

Appendix 20

Consultation with young people with autism: development of NICE guideline on the management and support of children and young people on the autism spectrum

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1. Introduction

The National Autistic Society (NAS) consulted with three different groups of young people on the autism spectrum to establish whether their experiences resonated with initial findings identified by the National Institute for Health and Clinical Excellence (NICE), as they develop their new guideline on managing and supporting autism¹ in children and young people.

About the National Autistic Society

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. We have around 20,000 members and over 100 branches, who are at the heart of what we do. We provide a wide range of advice, information, support and specialist services to 100,000 people each year. A local charity with a national presence, we campaign for lasting positive change for people affected by autism, and empower local people to influence change they will experience at a local level.

¹ Unless otherwise specified the term autism is used throughout this document to refer to all conditions on the autism spectrum, including Asperger syndrome, high functioning autism and Kanner autism

2. Response to findings

Three separate groups of young people with autism were consulted. Their views have been collated against each of the findings and are not presented as individual or group specific responses. There are two examples of the full responses given by two individuals in Appendix 4.4.

Initial Finding

All staff working with children and young people with autism should have an understanding of autism.

Views and feedback

The young people were very supportive of the suggested finding.

They felt all staff should have effective basic training but it was important that professionals understand that “when you’ve met one person with autism, you’ve met one person with autism”, and their autism was not their defining characteristic.

“My Teaching Assistant doesn’t change things with me because I have Aspergers; she changes things with me because she understands me and what I find difficult, which is what’s helpful. She got to know me”.

In commenting on another professional a young person trusted they remarked;

“He talks to me in a normal way and reads my body language and uses his own words to ask me if he is right. He doesn’t presume he knows”.

One young person said that “knowledge [of autism] is ideal but may also hinder because they apply the same ideas to everyone”. It was therefore important to learn by experience rather than follow what it says in a textbook, as that would be the same as “learning to swim from a book”. In this way, professionals were able to understand an individual child’s triggers: “she [my teacher] helps me calm down when other kids misbehave”.

We asked groups 2 and 3 to tell us about a professional that they liked working with. They told us about the reasons why they liked those professionals, for instance “listening to me”, “using a calm voice” or “giving me a break”. From this, we were able to infer some of the characteristics that young people with autism seek in professionals. However, it was difficult to infer from this line of questioning that the professionals they liked best necessarily had a good understanding of autism as opposed to simply a person-centred approach.

The young people’s frustration with professionals stemmed from when they felt as though they were “talked down to”, when they wanted to be treated “like a teenager and not like a three year old”. They also wanted professionals who were “open to difference” and respected them as individuals because “my life is just as valid”. They wanted professionals who were able to make adaptations based on the individual:

“Some people may need to be spoken to differently; they need to approach them differently, but that’s for some people”.

Initial Finding

In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment.

Views and feedback

The young people were very supportive of the suggested finding.

They felt professionals didn’t always give due consideration to the impact the physical environment has on a young person’s ability to cope during their appointments. The young people felt that the failure to simply be asked “is there some stuff [within the physical environment] that you seriously object to?” was demonstrative of this.

They commented that whilst “it’s not possible for them [professionals] to redecorate their room every time a new person comes in” simple steps could be taken. For example “if you don’t like fluorescent lights, it’s not hard for them to turn them off”.

“Every time I went to CAMHS there were just baby toys everywhere and I just felt like such a child....they could put them [toys] in the cupboard”.

One young person said that young people should be asked what adjustments they’d like in the same way it’s common practice to find out about dietary requirements.

To ensure environments are safe, comfortable and welcoming, the young people wanted them to be clean, clear, spacious and tidy. They wanted the appointment buildings to be located where they might ordinarily go to, as opposed to being out of the way, for example “in industrial estates or near busy roads”.

The young people expressed a desire to have more say on where their appointments should take place (see diagram 4 page 8), indicating that this was to have more control over the sensory environment, particularly when adaptations couldn’t be made or were in unfriendly locations.

We asked groups 2 and 3 to tell us about a building or place they particularly like, and then tell us what they liked about it. They were able to identify physical characteristics about it as reasons why they liked it. For instance, that it was 'bright' or 'quiet'. They were also able to identify physical characteristics they did not like, such as "busy" or "smelly". From this, we were able to infer that the physical and sensory characteristics of rooms and buildings are important to these groups, and that the young people consulted would support a recommendation to make physical adaptations to the sensory environment.

Initial Finding

Children and young people with autism should have access to a keyworker approach in order to manage and coordinate treatment, care and support, including the management of transitions, for the child or young person with autism and their family and carers.

Views and feedback

The young people were broadly in agreement on the suggested finding, though there was confusion on the role of a key worker.

