

Report on the Healthwatch Wandsworth consultation about support needs for autistic residents in Wandsworth.

Background

According to The National Autistic Society around 700,000 people in the UK have an Autistic Spectrum Condition. Together with their families, this means autism is a part of daily life for 2.8 million people¹. It is estimated that over 3500 people living in Wandsworth have an Autistic Spectrum Condition and approximately 1000 people are known to services.²

Autism Spectrum Condition is used to describe range of conditions, including Asperger syndrome. The severity of Autism Spectrum Condition (ASC) symptoms varies greatly, but all people with autism have some core symptoms in the areas of communication, thinking and imagination, social interaction and sensory sensitivities³. To better understand the needs of people with an Autistic Spectrum Condition, it is important that every voice is heard.

A need for improved support was highlighted to Healthwatch Wandsworth by a number of local residents and voluntary sector organisations. When we heard that Wandsworth Borough Council was updating their Autism Strategy we wanted to find out more about what Wandsworth residents think about services and how they can better support the needs of people with an Autistic Spectrum Condition.

Our Consultation Survey

The Healthwatch Wandsworth Autism survey comprised twenty one questions. It included questions about the challenges autistic people might face, what could help them better meet these challenges, and what support they would like more of in relation to work, housing and being a part of the local community.

Most of the questions were deliberately open to draw out people's experiences, thoughts and suggestions. From this information we hoped to draw conclusions about where support service provision could be strengthened to best support people with an Autistic Spectrum Condition.

Findings

The survey was advertised via our website and social media channels and was circulated to our local contacts between 27th April and 30th June 2017. We also took the survey to an Autism Fayre on 25th April and to many of our outreach visits during this period. In total we received 27 responses to our survey.

We also attended an event hosted by a local community organisation, A2ndVoice, on 29th March and spoke to 21 people, including autistic people, parents, carers and others. We

¹ National Autistic Society (2017), 'Autism Facts and History', Retrieved from <http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx> (Accessed July 2017)

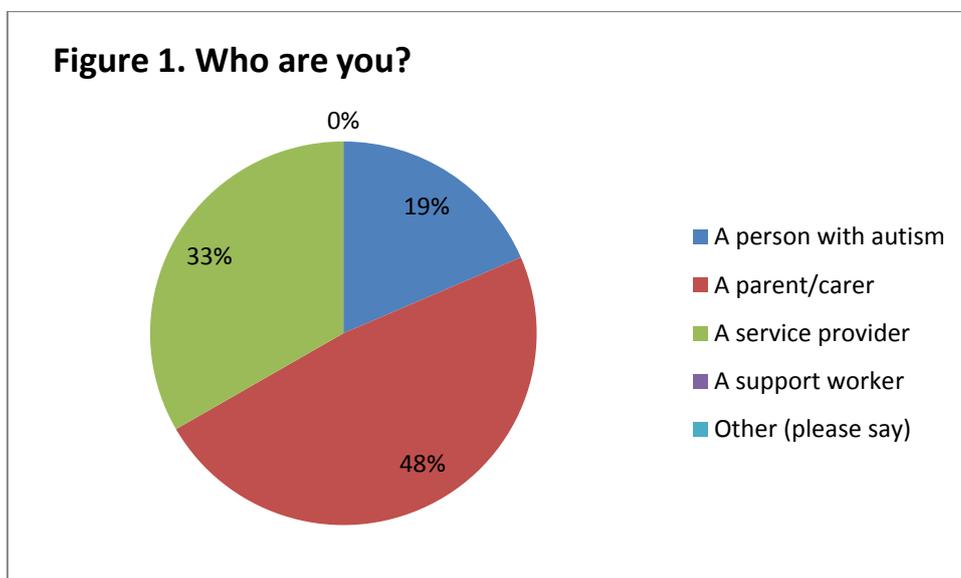
² 140 adults are presenting with needs to the local authority and 860 Wandsworth resident children known to LA services who have a diagnosis of autism, Wandsworth Borough Council Children's Services Survey

³ Autism Initiatives (2017), 'Symptoms of Autism', Retrieved from <http://www.autisminitiatives.org/about-autism/what-is-autism/symptoms-of-autism.aspx> (Accessed July 2017)

asked questions about needs and barriers to accessing support. We have incorporated their feedback in our report as well as feedback from other members of the public who have told us their experiences over the past year, where relevant.

