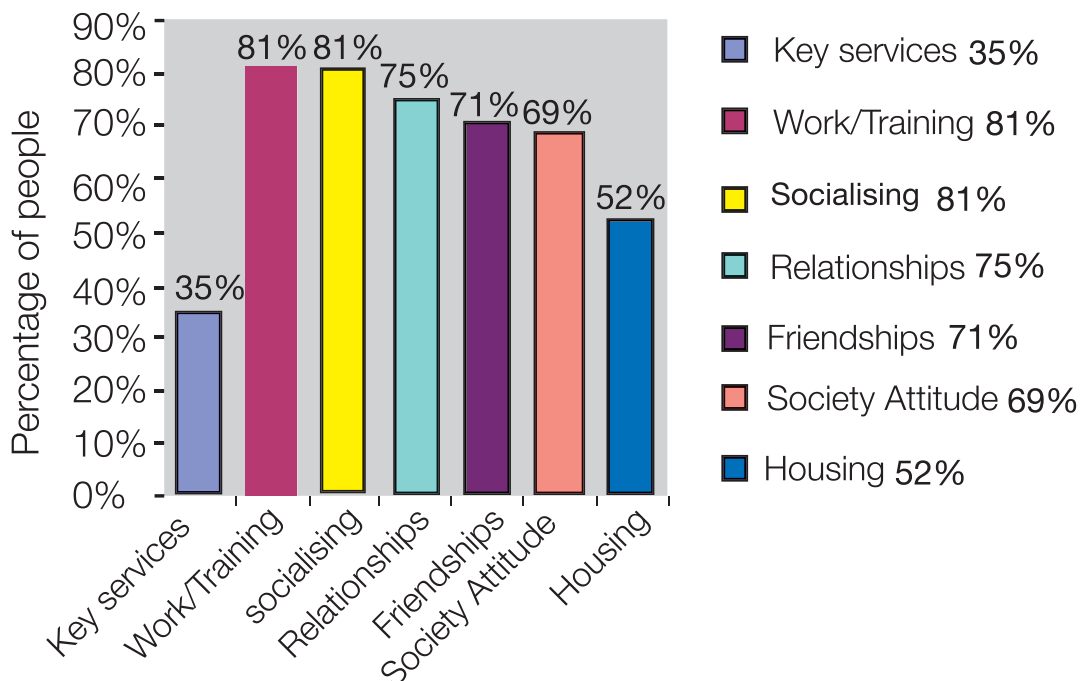
Section 3

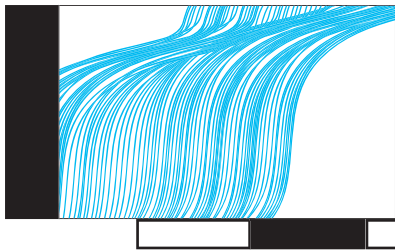


If there was a public conference for people with Asperger Syndrome, would you want to be part of it?



If yes, what subjects or issues would you like to be included?