Some of the young people had professionals they called key workers who worked within their schools and were often the named individual who they would discuss their problems with. Within this context the young people valued the relationship they could establish with one individual because “building a relationship is hard and it takes time, and when that relationship is good and solid you move on, which is weird and tricky”. One young person noted that “as I got to know the lady and started to trust her enough, she had to leave”.

Initial Finding

Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities.

Views and feedback

The young people were supportive of the suggested finding.

All the young people enjoyed participating in a range of hobbies and activities and were conscious of the support they needed to be able to do these.

“I like swimming, but I need someone I know nearby to help if something goes wrong. Also, travelling to where the event is happening is the main issue”.

“I was really scared about getting the buses and my mum did the routes with me on the buses”.

Consequently, the young people remarked that more independent skills training, such as travel training, should be taught across all schools. They expressed concern that those in mainstream schools were more likely to miss out on this type of learning, as it was more readily available in special schools.

“I was scared about everything, and I wrote a really, really long letter, all the reasons why I wouldn’t go to the corner shop, which literally is about twenty doors down. She did the walk with me and we went through the whole list and managed to cross off practically everything. But she was able to do that because she used to come to our house and do our meetings. Or it got to the

point where she'd book a room, so there was a meeting room about ten doors up that way and make me walk to the appointment on my own".

We asked groups 2 and 3 to tell us about activities they liked and why. They were able to identify how different activities helped them. For example, "it [art] makes me feel calm and happy". In some instances, they also told us why they were able to access a particular activity: "I like basketball because it is on my schedule and I know what to do".

Not having the right support acts as a barrier to accessing services that other young people would enjoy: "clubs I find tricky because I find the rules I look for in a club never really took on when I was at school. For example, there's lots of clubs and even if they were good, I tended to eventually stop going".

Initial Finding

Children and young people with autism, and their family and carers, should have easy access to short breaks.

Views and feedback

The young people were supportive of the suggested finding, although only some had direct experience of accessing short breaks.

One young person who had had an extended stay with foster carers described how she had not enjoyed it at the time, but overall felt it had been helpful for her and her family. All young people were able to identify activities they liked and acknowledged the positive impact it had on them.

Initial Finding

*Children and young people with autism, and their family and carers, should be provided with *post-diagnosis information about services available and support*, for example a family support worker.*

Views and feedback

The young people were very supportive of the suggested finding.

They valued having a person, who was often a family member, who they could turn to for support and to help them understand their autism:

"If I have one of my freak out moments, "Oh, my God! I can't believe I'm about to do this!" she [my mum] sort of gets you, like, calm and puts everything into perspective for me, which is what I need. Because everything just blows up in my head and it's this massive, massive ordeal, but really it's not. She sort of makes me see that".

However, having someone outside of the family who could support them would also be beneficial, particularly if sensitive issues arise.

It was one young person's perception that when "I got my diagnosis I always felt that I got it for other people, so that other people knew how to help me". Ultimately, "just because you found out you have autism it doesn't change how you already are".

They spoke strongly about learning to live with autism and it not being something "to be got rid of, [because] it's an integral part of who you are". Nevertheless, they broadly agreed that knowing more about how the condition might affect them would help alleviate the uncertainty of the diagnosis:

"I would like to have known how anxious I would be".

"It was bad being diagnosed so late, particularly as I saw the problems my sister experienced with her mental health. It was difficult to accept the diagnosis. I was scared. It would have been helpful if someone had explained that I wouldn't necessarily develop mental health problems...that it wouldn't all be bad".

One young person commented that if they had to give advice to a newly diagnosed peer they would say "not to get like discouraged if they found it difficult to do things that other people may necessarily find easier to do, like get on public transport and things like that, going out in the middle of town and mingle".

Initial Finding

Treatment and care of children and young people with autism should involve shared decision making and a collaborative approach that takes into account service user preferences.

Views and feedback

The young people were broadly supportive of the suggested finding, although there were mixed views on how much involvement they wanted in decision making.

These schematics give the views from some of the young people on involvement. Each young person was asked to plot how much involvement they currently have on a number of different topics, and how much they'd actually want. Whilst individuals have not been identified below, every single one did want more say than they currently have, but it differed depending on individual preference and the issue at stake.

Key



= Actual involvement

= Ideal involvement

Diagram 1

How much explanation professionals give about the treatments and care I need?



No involvement

Complete involvement

Diagram 2

Which professional gives me my treatments or care? For example, choosing your speech and language therapist or occupational therapist.



No involvement

Complete involvement

Diagram 3

What type of treatment I get. For example, medication or leisure activities



Diagram 4

Where I go for my health and medical appointments. For example, choosing if your appointments are at the CAMHS building, at home, the doctors surgery



No involvement

Complete involvement

Diagram 5

When your appointments take place. For example, during school time, in the evening, on weekends



No involvement

Complete
involvement

This diagram reflects the young people’s opinion on where the share of decision making control between themselves, their parents and relevant professionals should broadly sit. Again, some young people wanted to be heavily involved, others equally involved and some preferred if professionals and their families took control.