Question one: who are you?

The chart below shows the proportion of the survey responses from different respondent groups. Almost a fifth (19%) of responses were service users and half of the responses (48%) were parents and carers. Another third of respondents (33%) were people who provide a service to autistic people and who represent, to some extent, the experiences of a number of the people they have worked with. Therefore the results incorporate a variety of perspectives.



Question two: How would you describe your Autistic Spectrum Condition?

Almost half of respondents identified their feedback to be relating a person with **Asperger's** or '**High Functioning**' Autism (9 of 20). Two mentioned 'severe' autism and two included Dyslexia. The answers highlighted the variation of the condition for different people on the spectrum.

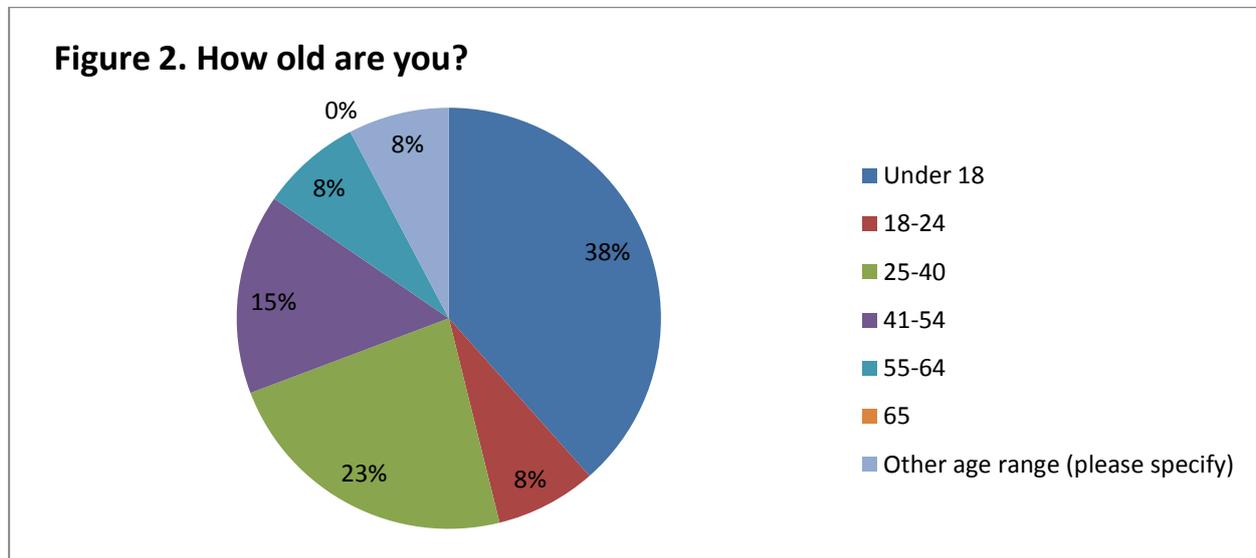
Many responded with descriptive answers about the condition and experiences including:

- Generalised and social anxiety disorder
- Insomnia
- Attention deficit hyperactivity disorder
- Sensory disability that impacts communication and interaction with environment
- Limited social interaction, isolation (no friends), no road safety awareness
- Difficult understanding letters
- PDA [Pathological Demand Avoidance]

One parent described the situation as a '24 hour struggle'.

Question three: How old are you?

The chart below shows that over a third (38%) of responses relate to people under 18. The majority of responses relate to adults; respondents answering 'other' stated that they provided services for people over 18 years old.



