The National Autistic Society

NORTH YORKSHIRE REPORT- INITIAL ENGAGEMENT WITH PEOPLE WITH AUTISM AND THEIR FAMILIES

March 2013

CONTENTS

Chapters

BACKGROUND

North Yorkshire County Council and North Yorkshire and York PCT commissioned the National Autistic Society to carry out a series of initial engagement events and survey in relation to the needs and experiences of adults with autism and Asperger syndrome and their obligations in relation to the Autism Act 2009 statutory guidance. The project has been carried out across the NYCC geographical footprint. North Yorkshire County Council and North Yorkshire and York PCT have been leading on the implementation of the local autism strategy and this is a joint piece of work across the organisations.

The Autism Act 2009 statutory guidance covers 4 areas:

- Training of staff who provide services to adults with autism
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Planning in relation to the provision of services to people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism

Autism is a lifelong development disability which affects the way the person understands the world around them. All people with autism have difficulty in social communication, social interaction and flexibility of thought, although to varying degrees. Many people with autism also have sensory difficulties.

In North Yorkshire, there could be as many as 3,500 young people over 18 and adults living with autism and Asperger syndrome, using the national prevalence figure of 1 in 100. Not all of these people will come in to contact with local services and for those that do, their needs will vary quite significantly.

WHAT IS AUTISM?

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Throughout this report, the term ‘autism’ will be used to incorporate all autism definitions including Asperger syndrome.

POLICY CONTEXT

Over recent years, autism has started to come to the fore in best practice guidance and policy documents. They have provided information and direction about how and why things can and should be done differently. They have incorporated a variety of perspectives; the individual and their family's well being, the service provider and how they can improve the services they provide and the financial aspect – how can we use money more effectively to meet growing need.

I Exist 2008

In 2008, the NAS launched a campaign to highlight the needs of adults with an ASD. The campaign and accompanying report are called, *I Exist.*

Over 1400 people responded to a survey about the needs of adults with an ASD. The survey found that: -

- 63% of adults with autism do not have enough support to meet their needs. Of those:
  - 82% say that with more support they would be less isolated
  - 79% say that with more support they would be able to do the things they want to do
  - 70% say that with more support they would be more independent.

- The consequences of this lack of support mean that:
  - two thirds of adults (67%) say they have experienced anxiety because of a lack of support
  - one third of adults (33%) say they have experienced serious mental health problems because of a lack of support.

- Over 60% of adults with AS or high-functioning autism say that they have experienced problems in trying to receive support from their local authority and/or health services. Of these, 52% were told that they do not fit easily in to MH or LD services.

- 60 % of parents say that a lack of timely support has resulted in their son or daughter having higher support needs in the long term

- 82% of parents and carers say that their son or daughter needs some level of daily support to live independently

Autism Act, strategy & statutory guidance *Fulfilling and Rewarding Lives* 2009/10

The Autism Act was passed in 2009 and was followed in March 2010 by, ‘Fulfilling and Rewarding Lives’: The strategy for adults with autism in England. In December 2010, Implementing ‘Fulfilling and Rewarding Lives’: Statutory Guidance for local authorities and NHS organisations to support the implementation of the autism strategy was published.
This committed to an initial three-year strategy
focusing on:

1. increasing awareness and understanding of autism among frontline professionals
2. developing a clear, consistent pathway for diagnosis in every area
3. improving access for adults with autism to the services and support they need
4. helping adults with autism into work, and
5. enabling local partners to plan and develop appropriate services for adults with autism.

Following the introduction of the new, outcomes-focused policy framework, in April 2011 a new set of seven outcome goals and three ‘service ambitions’ was established against which progress in these respects could be assessed.

Quality outcomes:

1. Adults with autism achieve better health outcomes
2. Adults with autism are included and economically active
3. Adults with autism are living in accommodation that meets their needs
4. Adults with autism are benefiting from the personalisation agenda in health and social
care, and can access personal budgets
5. Adults with autism are no longer managed inappropriately in the criminal justice system
6. Adults with autism, their families and carers are satisfied with local services
7. Adults with autism are involved in service planning.

Service ambitions:
1. Local authorities and partners know how many adults with autism live in the area
2. A clear and trusted diagnostic pathway is available locally
3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.
Whilst these outcomes are not intended to establish a new national dataset or central monitoring framework, they provide a clear and consistent basis for local authorities and their local stakeholders to evaluating their progress.

Essentially, the statutory guidance is the driver for this piece of work. As such, this report follows the five key outcome themes of the policy framework, along with other areas affecting the lives of people with autism, their families and others involved in their lives.

SEN & Disability Green Paper *Support and aspiration: a new approach to special educational needs and disability*

Preparing for adulthood

A significant proposal in the Green Paper is the extension of the Education, Health and Care Plans, which are to replace statements for young people up to the age of 25.

The Green Paper also highlights the importance of ensuring that young people with a disability are supported into work and that work experience is made available for them.

The Government says that it wants to ensure that by 2015 disabled young people and young people with SEN will have:

- early and well integrated support for and advice on the birth to 25 single assessment process.
- access to better quality vocational and work related learning opportunities to enable young people to progress in their learning post 16.
- good opportunities and support in order to get and keep a job
- a well co-ordained transition from children's to adult health services

NICE Guidelines 2012

In June 2012, National Institute for Health and Clinical Excellence (NICE) published the guideline, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. The guideline is rightly placed in the context of the Autism Act 2009, the autism strategy and statutory guidance. For this reason, it will also be referred to throughout this paper.

NHS Standard Contract

The Standard Contract for Mental Health and Learning Disabilities Services Contract 2010/2011 explicitly requires service providers to describe the reasonable adjustments they are making for people with autism.

‘People with learning disabilities and/or autistic spectrum conditions (ASC) should be able to access mainstream services when necessary: Reasonable adjustments are made to services to allow access to mainstream mental heath and other services as necessary.’

‘Primary and secondary diagnostic data will need to be collected to assess how people with learning disabilities and/or ASC access services. The capacity of local services to collect and report the required diagnostic data may need to be linked to the Data Quality Improvement Plan in order to collect:

- Number of people with mild or moderate learning disabilities/ASC using specialist mental health services with learning disability/ASC as a primary diagnosis – separate reporting on a) inpatients and b) service users in other settings
- Number of people with mild or moderate learning disabilities/ASC using specialist mental health services with learning disability/ASC as a secondary diagnosis – separate reporting on a) inpatients and b) service users in other settings

Local Data

Nationally, around 20.8% of statements of SEN are for autism. In North Yorkshire, this figure has risen over the last 2 years and in 2012 was 23.3%. Autism is the most common primary need among pupils with a statement of SEN in North Yorkshire.

According to the SEN Code of Practice, the proportion of children at School Action Plus (SA+) for autism in North Yorkshire is higher than that observed nationally. Children with autism at SA+ account for 4.8% of the SA+ population in North Yorkshire (4.6% observed nationally).

The current age profile for children with a statement for autism shows peaks around the age of 6 to 7 years old, 10 to 11 years old and 13 to 14. This may indicate that transition to Year 1 and from Key Stage 2 to Key Stage 3 is a focal point when schools, and parents, may become concerned at a child's progress.

Below are the figures from the Projected Adult Needs & Service Information system (PANSI).

North Yorkshire

People with autism	2012	2015	2020	2025	2030
18-24	485	457	414	408	440
25-34	610	661	681	647	610
35-44	699	647	653	742	770
45-54	889	876	785	684	698
55-64	808	805	883	895	812
Total	3,491	3,445	3,416	3,376	3,330

Source: www.pansi.org.uk

The information about ASD is based on *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007* was published by the Health and Social Care Information Centre in September 2009.

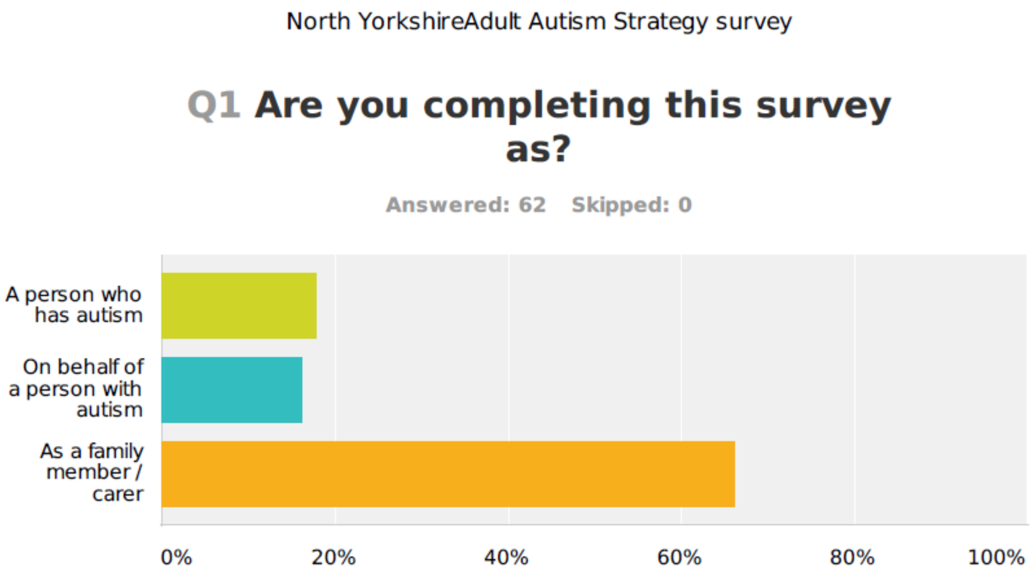
The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case.

Engagement Events

The National Autistic Society was commissioned to undertake four initial engagement events in the following geographical areas:
There were a total of 72 people who attended the events:
Selby- 4, Scarborough-23, Harrogate -29, Northallerton-16.
An online survey was available simultaneously for North Yorkshire residents over 14 years old with Autism, their family members, carers and adults with Autism. The online survey attracted 62 respondents.

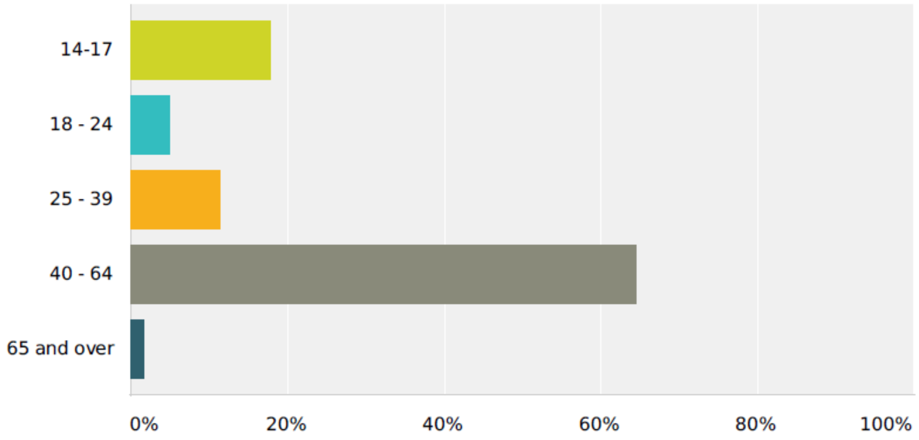
The events were publicised widely across the county including statutory agencies and voluntary/third sector organisations.