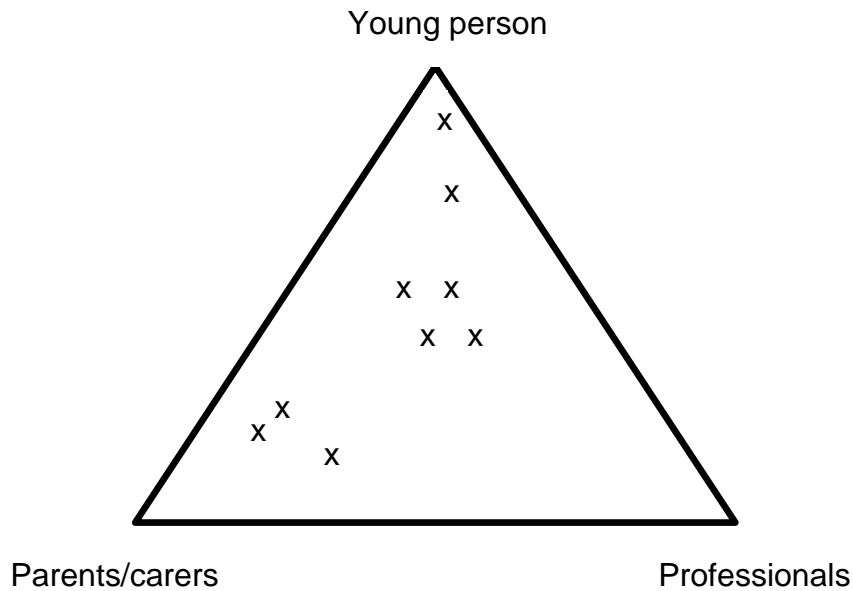


Diagram 6

The young people felt that they could and should be given more choice than they currently have and that “sometimes professionals think that she’s got autism; she’s not going to understand what I’m saying to her” and that professionals “don’t think we’re capable of knowing what we want”.

However, some young people were equally wary of taking on all the responsibility. “I know when I went through CAMHs I thought I was perfectly capable of making my decisions and that I don’t need my parents. But I know that if they weren’t around to sort things out I’d probably still be in that situation”.

Other comments included “I like my Mum to decide as it’s hard” and “sometimes it’s easier when teachers tell me what I need”. Another factor in addition to it simply being a case of individual preference was one of experience: “I reckon the more experience you have of the different types of treatment and you’ve had time to decide what works best, then, I reckon you would become more independent in deciding what kind of treatment you had”.

Initial Finding

All children and young people with autism should have access to healthcare and social care services, including mental health services, and access should not be restricted based on a child's intellectual ability, autism diagnosis, or any other eligibility criteria.

Views and feedback

The young people were very supportive of the suggested finding.

They strongly believed that “you should get exactly what you need” and one young person summed up the prevailing attitude when she commented that “if you're not well, they give you tablets to make you better, so why wouldn't you get help if you have some problems? If you find things hard, well, why wouldn't you get help with that?”

Concluding comments

Every young person really valued being asked to participate in the consultation and have their voice heard. The overriding message from the young people on what would best help them manage their autism was for professionals and services to treat their individual needs first and foremost and not the autism label. However, diagnosis was also important to them in helping them to begin to understand their difficulties and ensure that professionals could begin to have an understanding of how to help them. They believed all the findings presented by NICE would be beneficial for those living with autism, so long as there was “consistency” and sometimes all it takes is having “someone to talk to”. Together this would help them “embrace the fact they have autism and not necessarily let it define them, but just accept it as part of who they are”.

3. Methodology

Consultation took the form of individual and group work, with discussions centred on the issues which gave rise to each initial NICE finding. To ensure meaningful participation of those from across the autism spectrum, a variety of different consultative approaches were used. These adaptations detailed below were based on individual needs, following discussions with teachers and a speech and language therapist. Consequently, whilst we were able to explicitly ask young people in group one whether they agreed or disagreed with each initial finding, we've had to infer the extent of agreement in most responses given by groups two and three, and this wasn't always possible.

For all young people with higher levels of support (groups two and three), questions were presented in a structured format with a range of possible options to choose from. The young person was asked to put ticks against the statements they agreed with. Where possible, the discussions were opened up to apply the issues in a broader context: what young people in general might want, how the principles might apply in hypothetical situations. It was not possible to ask all young people their views on each of the findings.

Appendix 4.1. Outline of consultation groups

Group One

This group consisted of nine young people aged between 13 and 19, six boys and three girls from across England. Apart from one person, all the participants of this group have been or are current members of the NAS Young Campaigners' group.

