About The National Autistic Society

We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.8 million people whose lives are touched by autism every single day. From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

Local voices, local choices

A guide to consulting young people with autism on your local offer
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Introduction

Twenty per cent of children with statements of Special Educational Needs (SEN) have autism, and children with autism are the biggest disability group in receipt of statements of SEN. This means that it is essential that local authorities and their partners engage with this group of young people and incorporate their views into the area’s local offer.

In producing this guide, the NAS has consulted with three different groups of young people with autism. Each group held four separate sessions, and gave their feedback to a decision-maker from their local authority in the final session.

Two of the groups contained young people under 16 and aged 16 plus. Local authorities also have a duty to consult with young people aged 16 to 25.

Local authorities must:
- engage a cross section of young people with a range of SEN and disabilities, in a variety of settings and at different ages within the 16-25 age range
- establish which issues young people want to be engaged with
- consider a variety of methods, including surveys, social media and young people’s forums
- provide opportunities for young people to be engaged independently of their parents
- take into account timing, transport, physical accessibility, accessibility of content and age appropriateness.

This guide is applicable to consulting with young people with autism aged under the age of 16, and those aged 16 to 25. However, the techniques described may need adapting for the older age group.

Consulting with young people with 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 it affects people in different ways. But everyone with autism shares three main areas of difficulty:

- **Social interaction:** young people with autism can have difficulties recognising and understanding their own and other people's feelings. They may sometimes find it hard to manage stress and frustration. At school, they may not always understand the 'social rules' and how to interact appropriately with their peers. This can make it hard to form friendships and many experience bullying as a result of these difficulties.

- **Social communication:** young people with autism may have difficulty understanding both verbal and non-verbal language, such as people's gestures, facial expressions and tone of voice. They may need support with understanding and to express themselves.

- **Social imagination:** this affects young people's ability to imagine situations outside of their normal daily routine, to plan ahead and to cope with change. Many have special interests or a repetitive range of activities which, as well as being enjoyable, can be a way to deal with uncertainty, change or stress. Children with autism generally like set routines, familiar people and environments. They may, for example, find unexpected changes to the school timetable hard to cope with. Unstructured time during the school day – such as break times, lunchtime and moving between lessons – can be particularly difficult. They may also struggle to understand and predict other people's intentions.

Children with autism may also have sensory sensitivity, and be over- or under-sensitive to stimuli such as sound, touch, taste, smell, light or colour. It is important to make adjustments to the consultation process when seeking the views of young people with autism as it is a complex condition which affects each individual differently.

It can be challenging for local authorities to know how to adapt a consultation process for young people with autism. But there are a few general principles that can help make things more accessible for all people with autism. See Appendix A for tips on how to make consultations autism-friendly.
Local offer

The Children and Families Act comes into force in September 2014. From September local authorities will be required to develop a ‘local offer’. The local offer should set out, in one place, information about provision the local authority expects to be available for children and young people aged 0-25 with SEN or disabilities living in their area. In developing and reviewing the local offer, the local authority should involve children and young people with SEN, parents and carers, and service providers.

The local offer has two key purposes:

- to provide clear, comprehensive, accessible and up-to-date information about available provision and how to access it
- to make provision more responsive to local needs and aspirations by directly involving children and young people with SEN or disabilities and their parents, and service providers in its development and review.

The SEN Code of Practice 2014 is clear that the local offer should not simply be a directory of services:

“Its success depends as much upon full engagement with children, young people and their parents as on the information it contains. The process of developing the local offer will help local authorities and their health partners to improve provision.”

What should the local offer include?

Local authorities must:

- make their local offer widely available, accessible and it must be on a website
- publish arrangements for those without access to the internet about how they can get the information
- make sure that it is accessible for different groups, including disabled people and those with different types of SEN.

There is certain information that the local offer must contain. This includes:

- education, health and care provision for children and young people with SEN
- training provision including apprenticeships
- arrangements for identifying and assessing SEN, including requesting an education, health and care needs assessment
- other education provision outside of schools and colleges (for example, sports or arts provision)
- arrangements for travel to and from schools, colleges and early years providers
- support for children and young people moving between phases of education and to prepare for adulthood
- sources of information, advice and support in the area in relation to SEN (for example, an impartial Information, Advice and Support (IAS) service, such as the Parent Partnership Service, forums for parents and carers, support groups, childcare and leisure activities)
- arrangements for dispute resolution, mediation, complaints and the right of appeal against a local authority decision to the First-tier Tribunal.