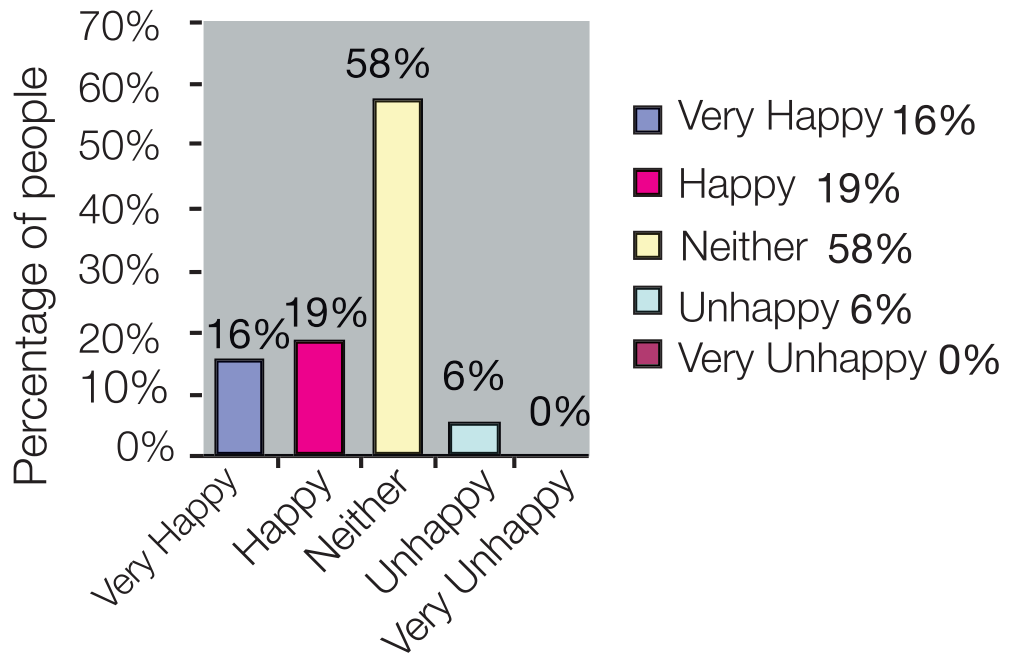
The Findings

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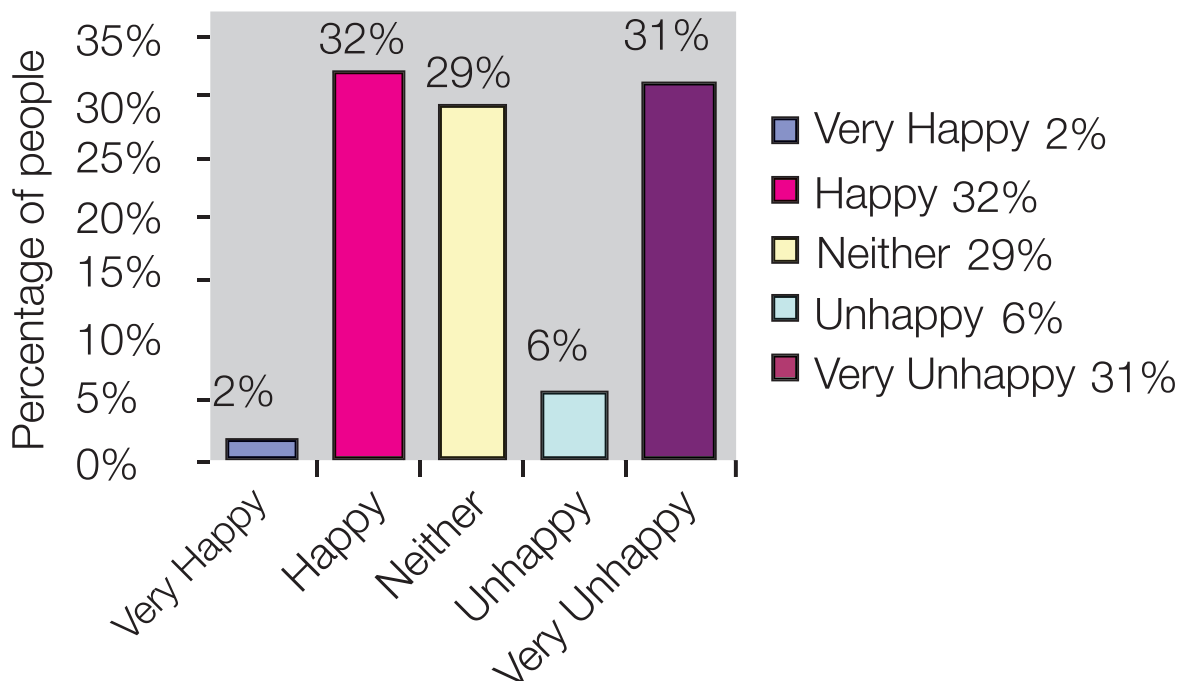


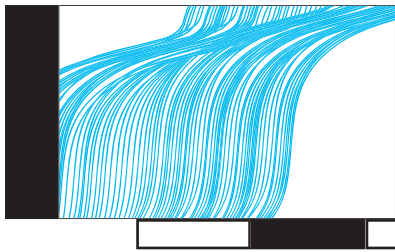
Are you happy with all the services you have?

