Appendix A: Autism Healthcare Accommodations Report (AHAT)

AHAT Survey - Autistic

<table>
<tr><td>

[warning_screen] #1

Autism Healthcare Accommodations Tool - Autistic Version

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(chapter: introduction:)
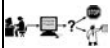
[order_num: 0; slide_id: 0] type: statement

Introduction

This tool will help you make a report for your <u>healthcare providers</u>.

You will take a survey. The computer will use your answers to make a report. The report will include information to help healthcare providers get to know you better. The report will also include personalized suggestions about what your healthcare providers can do to help you get better healthcare.

You will be able to look at the report after you finish making it. The report will be written in a way that we hope will make healthcare providers more willing to read it.

It is your choice if you would like to share the report with your healthcare providers. The suggestions in the report are just ideas. They may or may not work, but we hope they will start a useful conversation between you and your healthcare providers.

Popup for healthcare providers:

> Healthcare providers are physicians, nurse practitioners, or physician's assistants, and their office staff.

[order_num: 1; slide_id: 1] type: statement

It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the suggestions on the survey that you think will make a big difference in your healthcare.

The program will not display any more than 35 suggestions on the report. You can go back and change your selections. Giving the provider too many suggestions could overwhelm the provider, and could hurt the way he or she relates to you.

Pressing Next will start the report-making process.

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(chapter: how_communicate:)

[order_num: 0; slide_id: 0] type: statement

How You Communicate

The next section includes information to help your provider better understand how you communicate.

[order_num: 1; slide_id: 1] type: question

In general, how would you describe your ability to understand what people say?
- ○ I usually can understand spoken language well.
- ○ I often have a hard time understanding or processing what people say.
- ○ I understand very little spoken language.
- ○ My ability to understand spoken language changes so much, depending on the situation, that I cannot put it into one of these categories.

[order_num: 2; slide_id: 2] type: question

In general, how would you describe your ability to speak?
- ○ I usually can speak well.
- ○ I can speak, but often have a hard time saying what I want to say.
- ○ I have a very hard time speaking (for example, I only can use short phrases).
- ○ I have little or no ability to speak.
- ○ My ability to speak changes so much, depending on the situation, that I cannot put it into one of these categories.

[order_num: 3; slide_id: 3] type: question

How would you describe your ability to read?
- ○ I cannot read.
- ○ I can read some words and short sentences.
- ○ I can read at a basic level.
- ○ I can read at a high school level.
- ○ I can read at a college level.

[order_num: 4; slide_id: 4] type: question

How would you describe your ability to write or type?
- ○ I cannot write or type.
- ○ I can write or type a little bit.
- ○ I can write or type at a basic level.
- ○ I can write or type at a high school level.
- ○ I can write or type at a college level.

[order_num: 5; slide_id: 5] type: checkall

What types of alternatives to speech do you use, if any?
- ☐ Text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app)
- ☐ Picture-based alternatives to speech (picture-based AAC, picture boards, drawing)
- ☐ American sign language (ASL)
- ☐ Other signs, gestures, or behaviors
- ☐ None

Popup for AAC:

> Alternative and Augmentative Communication

(chapter: comm_suggestions:)

[order_num: 0; slide_id: 0] type: statement

Communication Suggestions

The next section asks about information that can help your providers communicate better with you. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in your healthcare.

If you need something that is not listed, check the box that says it isn't listed and the report will ask your healthcare provider to talk about it with you and/or your supporter. We chose not to allow write-in information because there is no way for the computer to check to make sure it is helpful to patients and providers.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall

What can your healthcare providers do to help you understand them better?

☐ Use simple words and short sentences.
☐ Use very precise language, even if it means using longer sentences or advanced vocabulary.
☐ Be very concrete and specific.
☐ Show me diagrams, pictures, or models whenever possible.
☐ Use medical words.
☐ Avoid medical words.
☐ Ask me to repeat what you said in my own words.
☐ Write down important information or instructions for me.
☐ Give me very detailed information.
☐ Focus only on the most important information.
☐ Be patient with me if I need to ask a lot of questions.
☐ Give me extra time to process what you have said and check to make sure I am ready to move on.
☐ Do not try to talk to me while there are other noises (for example, beeping sounds, outside noises, people talking, or babies crying).
☐ I **don't need** accommodations to help me understand providers.
☐ I need accommodations to help me understand providers, but they are **not listed** here.

Popup for medical words:

For example, "Gastroesophageal Reflux Disease (GERD)" is the medical word for heartburn.

[order_num: 2; slide_id: 2] type: checkall

What can your healthcare providers do to help you answer questions or give information?

☐ Ask very specific, concrete questions and avoid very broad questions.

☐ Ask mostly yes and no questions when possible.

☐ Give me extra time to respond to questions.

☐ Read written notes that I bring to the visit.

☐ Give me examples of the types of things people may experience and let me tell you if I experience them too.

☐ Show me lists of symptoms to choose from.

☐ Help me answer questions about time by linking to important events in my life.

☐ Offer to reword the question if I seem confused.

☐ Remind me that it is OK to not know the answers to your questions.

☐ Remind me that it is OK not to be 100% exact in my answers.

☐ I **don't need** accommodations to answer questions or give information.

☐ I need accommodations to answer questions or give information, but they are **not listed** here.

[order_num: 3; slide_id: 3] type: checkall

What do you want your healthcare provider to know about your communication?

☐ I may have a hard time communicating, even if my speech sounds fluent.

☐ I can be involved in decisions about my care, even though I have difficulty speaking.

☐ I often take language too literally.

☐ In general, I can read better than I can understand spoken language.

☐ In general, I can write or type better than I can speak.

☐ I may have difficulty understanding tone of voice, facial expressions, or body language.

☐ My ability to communicate changes a lot, depending on the situation.

☐ If I seem rude, I don't mean it. I'm just really direct.

☐ I have a hard time using the telephone.

☐ There **isn't anything** related to my communication that my provider needs to be aware of.

☐ There are things related to my communication that my provider needs to be aware of, but they are **not listed** here.

Popup for literally:

For example, a doctor may ask "what brings you to the clinic" as a way to say "what is the problem that caused you to come to the clinic. Someone who takes things literally may answer "the bus" if that is how he or she got to the clinic that day.

(chapter: before_the_visit:)

[order_num: 0; slide_id: 0] type: statement

Before the Visit

The next section asks about things your healthcare providers and their staff can do before your visit to

help make your visit more successful. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in your healthcare.

If you need something that is not listed, check the box that says it isn't listed and the report will ask your healthcare provider to talk about it with you or your supporter.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall

What can your healthcare provider's staff do before the visit to make it more successful?

☐ If possible, give me a way to make appointments without using the telephone.

☐ Schedule longer appointments if possible.

☐ Schedule appointments at a time when the provider is less likely to be late (for example, the first appointment).

☐ Let me or my supporters know what is likely to happen during an office visit (for example, what can I expect when checking in, during and after the visit, who I will be seeing, and how long things usually take).

☐ Notify me as soon as possible if there is an unexpected change (for example, I need to see a different provider).

☐ Let me or my supporters fill out paperwork at home.

☐ Give me pictures, or let me or my supporter take pictures, of the office and/or staff.

☐ Give me detailed information about how to communicate with your office staff between visits (for example, how to make appointments, contact my regular provider, or contact the clinic in an emergency).

☐ I **don't need** accommodations ahead of time.

☐ I need accommodations ahead of time, but they are **not listed** here.

[order_num: 2; slide_id: 2] type: checkall

What would make it easier for you to handle waiting after you show up for your visit?

☐ Let me wait in an exam room or other private area.