The breakdown of respondents is as follows:



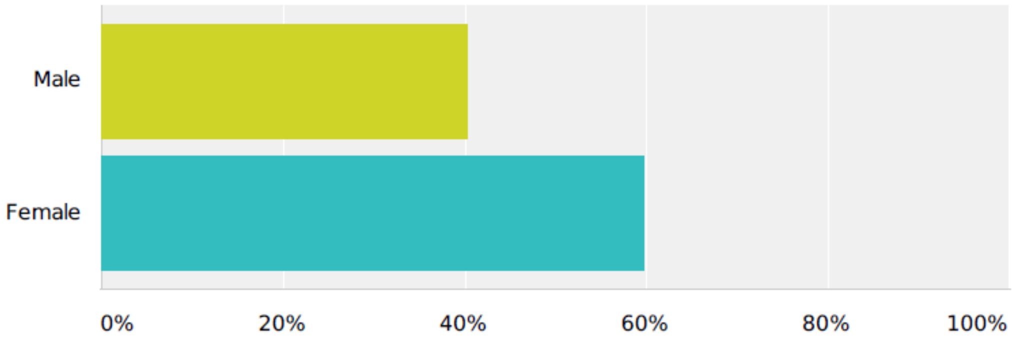
Q2 How old are you?

Answered: 62   Skipped: 0



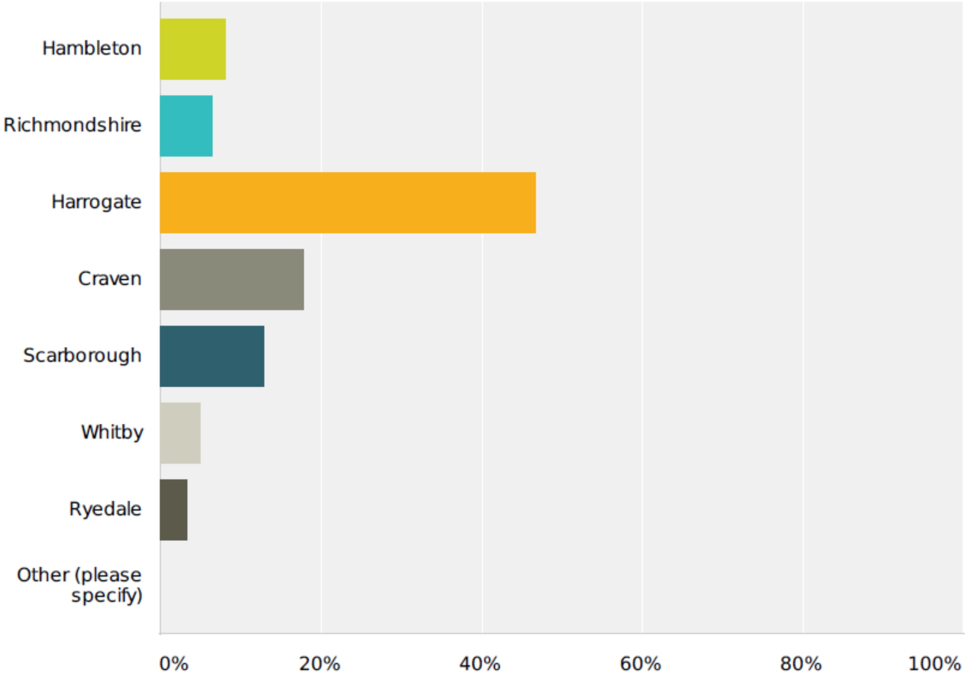
Q3 Are you:

Answered: 62   Skipped: 0



Q5 Where do you live?

Answered: 62 Skipped: 0



CHAPTER 1: INCREASING AWARENESS AND UNDERSTANDING OF AUTISM AMONG FRONTLINE PROFESSIONALS.

What the statutory guidance says:

- Local authorities, NHS bodies and NHS Foundation Trusts should seek ways to make autism awareness training available to all staff working in health and social care. In line with the principles set out in *Fulfilling and Rewarding Lives,* as a minimum, autism awareness training should be included within general equality and diversity training programmes.

- The core aims of this training are that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics.

- Those staff who are most likely to have contact with adults with autism are the priority groups for training.

- In addition to general autism awareness training for staff, local areas should develop or provide specialist training for those in key roles that have a direct impact on access to services for adults with autism – such as GPs or community care assessors – and those whose career pathways focus on working with adults with autism, such as personal assistants, occupational therapists or residential care workers. The end goal of this specialist training is that, within each area, there are some staff who have clear expertise in autism.

The NICE guideline also says:

9.1.1.2 All staff working with adults with autism should have an understanding of the:

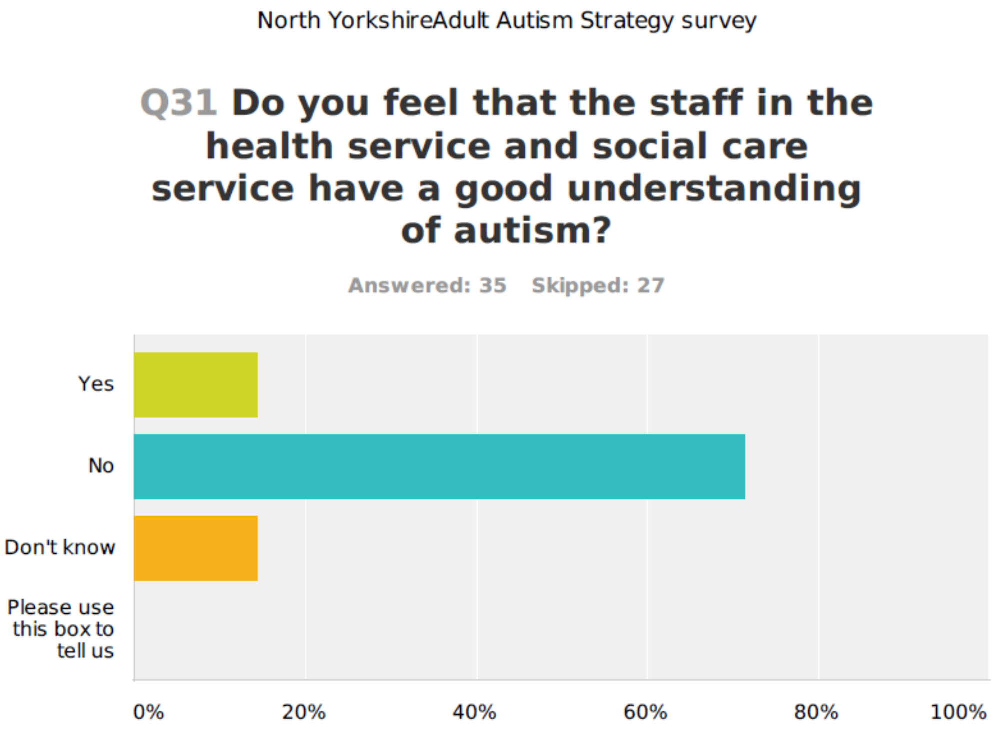
- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of the social and physical environment.

9.1.1.3 All health and social care professionals providing care and support to adults with autism should have a broad understanding of:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of and interaction with the social and physical environment
- impact on and interaction with other coexisting mental and physical disorders and their management
- potential discrepancy between intellectual functioning as measured by IQ and adaptive functioning as reflected, for example, by difficulties in planning and performing activities of daily living including education or employment.

Local Picture

The perceived level of understanding of autism in the professionals that came in to contact with people completing the online survey and attending the engagement event varied quite considerably:



At the engagement events there was a mixed view of what was working and not working.