National Autistic Society



Local Autistic Society





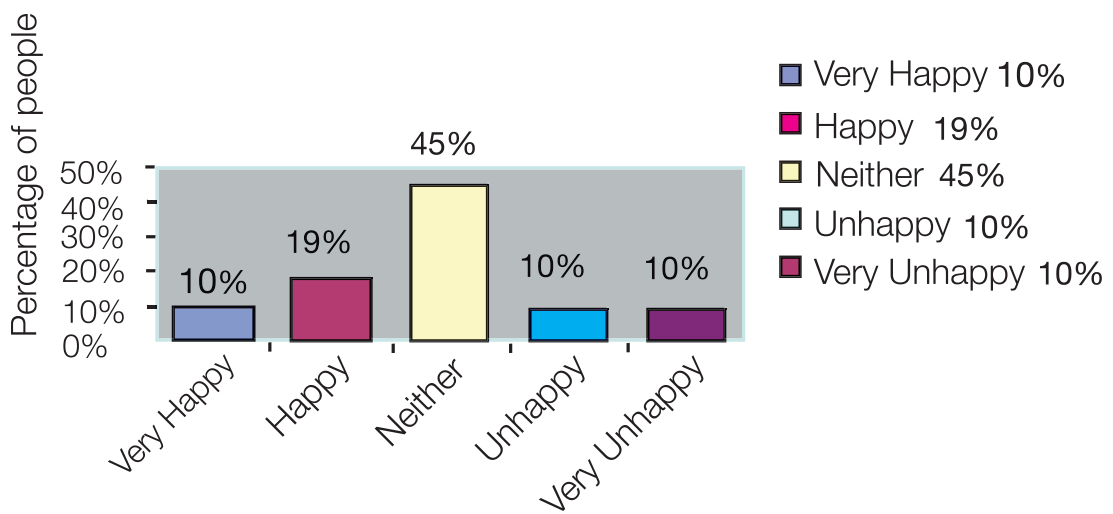
The Findings

Section 3

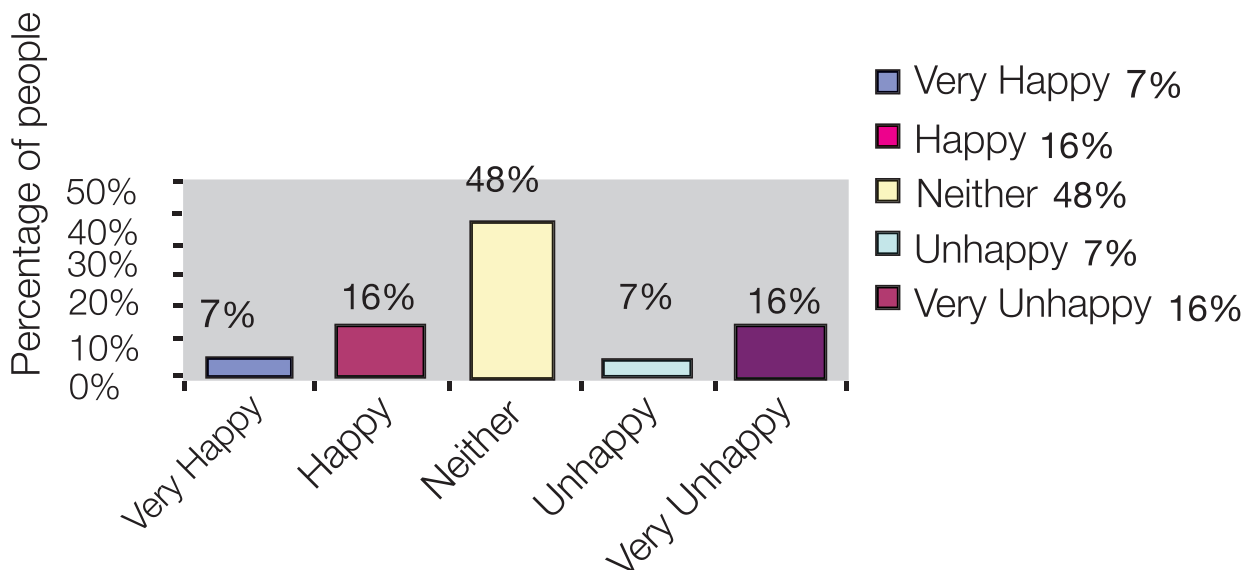


Are you happy with all the services you have?