The session took place in a venue which all but one young person had previously attended. They are familiar and comfortable with the format of sessions and ground rules, and have established relationship with the NAS staff and other members of the group. All participants are able to a greater or lesser degree to talk fluently about their experience, draw learning from those experiences and generalise them to other settings and for other people. Several members have accessed Child and Adolescent Mental Health Services for co-occurring mental health problems. One member of the group does not communicate verbally, and types her contributions, which are then shared aloud.

The consultation consisted of small group and plenary discussion and activities based around each finding. When working in groups, the young people were supported by a minimum of two NAS staff members, who used a series of prompt questions detailed in appendix 4.3. Timings for each session are indicated with this appendix. Following the completion of the respective activities the young people reconvened as one group to feedback their views, before being asked to vote on whether they agreed or disagreed with the suggested finding.

Group Two

Seven individual interviews were held with pupils from Queensmill School, an autism-specific maintained special school in West London. They were all boys and aged between 11 and 14. Interviews were held within the school building, and carried out by a lead interviewer from the NAS, with support from a speech and language therapist or another member of staff known to the pupil, and lasted between 5 and 20 minutes. The approach was adapted through the first few interviews as it became apparent what level of support and structure was most helpful to enable the pupils to participate. Interviews were restricted to the pupils' direct experiences of what they do and what they find helpful, and were structured using a range of choices. Their views have then been inferred against the findings. They were not explicitly asked whether they agreed or disagreed with the findings.

Group Three

Five individual interviews were held with pupils from the Jewish Community Secondary School (JCoSS) in New Barnet. They were all girls and aged between 12 and 13. Some of the pupils take all their lessons exclusively within the resource unit, whilst others are also able to access some the mainstream classes. Interviews were held within the school building, and carried out by a lead interviewer from the NAS,

with support from member of school staff known to the pupil, and lasted between 10 and 20 minutes.

As with group two the approach was adapted through the first few interviews as it became apparent what level of support and structure was most helpful to enable the pupils to participate. Some of the interviews were restricted to the pupils' direct experiences of what they do and what they find helpful, and were structured using a range of choices. Their views have then been inferred against the findings. They were not explicitly asked whether they agreed or disagreed with the findings. For two of the young people, it was possible for them to generalise their experiences so more detailed issues were explored. These questions were similar to those asked of group one participants.

Appendix 4.2. Group one agenda

**Agenda – The Young Campaigners Group
Saturday 6 October 2012
13.00 - 17.00**

Headrooms, Farringdon (London)

Arrival and lunch

Approximately 13.00 – 13.40

When you arrive at Headrooms, we will have lunch ready for you to eat. You will be able to speak to the other members of the Young Campaigners Group and some of the staff from the National Autistic Society if you would like to. There will also be a quiet space that you can go to, or an xbox you can use.

Introduction

Approximately 13.40 – 13.50

We will talk about what we are going to do at this meeting, including going over our Ground Rules.

You can ask us questions at any time during this session. You can also take a break at any time during this session if you need to.

Making things autism friendly

Approximately 13.50 – 14.40

We will talk about what makes professionals good at understanding autism, and what makes the places you go to autism friendly.

You can ask us questions at any time during this session. You can also take a break at any time during this session if you need to.

Break

Approximately 14.40 – 14.50

What support do young people with autism need

Approximately 14.50 – 15.30

We will talk about the activities you like to do and the support you need to do them. We will also look at what other activities would help you and your family.

You can ask us questions at any time during this session. You can also take a break at any time during this session if you need to.

Break

Approximately 15.30 – 15.45

Growing up with autism

Approximately 15.45 – 16.30

We will prepare a speech to help newly diagnosed young people understand what it is like to have autism

You can ask us questions at any time during this session. You can also take a break at any time during this session if you need to.

Being involved in decisions

Approximately 16.30 – 16.50

We will talk about how involved you are in choosing the support you get. You

can ask us questions at any time during this session. You can also take a break at any time during this session if you need to.

Have we missed anything

Approximately 16.50 – 17.00

A chance to talk about what we've discussed and if you have any other ideas

Finish

Approximately 17.00










Appendix 4.3. Group One Facilitation Guide

Making things autism friendly 13.50-14.40 (50 minutes)

INITIAL FINDINGS	SESSION ACTIVITY	FORMAT	TIMINGS
<p>All staff working with children and young people with autism should have an <u>understanding of autism.</u></p> <p>In all settings, professionals should take into account the <u>physical environment</u> in which children and young people with autism are supported and cared for and <u>make reasonable and appropriate adjustments.</u> Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment.</p>	<p>* Write/talk about a professional and physical environment you like, and why</p> <p>* Write/talk about a professional and physical environment you don't like, and why</p> <div data-bbox="929 590 1456 925" style="border: 1px solid black; padding: 5px; text-align: center;"> </div> <p>Questions to ask:</p> <ul style="list-style-type: none"> * How can you tell that one professional understands you and your autism better than someone else? * Are there places you don't go to because it's not autism friendly? * Have you or your parents ever asked someone to change a building (e.g. use different lights) so that it is more autism friendly? * Has anyone ever asked you what changes they could make? <p>At the end of the activity, we will ask them whether they agree or disagree with the finding</p>	<p>Small group work session, followed by group discussion</p> <p>Write on yellow post it notes things you like (people and building)</p> <p>Write on green post it notes things you don't like (people and building)</p>	<p>Approx 20 minutes for group work</p> <p>Approx 15 minutes for discussion</p>