Aspirations and barriers

Question four: What sort of things would you like to do in your life?

To get a general understanding of what support needs individuals might have we asked a very open question, 'What sorts of things would you like to do in your life? Respondents reported a variety of aspirations and needs.

Answers to this question followed the following themes:

- **Employment** and support to find employment
- **Independence**
- **Socialising within the community** and building a **support network** and friends with suggestions including sport, cafés and gardening
- **Awareness and acceptance**, within the community, in health services and at school
- **Play for children** with Autism and encouraging acceptance amongst other children

One parent/carer highlighted the importance of **support for carers** relating to work and housing and that they would appreciate more **support from schools** - '**more knowledgeable, less bureaucracy**'.

When we spoke to people at A2ndVoice in March, responses included creative activities, social activities and healthier living and exercise.

Question five: What stops you from doing the things you would like to do in your life? What barriers are there?

The main barriers described ran along the following themes.

- Understanding and awareness in the community
- The environment: 'An environment that causes anxiety for people with Autism with 'busy and loud areas''
- Communication difficulties
- Lack of appropriate social groups and difficulty making friends
- Assistance needed to access support
- Lack of accessible employment
- General lack of support

At A2ndVoice many people highlighted a lack of understanding amongst professionals and need for training professionals, particularly understanding the communication difficulties someone with autism might have.

The lack of knowledge of professionals was also highlighted in almost all stories relating to autism that we collected during our outreach activity in the past year.

Question six: What support do you feel you need to do the things you would like to do in your life?

We wanted to understand the support needs of people with autism. The suggestions broadly fitted in to the following suggestions:

Carers

- Recognition of role in working with health care systems, the hours involved in other types of support, e.g. completing housing applications and booking health care appointments
- Childcare support and after school clubs
- Support groups for parents

Schools

- Education support and after school clubs
- Better trained staff

Health and care

- Palliative care and physical support (including specialist equipment)
- Better trained staff, understanding and encouragement rather than discrimination (particularly amongst GPs and Social Workers who they most often come in to contact with)
- Understandable health and wellbeing information

Social life and mental health

- One to one support and mentoring - to deal with individual needs and issues as they arise
- Appropriate social groups
- Travel support

A2ndVoice respondents also mentioned that **more information and better knowledge for parents** would be really helpful. Others offering feedback to us over the year highlighted that waiting areas need **more information** to raise awareness of issues, and that **sensory specific areas** would really help.

Housing

Question seven: Do you live alone or in supported housing?

We wanted to understand housing support needs and began by finding out how many respondents represented people in supported housing.

Of those we spoke to only three were in supported housing. A couple of responses suggested that the individuals would like supported housing. Out of 18 responses, 7 said that the person was living with family, either parents or other family members.

Question eight: What do you like about living alone or in supported housing? What works well?

We wanted to understand how people might feel about their living situation and how this might affect their wellbeing.

We received a variety of responses but for many people **independence** was very important to respondents.

One respondent mentioned that they wanted interaction with others living in supported housing, while others valued family support. A couple of respondents highlighted that they would like support to deal with the attitudes of other people.

Question nine: What do you not like about living alone or in supported housing? What doesn't work too well?

We wanted to find out what people struggle most in their housing situation.

Responses related to **getting the right support for an individual and having choice in their living environment**:

"If you are seen as "low functioning" your abilities are ignored - if you are seen as "high functioning" your needs are ignored..."

"I can't make many decisions about the way the house is run"

Some responses highlighted that people were feeling **unsupported, isolated and bored living alone**. Another person was **worried about being evicted** because they didn't have support.

One parent highlighted the challenge of finding a suitable situation that their child would be happy with. **"He does not like having key workers around him. But it's for his safety and vulnerability"**

Question ten: What support would you like to help you to live alone or in supported housing?

To help us understand what might better support the needs of Autistic people respondents highlighted the following themes:

- **More autism friendly information**
- **More support throughout the day** from social services and support workers
- **One to one support and training** -help with services available, travel and other life skills
- **Employment/Financial support: 'I can't handle full time hours'**

Question eleven: What makes it difficult to apply for housing?