Social Services

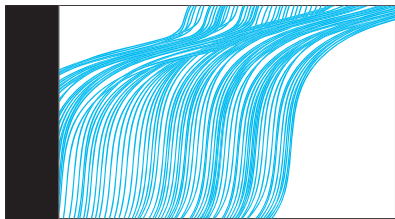


Mental Health Services

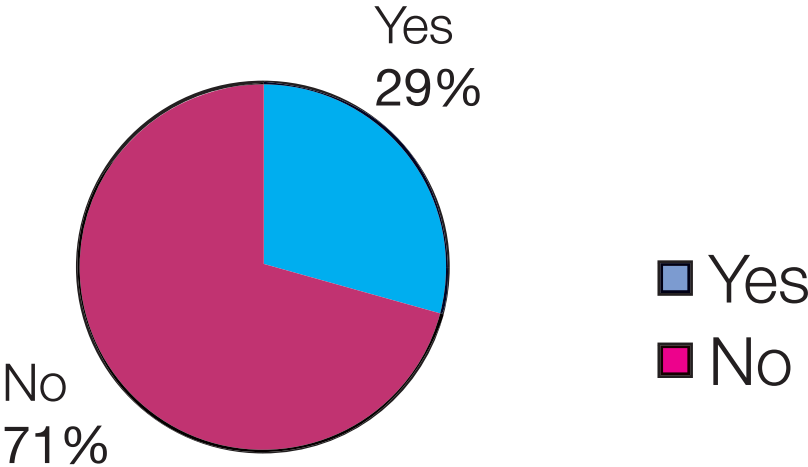


The Findings

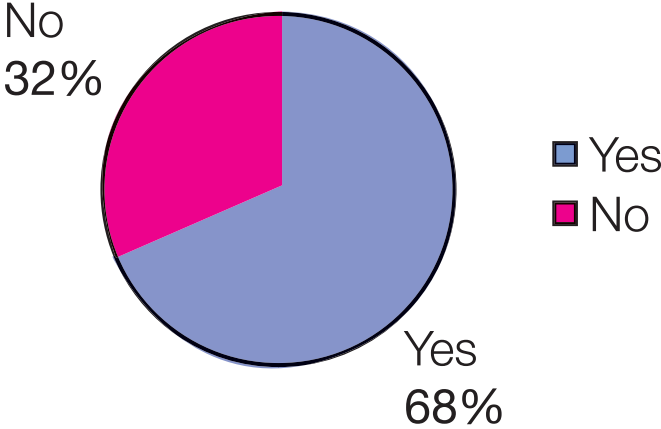
Section 3



Are you a National Autistic Society member

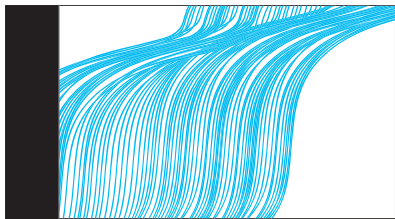


Are you a Local Autistic Society member