☐ Let me wait in the car or other place outside of the office building (and contact me or my supporter when it is time to go into an exam room).

☐ Turn off the TV, radio, or other things that make noise in the waiting room.

☐ If possible, make the lights in the waiting area dimmer or allow for natural light.

☐ Let me know how long the wait is likely to be, or if there is an unexpected delay.

☐ Don't expect that I will notice when you call my name--please come over to me or get my attention in another way.

☐ Show me where to go.

☐ I **don't need** accommodations to help with waiting.

☐ I need accommodations to help with waiting, but they are **not listed** here.

(chapter: during_the_visit:)

[order_num: 0; slide_id: 0] type: statement

During the Visit

The next section asks about things your healthcare providers and their staff can do during your visit so you can get better healthcare. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in your healthcare.

If you need something that is not listed, check the box that says it isnâ€™t listed and the report will ask your healthcare provider to talk about it with you or your supporter.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall

During office visits, what can your healthcare providers do to help you stay calm and comfortable?

- ☐ Allow me to bring a person, service animal, or item that helps me stay calm.
- ☐ Make a list with me of what needs to be addressed, and work with me to choose what we should address today.
- ☐ Tell me what is likely to happen at the visit (for example, first we talk, then you do an exam, then you tell me what you recommend).
- ☐ Write down a list of topics we will discuss and point out when we change topics.
- ☐ Let me take breaks if I need them.
- ☐ Tell me about changes in plans as soon as possible.
- ☐ Do not force me to make eye contact.
- ☐ Use natural light or turn off fluorescent lights if possible, or make the lighting dim.
- ☐ Try to give me a quiet room.
- ☐ Please do not sit or stand close to me unless it is necessary for an examination (having people in my personal space makes me feel uncomfortable or confused).
- ☐ Avoid chitchat (it may make me feel uncomfortable or confused).
- ☐ Be patient with me and use a calm voice.
- ☐ Ask me some questions about my life outside of the office.
- ☐ I **don't need** accommodations to help me stay calm.
- ☐ I need accommodations to help me stay calm, but they are **not listed** here.

[order_num: 2; slide_id: 2] type: checkall

What can make examinations or procedures more successful for you?

- ☐ Explain what parts of the visit the nurse will do and what parts of the visit the doctor will do.
- ☐ Explain what you are going to do before you do it.
- ☐ Show me equipment you will use before you use it.
- ☐ If possible, let me do a "trial run" of difficult exams or procedures before we do them for real.
- ☐ Tell me how long something is likely to take.
- ☐ Let me know when you are about to touch me or do something to me.
- ☐ Let me keep as many of my clothes on as possible or limit the amount of time I have to be undressed or in a gown.
- ☐ Give me extra time to process things I need to see, hear, or feel before I respond (for example, pressing and asking if something hurts).
- ☐ Touch me as little as possible.
- ☐ When touching me, please use a firm, deep pressure if possible (not a light touch).
- ☐ Allow me to sit, lie down, or lean on something during procedures, when possible.
- ☐ Let me use a signal to tell you that I need a break.
- ☐ Ask me from time to time if I am able to handle the pain or discomfort.

☐There may be times when I need anesthesia to tolerate a procedure.

☐I **don't need** accommodations to handle exams or procedures.

☐I need accommodations to handle exams or procedures, but they are **not listed** here.

[order_num: 3; slide_id: 3] type: checkall

What can help you make good decisions about your healthcare?

☐Give me extra time to make a decision, even if it means I need to come back or communicate the decision at a later time.

☐Give me very blunt and concrete examples of what would happen if I did or did not follow a recommendation.

☐Direct me to detailed information or resources about my health conditions.

☐Give a person I trust detailed information or resources about my health conditions.

☐Let me discuss my choices with a person I trust, and then come back to you.

☐I **don't need** accommodations make good decisions about my healthcare.

☐I need accommodations to make good decisions about my healthcare, but they are **not listed** here.

[order_num: 4; slide_id: 4] type: checkall

What do you want your healthcare provider to be aware of about you?

☐I may have difficulty recognizing and/or reporting pain or other symptoms.

☐I may have difficulty recognizing and/or describing emotions.

☐I may have difficulty recognizing bodily sensations such as hunger, the need to urinate, or where something hurts.

☐If I do not look at you, it does not mean I am not paying attention or am being dishonest.

☐If I fidget, move around, flap my arms, or make other sounds or motions, it does not mean I am not paying attention or that I am trying to be disruptive.

☐Try to remain patient if I become visibly upset, yell, or act in an unusual way.

☐I might have strong negative reactions to some smells found in medical environments.

☐I may have trouble processing more than one sense at a time, for example hearing you while looking at something.

☐I have trouble with balance, coordination, or fine motor skills.

☐I have trouble controlling my body, for example, starting, switching, and combining movements.

☐I may need physical or verbal prompts to do what you need me to do.

☐Using restraints may make things worse for me. Please work with me or my supporters during a calm period to find alternatives to restraints.

☐There **isn't anything** related to my being on the autism spectrum that my provider needs to be aware of.

☐There are things related to my being on the autism spectrum that my provider needs to be aware of, but they are **not listed** here.

(chapter: after_the_visit:)

[order_num: 0; slide_id: 0] type: statement

After the Visit

The next section asks about things your healthcare providers or their staff can do after the visit to help you with any next steps (for example, taking your medications or making a follow-up visit). It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in your healthcare.

If you need something that is not listed, check the box that says it isn't listed and the report will ask your healthcare provider to talk about it with you or your supporter.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall

What can help you better understand or follow recommendations?

☐ Write out your diagnoses, what you think is going on, and what the plan is for next steps or treatments.

☐ Write out detailed step-by-step instructions.

☐ Use pictures as much as possible.

☐ Explain medication instructions by showing me how much to take at each time of day.

☐ If possible, offer an alternative to pills, such as a liquid form of a medication.

☐ Have office staff help me schedule follow-up visits, referrals, or tests.

☐ Show me how to get to the lab or other places in your office or medical center (or have someone come with me).

☐ Have office staff contact me or my supporter after the visit to make sure that I have been able to do what I was supposed to do.

☐ Give me worksheets or diaries to keep track of symptoms.

☐ Make sure I get a visual schedule of what I need to do.

☐ I **don't need** accommodations to understand or follow recommendations.

☐ I need accommodations to understand or follow recommendations, but they are **not listed** here.

[order_num: 2; slide_id: 2] type: question

Can you use the telephone to communicate between visits?

○ Yes

○ No

[order_num: 3; slide_id: 3] type: question

Do you have a very hard time with blood draws?

○ Yes

○ No

[order_num: 4; slide_id: 4] type: checkall

Which of these things can help you with blood draws?

☐ Only order blood tests when absolutely necessary and group them together to avoid having to get stuck more than once.

☐ Use a numbing spray or cream.

☐ Be very patient and use a calm voice.

☐ Give me a very detailed explanation of what will happen, including how many tubes of blood you will fill.

☐ Consider giving me an anti-anxiety medication before the blood draw.

☐ Give me a lot of advance warning so I can prepare myself emotionally.

☐ Tell me before you stick the needle.

☐ Do not let me know when you will stick the needle.

☐ Give me something to distract my attention.

☐ I need accommodations for blood draws, but they are **not listed** here.

Popup for numbing spray or cream:

A spray or cream on your skin that makes it so you won't feel as much pain when the needle goes in.

(chapter: getting_to_know:)

[order_num: 0; slide_id: 0] type: statement

Getting to Know You

Healthcare providers often like knowing a little bit about their patients' lives outside of what they see in the doctor's office. The next section includes information that may help your provider better understand who you are as a person. We think this information may be helpful, but it is OK to leave it blank if you do not want to answer.