We wanted to understand if everyone was aware of the current support available for housing so we asked 'What makes it difficult to apply for housing?'

The majority of feedback related to staff understanding of the needs of people with autism and the accessibility of information. Many felt that they didn't know where to go or what to do to get help. Feedback highlighted people struggled to get support for the following reasons:

- **Accessibility of the housing assessment department: 'We have difficulty getting access to a 14th floor building with autistic child.'**
- **Understanding of staff in the housing department or other services: 'Autism is not taken seriously by housing assessment department' 'Customer services not understanding individualised needs of the autistic person.'**
- **Waiting lists and delayed assessments**
- **Not meeting the criteria**
- **Living somewhere safe and with a nice environment**
- **Not knowing where to go and what to do**

Employment

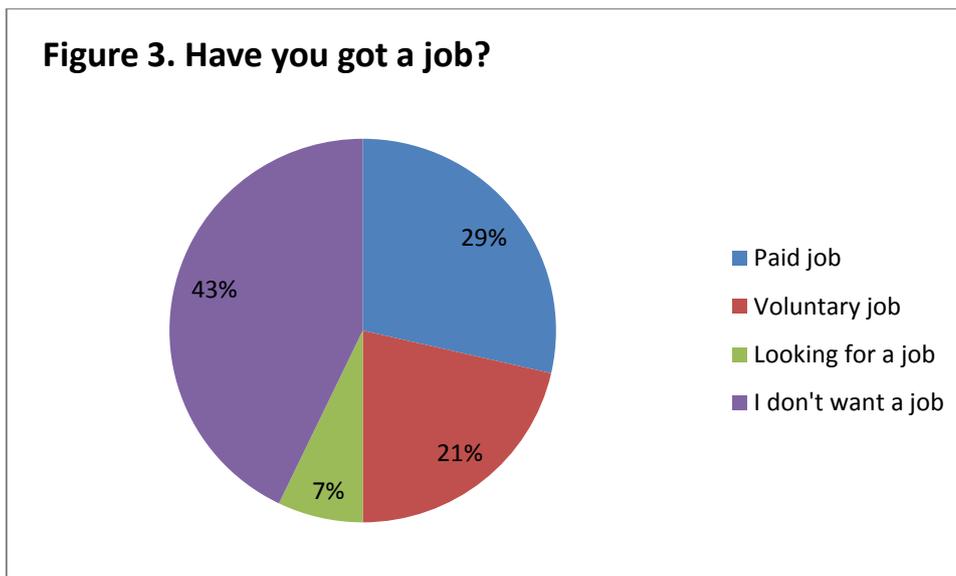
Question twelve: Do you have a job?

We wanted to understand people's experiences of getting employment to understand if they might need support in this area. Firstly we wanted to understand how many people had a job.

Half of respondents (50%) mentioned that the person with autism had a paid or voluntary job. Most respondents indicated that they didn't want a job.

A third had a paid job (29%) and we should note here that in responses to earlier questions people already highlighted worries about finances.

Figure 3. Have you got a job?



Question thirteen: If you have a job, please tell us about your experiences. What has worked well and not so well?

Responses **highlighted additional needs for being in a workplace and employers' lack of understanding of this.** Needs included:

- **Prioritising work** correctly
- Working with **authority**
- **Sensory overload** in big/busy office environment
- **Needing flexibility and adjustment**

One person mentioned that they lacked confidence because of bullying at school.

Question fourteen: What would you really like to do as a job?

We wanted to understand what types of employment people would like to be supported to do. In most responses people valued the **social aspects of employment and helping others.**

- **Meeting people**
- **Community work**
- **Helping others to cope** with disability
- **Life coach** or motivational speaker

Specific job roles included, I.T. and Web design, maths or science related jobs, administration, and train drivers.