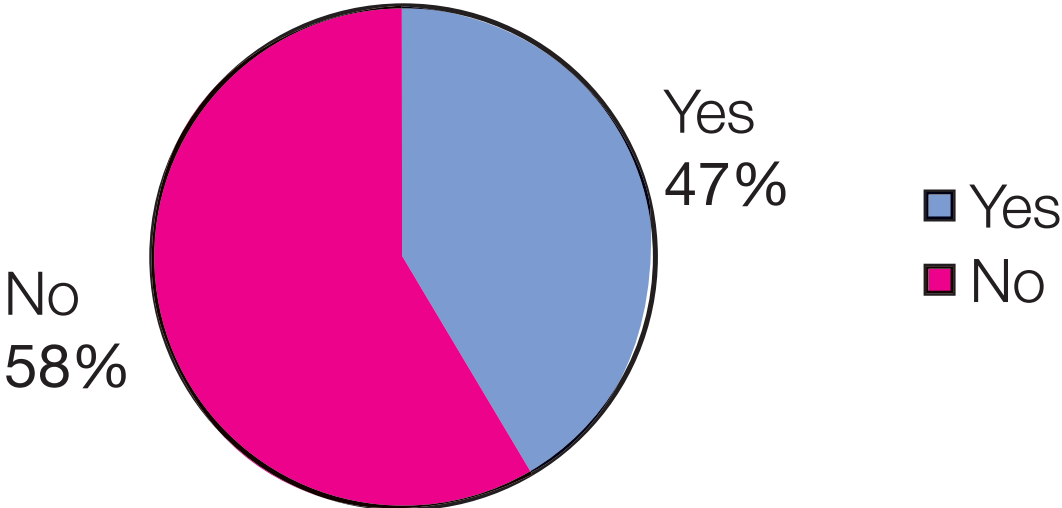


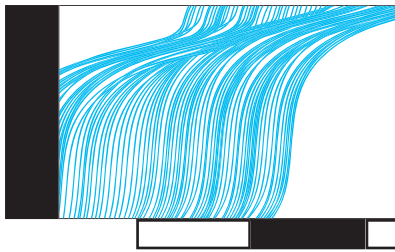
The Findings

Section 3



Do you currently have a Social Worker?



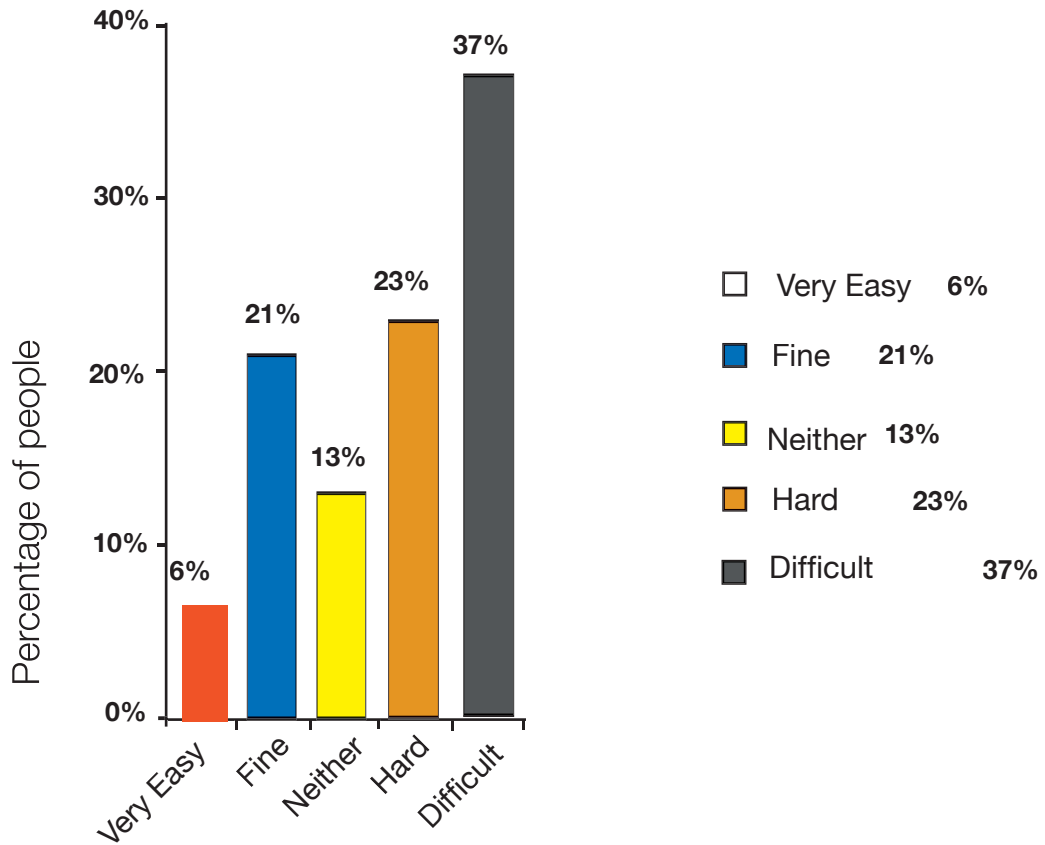


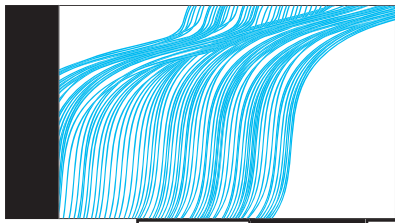
The Findings

Section 3



How easy is it for you to explain Asperger Syndrome to other people?