[order_num: 1; slide_id: 1] type: fillinblank

In general, what are your strengths or the things you do best? (Examples of things some people might say are: memorizing things, drawing, following routines, or programming computers.)

[order_num: 2; slide_id: 2] type: fillinblank

What are your special interests? (Examples of things some people might say are: 16th century Russian literature, things that spin, ballet, or the muppets.)

[order_num: 3; slide_id: 3] type: statement

Sometimes individuals on the autism spectrum may have such bad experiences in healthcare settings that they become overwhelmed, meltdown, shut-down, become very anxious or upset, or are unable to function. If this sometimes happens to you, it would help your providers to know more about how to possibly keep these types of things from happening, or to know how to respond if they do happen.

[order_num: 4; slide_id: 4] type: fillinblank

What are some things that make you anxious at the doctor's office?

[order_num: 5; slide_id: 5] type: fillinblank

How do you show you're anxious in the doctor's office?

[order_num: 6; slide_id: 6] type: fillinblank

What are some things that calm you down at the doctor's office?

[order_num: 0; slide_id: 0] type: statement

Your Supporters

Sometimes other people, such as family members, caregivers, or friends, may help patients with their healthcare. For example, a supporter may help a patient communicate, may be the contact person between visits or for emergencies, may be a guardian or healthcare decision-maker, or may provide additional information to healthcare providers. The next section includes information about the people who support you with your healthcare.

[order_num: 1; slide_id: 1] type: question

Does anyone help you with your healthcare?
- ○ Yes
- ○ No

[order_num: 2; slide_id: 2] type: contact

Contact Information for the person

Name [_____]

City [_____]

State [_____]

Zip [_____]

Telephone [_____]

Email [_____]

Other [_____]

[order_num: 3; slide_id: 3] type: question

Relationship to you
- ○ Parent
- ○ Sibling
- ○ Other family member
- ○ Husband/wife or domestic partner
- ○ Other friend
- ○ Caregiver (for example, foster parent, case manager, personal assistant)
- ○ Other

[_____]

[order_num: 4; slide_id: 4] type: checkall

Preferred role(s) in supporting you in healthcare
- ☐ I want this person to help me communicate for myself during visits, as needed.

☐I want this person to do most of the communication with my providers during visits (but please also communicate with me as well as possible).

☐I want this person to be the main contact for communication between visits.

☐I want providers to contact this person if there is an emergency.

☐This person may have more information to give providers about my health or healthcare (for example, this person may know about my childhood or family history).

☐This person may help me with things like making appointments, handling insurance, or dealing with paperwork.

☐Other

[order_num: 5; slide_id: 5] type: question
Does anyone else help you with your healthcare?
○ Yes
○ No

[order_num: 6; slide_id: 6] type: contact
Contact information for the person

Name

City

State

Zip

Telephone

Email

Other

[order_num: 7; slide_id: 7] type: question
Relationship to you
○ Parent
○ Sibling
○ Other family member
○ Husband/wife or domestic partner
○ Other friend
○ Caregiver (for example, foster parent, case manager, personal assistant)
○ Other

[order_num: 8; slide_id: 8] type: checkall
Preferred role(s) in supporting you in healthcare
☐I want this person to help me communicate for myself during visits, as needed.

☐I want this person to do most of the communication with my providers during visits (but please also communicate with me as well as possible).

☐ I want this person to be the main contact for communication between visits.

☐ I want providers to contact this person if there is an emergency.

☐ This person may have more information to give providers about my health or healthcare (for example, this person may know about my childhood or family history).

☐ This person may help me with things like making appointments, handling insurance, or dealing with paperwork.

☐ Other

[   ]

[order_num: 9; slide_id: 9] type: question

Does anyone else help you with your healthcare?

○ Yes

○ No

[order_num: 10; slide_id: 10] type: contact

Contact information for the person

Name [   ]

City [   ]

State [   ]

Zip [   ]

Telephone [   ]

Email [   ]

Other [   ]

[order_num: 11; slide_id: 11] type: question

Relationship to you

○ Parent

○ Sibling

○ Other family member

○ Husband/wife or domestic partner

○ Other friend

○ Caregiver (for example, foster parent, case manager, personal assistant)

○ Other

[   ]

[order_num: 12; slide_id: 12] type: checkall

Preferred role(s) in supporting you in healthcare

☐ I want this person to help me communicate for myself during visits, as needed.

☐ I want this person to do most of the communication with my providers during visits (but please also communicate with me as well as possible).

☐ I want this person to be the main contact for communication between visits.

☐ I want providers to contact this person if there is an emergency.

☐ This person may have more information to give providers about my health or healthcare (for example, this person may know about my childhood or family history).

☐ This person may help me with things like making appointments, handling insurance, or dealing with paperwork.

☐ Other

[order_num: 13; slide_id: 13] type: question

Does anyone else help you with your healthcare?

○ Yes

○ No

[order_num: 14; slide_id: 14] type: contact

Contact information for the person

Name

City

State

Zip

Telephone

Email

Other

[order_num: 15; slide_id: 15] type: question

Relationship to you

○ Parent

○ Sibling

○ Other family member

○ Husband/wife or domestic partner

○ Other friend

○ Caregiver (for example, foster parent, case manager, personal assistant)

○ Other

[order_num: 16; slide_id: 16] type: checkall

Preferred role(s) in supporting you in healthcare

☐ I want this person to help me communicate for myself during visits, as needed.

☐ I want this person to do most of the communication with my providers during visits (but please also communicate with me as well as possible).

☐ I want this person to be the main contact for communication between visits.

☐ I want providers to contact this person if there is an emergency.

☐ This person may have more information to give providers about my health or healthcare (for example, this person may know about my childhood or family history).

☐This person may help me with things like making appointments, handling insurance, or dealing with paperwork.

☐Other

[text field]

Does anyone else help you with your healthcare?
○ Yes
○ No

Contact information for the person

Name [text field]

City [text field]

State [text field]

Zip [text field]

Telephone [text field]

Email [text field]

Other [text field]

Relationship to you
○ Parent
○ Sibling
○ Other family member
○ Husband/wife or domestic partner
○ Other friend
○ Caregiver (for example, foster parent, case manager, personal assistant)
○ Other

[text field]

Preferred role(s) in supporting you in healthcare
☐I want this person to help me communicate for myself during visits, as needed.
☐I want this person to do most of the communication with my providers during visits (but please also communicate with me as well as possible).
☐I want this person to be the main contact for communication between visits.
☐I want providers to contact this person if there is an emergency.
☐This person may have more information to give providers about my health or healthcare (for example, this person may know about my childhood or family history).
☐This person may help me with things like making appointments, handling insurance, or dealing with paperwork.

☐Other

[order_num: 21; slide_id: 21] type: question
Do you have a Guardian(s)/Conservator(s)?
○ Yes
○ No
○ I do not know

[order_num: 22; slide_id: 22] type: fillinblank
What is/are the name(s) of your Guardian(s)/Conservator(s)?

[order_num: 23; slide_id: 23] type: question
Do you have a Healthcare Power of Attorney or Healthcare Power of Attorneys?
○ Yes
○ No
○ I do not know

[order_num: 24; slide_id: 24] type: fillinblank
What is/are the name(s) of your Healthcare Power of Attorneys?

(chapter: sharing_the_report:)
[order_num: 0; slide_id: 0] type: statement

Sharing the Report

The next section includes information to help share your report with your healthcare providers.