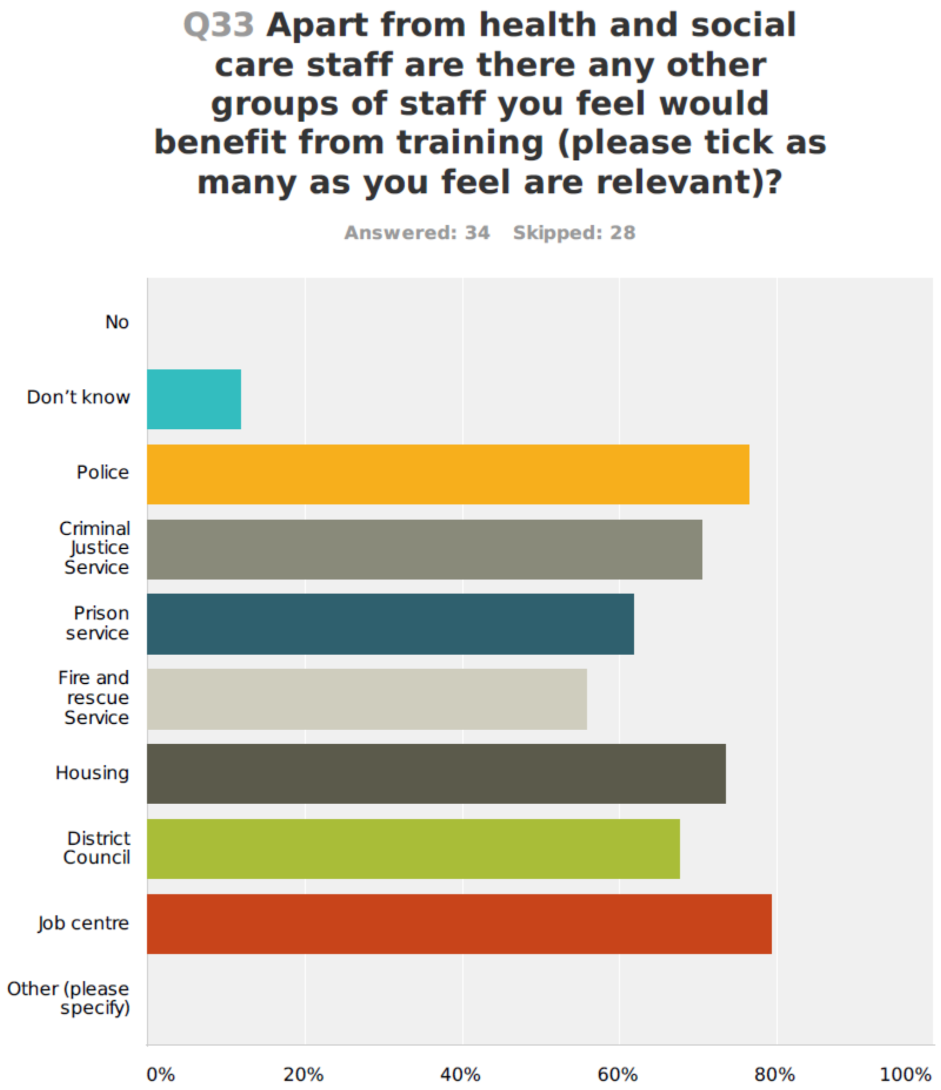
Positive comments

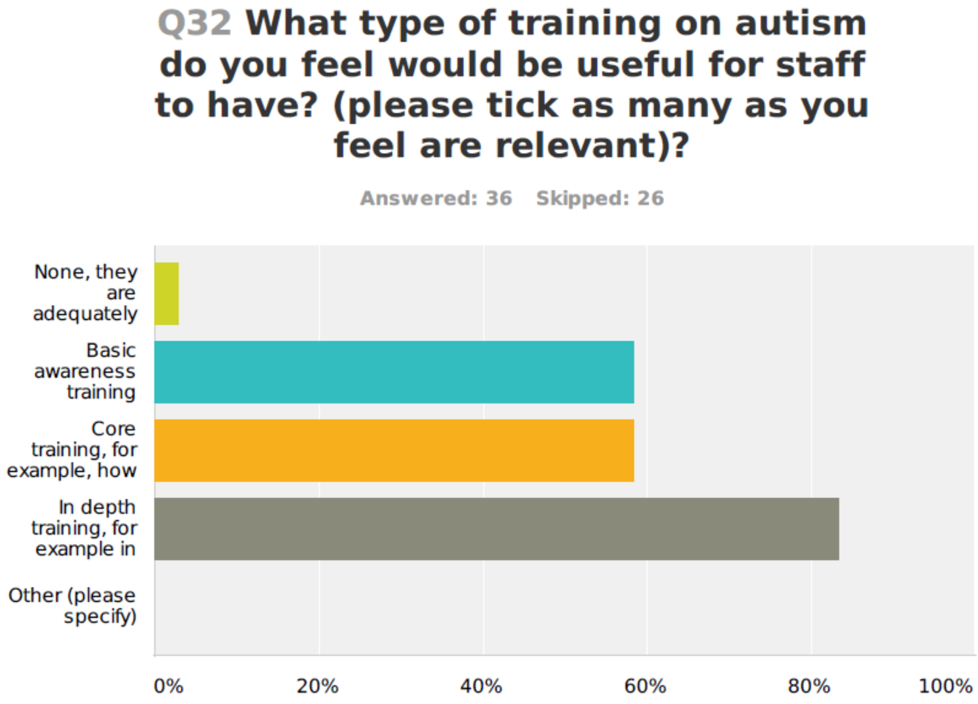
- The National Strategy had raised awareness
- Evidence of training taking place
- Evidence of training being “standardised” and accredited.

Areas for improvement

- The lack of awareness amongst GP’s
- Autism being “stereotyped” a one size fits all approach.
- A strong view that people with autism should be involved in delivering training including real life stories
- carer/family training post diagnosis
- Condition management type of training for adults newly diagnosed.
- Training should be mandatory for all front line staff in social care and health.

- Training to be extended to other public services used by people with autism eg: Job centres, libraries, leisure centres and Police staff .
- Training for staff in non special schools and colleges, including teaching assistants.
- Training should help agencies to recognise autism in girls and women.





"Employers need a training package and definitely more INFORMATION available locally"

It was raised at the consultation events that housing providers would benefit from autism training, in order to understand the difficulties tenants with autism find themselves in or may create.

CHAPTER 2: DEVELOPING A CLEAR, CONSISTENT PATHWAY FOR DIAGNOSIS IN EVERY AREA, FOLLOWED BY THE OFFER OF A PERSONALISED NEEDS ASSESSMENT

What the statutory guidance says:

For health and social care
From identification to diagnosis

- … it is important that staff across health and social care receive autism awareness training so that they are better able to identify potential signs of autism.

The aim of this training is that staff can:

    - inform the person who may have autism, or their families or carers, about the availability of diagnosis, and direct them appropriately if they want to access diagnosis – for example, explaining how they can get formally referred for diagnosis
    - make reasonable adjustments to the way they provide services to the person who may have autism.

- Each area should put in place a clear pathway for diagnosis of autism, from initial referral through to assessment of needs. An important starting point will be to review the current pathway to diagnosis in their area or organisation. Where there is an effective pathway locally, which has the support of clinicians and adults with autism, their families and carers; this should form the foundation of any further changes.

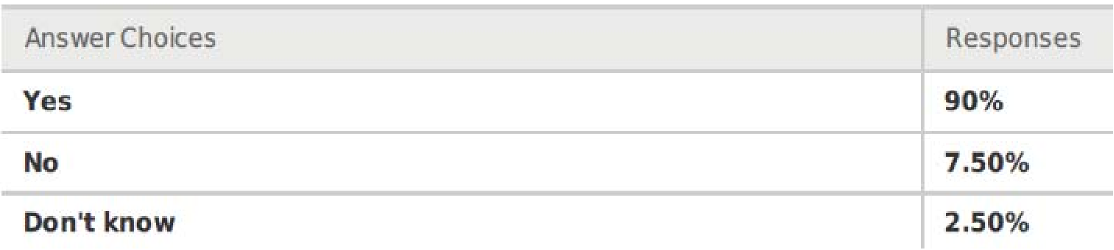
- The NICE clinical guideline for adults with autism was published in July 2012. In order to be able to implement the guidance in full , NHS bodies and NHS Foundation Trusts that commission or provide diagnostic and assessment services need to review their diagnostic processes and services against NICE's best practice guidance. The aim of this is to make the diagnostic process more accessible and consistent.

- It is important that all relevant local organisations such as social care teams understand what the pathway to diagnosis is.

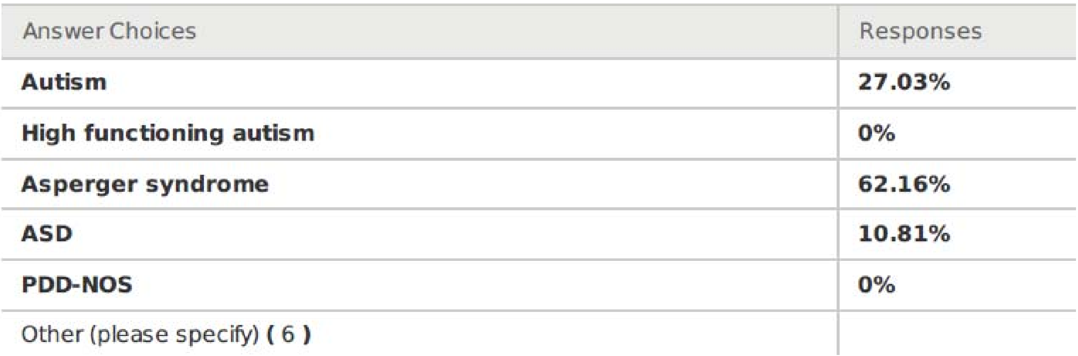
Local Picture

There was a high degree of consistency within the experiences described at the engagement events with the responses on the online survey.

Q10 . Do you / or the family member or cared for person have a formal diagnosis of autism?

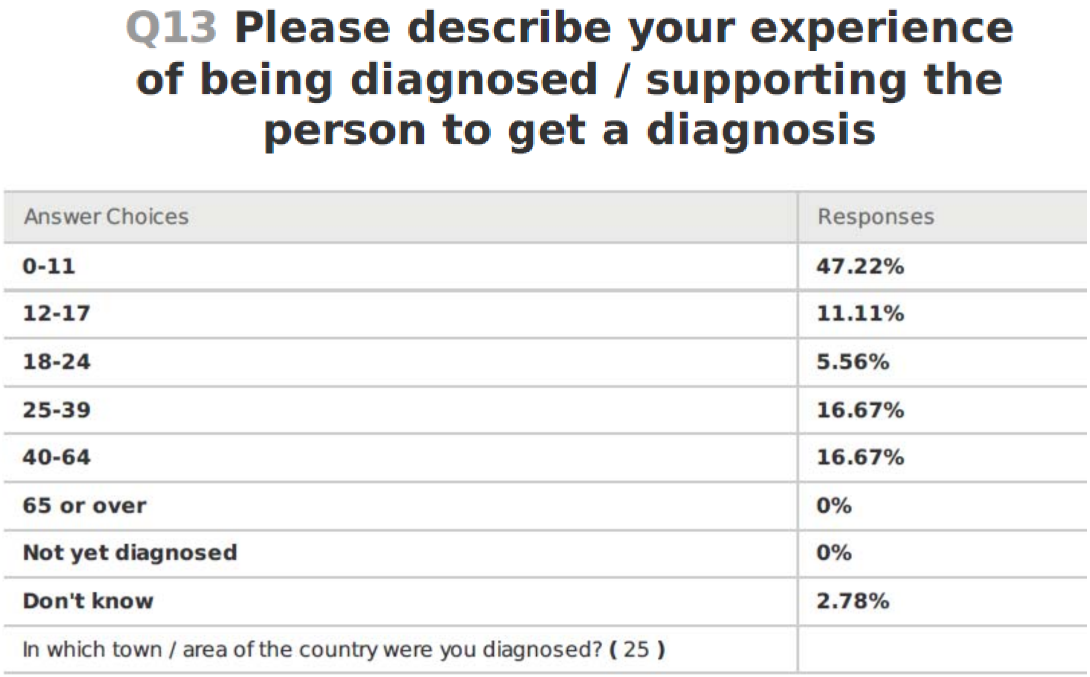


Answer Choices	Responses
Yes	**90%**
No	**7.50%**
Don't know	**2.50%**



Answer Choices	Responses
Autism	**27.03%**
High functioning autism	**0%**
Asperger syndrome	**62.16%**
ASD	**10.81%**
PDD-NOS	**0%**
Other (please specify) **(6)**	

Additional answers included learning difficulties, dyspraxia and chronic bowel condition.



Q13 Please describe your experience of being diagnosed / supporting the person to get a diagnosis

Answer Choices	Responses
0-11	47.22%
12-17	11.11%
18-24	5.56%
25-39	16.67%
40-64	16.67%
65 or over	0%
Not yet diagnosed	0%
Don't know	2.78%
In which town / area of the country were you diagnosed? (25)	

From 25 responses the question “in which town” 14 were diagnosed within the county, 5 in Sheffield, 2 in Keighley, West Yorkshire, 1 in Bromley, 1 in Airedale and 1 in Chester and 1 in Huddersfield

Positive comments

- Positive experiences highlighted from a variety of professionals despite there being a clear pathway
- diagnosis experience for children

Areas for improvement

- Out of county diagnosis
- Lack of post diagnosis support
- Professionals unclear about pathway
- Length of time to receive a diagnosis
- Early recognition by GP and School staff and other frontline staff
- Issues were raised about people with AS falling between mental health and LD services
- The statutory duty to receive an assessment needs to be publicised

Selection of online responses:

“The whole process was horrific and it was a great problem to have to travel 60 miles each way to Sheffield. Prior to this, with hindsight, it is remarkable that the medical people attending me over the previous 14 years had not noticed the obvious documented signs of autism/Aspergers”

“We were very lucky. Co-operative GP was a fund holder at the time and agreed to pay for diagnosis by NAS”

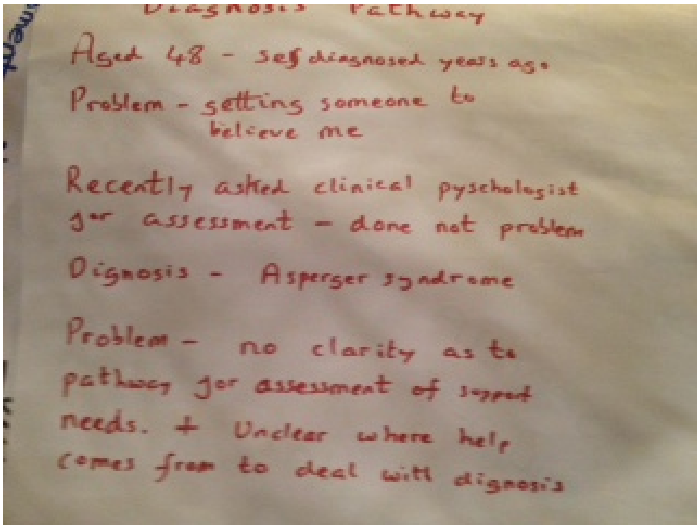
“Referred to Child development centre by a private ENT consultant after no one took me seriously when I had expressed my concerns for my child. Once referred diagnosis was quite straightforward and quick-problems were in getting initial referral.”