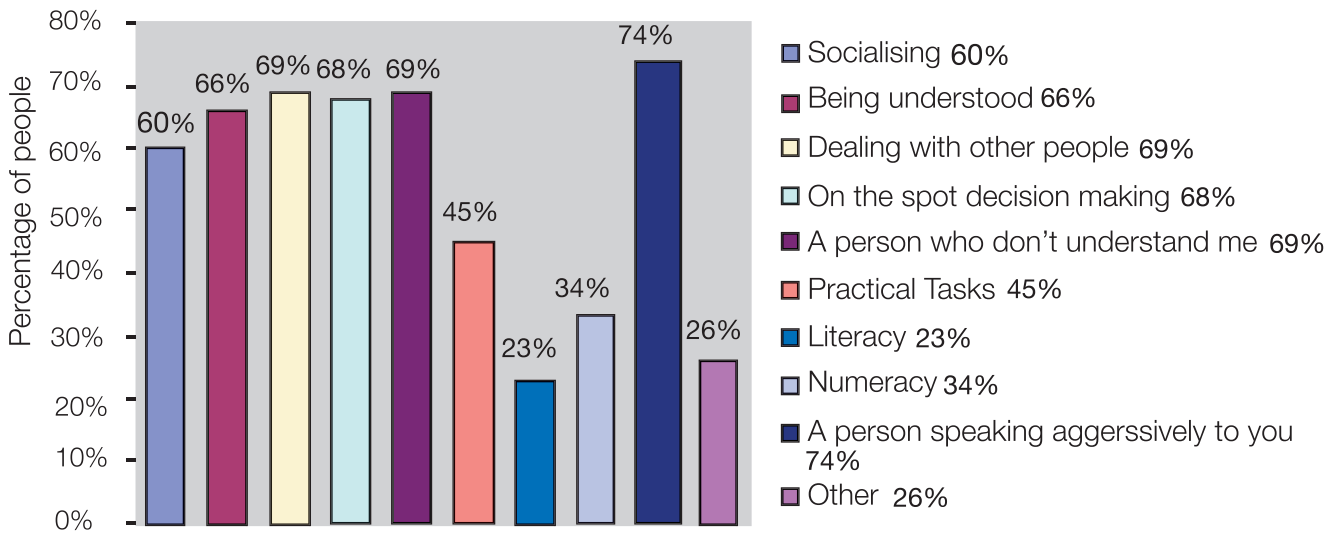


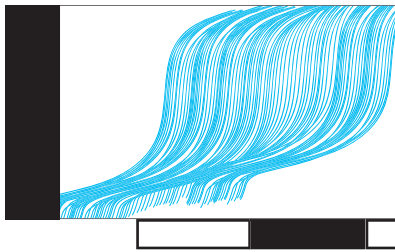
The Findings

Section 3



What subjects do you find difficult to manage?





An Analysis of findings

Section 4



This section of the report analyses the findings of the completed questionnaires. It is apparent that a large percentage of people with AS would like to attend a conference. However it is very important for a conference to focus on relevant issues. The relevant subjects that people with AS identified in the survey were Work/Training, Socialising, Relationships and Friendships. Various factors need to be taken into consideration when considering a conference for people with AS, particularly costs and accessibility. The prices need to be affordable and the venue needs to be accessible to good public transport links as well as car parking. It is important that the language used must be clear and concise and back up with visual support strategies to overcome difficulties with communication and memory retention.

From the completed survey questionnaires it is clear that the majority of those who have a strong opinion indicated a happy or neither response with National Autistic Society (NAS) however a high number of people are neither happy nor unhappy with the NAS and many were not members NAS. There may be many reasons why a high number of applicants of the survey were not members of the NAS, or had no preference as to whether they were happy or not happy with the service received. Below are possible reasons:

People may not have heard of National Autistic Society

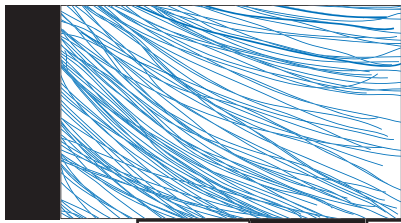
People may have heard of National Autistic Society but might not fully understand what they do.

People are not clear on how the National Autistic Society could help them.