This information is used to label the report so that when healthcare providers get a copy, they know who it is about. It also makes sure the report uses the right word -- "he" or "she" -- when describing you.

Filling out this section will NOT automatically share your report with your provider. You will have a chance to look at the finished report and make changes to your selections. **After the report is created, it is up to you to give it to your provider.**

[order_num: 1; slide_id: 1] type: fillinblank
Your full name:

[order_num: 2; slide_id: 2] type: birthdate
Your date of birth:
birthdate

[order_num: 3; slide_id: 3] type: question

Your gender:

○ Male

○ Female

○ Other, but prefer to be referred to has "he"

○ Other, but prefer to be referred to as "she"

○ I do not wish to say

[order_num: 4; slide_id: 5] type: question

The letter addressed to your healthcare provider can include special requests for help with making or getting to appointments. The next questions will ask if you would like these requests included.

If possible, would you like the provider's office to help you with scheduling appointments?

○ Yes

○ No

[order_num: 5; slide_id: 6] type: question

If possible, would you like the healthcare provider's office to help you find transportation to appointments?

○ Yes

○ No

(chapter: report_preview:)

[order_num: 0; slide_id: 0] type: statement

Report Preview

When you click next, the computer will generate a preview of your report.

If you see a part of the report you want to change, use the green "back" button at the bottom of this page, or click on one of the blue chapter headings, to go back and change it.

When you are done making changes, click on the "Report Preview" chapter and click the green "next" button at the bottom of this page to see the updated report.

Do not use the browser's back button.

[order_num: 1; slide_id: 1] type: pdf_preview

Here is a preview of your report. It has been formatted in a way that we hope will work well for healthcare providers. Some items have been reworded a little to make them more acceptable to healthcare providers. Please look it over.

If you want to make changes to what you picked to include on the report, use the green "back" button at the bottom of this page, or click on one of the blue chapter headings, to go back and change it.

If you are happy with what you picked to include on the report, save it or print it. It is up to you to give the print out or file to your healthcare provider.

pdf_preview

[order_num: 2; slide_id: 2] type: question

If you want to make changes to the report, or print or download more copies, just log back into the system. Your answers will be saved for one year.

How would you rate the Autism Healthcare Accommodations Tool you just used?

   ○   ○ ○ ○ ○ ○ ○ ○ ○   ○
   1   2 3 4 5 6 7 8 9   10
not at all useful   very useful

[order_num: 3; slide_id: 3] type: fillinblank
Please give us comments about what you liked and didn't like.

AHAT Survey - Supported Female

(supported male version is the same but with male pronouns)

[warning_screen] #1

Autism Healthcare Accommodations Tool - Supported Female Version

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(chapter: introduction:)
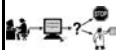
[order_num: 0; slide_id: 0] type: statement

Introduction

This tool will help you make a report for the patient's healthcare providers.

You will take a survey. The computer will use your answers to make a report. The report will include information to help healthcare providers get to know the patient better. The report will also include personalized suggestions about what healthcare providers can do to help her get better healthcare.

You will be able to look at the report after you finish making it. The report will be written in a way that we hope will make healthcare providers more willing to read it.

It is your choice if you would like to share the report with healthcare providers. The suggestions in the report are just ideas. They may or may not work, but we hope they will start a useful conversation between the patient and her healthcare providers.

[order_num: 1; slide_id: 1] type: statement

It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the suggestions on the survey that you think will make a big difference in her healthcare.

The program will not display any more than 35 suggestions on the report. You can go back and change your selections. Giving the provider too many suggestions could overwhelm the provider, and could hurt the way he or she relates to the patient.

Pressing Next will start the report-making process.

(chapter: how_communicate:)

[order_num: 0; slide_id: 0] type: statement

How She Communicates

The next section includes information to help the provider better understand how she communicates.

In general, how would you describe her ability to understand what people say?

◯ She usually can understand spoken language well.

◯ She often has a hard time understanding or processing what people say.

◯ She understands very little spoken language.

◯ Her ability to understand spoken language changes so much, depending on the situation, that I cannot put it into one of these categories.

In general, how would you describe her ability to speak?

◯ She usually can speak well.

◯ She can speak, but often has a hard time saying what she wants to say.

◯ She has a very hard time speaking (for example, she only can use short phrases).

◯ She has little or no ability to speak.

◯ Her ability to speak changes so much, depending on the situation, that I cannot put it into one of these categories.

How would you describe her ability to read?

◯ She cannot read.

◯ She can read some words and short sentences.

◯ She can read at a basic level.

◯ She can read at a high school level.

◯ She can read at a college level.

How would you describe her ability to write or type?

◯ She cannot write or type.

◯ She can write or type a little bit.

◯ She can write or type at a basic level.

◯ She can write or type at a high school level.

◯ She can write or type at a college level.

What types of alternatives to speech does she use, if any?

☐ Text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app)

☐ Picture-based alternatives to speech (picture-based AAC, picture boards, drawing)

☐ American sign language (ASL)

☐ Other signs, gestures, or behaviors

☐ None

Popup for AAC:

Alternative and Augmentative Communication

Communication Suggestions

The next section asks about information that can help providers communicate better with her. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in her healthcare.

If she needs something that is not listed, check the box that says it isn't listed and the report will ask the healthcare provider to talk about it with her and/or her supporter. We chose not to allow write-in information because there is no way for the computer to check to make sure it is helpful to patients and providers.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall
What can her healthcare providers do to help her understand them better?
☐ Use simple words and short sentences.
☐ Use very precise language, even if it means using longer sentences or advanced vocabulary.
☐ Be very concrete and specific.
☐ Show her diagrams, pictures, or models whenever possible.
☐ Use medical words.
☐ Avoid medical words.
☐ Ask her to repeat what you said in her own words.
☐ Write down important information or instructions for her.
☐ Give her very detailed information.
☐ Focus only on the most important information.
☐ Be patient with her if she needs to ask a lot of questions.
☐ Give her extra time to process what you have said and check to make sure she is ready to move on.
☐ Do not try to talk to her while there are other noises (for example, being sounds, outside noises, people talking, babies crying).
☐ She **doesn't need** accommodations to help her understand providers.
☐ She needs accommodations to help her understand providers, but they are **not listed** here.

Popup for medical words:

For example, "Gastroesophageal Reflux Disease (GERD)" is the medical word for heartburn.

[order_num: 2; slide_id: 2] type: checkall
What can her healthcare providers do to help her answer questions or give information?
☐ Ask very specific, concrete questions and avoid very broad questions.
☐ Ask mostly yes and no questions when possible.
☐ Give her extra time to respond to questions.
☐ Read written notes that she brings to the visit.
☐ Give her examples of the types of things people may experience and let her tell you if she experiences them too.
☐ Show her lists of symptoms to choose from.
☐ Help her answer questions about time by linking to important events in her life.
☐ Offer to reword the question if she seems confused.
☐ Remind her that it is OK to not know the answers to your questions.
☐ Remind her that it is OK not to be 100% exact in her answers.
☐ She **doesn't need** accommodations to answer questions or give information.
☐ She needs accommodations to answer questions or give information, but they are **not listed** here.

What do you want her healthcare provider to know about her communication?

☐ She has a hard time communicating, even if her speech sounds fluent.

☐ She can be involved in decisions about her care, even though she has difficulty speaking.

☐ She often takes language too literally.

☐ In general, she can read better than she can understand spoken language.

☐ In general, she can write or type better than she can speak.

☐ She may have difficulty understanding tone of voice, facial expressions, or body language.

☐ Her ability to communicate changes a lot, depending on the situation.

☐ If she seems rude, she doesn't mean it. She's just really direct.