Some respondents highlighted that **flexible working arrangements** might help them, such as part time work or working from home.

A couple of respondents highlighted that good pay was important.

Question fifteen: Do you feel you have been given enough help and support to get a job?

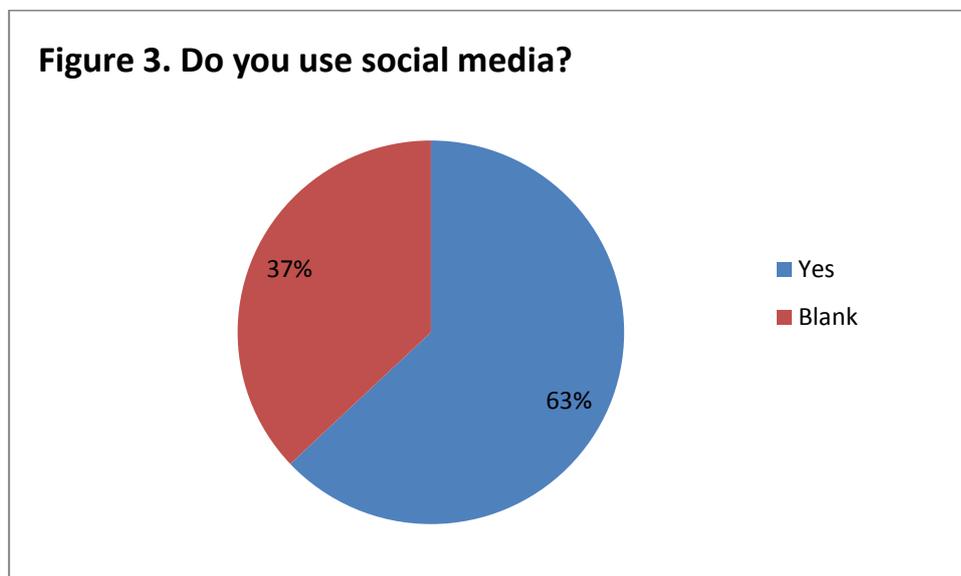
Most respondents, 8 out of the 12 who answered this question, felt that they had not been given enough support. However, there were a few who had already received some help.

Communication and being part of the community

Question sixteen: Do you use the internet or social media?

Firstly, we wanted to understand the experiences of autistic people when communicating and finding information online, as many people use online resources for information, but there could be additional challenges for someone with an Autistic Spectrum Condition.

We began by asking if people use social media. The majority of people (63%) said that they did use social media.



Question seventeen: What do you find good and not so good about using the internet or social media?

We wanted to understand people's experiences of using the internet and online communication. People valued the internet **for a variety of things** they needed to do including ordering groceries, to find support, information and online communities or interaction that doesn't involve as much pressure as face to face social situations.

However, people highlighted **concerns for safety online** including cyberbullying and fear of not knowing who they are really speaking to, security of information and distracting and false information.

Question eighteen: Do you feel that you might need support to use the internet or social media? If yes, what type of support?

We wanted to know if autistic people might need additional support using the internet. About as many people felt they did need support as those who felt they didn't.

Most wanted help understanding the internet and using it to find information relating to their interests and hobbies.

Question nineteen: Do you sometimes feel alone or isolated?

16 people who responded to this question said that they or the person they know with Autism feels isolated. Two said that they only felt isolated sometimes.

One parent highlighted the isolation they felt themselves.

Question twenty: What do you think are the biggest social issues for people with autism?

The overall important issue for most respondents was understanding and acceptance in the community.

'Society not accommodating their social needs, expecting them to fit in. As they can't understand that autism is a hidden disability'

People told us that lack of acceptance resulted in feelings of **exclusion and anxiety**, and meant many were **not getting the social interaction that they seemed to want**.

With regards to services, some respondents highlighted that it can be difficult to get support due to long processes to get support and limited service support for children.

Question twenty one: What sort of things would help people with autism feel more like part of their community?