“GP unable to find anyone who could diagnose me on NHS so paid for myself privately (£1000). A gruelling experience but very relieved to have result as it explains basically everything, my whole life experience and difficulties”

Selection of responses for engagement events

“A19 year old has recently been told he must wait a year for an autism assessment in Scarborough”

“Personalised needs assessments do not exist for adults with Aspergers! There should be follow up once diagnosed-do not leave us alone its cruel!”



Diagnosis Pathway
Aged 48 - self diagnosed years ago
Problem - getting someone to
believe me
Recently asked clinical pyschologist
for assessment - done not problem
Dignosis - Asperger syndrome
Problem - no clarity as to
pathway for assessment of support
needs. + Unclear where help
comes from to deal with dignosis

“Why do we have to go miles away for a diagnosis?”

“We need a full diagnostic service, post diagnostic support with agreed plan based on peoples needs”

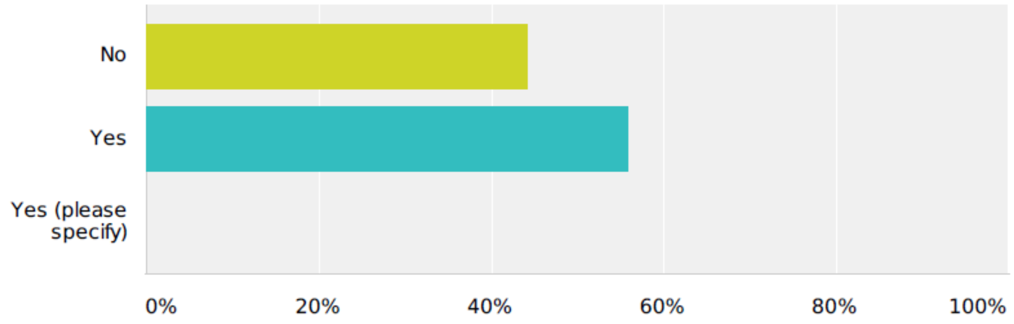
Q14 How could the process of being diagnosed be improved?

Selection of online responses:
“Earlier diagnosis , more expertise , please also tell parents what is suspected even though not formally diagnosed ; there was a reluctance to use the word autism , though it is now clear that this is what all the medics thought . Also the way in which the large team meetings are held is awful for parents - much smaller would be better with consultant only.”
“All GPs and mental health staff should be much better taught how to look out for signs of autism/Aspergers rather than pushing powerful mental health drugs into people. All cities and major towns should have an autism diagnostic centre.”
“FASTER! Initially I was told that I'd be 'assessed' in Harrogate and the probably be referred to somewhere like Sheffield...and that the process could take anywhere up to 4 years. Can you imagine how frustrating that is?”
“I saw my GP, several CPNs, 2 psychiatrists and a psychologist at regular intervals and over a period of six years (whilst suffering awful physical symptoms) not one of them had a clue what the cause was. There should be much more done to raise awareness about autism in girls and women.”
“more localised and more timely”

At the engagement events there were a few suggestions about what could be improved. Transition into adult services needs to be better, most found this experience difficult. Overwhelmingly the support post diagnosis was discussed as being inadequate, due to a lack of understanding of the impact on people’s lives.

Q15 Did you receive any support or advice following your / the diagnosis?

Answered: 34 Skipped: 28



Some of the online Yes answers:

"my superb psychotherapist on "as needed" basis. GP style. She has now retired and I am left "unattended"

"other than GP prescribing anti-depressants at my request. Managed to access 10 free counselling sessions through a workplace scheme, but not specific to Aspergers"

"Been on Cygnet course. As parents we attend AWARE (Airedale and Wharfedale Autism Resource) monthly meetings and National Autistic Society Keighley and Worth Valley group support monthly meetings."

Q16 What advice and support would have been useful?

Positive comments

- The strategy has raised awareness and more information was generally available.
- The NAS publications

Areas for improvement

- More public information
- More information for people who do not meet LA eligibility criteria

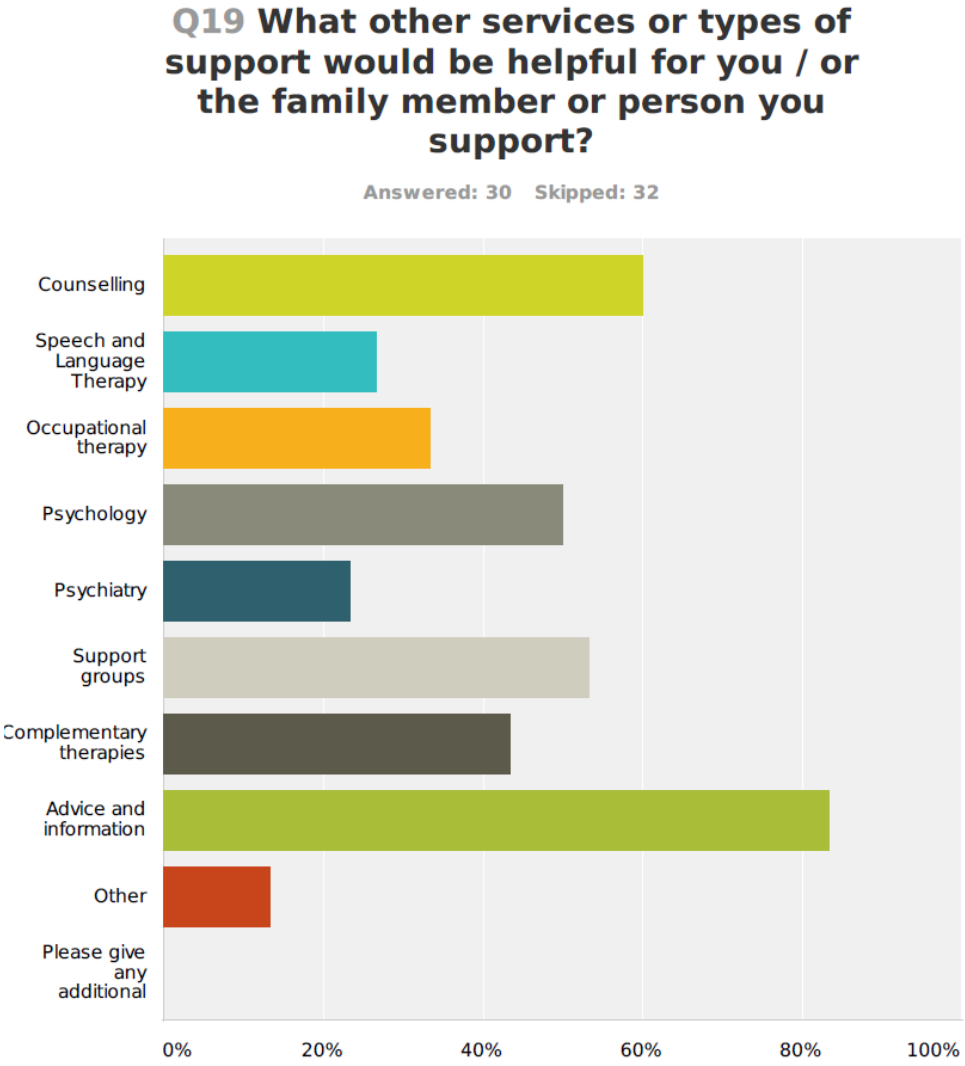
- Employment
- Information on how to access support for university or colleges

Selection of online responses

“Clear straightforward information about the condition, it’s effects on the person and their families /carers, help and direction regarding services available, advice about financial support if required and emotional support to come to terms with the diagnosis.”

“Key worker assigned to support the family.”

“Counselling to put things into perspective. When getting a diagnosis in adult life you often find that you need to "reframe" your life events/history in the context of that diagnosis and this can be really unsettling. However, it can also be a slow process, happening months after the actual diagnosis takes place. More information about the implications for those who are not managing to live a full and varied life.”



Both the online survey (83%) and engagement events views were highlighting advice and information as most needed.

CHAPTER 3: IMPROVING ACCESS TO THE SERVICES AND SUPPORT WHICH ADULTS WITH AUTISM NEED TO LIVE INDEPENDENTLY WITHIN THE COMMUNITY

What the statutory guidance says

What this means for health and social care

• Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area.

• Local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually.

• The commissioning of services should take account of the need for appropriate services such as care and support, travel training, etc.

• To develop such plans, it will typically be necessary to gather information locally about:

- The number of adults known to have autism in the area
- The range of need for support to live independently
- The age profile of people with autism in the area – including those approaching 65 or above working age and the number of children approaching adulthood, to enable local partners to predict how need and numbers will change over time.

• In addition, it will also be valuable for local authorities to collect information about the numbers of adults with autism who are:

- in employment in the area
- likely to need employment support in order to work
- placed in the area (and funded by) other local authorities
- placed out of area by local authorities
- in hospital or living in other NHS-funded accommodation
- resettled from long-stay beds or NHS residential campuses to community
- provision
- living at home on their own, or with family members, and not receiving health or
- social care services, or
- living with older family carers.

• It will also be useful to gather information about the ethnicity, gender, religion or belief and sexual orientation of adults with autism so that local authorities, NHS bodies and NHS Foundation Trusts can understand the numbers of people from different backgrounds with autism.

• In developing these plans, local authorities, NHS bodies and NHS Foundation Trusts should consider the role of family carers and the support they need. Consideration should also be given to the role of the Big Society – in particular, local community and volunteer groups – in delivering services to meet the needs of adults with autism, their families and carers.

- Local commissioning plans should set out how the local authority will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of social care. As part of this, it will be important to consider the practical challenges involved in granting more choice to adults with autism, drawing on the principles set out in the Mental Capacity Act 2005.

- All local authorities, NHS bodies and NHS Foundation Trusts who provide mental health and learning disability services are recommended to review the DH guidance about the adjustments to service delivery to include adults with autism.

- All local authorities, NHS bodies and NHS Foundation Trusts and organisations with whom they have contracted to provide services are expected to take into account the views of adults with autism and their families and carers in developing and commissioning services for adults with autism. In some cases, this may require the use of advocates to speak on behalf of adults with autism.

- The DASS in each area is responsible for:
    - developing the area’s commissioning plan around services for adults with autism, using the best available information about adults with autism in the area
    - appointing a joint commissioner/senior manager who has in their portfolio a clear commissioning responsibility for adults with autism
    - ensuring that the views of adults with autism and their carers are taken into account in the development of services locally.

NICE Guideline says:

9.1.1.6 All health and social care professionals providing care and support for adults with autism and their families, partners and carers should ensure that they are:

- familiar with recognised local and national sources (organisations and websites) of information and/or support for people with autism
- able to discuss and advise on how to access and engage with these resources.

9.1.1.7 Encourage adults with autism to participate in self-help or support groups or access one-to-one support, and provide support so that they can attend meetings and engage in the activities.

9.1.1.12 In order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers.

9.7.1.2 Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway.