	<p>appointments (e.g. annual review of statement)</p> <ul style="list-style-type: none">* Do you think you need someone other than your family members to help organise these appointments?* Has anyone talked to you about moving from child to adult health services?* Is there someone who is going to help you manage that move? <ul style="list-style-type: none">* Think about a time what you changed school or class. What was good about it?* What was bad about it?* What could have made it easier?* Did you have anyone at school that you could go to when you changed school years?* Who was it?* Was this helpful or not? <p>At the end of the discussion, we will ask them whether they agree or disagree with the finding.</p>		
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What support do young people with autism need? 14.50-15.30 (40 minutes)

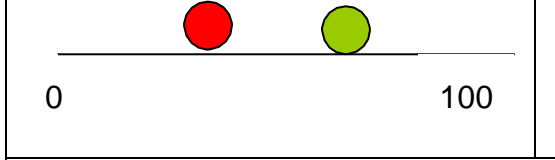
<p>Children and young people with autism should be offered evidence-based <u>intervention aimed at preparation and coping strategies to facilitate access to community services</u>, including the skills to access public transport, employment and leisure facilities.</p>	<p>Questions to ask:</p> <ul style="list-style-type: none"> * What do you like doing? * What support do you need to do these activities? <p>For example...</p> <div data-bbox="936 475 1435 1059" style="border: 1px solid black; padding: 10px; margin: 10px 0;"> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; vertical-align: top; padding-right: 20px;">I like...</td> <td style="width: 50%; vertical-align: top;">The help I get to do this activity is....</td> </tr> <tr> <td style="text-align: center; vertical-align: middle;">  </td> <td></td> </tr> <tr> <td style="text-align: center; vertical-align: middle;">  </td> <td></td> </tr> <tr> <td style="text-align: center; vertical-align: middle;">  </td> <td></td> </tr> </table> </div> <p>Questions to ask:</p> <ul style="list-style-type: none"> * Who first got you interested in the activities you like to do? * If it's your parents, do you think that without them you never would have done these activities? * Who do you rely on to support you with your activities? * Is there anything you can't do or go to 	I like...	The help I get to do this activity is....							<p>Small group work session, followed by group discussion</p>	<p>Approx 15 minutes for group work</p> <p>Approx 10 minutes for discussion</p>
I like...	The help I get to do this activity is....										
											
											
											

	<p>because the support you need isn't there?</p> <p>At the end of the activity, we will ask them whether they agree or disagree with the finding.</p>		
<p>Children and young people with autism, and their family and carers, should have easy <u>access to short breaks.</u></p>	<p>Example questions to ask:</p> <ul style="list-style-type: none"> * Are there times when you need a break from your family? * Are there times when they need a break from you? * Do you and your family have this chance for a break? * What kind of break do you want (overnight, a few hours)? * What kind of things would you like to do? <p>At the end of the discussion, we will ask them whether they agree or disagree with the finding.</p>	<p>Full group discussion</p>	<p>Approx 15 minutes</p>

Growing up with autism 15.45-16.30 (45 minutes)

<p>Children and young people with autism, and their family and carers, should be provided with <u>post-diagnosis information about services available and support</u>, for example a family support worker.</p>	<p>* If you were talking to students who had just found out they had autism, what would you say? * What kind of information do you wish someone had told you, that would have made it easier to understand your autism and cope with being diagnosed? * How do you or your parents find out about what support is available?</p> <p>At the end of the discussion, we will ask them whether they agree or disagree with the finding.</p>	<p>Small group work session, followed by group discussion</p> <p>This activity should also let us explore if there are others gaps in what young people need.</p>	<p>Approx 25 minutes for group work</p> <p>Approx 20 for group discussion, including asking them if they want to read out their speeches.</p>
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Being involved in decisions 16.30-16.50 (20 minutes)