☐ She has a hard time using the telephone.

☐ There **isn't anything** related to her communication that her provider needs to be aware of.

☐ There are things related to her communication that her provider needs to be aware of, but they are **not listed** here.

Popup for literally:

For example, a doctor may ask "what brings you to the clinic" as a way to say "what is the problem that caused you to come to the clinic. Someone who takes things literally may answer "the bus" if that is how he or she got to the clinic that day.

Before the Visit

The next section asks about things healthcare providers and their staff can do before her visit to help make her visit more successful. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in her healthcare.

If she needs something that is not listed, check the box that says it isn't listed and the report will ask her healthcare provider to talk about it with her or her supporter.

It is OK to skip the question.

What can her healthcare provider's staff do before the visit to make it more successful?

☐ If possible, give her a way to make appointments without using the telephone.

☐ Schedule longer appointments if possible.

☐ Schedule appointments at a time when the provider is less likely to be late (for example, the first appointment).

☐ Let her or her supporters know what is likely to happen during an office visit (for example, what can she expect when checking in, during and after the visit, who she will be seeing, and how long things usually take).

☐ Notify her as soon as possible if there is an unexpected change (for example, she needs to see a different provider).

☐ Let her or her supporters fill out paperwork at home.

- ☐ Give her pictures, or let her or her supporter take pictures, of the office and/or staff.
- ☐ Give her detailed information about how to communicate with your office staff between visits (for example, how to make appointments, contact her regular provider, or contact the clinic in an emergency).
- ☐ She **doesn't need** accommodations ahead of time.
- ☐ She needs accommodations ahead of time, but they are **not listed** here.

[order_num: 2; slide_id: 2] type: checkall

What would make it easier for her to handle waiting after she shows up for her visit?
- ☐ Let her wait in an exam room or other private area.
- ☐ Let her wait in the car or other place outside of the office building (and contact her or her supporter when it is time for her to go into an exam room).
- ☐ Turn off the TV, radio, or other things that make noise in the waiting room.
- ☐ If possible, make the lights in the waiting area dimmer or allow for natural light.
- ☐ Let her know how long the wait is likely to be, or if there is an unexpected delay.
- ☐ Don't expect that she will notice when you call her name--please come over to her or get her attention in another way.
- ☐ Show her where to go.
- ☐ She **doesn't need** accommodations to help with waiting.
- ☐ She needs accommodations to help with waiting, but they are **not listed** here.

(chapter: during_the_visit:)

[order_num: 0; slide_id: 0] type: statement

During the Visit

The next section asks about things healthcare providers and their staff can do during her visit so she can get better healthcare. It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in her healthcare.

If she needs something that is not listed, check the box that says it isn't listed and the report will ask her healthcare provider to talk about it with her or her supporter.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall

During office visits, what can healthcare providers do to help her stay calm and comfortable?
- ☐ Allow her to bring a person, service animal, or item that helps her stay calm.
- ☐ Make a list with her of what needs to be addressed, and work with her to choose what should be addressed today.
- ☐ Tell her what is likely to happen during the visit (for example, first you talk with her, then you do an exam, then you tell her what you recommend).
- ☐ Write down a list of the topics you will discuss with her and point out when there is a change of topic.
- ☐ Let her take breaks if she needs them.
- ☐ Tell her about changes in plans as soon as possible.
- ☐ Do not force her to make eye contact.
- ☐ Use natural light or turn off fluorescent lights if possible, or make the lighting dim.
- ☐ Try to give her a quiet room.
- ☐ Please do not sit or stand close to her unless it is necessary for an examination (having people in her personal space makes her feel uncomfortable or confused).

☐Avoid chitchat (it may make her feel uncomfortable or confused).
☐Be patient with her and use a calm voice.
☐Ask her some questions about her life outside of the office.
☐She **doesn't need** accommodations to help her stay calm.
☐She needs accommodations to help her stay calm, but they are **not listed** here.

[order_num: 2; slide_id: 2] type: checkall

What can make examinations or procedures more successful for her?

☐Explain what parts of the visit the nurse will do and what parts of the visit the doctor will do.
☐Explain what you are going to do before you do it.
☐Show her equipment you will use before you use it.
☐If possible, let her do a "trial run" of difficult exams or procedures before doing them for real.
☐Tell her how long something is likely to take.
☐Let her know when you are about to touch her or do something to her.
☐Let her keep as many of her clothes on as possible or limit the amount of time she has to be undressed or in a gown.
☐Give her extra time to process things she needs to see, hear, or feel before she responds (for example, pressing and asking if something hurts).
☐Touch her as little as possible.
☐When touching her, please use a firm, deep pressure if possible (not a light touch).
☐Allow her to sit, lie down, or lean on something during procedures, when possible.
☐Let her use a signal to tell you that she needs a break.
☐Ask her from time to time if she is able to handle the pain or discomfort.
☐There may be times when she needs anesthesia to tolerate a procedure.
☐She **doesn't need** accommodations to handle exams or procedures.
☐She needs accommodations to handle exams or procedures, but they are **not listed** here.

[order_num: 3; slide_id: 3] type: checkall

What can help her make good decisions about her healthcare?

☐Give her extra time to make a decision, even if it means she needs to come back or communicate the decision at a later time.
☐Give her very blunt and concrete examples of what would happen if she did or did not follow a recommendation.
☐Direct her to detailed information or resources about her health conditions.
☐Give a person she trusts detailed information about her health conditions and choices.
☐Let her discuss her choices with a person she trusts, and then come back to you.
☐She **doesn't need** accommodations make good decisions about her healthcare.
☐She needs accommodations to make good decisions about her healthcare, but they are **not listed** here.

[order_num: 4; slide_id: 4] type: checkall

What do you want her healthcare provider to be aware of about her?

☐She may have difficulty recognizing and/or reporting pain or other symptoms.
☐She may have difficulty recognizing and/or describing emotions.
☐She may have difficulty recognizing bodily sensations such as hunger, the need to urinate, or where something hurts.
☐If she does not look at you, it does not mean she is not paying attention or is being dishonest.
☐If she fidgets, moves around, flaps her arms, or makes other sounds or motions, it does not mean she is not paying attention or that she is trying to be disruptive.
☐Try to remain patient if she becomes visibly upset, yells, or acts in an unusual way.
☐She might have strong negative reactions to some smells found in medical environments.
☐She may have trouble processing more than one sense at a time, for example hearing you while looking at

something.

☐ She has trouble with balance, coordination, or fine motor skills.

☐ She has trouble controlling her body, for example, starting, switching, and combining movements.

☐ She may need physical or verbal prompts to do what you need her to do.

☐ Using restraints may make things worse for her. Please work with her or her supporters during a calm period to find alternatives to restraints.

☐ There **isn't anything** related to her being on the autism spectrum that her provider needs to be aware of.

☐ There are things related to her being on the autism spectrum that her provider needs to be aware of, but they are **not listed** here.

(chapter: after_the_visit:)

[order_num: 0; slide_id: 0] type: statement

After the Visit

The next section asks about things healthcare providers or their staff can do after the visit to help her with any next steps (for example, taking her medications or making a follow-up visit). It may be easier for providers to work with a shorter list of suggestions. We recommend you only pick the things that you think will make a big difference in her healthcare.

If she needs something that is not listed, check the box that says it isn't listed and the report will ask her healthcare provider to talk about it with her or her supporter.

It is OK to skip the question.

[order_num: 1; slide_id: 1] type: checkall

What can help her better understand or follow recommendations?

☐ Write out your diagnoses, what you think is going on, and what the plan is for next steps or treatments.

☐ Write out detailed step-by-step instructions.