ENABLING LOCAL PARTNERS TO PLAN AND DEVELOP APPROPRIATE SERVICES FOR ADULTS WITH AUTISM TO MEET IDENTIFIED NEEDS AND PRIORITIES

Developing local care pathways

9.7.1.1 Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:

- negotiable, workable and understandable for adults with autism, their families, partners and carers, and professionals
- accessible and acceptable to all people in need of the services served by the pathway
- responsive to the needs of adults with autism and their families, partners and carers
- integrated so that there are no barriers to movement between different levels of the pathway
- outcome focused (including measures of quality, service user experience and harm).

Improving access to care

9.7.1.8 There should be a single point of referral (including self-referral) to specialist services for adults with autism.

9.7.1.9 Support access to services and increase the uptake of interventions by:

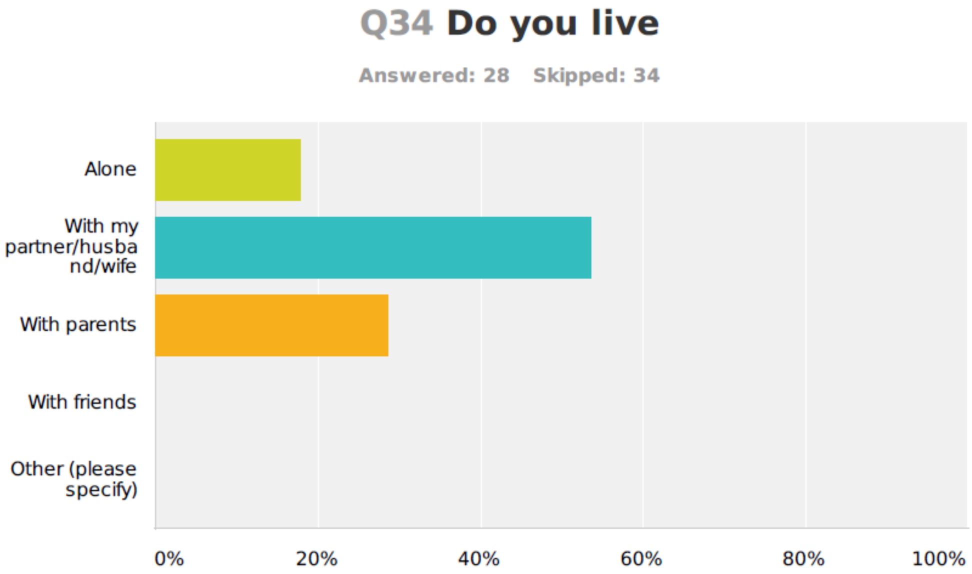
- delivering assessment and interventions in a physical environment that is appropriate for people with hyper- and/or hypo-sensory sensitivities (see recommendation 9.1.1.9)
- changing the professional responsible for the person's care if a supportive and caring relationship cannot be established.

9.7.1.10 Support access to services and increase the uptake of interventions by:

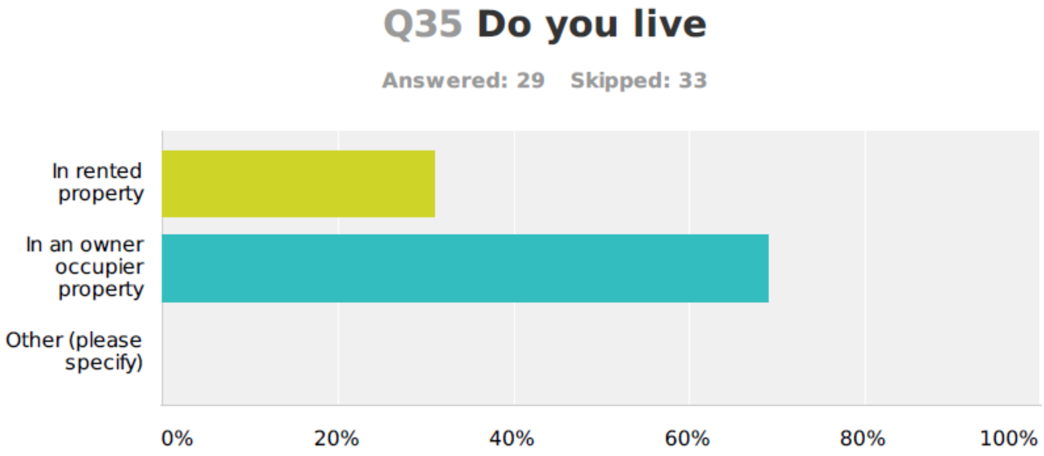
- ensuring systems (for example, care coordination or case management) are in place to provide for the overall coordination and continuity of care for adults with autism

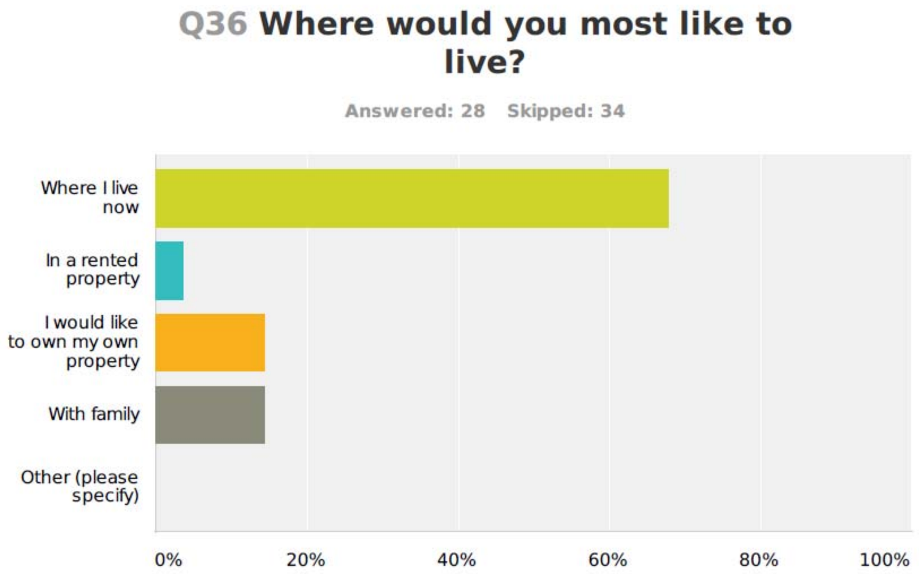
designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service).

Local Picture



At the engagement events people said what was working well for them was community living and supported housing. Where support was “personalised”, the best comments arose.





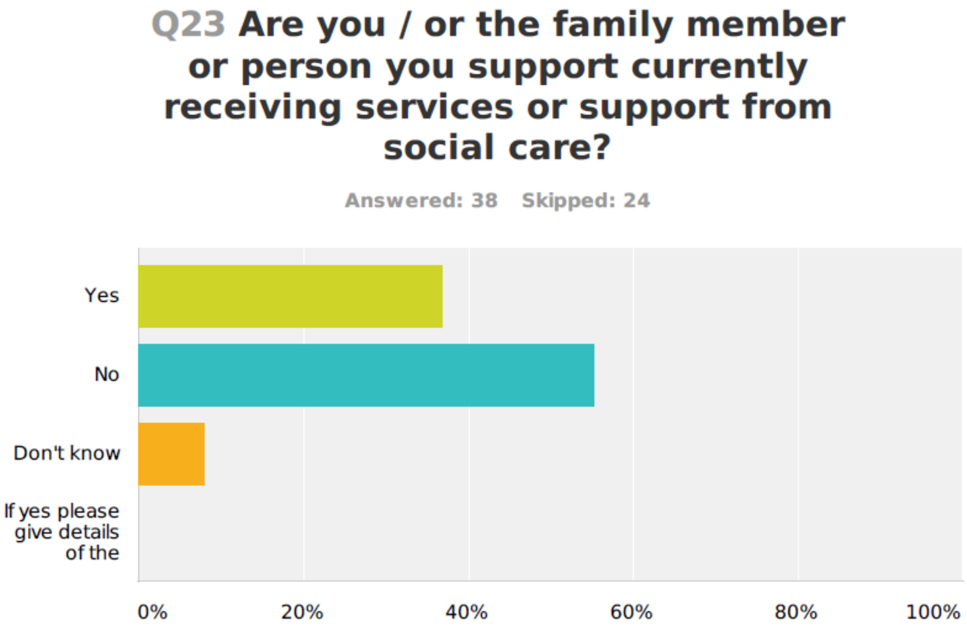
Positive comments

- Community living and supported housing. Where support was “personalised”
- Evidence of creative and personalised support
- START helps transition to independent living
- Personal budget and providers response to need
- Future option for personal health budgets

Areas for improvement

- Concern about lack of planning for people living with aging parents
- A range of living options should be available, not a one size fits all approach
- Advocacy
- one stop shop for people with autism and carers
- Support for carers, support for partners of people with AS
- Social groups with transport
- Improve universal services
- Preventative services, not crisis led
- Produce a clear housing strategy for adults with autism.
- Respite

67% of people answering the online survey were happy about where they were living now. At the events views were expressed about living with aged parents, and what happens when they pass away-are there plans in place.
Views captured talked about it being the “cheap and easy option” to not address living arrangements. It was also expressed a range of living options should be available, not a one size fits all approach.



Sample of online Yes answers:
“18 hours per week over five days Monday to Friday (a support worker visits his home takes him shopping etc.)”

“In Autism specific residential home”

“Our son receives funding for a paid carer to accompany him swimming once weekly and transport to and attendance for one day at a commercially run garden centre for people with disabilities .”

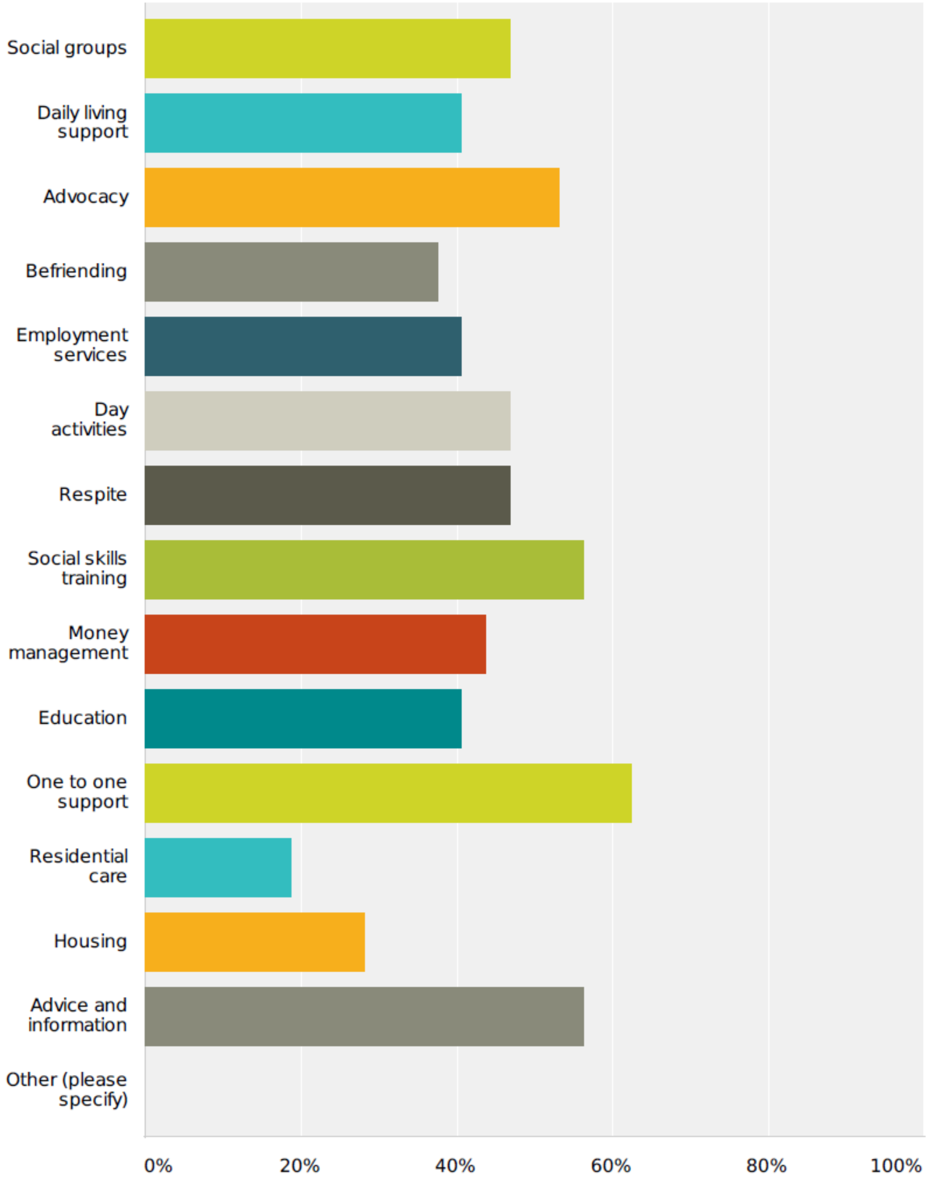
The views at the engagement events were varied:

“Transitions Managers- Useless, they hinder you and deny access to services, only fighters stand a chance- and I’m tired of fighting, I shouldn’t need to do this.”

"START" helps transition to independent living –it is working well and monitored too"
"Personal Health Budgets very positive, lack of advocacy very negative!"
"Providers are gearing up for individual budgets"

Q25 What services or types of support would be helpful for you / or the family member or person you support?

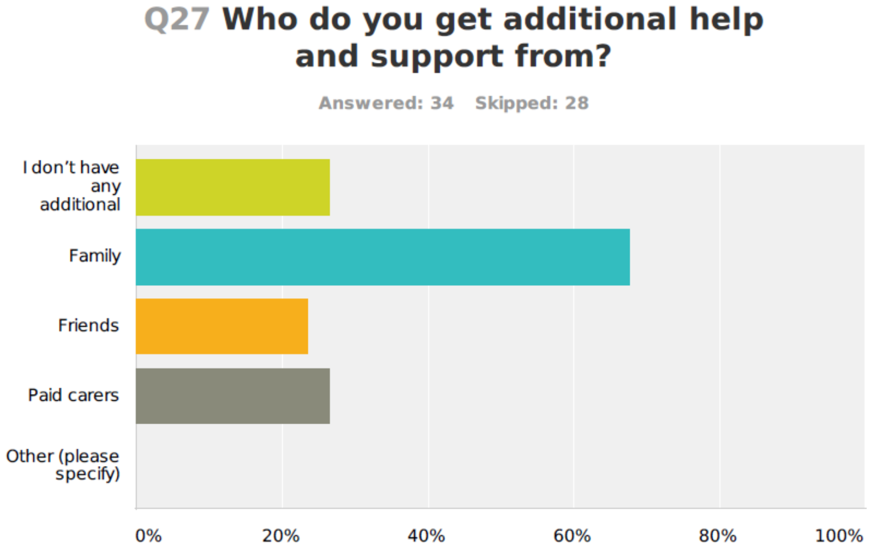
Answered: 32 Skipped: 30



Q26 Please give any additional information on the type of support from social care which would be helpful for you

There were lots of responses both online and at the engagement events:

"More access to individual budgets, and more links to providers"
"Shop for support type online information- like trip advisor"
"More information on what is out there"
"Advocacy and "one stop shop"
"Support for carers, support for partners of people with AS"
"Social groups with transport-its hard to get to places easily"
"Support with relationships-dating and 'such like' service"
"WE WANT LOCAL SERVICES"
"What about an internet forum, or Facebook page? Skype, webinars, emails and newsletters"
"You could try to improve universal services so we can access everything just like everyone else"
"Spend your money more wisely!"
"To be respected, listened to, to continue services not end them when things are going well"
"mentoring"
"Preventative services not crisis led"
"At the moment we are coping pretty well but we are both over 65 so in a few years we will be looking to find suitable local accommodation for our son near enough so he can continue to travel to his day activities and visit us and, while we are able, for us to visit him. It would be enormously helpful to older parents like ourselves when N. Yorkshire are able to produce a clear housing strategy for autistic adults as at the moment it seems rather murky. Respite is extremely important for some parents/carers who are not as fit as us or their son/daughter has greater/more demanding needs."



“I have a friend who visits very occasionally to support my daughter's interest in textiles but it is not a regular arrangement.”
“Parents are members of National Autistic Society and they have attended many NAS conferences/meetings”

Q28 If you receive support, what do they support you with?

“Looking after my son when I am at work .”

“Personal care advocacy emotional well being activities accessing community courses most things”

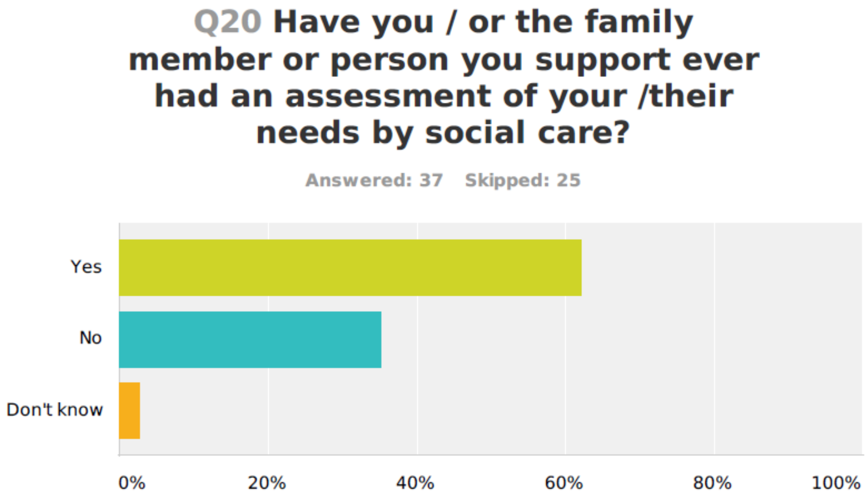
“We support our daughter by providing her with somewhere to live (with us), we don't charge her for rent, food, bills etc. We give her lifts to places. I accompany her to medical visits and other appointments where I can. I take care of her paperwork due to organisational problems and stress. We step in when she is being taken advantage of. We try to make sure she gets up during the day. We discuss her problems with her and when she has put herself in danger. We support her in her day-to-day management of her AS and mental health. Make lists of what she needs

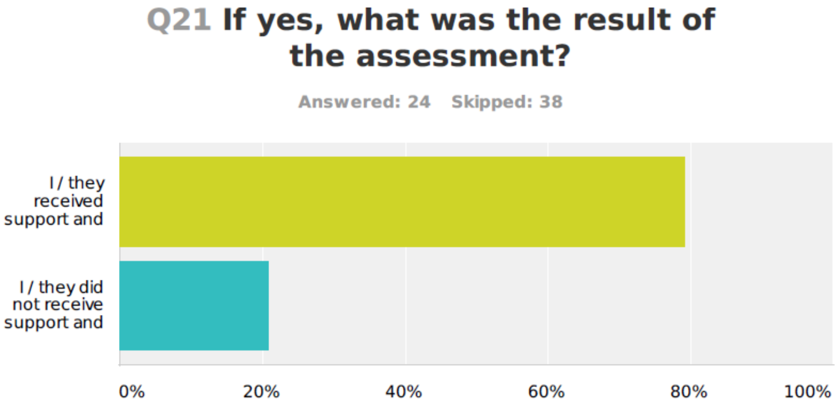
to do during the day. Make calls on her behalf, write letters on her behalf and generally try to make life the least stressful as we can for her."

"24/7 residential care"

"Living independently, managing finances, attending appointments, holidays"

From the online survey only 4 people had used an advocacy service, where they had, 2 had found it very useful, 1 not very useful and 1 not useful at all. Advocacy was mentioned extensively at the engagement events, a lack of advocates





"If not" answers:

“No suitable services were available in North Yorkshire for respite care when my son was a child”

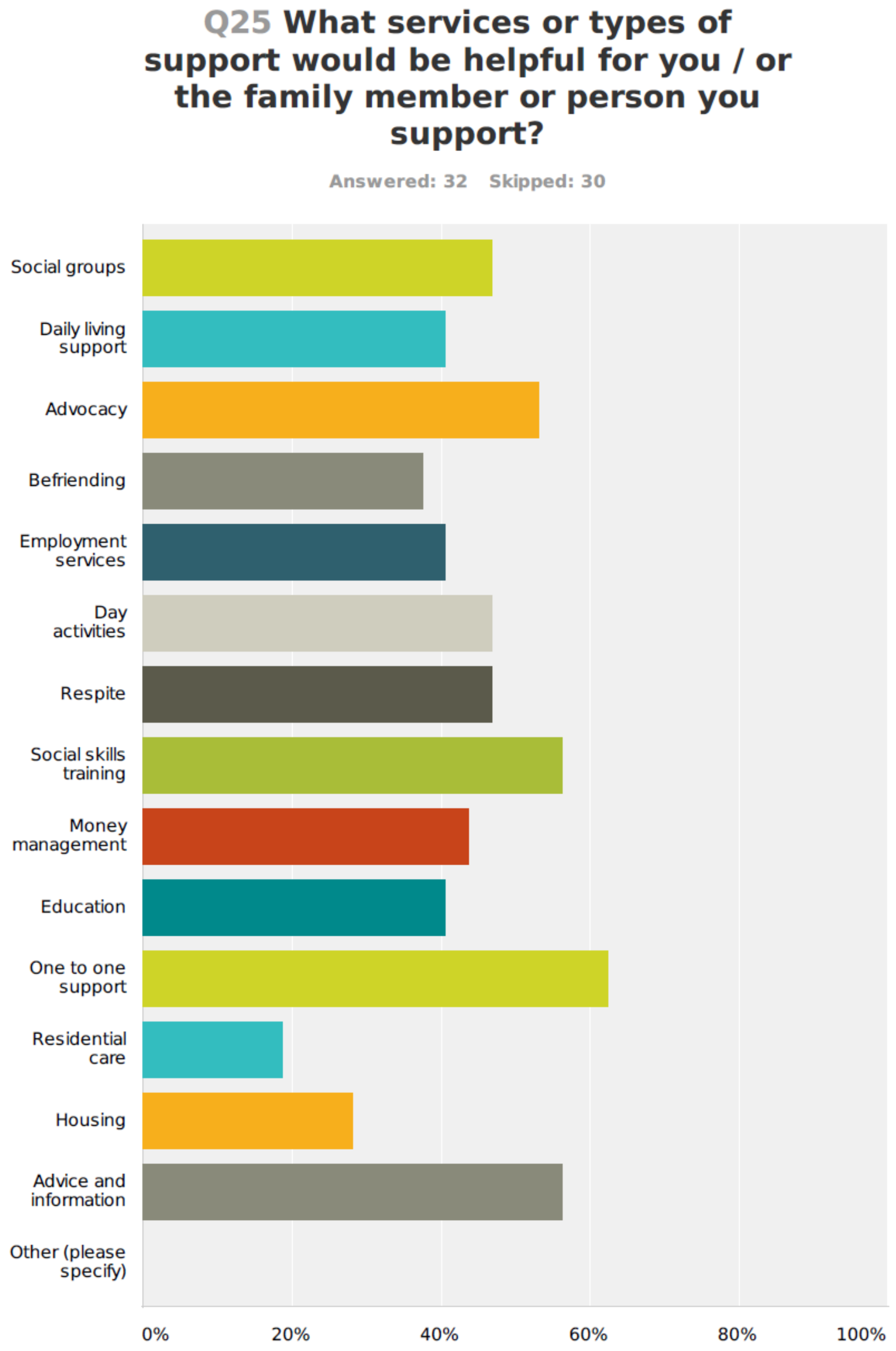
“I am not sure what we could have accessed - I know that in the future we will be looking for support to promote my daughter’s independence and to help her be an active and social member of the community and to be able to live away from us as we get older”
“None of her needs were met. They assessed me, as her main carer; she has having substantial needs, but could not come up with anything that would help us so that was the end of that. We continue to struggle and our own health declines as a result our quality of life is extremely poor.”