Local authorities should make sure that the special educational and social care provision available inside and outside their area for children and young people with SEN and disabilities is kept under review.

This should be done in consultation with parents, children and young people in the area. Any comments received about the local offer must be published if they relate to:

- the content of the local offer and any gaps in the content
- the accessibility of the information provided in the local offer
- how the local offer has been developed or reviewed.

These comments should be used when the local offer is being developed and/or reviewed and should be shared with any services that have been commented upon.

Local authorities must publish a summary of comments at least annually and this must include details of the action they intend to take in response. They should also consult children and young people with SEN or disabilities, and their parents, in relation to the action they intend to take.

Working with different groups

Key recommendations

- Be prepared to adapt sessions for young people with different support needs.
- Ensure a wide range of young people across the autism spectrum are consulted on the local offer.
- Ensure both boys and girls are consulted on the local offer.
- Ensure a representative sample of young people from BAME communities are consulted on the local offer.

Young people across the full range of the autism spectrum should be consulted on their views. However, consultations need to be structured differently for different groups, and the leader of the group must be prepared to be flexible to adapt sessions as they get to know the group and their support and communication needs.

The young people in the South East local offer group, run with Parents of Autistic Children Together (PACT) Barking and Dagenham, were asked to give their views on whether support workers/personal assistants help them. The worker gave examples of what a support worker might do. One boy with limited speech answered the question by repeatedly shouting out ‘Ted’. Ted was an older man sitting next to him, who turned out to be his befriender.

This example shows that the person asking the questions needs to probe and ask further questions to understand certain answers. It also shows that even if young people are less verbal, this does not mean that they don’t understand the question put to them. They may need some communication support to allow the worker to extrapolate the meaning of their answers.

Some young people may find it hard to think about services they don’t use very often. For example, although most members of the South East local offer group agreed they had been to see a doctor, they found it very difficult to give examples of why or when they had been. As it is not part of most of their everyday routines to visit a healthcare professional, it seemed much harder for them to recall what they like or dislike about it. This suggests that some young people with autism may find it easier and more relevant to give opinions about specific services when they are actually in that environment.

Some may also only be able to give simple responses or negative comments to a particular service that they don’t access regularly, such as CAMHS. These views are still valid, even if a young person is not able to describe their concerns in detail or offer suggestions for improvement.

Consulting with boys and girls

It is important to consult with girls as well as boys with autism. It may be harder to reach girls with autism, because they are less likely to be diagnosed. However, girls with autism often have very different support needs to boys, so are likely to have different views on the local offer.

The North local offer group, run with Asperger’s Children and Carers Together (ACCT) included a large group of girls with autism. While the girls shared some of the concerns of the boys in the group, they also placed more emphasis on their social needs. In particular, almost every girl in the group mentioned bullying as a significant issue in school, whereas few of the boys did.

This demonstrates that in order to get an accurate idea of the views and needs of young people with autism, it is important to consult with both boys and girls.

BAME communities

Black, Asian and Minority Ethnic (BAME) communities are generally under-represented in autism consultations. As with consulting with girls, it can be more challenging to identify young people from BAME communities with autism. However, it is important to get the views of these young people, because they may have a different perspective both on the local offer and the support they require. It is also important to remember to consult with young people from a range of BAME communities in your local area, not just a token sample from one group.
Structuring sessions for different environments

Key recommendations
- Use workers the young people are familiar with.
- Keep youth club-based sessions informal.
- Plan for school-based sessions to last the length of a normal class.
- Adjust your expectations of discussion topics depending on the setting.

Schools
Young people in secondary schools are more accustomed to working with different people in different classes. However, the teaching assistants who the young people are familiar with are still key to involving those who may otherwise struggle to give their views.

A school environment is more prone to disruption than a youth club, despite the fact that a youth club is generally noisier. This is because the school environment is more controlled, so any changes to routine or activities are more noticeable. However, young people may have a greater sense of purpose in a school, as they expect to learn and be asked to contribute ideas.

Because a school environment is less flexible, there are likely to be more constraints on what young people are prepared to say in front of their peers. Young people in a school setting are also more inclined to focus on their views of school, and talk less about other aspects of their lives.