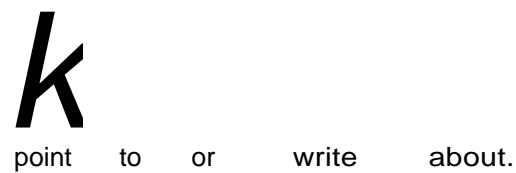
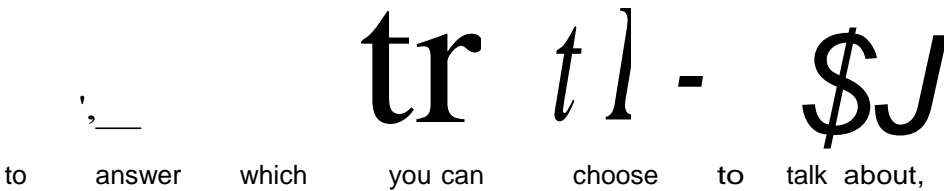
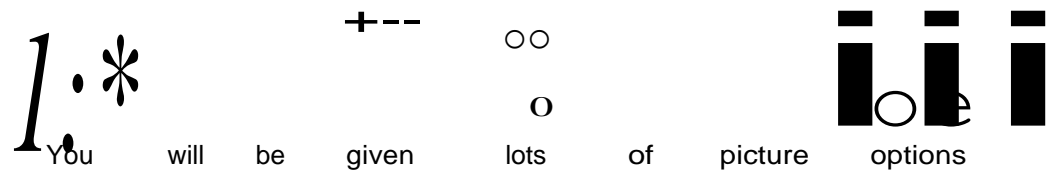
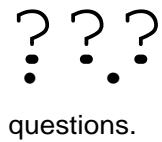
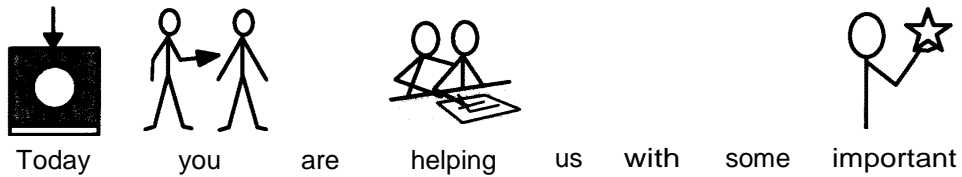
<p>Treatment and care of children and young people with autism should <u>involve shared decision making and a collaborative approach</u> that takes into account service user preferences.</p> <p>All children and young people with autism should have <u>access to healthcare and social care services</u>, including mental health services, and access should <u>not be restricted based on a child's intellectual ability</u>, autism diagnosis, or any other eligibility criteria.</p>	<p>* Put a red dot on how much say you actually have in...</p> <p>* Put a green dot on how much say you want to have in...</p> <div data-bbox="853 368 1406 683" style="border: 1px solid black; padding: 10px; text-align: center;"> <p>Which professional gives me my treatments or care?</p>  <p>0 100</p> </div> <p>* Who should have access to these types of services? Should there be any restrictions for example, based on IQ or your diagnosis?</p> <p>At the end of the activity, we will ask them whether they agree or disagree with the finding.</p>	<p>Individual exercise followed by full group discussion</p>	<p>Approx 10 minutes for activity</p> <p>Approx 10 minutes for discussion.</p>
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Have we missed anything 16.50-17.00 (10 minutes)

Full group discussion to see if we've missed anything and to show which findings we have agreed/disagreed with and comments we have made

4.4. Group two and three facilitation materials

This worksheet was used to explain what was going to happen during the interview.



AA ✓ ? ? AA
We will tick the questions as we

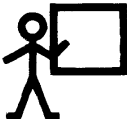


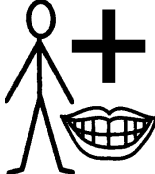




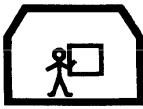
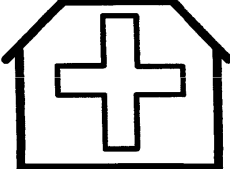




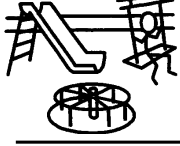


go along.

654321
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ir
Thank you for helping.

ff *cP* (@)
We appreciate it.

This worksheet is an example of some of the symbols the young people could choose to help make decisions on the activities they like to do and the support they receive.

 teacher	 doctor	 nurse	 dentist
 teacher assistant	 listening	€it  talking	 quiet
 school	 hospital	 sport	IQ** club
 horse riding	 football	 tennis	ling runn1ng
.AO ing swimming	 playgroun	 computer	 art

Example 1: Complete feedback from one young person using structured worksheet

This worksheet explained the questions that were going to be asked. The young person was asked to tick off each question as they were completed.

1. Who do you work with? <i>f? S-t-c,ccc</i>	<input checked="" type="checkbox"/>
2. What do they do to help? <i>lA/p</i>	<input checked="" type="checkbox"/>
3. What places do you like in school? <i>?9 1f:J</i>	<input checked="" type="checkbox"/>
4. What do you like about them? <i>@</i>	<input type="checkbox"/>
5. What activities do you like to do? <i>@</i>	<input type="checkbox"/>
6. Why do you like them? <i>@</i>	<input checked="" type="checkbox"/>

7. Other questions.


✓ _____)

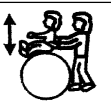
This worksheet was used to help the young person share how a particular professional helped them. This information was used to infer a response to the finding "All staff working with children and young people with autism should have an understanding of autism".