We wanted to find out how autistic people might feel more included in the community and perhaps tackle some of the worries highlighted above.

- **Awareness raising and encouraging acceptance** as well as increased participation in everyday life. This might also make people with autism feel safe in public places
- Support in schools
- **Autism friendly places** with trained customer service and front line staff
- **Accessible local facilities and services** with more visual information and instruction available
- **Activities, social groups and learning communication skills** and support to find appropriate groups
- **Training and support for parents**

Question twenty two: What do you feel are the best ways to communicate with you or other people with autism?

We wanted to know how autistic people might prefer to communicate to gain some ideas about how local services might better reach people with autism, provide information and work with them. Ideas suggested by respondents included the following:

- **Listening and engagement** with people with autism
- **Visual information and communication**, including Makaton
- **More precise, direct and clear language**
- **Allowing time** for understanding and repetition if needed
- **Awareness raising**
- **Social media or face to face**

Question twenty three: What services and types of support do you think have worked well for people with autism?

We wanted to hear examples of the types of services that have worked for them in the past. Responses included:

- **Self-help groups and social groups**
- **Cinema showings for autistic people**
- **One to one support**
- **More information - via newspapers**
- **Benefits and direct payments**
- **Employment placements**
- **Respite and day centres**

Specific services mentioned included Garratt Park Advisory Service, Contact a Family special groups, Generate, Mencap, People First, Joan Bicknell Springfield surgery, dental hospital, foot and eye clinics.

Question twenty four: Is there anything else you would like to say?

To make sure our respondents had opportunities to highlight to us what is important to them, we asked them if they had anything further to add. People mentioned the topics below.

- **Travel and accessibility**
- **Clearer, visual information**
- **Courses for parents** - strategies, training and tools to support behaviour of a child
- **Getting a diagnosis**
- **Life skills-** budgeting and finance, managing bills, banks and writing letters.

Conclusions and observations

Feedback collected highlighted the following support needs for autistic residents:

Raising awareness and knowledge within services and the wider community:

Help for health and care professionals to understand the needs of autistic people and to improve communication, particularly at key points where people might access support, such as schools, GP surgeries, with social workers and service access teams. Wider community awareness and knowledge could help people to better interact with autistic residents.

More information about support and clearer communication:

Parents and carers wanted more support. Most respondents including autistic people, parents and carers, wanted more information about autism and support services.

Information could be communicated online, via social media and in public places. It needs to be clear, direct and visual and is particularly important at the point of access to services.

Community and social interaction:

More opportunities for social interaction and community activities that meet the needs of autistic people. Worries about safety online and in public places should be considered.

Housing:

The housing situation of our respondents varied. Many wanted support with managing housing arrangements, finances and keeping safe and generally wanted more information about the support that is available.

Removing isolation and increasing independence and control over someone's living situation was not necessarily associated with any particular type of housing situation. However, responses to a variety of questions highlighted the importance of community awareness and acceptance and a need for support with social activities.

Employment:

Many respondents said they would like a job, the income it would bring and to be working with others. The type of work people wanted varied from person to person.

Responses suggested a need for person centred and holistic support. Support needs varied and people mentioned that they wanted help with flexible work arrangements and how they are communicated with in the workplace. Issues relating to transport and housing locations and managing travel also related to how suitable and successful employment will be.

An employment support service may want to look at how they support employers and promote good workplace practices and could incorporate help managing finances so that jobs accommodate the need for flexibility.

To conclude, the findings suggest that people diagnosed with an Autistic Spectrum Condition have different support needs. People across the spectrum have support needs, not just those who also have a learning difficulty or mental health diagnosis. Support needs cross many aspects of a person's life and there are interrelated concerns, particularly around managing finances, information and communication. If support needs are not met in one area, other areas of that person's life are affected. One respondent noted:

'Getting a diagnosis as a female and as an adult is ridiculously hard, and I am fed up of waiting for support. I can feel myself headed for a mental health crisis and potentially becoming unemployed'