With the Local Autistic Societies (LAS) many viewpoints are split between people who are happy, very happy, Unhappy and people who are neither happy nor unhappy. However the majority of the people are a member of the Local Autistic Societies. The numbers show individuals do have a closer links with their Local Autistic Society than with the National Autistic Society. However, a small number of people feel unhappier with their LAS than the NAS. This may be attributable to the fact that service delivery differs depending where you live.

The high number of people who took part are neither happy nor unhappy with Social services and Mental Health Services. Of the high numbers of those who do have a strong opinion there's a split between happy and unhappy. Once again this may be due to different service delivery depending where you live. Despite that there is an overall split between those who do or don't have a Social worker the percentage of number slightly higher for people who do not have a Social worker.

From the findings it is clear that people with AS have difficulty explaining about Asperger Syndrome. Closely behind the majority find it hard or don't find it a problem. This clearly shows there is a long way to go to spread autism awareness both to people with AS and others. The majority of people who responded to the survey feel that a person speaking aggressively to them is very difficult to manage. In addition people with AS find difficult being understood, dealing with other people, making on the spot decisions and interacting with people that do not understand them.



Recommendations

Section 5



Service User Involvement

People with Asperger Syndrome (AS) need to have a greater voice on the services they receive. People with AS should play an instrumental role in service and policy development and implementation, research agendas and decision-making. To ensure that National and Local Autistic Society Organisations agendas are focused on the needs of people with AS, they should utilise National and Local Service User Groups. Being involved with a National and/or Local Service User Groups will help influence and direct agendas and would enable people with AS to have a greater voice. From the Service User Group a person should be nominated as representative to advocate on behalf of the Service User Group and feedback outcomes.

National/Local Autistic Society Management Meetings



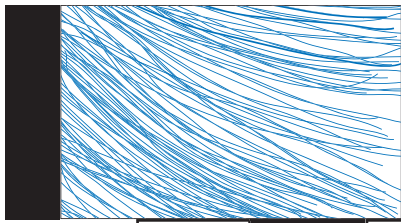
Nominated Service User Representative



National/Local Autistic Service user Group

Conferences and workshops

It is apparent that there exists the need to have Regional, National and Local conferences planned, organised and delivered by people with AS for people with AS. This will enable relevant topics to be addressed whilst permitting opportunities for networking sharing experience and knowledge. Knowing that you are not alone can be of great comfort. Within these conferences or separately people with AS could deliver workshops to other people with AS, family, carers, supporters and members of professional organisations. The examples of organisations that could benefit from workshops that increase awareness of AS are Police, Employers, Transport and Jobcentres.



Recommendations

Section 5



Education/Training

A new approach is needed to encourage understanding and increase awareness of AS for professionals, families, carers and supporters. This includes improving education materials. This does not mean just improving documents on paper but includes creating user-friendly education guides on the Internet, CD-Rom and DVD. People with Asperger Syndrome should take a pivotal role in developing educational materials to encourage understanding and increase awareness of AS.

Forums

Networking forums for people with Asperger syndrome and professionals at National, Regional and Local levels could be created to share knowledge and good practice. This idea is designed to have closer links with all the regions of the UK to work and learn from each other. However there are major personal security issues that would be needed to be addressed.

Help Line

As people with AS can have great difficulty communicating with others a Help Line specifically for people with AS, their families, carers and supporters could be a first point contact for help, guidance, advice and a listening ear. A specific contact point could help address issues if people are struggling and have problems with coping a situation and they feel they can't share it anyone. The National Autistic Society have recently relaunched their helpline however it is recommended that this available 24 hours a day, 7 days a week.