Sessions in school should last the same length of time as a lesson. This ensures that pupils only need to miss one academic lesson, keeps the disruption of the daily schedule to a minimum, and is likely to make the school and teachers more supportive of their pupils’ involvement in the project.

Youth clubs
It can be helpful to hold consultation sessions in an environment familiar to young people with autism, such as a regular youth club that they attend. It is important to liaise beforehand with the youth club staff and to gather as much information as possible about the young people’s language and communication needs and abilities.

Young people in a youth club setting are likely to be less comfortable with people they don’t know. Existing youth workers have a much stronger relationship with the young people and so are able to get more information, because they know them well and have gained their trust. Existing workers are also likely to have discussed some of the issues with the young people before, so may be able to remind them about particular experiences.

Young people with autism may need these prompts, as they may struggle to recall issues that haven’t recently affected them. Young people with autism often have a fixed expectation of what will happen in certain settings. They expect a youth club to be relaxed and informal, so any consultation run at a youth club must match these expectations.

Youth clubs have a lot of different activities available for young people to engage in. Imposing activities on them that are not used to in that setting is unlikely to receive a good response.

Getting young people’s views

Key recommendations
- Be prepared to use different methods to get answers from the young people, including games, drawings and discussions.
- Think about how the language you use may be interpreted by young people with autism.
- Don’t expect the young people to write down their answers.
- Provide interactive ways for young people to deliver their answers.
- Find creative and engaging ways of talking about the local offer.

The group was most engaged when playing the yes/no game. The worker running the group told them that she was going to say the names of some types of people who can give them help in their lives, for example, their doctor. She asked the group to go and stand under ‘yes’ or ‘no’ signs that she’d stuck on the walls to show whether they had ever received support from these people. Making activities fun and interactive was the best way to get responses from this group.

Language/concepts
For most young people with autism, a general question such as ‘What additional support would you like to have?’ is too broad and abstract, and so can be very difficult for them to answer. They might need examples, prompts and/or more specific questions to be able to give their views.

Even with prompts some questions are still too abstract. Young people with autism may still find it hard to give examples of extra support they would like, because they don’t know what different sorts of support exist.

It can be useful to present some young people with autism with very specific questions or with questions with a limited choice of answers. For some young people with autism open-ended questions can be very challenging because there could be an infinite number of answers, so the choice is overwhelming.

Different groups may also respond to language differently. For example, some young people might take the idea of a ‘nightmare school’ very literally, and talk about murder/horror scenarios, while others might view the concept more flexibly, and talk about the worst type of school they can imagine.

It is important to note that the concept of the local offer is a challenging idea for young people. The workers running the groups all found that talking about the local offer confused the young people. Young people found it much clearer and simpler when they were asked about their views on education, health and social care.

An example questionnaire with ‘yes/no’ questions about young people’s experiences of school and youth clubs.

Games
Games are particularly effective with young people who cannot concentrate for long periods of time.

1 The Children and Families Act S.4 paragraph 4.11, page 51 Code of Practice
It can be useful to present young people with autism with very specific prompt questions.

**Ways of providing answers**

For some young people drawing pictures is the easiest way for them to give their views. They can answer questions through pictures, for instance by drawing pictures of the people who have helped them the most. Other young people might like to combine drawing with writing, for example writing about their perfect school, while drawing a picture of it.

Even when not writing down their answers, young people may still enjoy submitting their answers themselves, for example sticking post-it notes on a board or posting their answers into a box. This allows young people to have ownership of their answers, and also adds some novelty to the process.

**Discussion**

In a more structured setting such as a school, there is greater opportunity to develop discussions between young people.

The Central local offer group, at Comberton Village College, discussed what would make a perfect school and a nightmare school. First they were shown a presentation which had pictures for each category, and then they were split into two groups. The workers took each group through the categories and engaged them in discussions about what would make a school perfect and what would make it a nightmare. This process worked well as it generated a lot of discussion, activity and ideas. Pupils were able to discuss within their groups and spark ideas off each other. Some of the less talkative pupils could be engaged more directly.

**Presenting to the decision-maker**

**Key recommendations**

- Allow some specific time to help young people think about how to change minds. This can be quite a challenging idea for young people with autism and needs explaining clearly.
- Be flexible about how the young people’s views are presented.
- Participation in the presentation and discussion should be voluntary.
- Provide an opportunity for young people to talk one-to-one with the decision-maker.
- Use a familiar environment and ensure workers who know the young people well are present.