“Due to my daughter having an IQ above 70 and no learning difficulties, there isn't the help or support available; this is not funded. My husband contacted social Services as we felt that our daughter was in a vulnerable position. She was being taken out of during the day when we were at work by someone she knew and taken to houses where people were taking drugs. We wondered whether there were any activities she could be engaged in during the day whilst we were at work, so that we knew she was somewhere safe. I must point out that the social worker couldn't have been more helpful and accommodating. Employment Support Services are also keen to help.”

“Assessments have been done on our daughter over the last 2-3 years, but not very effectively initially due to poor understanding and assessment processes (including financial assessment) not fit for purpose. We eventually were allocated to a Transitions social worker who was much more helpful. On the third attempt at assessment my daughter was allocated a reasonable personal budget and we are now exploring ways of using it. However progress has been difficult because our social worker's caseload has become so great she is unable to help us consistently - she readily acknowledges this.”

“We were offered a personal budget, but because we couldn’t spend it on what the social worker said we wanted it was taken off us!”

The types of support people identified they needed are listed below;



The engagement events comments suggest that there are some work still needs to be done in not only identifying peoples needs, but also in providing the most suitable support in a timely manor.

“Expectations need to be raised, common sense, do it now”
“A key person would help coordinate all the information”

“Really clear visible senior leadership, to make a difference. Develop clear behaviours required of key staff”
“Cradle to grave services and support, from schools, diagnosis, further education and employment, then getting old”
“Please make sure we are involved, as parents, relatives and young people-Nothing about us, without us!”
“Personalised support and services work well, needs to be imbedded at all levels in health and social care”

People with autism who do not have a learning disability or a diagnosable mental illness often fall between services and can not access the support they need.

‘They may therefore fall through a gap between learning disability and mental health services, only accessing the latter in the form of costly and acute interventions if they subsequently develop mental health problems, which may be brought on by depression and social isolation associated to their autism.’ (*Supporting People with Autism Through Adulthood*, National Audit Office)

It was apparent at the engagement events and in some of the surveys, that it isn’t clear what is currently available locally. This needs to be available on the Council’s website.

CHAPTER 4: HELPING ADULTS WITH AUTISM INTO WORK

What the strategy says:
Ensuring adults with autism benefit from wider employment initiatives

Young people are a particular area of focus for the Government during this period of economic downturn. *Building Britain's recovery: Achieving full employment* therefore announced over 100,000 new opportunities for young people, meaning that from January 2010 all 18-24 year olds, including those with autism, will be guaranteed a job, work placement or work related skills training from the six month point of their claim to Jobseeker's Allowance (JSA). This will be delivered through:

- a new job created through the Future Jobs Fund
- help with getting an existing job in a key employment sector
- new work-focused training opportunities, and/or
- a place on a Community Task Force, delivering real help within local communities. (5.6)

[The Department for Work and Pensions (DWP)] is committed to ensuring that these programmes work for young people with autism, and that the choices and support they are offered reflect their specific needs. (5.8)

Personalising welfare and work support

The Government will continue to take forward welfare reform to personalise the support given to people seeking work. At the core of this process is the principle that the ability to get and keep a job, and then to progress in work, is the best route out of welfare dependency. But the personal needs of individuals can differ vastly. Some require intensive support to build skills and overcome barriers to work, while others need little more than access to job opportunities. (5.9)

Reforming existing provision

Following recommendations for improvement made by the NAO, the Prime Minister's Strategy Unit report Improving the life chances of disabled people, the PAC and the views of many disabled people, employers, external delivery partners and Jobcentre Plus staff, DWP undertook a major review of its existing specialist disability employment provision (ie WORKSTEP, Work Preparation and the Job Introduction Scheme).

As a result, this provision has be replaced by a new programme – Work Choice. Work

Choice will be a pan-disability programme, designed to help customers who face complex disability-related barriers and have the highest support needs to find and keep a paid job, or progress in work. The new programme will provide specialist support for adults with autism where DWP mainstream provision may not be appropriate or does not meet the particular needs of the individual. (5.17-5.18)

Jobcentre Plus has now changed Access to Work to improve support services for customers with autism. (5.21)

Developing new approaches that will better support adults with autism

Many of the initiatives recognise the importance of co-ordinated health and employment support for jobseekers. They build on the strong partnerships already created with GPs through the Pathways Advisory Services pilots, which tested placing Jobcentre Plus advisers in GP surgeries. These pilots are now being expanded to treble the capacity. (5.32)

As part of the ongoing goal to personalise support for disabled people – including adults with autism – the [Office for Disability Issues (ODI)]... has worked with disabled people to develop the Right to Control. This will give disabled people greater choice and control over the support and services they receive, and shift the balance of power from the state to the individual. (5.33)

DWP will also ensure Jobcentre Plus advisers are aware both of the need to make suitable adjustments for adults with autism and of the kinds of adjustments that may be beneficial. (4.11)

NICE Guideline says:
9.3.1.11 For adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.
9.3.1.12 An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews
- training for the identified work role and work-related behaviours
- carefully matching the person with autism with the job
- advice to employers about making reasonable adjustments to the workplace
- continuing support for the person after they start work
- support for the employer before and after the person starts work, including autism awareness training.

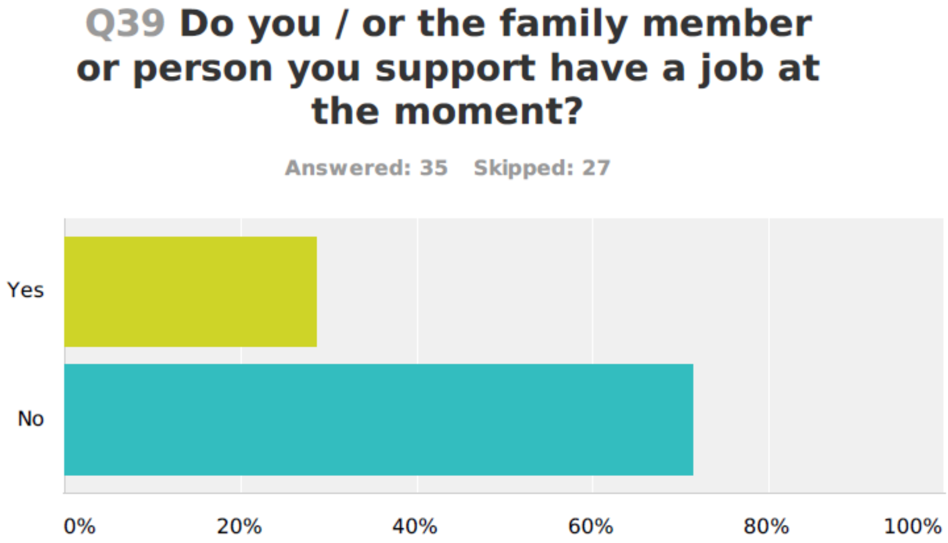
Additional information

'People with autism can have valuable skills to offer employers, but employment rates for people with autism are low, with many finding lack of understanding of autism amongst employers a significant barrier to work. Recent estimates suggest that only 15% of adults with autism are in full-time employment. Yet with appropriate awareness training and support, a number of employers have successfully integrated people with autism in their workforce.' Supporting People with Autism Through Adulthood, National Audit Office)

'For an adult with high-functioning ASD we estimate the annual cost of living in a private household (with or without family – we are unable to separate the two with our cost data) to be £32,681. A sizeable part of this (£19,785) is the imputed cost of lost employment for the individual with ASD (and hence also lost productivity to the economy).' (The Economic Consequences of Autism in the UK, Knapp et al)

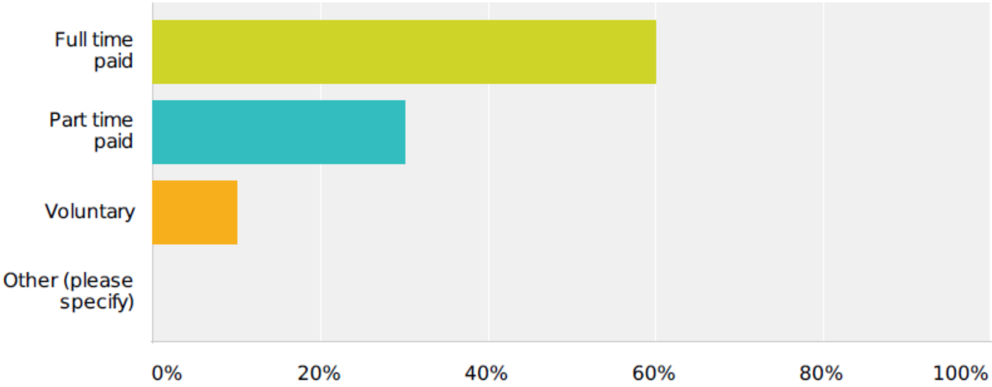
Local Picture

The events and survey produced some exciting ideas around employment, self employment and job carving. People's experiences of trying to access work are not great, and with welfare reforms on the horizon there was great concern in this area.