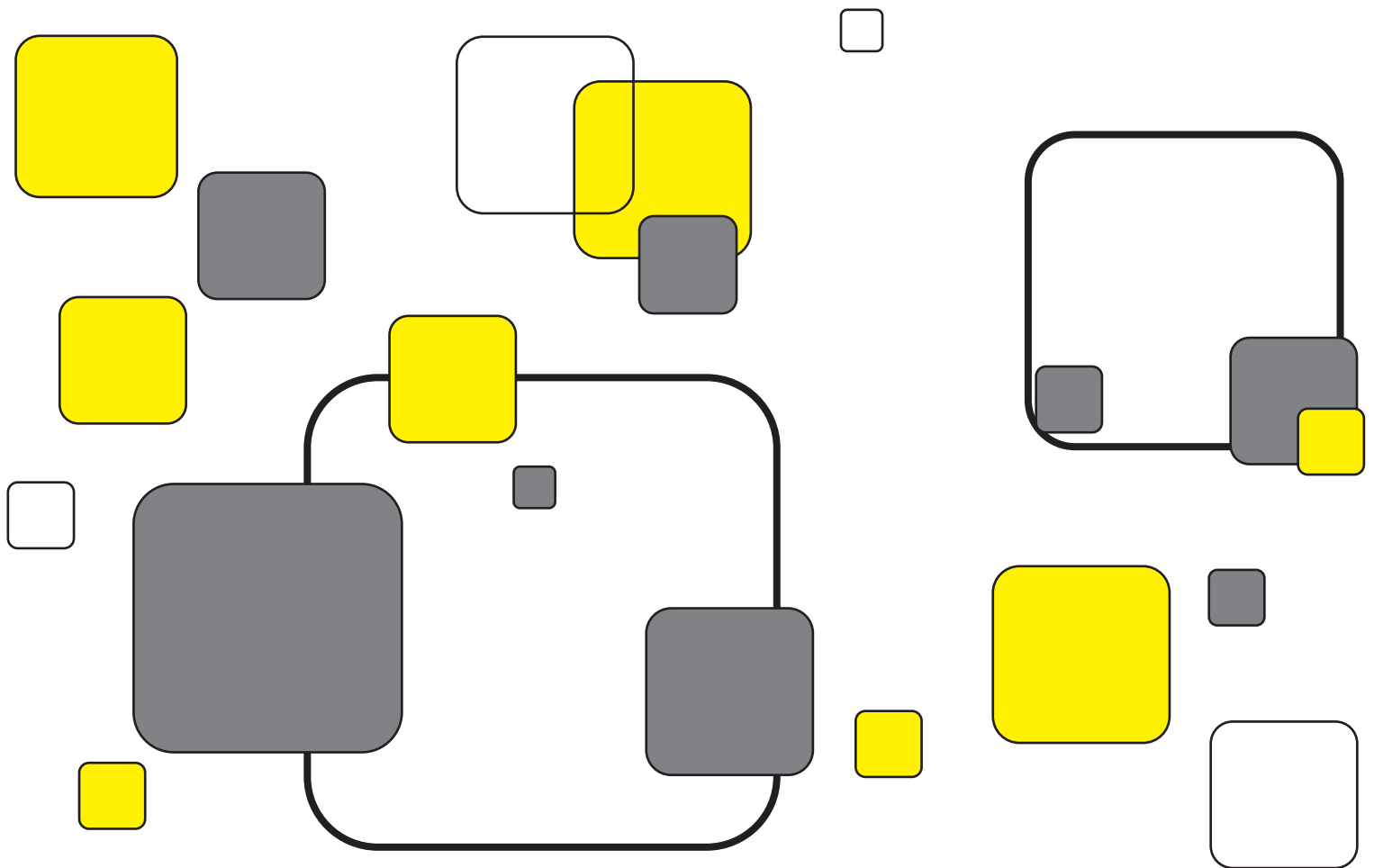
Dealing with Emergencies

Creating a summary of Asperger Syndrome information on a business card, which displays contact information of the local autistic society could be used in emergencies and in situations when people with AS could be wrongly blamed, when is not their fault. This would also overcome issues surrounding communication and interaction difficulties. autism.west midlands have piloted the personal information cards.

Empowering and Encouraging Personal Development

People with AS would benefit from having direct access for self-help / self-management based information systems. This information should be presented in a clear, legible manner, which uses language that does not intimidate the reader. The information should cover a variety of topics and social situations. For example topics could cover body language, developing a variety of communication styles and how to diffuse conflict situations. This self-help concept could be in different forms such as a CD-Rom and on the Internet. This concept will help people with AS and stop suffering in silence.

All Key Services need to encourage people with AS to develop their own support network with expanding more contacts. This includes more numbers of friends, acquaintances, people in their local community as well as improving family links. This will overcome long-term prospect of self-dependency on a small number of people and this can avoid jealousy and hostility. Improving independence and self-esteem will reduce social isolation.



autism challenge

Autism Challenge is a Personal Development initiative by Keith Mckenzie
This survey is created by Keith Mckenzie with assistance from autism.west midlands
April 2004
E-mail: keith_mckenzie@talk21.com