☐ Use pictures as much as possible.

☐ Explain medication instructions by showing her how much to take at each time of day.

☐ If possible, offer an alternative to pills, such as a liquid form of a medication.

☐ Have office staff help her schedule follow-up visits, referrals, or tests.

☐ Show her how to get to the lab or other places in your office or medical center (or have someone come with her).

☐ Have office staff contact her or her supporter after the visit to make sure that she has been able to do what she was supposed to do.

☐ Give her worksheets or diaries to keep track of symptoms.

☐ Make sure she gets a visual schedule of what she needs to do.

☐ She **doesn't need** accommodations to understand or follow recommendations.

☐ She needs accommodations to understand or follow recommendations, but they are **not listed** here.

[order_num: 2; slide_id: 2] type: question

Can she use the telephone to communicate between visits?

○ Yes

○ No

[order_num: 3; slide_id: 3] type: question

Does she have a very hard time with blood draws?

○ Yes

○No

Which of these things can help her with blood draws?

☐Only order blood tests when absolutely necessary and group them together to avoid having to get stuck more than once.

☐Use a numbing spray or cream.

☐Be very patient and use a calm voice.

☐Give her a very detailed explanation of what will happen, including how many tubes of blood you will fill.

☐Consider giving her an anti-anxiety medication before the blood draw.

☐Give her a lot of advance warning so she can prepare herself emotionally.

☐Tell her before you stick the needle.

☐Do not let her know when you will stick the needle.

☐Give her something to distract her attention.

☐She needs accommodations for blood draws, but they are **not listed** here.

Popup for numbing spray or cream:

A spray or cream on your skin that makes it so you won't feel as much pain when the needle goes in.

Getting to Know Her

Healthcare providers often like knowing a little bit about their patients' lives outside of what they see in the doctor's office. The next section includes information that may help her provider better understand who she is as a person. We think this information may be helpful, but it is OK to leave it blank if you do not want to answer.

In general, what are her strengths or the things she does best? (Examples of things some people might say are: memorizing things, drawing, following routines, or programming computers.)

What are her special interests? (Examples of things some people might say are: 16th century Russian literature, things that spin, ballet, or the muppets.)

Sometimes individuals on the autism spectrum may have such bad experiences in healthcare settings that they become overwhelmed, meltdown, shut-down, become very anxious or upset, or are unable to function. If this sometimes happens to her, it would help her providers to know more about how to possibly keep these types of things from happening, or to know how to respond if they do happen.

What are some things that make her anxious at the doctor's office?

[   ]

How does she show she's anxious in the doctor's office?

[   ]

What are some things that calm her down at the doctor's office?

[   ]

Her Supporters

Sometimes other people, such as family members, caregivers, or friends, may help patients with their healthcare. For example, a supporter may help a patient communicate, may be the contact person between visits or for emergencies, may be a guardian or healthcare decision-maker, or may provide additional information to healthcare providers. The next section includes information about the people who support her with her healthcare.

Does anyone help her with her healthcare?
◯ Yes
◯ No

Contact information for this person:

Name [   ]

City [   ]

State [   ]

Zip [   ]

Telephone [   ]

Email [   ]

Other [   ]

Relationship to her:

◯ Parent
◯ Sibling
◯ Other family member
◯ Husband/wife or domestic partner
◯ Other friend
◯ Caregiver (for example, foster parent, case manager, personal assistant)
◯ Other

[_____]

Preferred role(s) in supporting her in healthcare:

☐ She wants this person to help her communicate for herself during visits, as needed.
☐ She wants this person to do most of the communication with providers during visits (but please also communcate with her as well as possible).
☐ She wants this person to be the main contact for communication between visits.
☐ She wants providers to contact this person if there is an emergency.
☐ This person may have more information to give providers about her health or healthcare (for example, this person may know about her childhood or family history).
☐ This person may help her with things like making appointments, handling insurance, or dealing with paperwork.
☐ Other

[_____]

Does anyone else help her with her healthcare?

◯ Yes
◯ No

Contact information for this person:

Name [_____]

City [_____]

State [_____]

Zip [_____]

Telephone [_____]

Email [_____]

Other [_____]

Relationship to her:

◯ Parent
◯ Sibling
◯ Other family member

○ Husband/wife or domestic partner
○ Other friend
○ Caregiver (for example, foster parent, case manager, personal assistant)
○ Other

[_____]

[order_num: 8; slide_id: 8] type: checkall

Preferred role(s) in supporting her in healthcare:

☐ She wants this person to help her communicate for herself during visits, as needed.
☐ She wants this person to do most of the communication with providers during visits (but please also communcate with her as well as possible).
☐ She wants this person to be the main contact for communication between visits.
☐ She wants providers to contact this person if there is an emergency.
☐ This person may have more information to give providers about her health or healthcare (for example, this person may know about her childhood or family history).
☐ This person may help her with things like making appointments, handling insurance, or dealing with paperwork.
☐ Other

[_____]

[order_num: 9; slide_id: 9] type: question

Does anyone else help her with her healthcare?

○ Yes
○ No

[order_num: 10; slide_id: 10] type: contact

Contact information for this person:

Name [_____]

City [_____]

State [_____]

Zip [_____]

Telephone [_____]

Email [_____]

Other [_____]

[order_num: 11; slide_id: 11] type: question

Relationship to her:
○ Parent
○ Sibling
○ Other family member
○ Husband/wife or domestic partner
○ Other friend
○ Caregiver (for example, foster parent, case manager, personal assistant)
○ Other

[ ]

[order_num: 12; slide_id: 12] type: checkall
Preferred role(s) in supporting her in healthcare:
☐ She wants this person to help her communicate for herself during visits, as needed.
☐ She wants this person to do most of the communication with providers during visits (but please also communcate with her as well as possible).
☐ She wants this person to be the main contact for communication between visits.
☐ She wants providers to contact this person if there is an emergency.
☐ This person may have more information to give providers about her health or healthcare (for example, this person may know about her childhood or family history).
☐ This person may help her with things like making appointments, handling insurance, or dealing with paperwork.
☐ Other
[ ]

[order_num: 13; slide_id: 13] type: question
Does anyone else help her with her healthcare?
○ Yes
○ No

[order_num: 14; slide_id: 14] type: contact
Contact information for this person:

Name [   ]

City [   ]

State [   ]

Zip [   ]

Telephone [   ]

Email [   ]

Other [   ]

[order_num: 15; slide_id: 15] type: question
Relationship to her:
○ Parent
○ Sibling
○ Other family member
○ Husband/wife or domestic partner
○ Other friend
○ Caregiver (for example, foster parent, case manager, personal assistant)
○ Other
[ ]

[order_num: 16; slide_id: 16] type: checkall
Preferred role(s) in supporting her in healthcare:
☐ She wants this person to help her communicate for herself during visits, as needed.

☐ She wants this person to do most of the communication with providers during visits (but please also communcate with her as well as possible).

☐ She wants this person to be the main contact for communication between visits.

☐ She wants providers to contact this person if there is an emergency.

☐ This person may have more information to give providers about her health or healthcare (for example, this person may know about her childhood or family history).

☐ This person may help her with things like making appointments, handling insurance, or dealing with paperwork.

☐ Other

[_____]

[order_num: 17; slide_id: 17] type: question

Does anyone else help her with her healthcare?