**Talking about changing minds**

Young people can be introduced to the idea of ‘changing minds’. This needs to be explained clearly, so they don’t interpret the term literally. Once they are clear on this idea, they can practice making an argument on a subject they are comfortable with.

In order to get the Central local offer group to think about changing minds, the workers posed a challenge. The group was told that the workers wanted the school day to be 10 hours long. The group split into two and each group had to persuade the workers to change their minds.

Initial contributions involved reference to violent video games, and comments like ‘we would start a riot’. However, they quickly moved onto more constructive suggestions. The group were full of excellent ideas of how to persuade a person, although they didn’t realise they were using effective techniques and persuasive arguments. To get them to realise which arguments were persuasive the different arguments were grouped into different categories called ‘threats’, ‘bribes’ and ‘persuasive arguments’. The group then thought about how to use these persuasive arguments when talking to the decision-maker.

**Templates can be used to help young people structure their arguments. For example:**

‘I think………………’

‘Because………………’

‘It would be better if………………’

This helps the young person construct their argument in stages, first identifying their current idea, then reflecting on it, and finally looking at something which could happen in the future, which is a more abstract idea. Many young people are unable to jump straight to the abstract idea.

**Preparing for the presentation**

Young people can present their views to the decision-maker in a number of different ways. One or two young people can present the views of the group, the whole group can present, or the decision-maker can spend some time with the group and get their views informally.

The worker running the North local offer group with ACCT identified two young people who would enjoy giving the presentation to the decision-maker. They both agreed to do the presentation. The young people needed much less support to put together the presentation than expected. The only support they needed was to plan the structure of the presentation; they wrote all the words and arranged the speaking between them. The young people then sent through comments on the proposed presentation by email during the next week. They felt confident to send changes, and made a number of changes to the content and design of the presentation during the week.

Other groups may need more support in putting together their presentation. A worker can prepare notes for the young people to read from, or summarise the group’s views on their behalf.
Delivering a formal presentation

Even if only a few members of the group are delivering the presentation, other young people should be encouraged to sit in and support their friends, and to talk to the decision-maker. It should be clear that this is the young people’s choice, so that the young people stay in control of the process of giving their views. Some young people may be happy to read out prepared points, but not to answer questions from the decision-maker afterwards. Young people in a school setting may be more likely to participate in the presentation, because the setting is more formal.

Even when the formal presentation is the main focus, a discussion with the decision-maker is very helpful. This helps young people to see that their views are being listened to by the decision-maker, and also gives them the chance to talk about things not included in the presentation.

It is important that the decision-maker is able to be responsive to the points the young people raise, and to acknowledge their concerns. If a young person feels they are being listened to seriously, they are more likely to share their ideas.

Talking to the decision-maker informally

When consulting with a group with high or complex needs, more flexibility is needed in the meeting with the decision-maker.

When the decision-maker met with the PACT group in the South East, the worker started the session by sitting down with the decision-maker and the group, and explaining to them that the council wanted to hear their views. She also summarised what they had talked about over the past three weeks.

The rest of the session was run like a normal youth club, and the decision-maker went round the group and was introduced to each of the young people. It was difficult for some of the less verbal young people to speak directly to the decision-maker, so their support workers talked to the decision-maker about the young people and their support needs.

Young people may also want to use pictures to illustrate their views. These can be used to start a conversation with the decision-maker, or can illustrate young people’s views on their own.

After the presentation

Key recommendations

Ensure young people are told how their views have been used.
Ensure the views of young people are meaningfully incorporated into the local offer.

Following consultation with young people, it is important that they are informed about how the feedback they provided has been used.

It should be explained clearly how their views have influenced the content of the local offer. This can be done in a number of ways depending on the group, their levels of understanding and their support needs.

A decision-maker should offer to visit the young people who have been consulted, once it is known how the information they provided has been used. The group should be told what has happened to their feedback, and how it has been incorporated into the local offer.

A lot of people with autism understand information better if it is presented visually. A clear way of demonstrating how their feedback has influenced the local offer is to highlight sections of the local offer which include information they have provided.

Many young people with autism have different processing times, and find it easier to process written information than information given verbally. A clear, short, bullet-pointed summary of the points the group made which have been incorporated into the local offer can be provided to the young people so they can process the information in their own time.