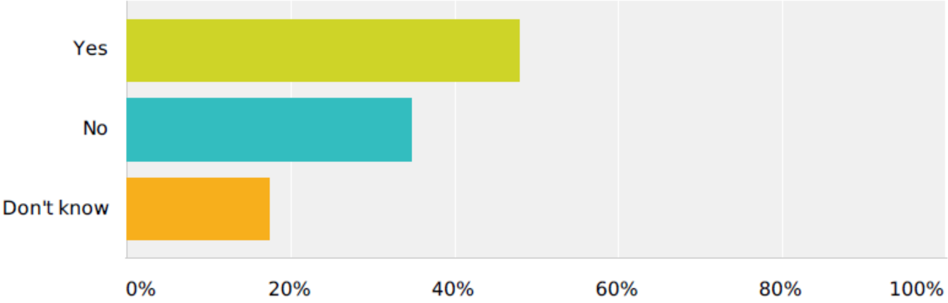
Q40 If yes, is your job

Answered: 10 Skipped: 52



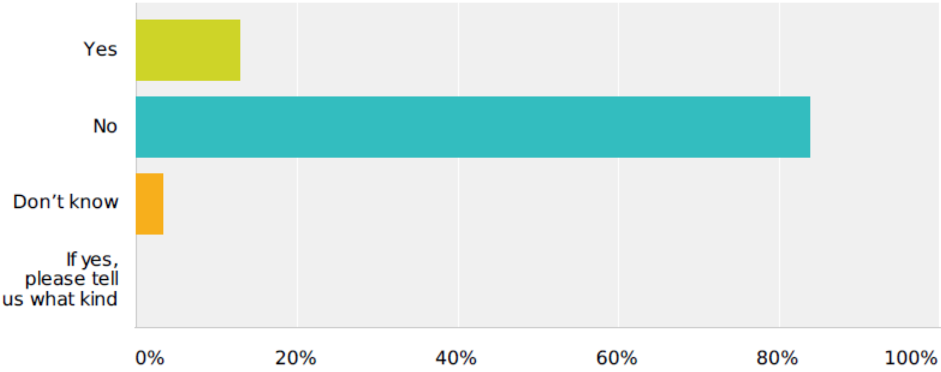
Q41 If no, would you like to work?

Answered: 23 Skipped: 39



Q42 Have you / or the family member or person you support received support to find work?

Answered: 31 Skipped: 31



Positive comments

- NYCC Supported Employment service

Areas for improvement

- Geography and rural nature of county therefore lack of employment opportunities
- Self employment opportunities
- Support with work skills, interview techniques, application forms
- Job coaches

Online comments

"Excellent support from NYCC Supported Employment service"

"Job centre was a disaster to start with. In the end we had to go with him to make sure they had some understanding of his difficulties. Requirements have been altered slightly so that he can claim Job Seeker Allowance."

"Keep trying to get a work placement through school as it is part of our daughter's package of support. It is clearly not seen as a priority."

The engagement event produced some very relevant discussions around work, what was working and not working.

"Geography is a problem, we are very rural there are no jobs anyway"

"Self employment needs to be explored, support to start your own business or social enterprise, and ongoing support for any issues you might face in your first year, a mentor or something like that"

"Help to identify my employment strengths"

"Transition support from education to employment"

"Job carving-the council could start first!"

"I can't do interviews; I always get application forms wrong"

“Job coaches work in other areas, just for people with Autism”

The current financial situation and challenging job market is making things even more problematic for people with disabilities, including those with autism.
Again, it was felt that a greater understanding of the specific needs of people with autism would be beneficial for job centre staff and employers.

SUMMARY

Although there is a mixed picture about the services and support available to people with autism in North Yorkshire, there is a lot of work taking place which will hopefully make a real difference to the lives of people with autism and their families.
Senior leadership was visible at the events, which was well received, and commitments made to work together, really listen and engage further.

Positives comments

- The National Strategy had raised awareness
- Evidence of training taking place
- Evidence of training being "standardised" and accredited.
- Positive diagnosis and support experiences highlighted from a variety of professionals despite there being a clear diagnostic pathway
- Improving 'transition' arrangements
- Diagnosis experience for children
- Community living and supported housing. Where support was 'personalised'
- Evidence of creative and personalised support
- START helps transition to independent living
- Personal budget and providers responding to needs
- Future option for personal health budgets
- NYCC Supported Employment service

Areas for improvement

- The lack of awareness amongst GP's
- Autism being 'stereotyped' a one size fits all approach.
- A strong view that people with autism should be involved in delivering training including real life stories
- Carer/family training post diagnosis
- Condition management type of training for adults newly diagnosed.
- Training should be mandatory for all front line staff in social care and health.
- Training to be extended to other public services used by people with autism eg: Job centres, libraries, leisure centres and Police.

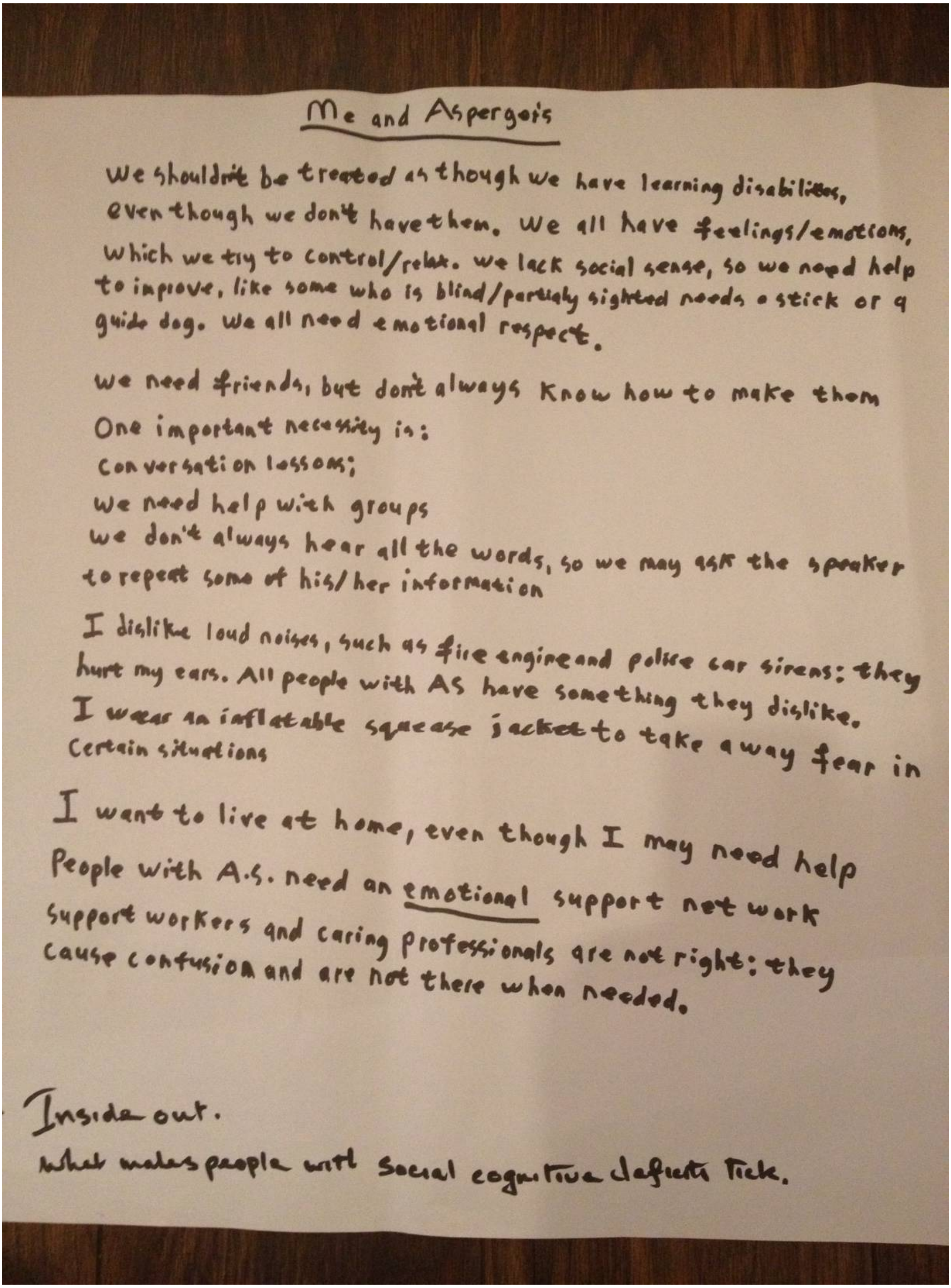
- Training for staff in non special schools and colleges, including teaching assistants.
- Training should help agencies to recognise autism in girls and women.
- Out of county diagnosis
- Lack of post diagnosis support
- Professionals unclear about pathway
- Length of time to receive a diagnosis
- Early recognition by GP and School staff and other frontline staff
- Issues were raised about people with autism falling between mental health and learning disability services
- The statutory duty to receive an assessment needs to be publicised
- Concern about lack of planning for people living with aging parents
- Concern about young people with autism in main stream schools missing out on transition arrangements
- A range of living options should be available, not a ‘one size fits all’ approach
- Advocacy
- One stop shop for people with autism and carers
- Support for carers, support for partners of people with autism
- Social groups with transport
- Improved universal services
- Preventative services, not crisis led
- Produce a clear housing strategy for adults with autism.
- Respite
- Geography and rural nature of county therefore lack of employment opportunities
- Self employment opportunities
- Support with work skills, interview techniques, application forms
- Job coaches

Diagnosis, training and greater understanding of the specific needs of people with autism are major issues. These issues are being addressed, but further work is required.

- A training portfolio needs to be developed to ensure that those requiring further, more in-depth, role specific training can access it, and access to basic awareness raising needs to be available to universal services. GP’s particularly stand out as a priority group.

- A diagnostic pathway needs to be developed in county and promoted extensively to all health professionals. Where a diagnosis is made protocols need to be in place to ensure access to relevant support is available.
- Awareness of the local services available to young people and adults needs to be made available to all. Information and signposting needs to be addressed.
- Support needs to be provided for people to access work, volunteering and self employment.
- Advocacy needs to be available and more work to signpost to it.
- Personalisation, Individual Budgets and self directed support needs to be promoted widely, including market place development for a range of providers.

The key to any local development is having all stakeholders involved with the process. At the heart of that are people with autism and their families, but the issue of better working relationships and developing trust needs to be addressed from the offset. A number of people that contributed to the surveys and consultation events said that they would like to be involved in shaping future services, but didn’t always believe that their voices would be listened to. This needs to be addressed.



Me and Asperger's

We shouldn't be treated as though we have learning disabilities, even though we don't have them. We all have feelings/emotions, which we try to control/relax. we lack social sense, so we need help to improve, like some who is blind/partialy sighted needs a stick or a guide dog. We all need emotional respect.

we need friends, but don't always Know how to make them

One important necessity is:

conversation lessons;

we need help with groups

we don't always hear all the words, so we may ask the speaker to repeat some of his/her information

I dislike loud noises, such as fire engine and police car sirens; they hurt my ears. All people with AS have something they dislike.

I wear an inflatable squease jacket to take away fear in Certain situations

I want to live at home, even though I may need help

People with A.S. need an emotional support network

support workers and caring professionals are not right; they cause confusion and are not there when needed.

Insides out.

What makes people with Social cognitive deficits Tick.

REFERENCES

Department for Education (2012) *Support and aspiration: a new approach to special educational needs and disability – Progress and next steps.* Department for Education

Department of Health (2012) *2012/13 NHS Standard Contract for Acute, Ambulance, Community and Mental Health and Learning Disability Services*. Department of Health

Department of Health (2010) *Fulfilling and Rewarding Lives: the strategy for adults with autism in England.* Department of Health

Department of Health (2010) *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy.* Department of Health

Department of Health (2010) *Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care - guidance on eligibility criteria for adult social care, England 2010.* Department of Health

Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK* Foundation for People with Learning Disabilities, London

National Institute for Health and Clinical Excellence (NICE) (2012) *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*. NICE

National Audit Office (2009) *Supporting People with Autism Through Adulthood.* National Audit Office, London

Rosenblatt, M. (2008) *I Exist: the message from adults with autism in England*. The National Autistic Society, London