◯ Yes

◯ No

[order_num: 18; slide_id: 18] type: contact

Contact information for this person:

Name [_____]

City [_____]

State [_____]

Zip [_____]

Telephone [_____]

Email [_____]

Other [_____]

[order_num: 19; slide_id: 19] type: question

Relationship to her:

◯ Parent

◯ Sibling

◯ Other family member

◯ Husband/wife or domestic partner

◯ Other friend

◯ Caregiver (for example, foster parent, case manager, personal assistant)

◯ Other

[_____]

[order_num: 20; slide_id: 20] type: checkall

Preferred role(s) in supporting her in healthcare:

☐ She wants this person to help her communicate for herself during visits, as needed.

☐ She wants this person to do most of the communication with providers during visits (but please also communcate with her as well as possible).

☐ She wants this person to be the main contact for communication between visits.

☐ She wants providers to contact this person if there is an emergency.

☐ This person may have more information to give providers about her health or healthcare (for example, this person may know about her childhood or family history).

☐ This person may help her with things like making appointments, handling insurance, or dealing with paperwork.

☐ Other

[_____]

[order_num: 21; slide_id: 21] type: question

Does she have Guardian(s)/Conservator(s)?

○ Yes
○ No
○ I do not know

[order_num: 22; slide_id: 22] type: fillinblank

What is/are the name(s) of her Guardian(s)/Conservator(s)?

[_____]

[order_num: 23; slide_id: 23] type: question

Does she have a Healthcare Power of Attorney or Healthcare Power of Attorneys?

○ Yes
○ No
○ I do not know

[order_num: 24; slide_id: 24] type: fillinblank

What is/are the name(s) of her Healthcare Power of Attorneys?

[_____]

(chapter: sharing_the_report:)

[order_num: 0; slide_id: 0] type: statement

Sharing the Report

The next section includes information to help share her report with her healthcare providers.

This information is used to label the report so that when healthcare providers get a copy, they know who it is about.

Filling out this section will NOT automatically share the report with the provider. You will have a chance to look at the finished report and make changes to your selections. **After the report is created, it is up to you to give it to the provider.**

[order_num: 1; slide_id: 1] type: fillinblank

The patient's full name:

[_____]

[order_num: 2; slide_id: 2] type: birthdate

The patient's date of birth:

birthdate

The report comes with a letter addressed to her healthcare provider. In order to personalize the letter we need to know the name of the person filling out the report.

What is your name?

[text box]

The letter addressed to healthcare provider can include special requests for help with making or getting to appointments. The next questions will ask if you would like these requests included.

If possible, would you like the provider's office to help you with scheduling appointments?

○ Yes
○ No

If possible, would you like the healthcare provider's office to help you find transportation to appointments?

○ Yes
○ No

Report Preview

When you click next, the computer will generate a preview of your report.

If you see a part of the report you want to change, use the green "back" button at the bottom of this page, or click on one of the blue chapter headings, to go back and change it.

When you are done making changes, click on the "Report Preview" chapter and click the green "next" button at the bottom of this page to see the updated report.

Do not use the browser's back button.

Here is a preview of your report. It has been formatted in a way that we hope will work well for healthcare providers. Some items have been reworded a little to make them more acceptable to healthcare providers. Please look it over.

If you want to make changes to what you picked to include on the report, use the green "back" button at the bottom of this page, or click on one of the blue chapter headings, to go back and change it.

If you are happy with what you picked to include on the report, save it or print it. It is up to you to give the print out or file to your healthcare provider.

pdf_preview

[order_num: 2; slide_id: 2] type: question

If you want to make changes to the report, or print or download more copies, just log back into the system. Your answers will be saved for one year.

How would you rate the Autism Healthcare Accommodations Tool you just used?

○   ○ ○ ○ ○ ○ ○ ○ ○   ○
1   2 3 4 5 6 7 8 9   10

not at all useful   very useful

[order_num: 3; slide_id: 3] type: fillinblank
Please give us comments about what you liked and didn't like.

Academic Autistic Spectrum Partnership in Research and Education;
www.aaspire.org   www.autismandhealth.org

c/o Regional Research Institute
Portland State University

1600 SW 4th Avenue, Suite 00, Portland, OR 97201
tel 503 723-4040, fax 503 725-4180; www.rri.pdx.edu

September 12, 2015

Re: John Doe (DOB 1981-6-6)

John Doe has used the Autism Healthcare Accommodations Tool (AHAT).

The attached report was custom generated from his responses to the AHAT survey. It includes recommendations for strategies and accommodations to facilitate care. Most of these suggestions can be implemented at no cost or low cost. We hope this information will make it easier for you and your staff to comply with Americans with Disabilities Act (ADA) requirements.

We recommend that you schedule an appointment to review the report with John Doe and, if appropriate, his supporters. Note: an extended visit or other longer time-slot may work best for this type of discussion.

Please also visit our website at www.autismandhealth.org for more information and resources about providing healthcare to adults on the autism spectrum.

John Doe noted that he has difficulty scheduling appointments on his own. Please help him schedule an appointment. his contact information is in the report. John Doe also noted that he has difficulty with transportation. If your office has the resources to do so, please help him arrange medical transportation.

The ideas for strategies and accommodations listed in the report are only meant as starting points to a more in-depth discussion. Patients and supporters have been informed that these are only ideas and that they are not necessarily possible or helpful.

We greatly appreciate your efforts to provide high quality patient-centered care to adults on the autistic spectrum and hope you find the enclosed report useful.

Sincerely,

Christina Nicolaidis, MD, MPH Co-Director, Academic Autistic Spectrum Partnership in Research and Education
Professor and Senior Scholar in Social Determinants of Health, Portland State University
Adjunct Associate Professor of Medicine, Oregon Health & Science University
www.aaspire.org

Autism Healthcare Accommodations Report

Name: John Doe   **Date of Birth: 1981-6-6**

The purpose of this report is to help you, your staff, and John Doe have more successful visits. Due to the heterogeneous nature of autism spectrum disorders (ASD), the information and recommendations in this report have been **custom generated** to be specific to John Doe.

I   Information to Assist with Patient Communication

Receptive speech: He can usually understand spoken language well.

Expressive speech: His ability to speak changes depending on the situation.

Alternatives to speech: He uses text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app).

Reading: He can read at a college level.

Writing: He can write or type at a college level.

Telephone: He cannot use the telephone.

Other important information about John Doe's communication.

- He may have difficulty communicating, even if his speech sounds fluent.
- He often takes langauge too literally.
- He can write or type better than he can speak.

To help <u>John Doe better understand</u> what you are saying.

- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Write down important information or instructions.
- Try not to talk to him while there are other noises.

To help <u>John Doe provide information</u> more effectively.

- Read written notes that he brings to visits.
- Give him examples of the types of things people may experience and ask him if he experiences them too.
- Help him answer questions about time by linking to important events in his life.

II   Other Recommendations to Help Visits Go Smoothly

- Tell him what is likely to happen during the visit.
- Write down a list of topics discussed, and point out when there is a change of topic.

III   Recommendations to Help John Doe with Tolerating Exams

- If possible, let him do a "trial run" of difficult exams or procedures.
- Give him extra time to process things he needs to see, hear, or feel before he responds.
- Let him use a signal to tell you that he needs a break.

IV   Recommendations to Assist with Shared Decision Making

- Give him time to make a decision and communicate with you about it at a later time.

- Give him blunt and concrete examples of what would happen if he does not follow a recommendation.
- Direct him to detailed information or resources about his health conditions.

V Recommendations to Help John Doe Comply with Recommendations

- Show pictures as much as possible.
- Have office staff help him schedule follow-up visits, referrals, or tests.

VI Information to Help You Better Understand John Doe

- He may have difficulty recognizing bodiliy sensations such as hunger, the need to urinate, or pain.
- If he fidgets, moves around, flaps his arms, or makes other sounds or motions, it does not mean he is not paying attention.
- He may have trouble processing more than one sense at a time, for example understanding what is said while looking at something.