The local authority decision-maker who received feedback from the South East group included copies of the young people’s drawings, as well as their answers to a questionnaire, and all four consultation session write-ups as an appendix to the final local offer.

Conclusion

This guide gives local authorities several techniques and ideas for running consultations for young people with autism.

The purpose of this guide is to support local authorities to carry out a variety of consultation exercises with young people on the autism spectrum. There are many different ways to consult with young people with autism, whether that is in a group, on a one-to-one basis or through enabling parents, friends or professionals who know the young person well to help gather their opinions. Local authorities should not be afraid to try different methods and activities to gain the feedback and views of young people with autism – there is no one right way of doing it.

When working with young people on the autism spectrum, the key thing to remember is to link up with professionals already in contact with those young people, and to use their existing knowledge of and relationship with the young people, to help to plan and deliver a meaningful consultation exercise. Autism is a spectrum condition which means that every young person with autism will have different levels of need and ability, and varying communication styles.

This guide encourages local authorities to try a variety of methods to collect and incorporate the views and needs of young people with autism, and to provide the tools to do this in a way most suited to the young people in their area.

Education, health and social care professionals may also be interested in our toolkit This is Me! My Assessment Profile. This was developed in partnership with a group of young people with autism to identify how they want to be involved in the planning and delivery of the new Education, Health and Care Plans, coming into use in September 2014.
Appendices

Appendix A
Top tips for consulting with young people with autism

- Use clear, simple and literal language.
- Avoid using metaphors or idioms (eg ‘It’s raining cats and dogs’).
- Be specific and use concrete questions with clear choices. Specified options are better than open choices (eg ‘Do you prefer history or English lessons?’ rather than ‘what is your favourite subject at school?’).
- Use images or pictures to support verbal or written information.
- Give information in short chunks – ie short sentences, short specific questions.
- Allow for regular breaks.
- Reiterate verbal information by providing it in a written form so that young people can read and process it in their own time.
- Provide a quiet space for young people who need it.
- If running a series of consultation workshops/meetings, make sure the same person leads each one. Consistency is important for earning the trust of young people with autism.
- Be clear about how long each activity and session will last.
- Always provide clear timings for sessions and stick to them. If this is a problem provide a timetable of ‘approximate’ timings for the session.
- Be clear about what you want from the young people.
- Be prepared to be proactive in eliciting answers and alert to the possibility that you may need to change how you ask a question – ie you may need to make a question more specific if the young person does not understand it the first time.
- Be clear about when you are starting an activity, how long you will spend on it, and when the activity has finished.

Appendix B
Sample yes/no questions

- I have someone who helps me with my work at school.
- The school teachers don’t listen to me.
- I have made lots of friends at youth club.
- No one helps me travel to youth club.
- I have been bullied at school.
- I have a quiet place to go at break times when I am at school.

Appendix C
Sample session plan

Context:
Young people to understand the purpose of these sessions and that it is a forum in which they can share their ideas on local support and assessments, as well as what other support they think they need.

Objectives:
- Exploring what kind of support there is and what should be available.
- Getting used to the idea of giving opinions and reflecting on experiences.

Before the first session
- Leader attends youth club and discusses project with young people/parents and carers.
- Introductory letter given to young people and parents/carers, including explanation of the project for parents/carers to go through with their child(ren).

Set up of the session
- Run like the regular youth club, with computers, arts and crafts, pool etc.
- Ten young people instead of 30, five workers supporting.
- Young people attending the sessions know in advance what the session will involve, and are willing to participate to a greater or lesser extent.

At the session
- Aim one: Identifying things and people who have helped me.
- Aim two: What other support would I like to have?

Technique one:
- Line drawing of a balloon on A3 paper which young people can decorate/colour in.
- Include prompt questions to help young people think about how to answer the main question.
- Write on the drawing or add post-it notes on: things and people who have helped me and what extra support I would like.
- Workers take the drawing round the setting, encouraging different groups of young people to contribute their ideas.

Technique two:
- Make two 3D cardboard Minecraft boxes with some of the young people at the session prior to the first session.
- Label one box: ‘Things and people who have helped me’ and one: ‘What extra support I would like.’
- Young people can write their responses onto post-it notes and post them into the relevant box.
- These responses can then be added to the balloon drawing after the session.
- The young people who play on the computers at the youth club are more likely to engage with this format.

You could make a cardboard Minecraft box for the young people to post their responses into.