Listening to me

Talking to me

Using pictures, written words and signing

Giving me a  ✓

Giving me time in the  body shop ✓

Using a  calm  voice ✓

Helps me calm down.

This worksheet was used to help the young person share which environment they felt most comfortable in. This information was used as a starting point to explore the finding *“In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment”*.


Which room do you like?

Classroom

DT room

Hall

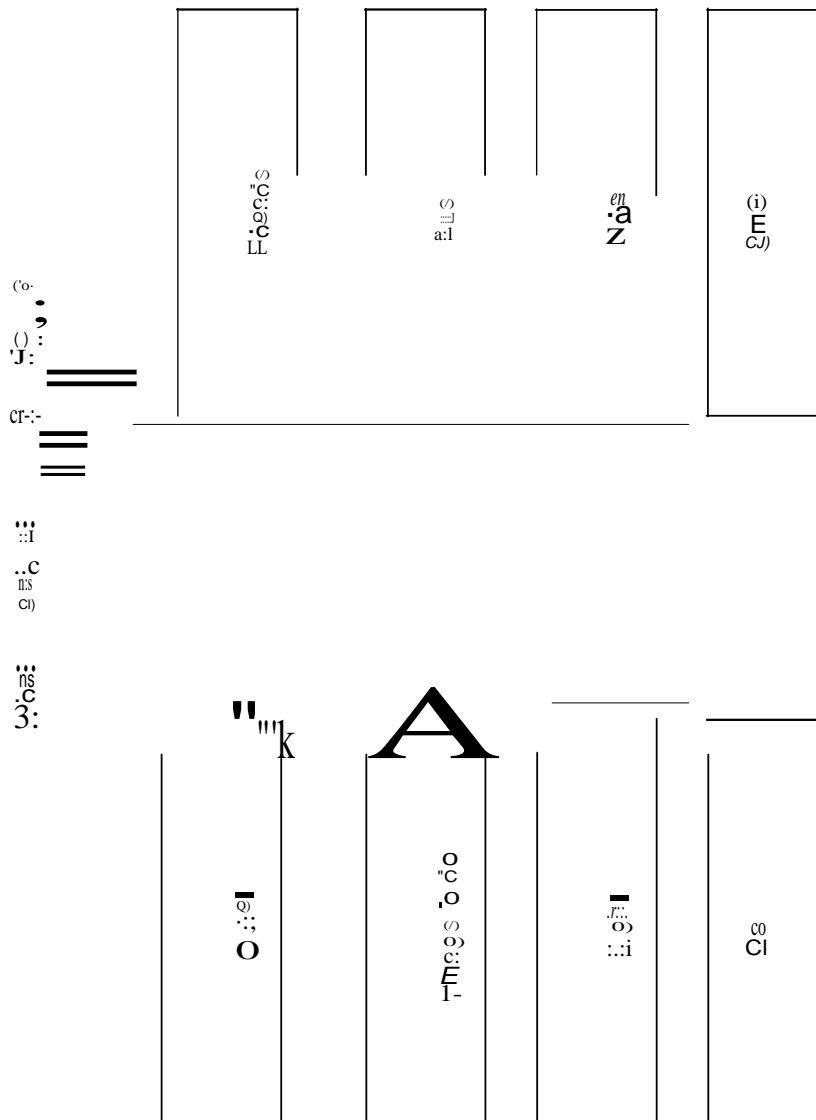
Dining Room




Playground


Cage


This worksheet was used to help the young person share what they liked about a particular environment. This information was used to infer a response to the finding *"In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment"*.




Having chosen one activity they liked doing, this worksheet was used to help the young person share why they liked it. This information was used as a starting point to explore the findings “Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities” and “Children and young people with autism, and their family and carers, should have easy access to short breaks”.