Strengths: "Recognizing patterns; programming computers"

Interests: "Transportation systems"

Anxiety or overload triggers: "Unexpected changes in plans"

Ways that John Doe may show that he is anxious, upset, or overwhelmed: "I may stim or rock more or may shut down and stop talking"

Things that may help John Doe: "A quiet area; clear explanations"

Information for Office Staff

Your staff may use the following information to help make visits more successful.

VII   Recommendations for Setting Up an Appointment

- Give him a way to make appointments without using the telephone.
- Provide information about the sequence of events that are likely to occur before and during the appointment.
- Provide paperwork ahead of time so it can be filled out at home.

VIII   Recomendations to Help John Doe Tolerate the Wait

- Let him to wait outside the office/clinic and contact him when it is time to enter the exam room.
- Where possible, dim the lights or allow for natural lighting.
- Rather than calling his name, get his attention in another way when it is time for him to see the provider.

IX   Recommendations for Rooming John Doe

- Use natural light, or turn off fluorescent lights if possible, or make the lighting dim.

X   Recommendations to Assist with Blood Draws

- Give him a detailed explanation of what will happen, including how many tubes of blood you will fill.

⛑ Supporter Information

John Doe's **Healthcare Power/s of Attorney** is/are Sally Doe.

Supporter Name	Relationship	Healthcare Role(s)	Contact Information
Sally Doe	Spouse or domestic partner	assist with communication during visits; emergency contact	2345 NE Main Stret, Portland, OR, 97232, 503-345-2345, sally-doe@gmail.com
Jane Smith	Parent	main contact between visits; may have additional health information; help coordinate care	2342 SW Banes Blvd, Portland, OR, 92701, 503-234-4534, jane-smith@yahoo.com

September 12, 2015

Re: Amy Doe (DOB 1967-2-2)

Amy Doe has used the Autism Healthcare Accommodations Tool (AHAT).

The attached report was custom generated from her responses to the AHAT survey. It includes recommendations for strategies and accommodations to facilitate care. Most of these suggestions can be implemented at no cost or low cost. We hope this information will make it easier for you and your staff to comply with Americans with Disabilities Act (ADA) requirements.

We recommend that you schedule an appointment to review the report with Amy Doe and, if appropriate, her supporters. Note: an extended visit or other longer time-slot may work best for this type of discussion.

Please also visit our website at www.autismandhealth.org for more information and resources about providing healthcare to adults on the autism spectrum.

The ideas for strategies and accommodations listed in the report are only meant as starting points to a more in-depth discussion. Patients and supporters have been informed that these are only ideas and that they are not necessarily possible or helpful.

We greatly appreciate your efforts to provide high quality patient-centered care to adults on the autistic spectrum and hope you find the enclosed report useful.

Sincerely,

Christina Nicolaidis, MD, MPH Co-Director, Academic Autistic Spectrum Partnership in Research and Education
Professor and Senior Scholar in Social Determinants of Health, Portland State University
Adjunct Associate Professor of Medicine, Oregon Health & Science University
www.aaspire.org

Autism Healthcare Accommodations Report

Name: Amy Doe   **Date of Birth: 1967-2-2**

The purpose of this report is to help you, your staff, and Amy Doe have more successful visits. Due to the heterogeneous nature of autism spectrum disorders (ASD), the information and recommendations in this report have been **custom generated** to be specific to Amy Doe.

💬 I   Information to Assist with Patient Communication

Receptive speech: She often has a hard time understanding what people say.

Expressive speech: She can speak, but often has a hard time saying what she wants to say.

Alternatives to speech: She uses picture-based alternatives to speech (picture-based AAC, picture boards, drawing).

Reading: She can read some words and short sentences.

Writing: She can write or type a little bit.

Telephone: She cannot use the telephone.

Other important information about Amy Doe's communication.

- She can be involved in decisions about her healthcare, even though she has difficulty speaking.
- She often takes langauge too literally.

To help Amy Doe better understand what you are saying.

- Use simple words and short sentences.
- Use diagrams, pictures, or models whenever possible
- Ask her to repeat what you said in her own words.
- Give her time to process what has been said and check to make sure she is ready to move on.

To help Amy Doe provide information more effectively.

- Ask very specific, concrete questions and avoid very broad questions.
- Ask mostly yes and no questions when possible.
- Show her lists of symptoms to choose from.

👍 II   Other Recommendations to Help Visits Go Smoothly

- Allow her to bring a person, animal, or item that helps her stay calm.
- Tell her what is likely to happen during the visit.
- Write down a list of topics discussed, and point out when there is a change of topic.
- Let her take breaks if she needs them.

🔬 III   Recommendations to Help Amy Doe with Tolerating Exams

- Show her equipment before using it.
- Warn her before touching her.
- Give her extra time to process things she needs to see, hear, or feel before she responds.
- When touching her, use firm, deep pressure if possible.
- Let her use a signal to tell you that she needs a break.
- There may be times she needs anesthesia to tolerate a procedure.

IV   Recommendations to Assist with Shared Decision Making

- Give her blunt and concrete examples of what would happen if she does not follow a recommendation.
- Let her discuss her choices with a trusted individual before giving you an answer.

V   Recommendations to Help Amy Doe Comply with Recommendations

- Write out detailed, step-by-step instructions.
- Explain medication instructions by showing her how much to take at each time of day.
- Show or have someone show her how to get to other places in your office or medical center.

VI   Information to Help You Better Understand Amy Doe

- She may have difficulty recognizing or reporting pain or other symptoms.
- If she fidgets, moves around, flaps her arms, or makes other sounds or motions, it does not mean she is not paying attention.
- She may have strong negative reactions to smells found in medical environments.
- She may have trouble processing more than one sense at a time, for example understanding what is said while looking at something.
- She has trouble with balance, coordination, or fine motor skills.
- She has trouble controlling her body (e.g., starting, switching, or combining movements).

Strengths: "I am really good with numbers."

Interests: "The number Pi, old movies, shiny things"

Anxiety or overload triggers: "Not knowing if the doctor is going to poke me with a needle."

Ways that Amy Doe may show that she is anxious, upset, or overwhelmed: "I have a harder time talking. Sometimes if it gets really bad, I run out of the office."

Things that may help Amy Doe: "Telling me in advance what will happen. Playing on my iPad by myself."

Information for Office Staff

Your staff may use the following information to help make visits more successful.

VII   Recommendations for Setting Up an Appointment

- Schedule longer appointments if possible.
- Provide information about the sequence of events that are likely to occur before and during the appointment.
- Give pictures of the office or staff, or allow her or her supporters to take pictures.

VIII   Recomendations to Help Amy Doe Tolerate the Wait

- Let her to wait in an exam room or other private area.
- Show her where to go.

IX   Recommendations to Assist with Blood Draws

- Use a numbing spray or cream.
- Be patient and use a calm voice.
- Give her plenty of advance warning, so that she can prepare herself emotionally.
- Do not give a warning immediately before inserting the needle.
- Give her something to distract her attention.

♨ Supporter Information

Amy Doe's **Guardian/s** is/are Samantha Doe.

Supporter Name	Relationship	Healthcare Role(s)	Contact Information
Jane Smith	Professional care-giver	responsible for majority of communication during visits; main contact between visits; help coordinate care	111 Brown Street, Portland, OR, 97232, 503-342-2345, jane@gmail.com
Samantha Doe	Parent	emergency contact; may have additional health information	432 Central Ave, Caldwell, NJ, 07006, 201-226-8122, samantha123@yahoo.com