It's fun


It makes me feel calm ✓

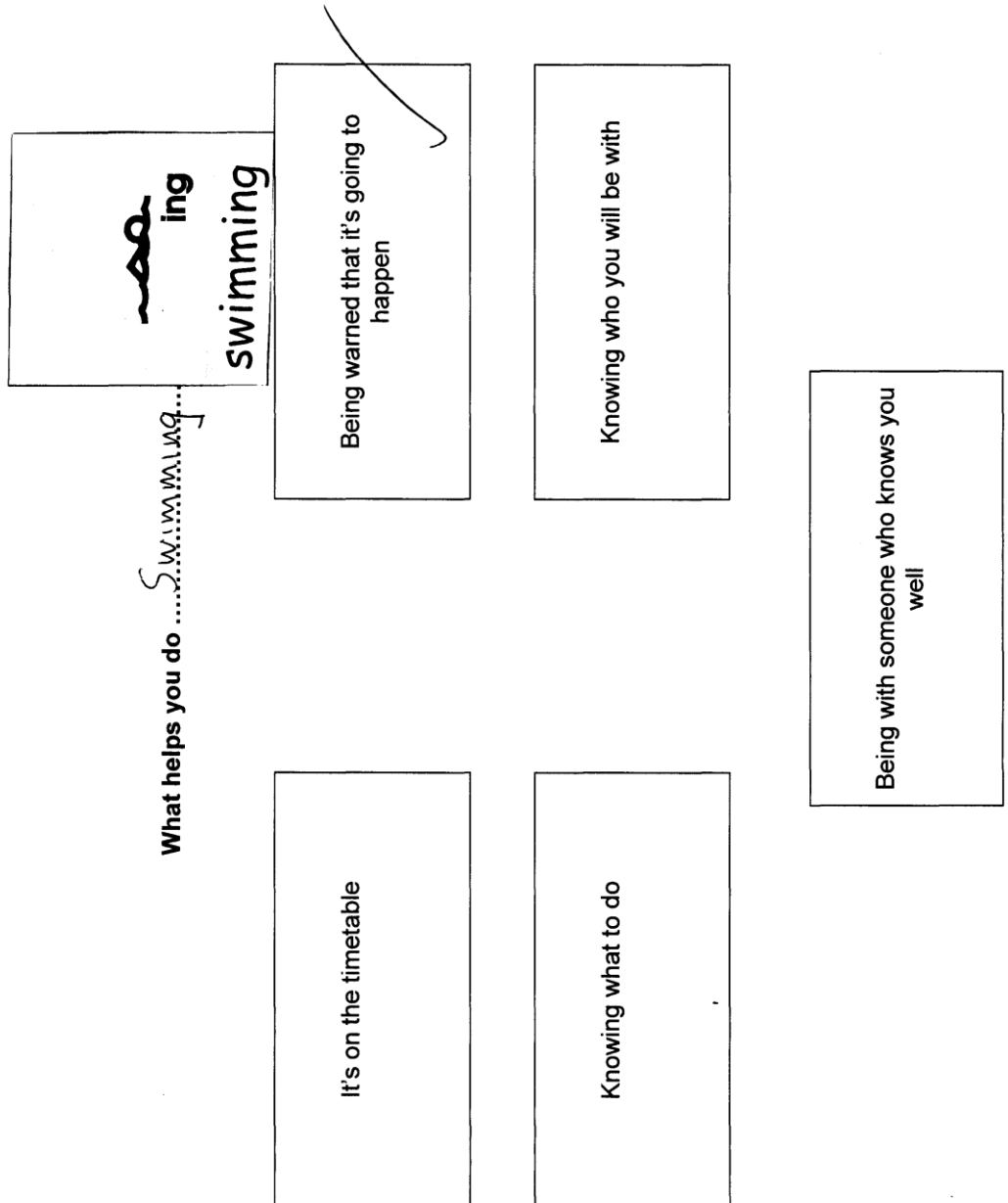

I like being with friends ✓


I like being with adults


It makes me feel happy or excited





I like learning with my teacher

This worksheet was used so the young person could say what help they needed to do their preferred activity. This information was used to infer a response to the finding “Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities”.



Example 2: Complete feedback from one young person using structured worksheet

This worksheet explained the questions that were going to be asked. The young person was asked to tick off each question as they were completed.

t? 1. Who do you work with?	✓ mrtodd
2. What do they do to help?	French
.l 3. What places do you like in school	HCA ■ ■
4. What do you like about them?	Quiet
5. What activities do you like to do? 	Busy
6. Why do you like them? 	Reading art computer cooking playing reading Football

This worksheet was used to help the young person share how a particular professional helped them. This information was used to infer a response to the finding "All staff working with children and young people with autism should have an understanding of autism".

∴ <ii>
[Lis;: g to me]

[T:g to me]

+++
Using . ✓ written ✓ and ~~signing~~

Giving me a  X

[Using a calm voice V]

This worksheet was used to help the young person share which environment they felt most comfortable in. This information was used as a starting point to explore the finding *“In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment”*.

Which rooms do you like?


Classroom	Hall	
Dining Room	Playground	


This worksheet was used to help the young person share what they liked about a particular environment. This information was used to infer a response to the finding “In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment”.


What I like about these places?

Friends	Busy	Noisy	Dark
Quiet	Things to do	Light	Smelly


Having chosen one activity they liked doing from a range of symbols, this worksheet was used to help the young person share why they liked it. This information was used as a starting point to explore the findings “Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities” and “children and young people with autism, and their family and carers, should have easy access to short breaks”.




It's fun ✓


It makes me feel calm ✓


I like being with friends ✓


I like being with adults ✓


It makes me feel happy or excited ✓

 
I like learning with my teacher ✓