

Explanation of the

AFK-Checklist for autism-friendly research with adults on the autism spectrum



Autismus-Forschungs-Kooperation
Checklist autism-friendly research

I Predictability	Please note!
<p>People on the autism spectrum (AS) need time to mentally and emotionally adjust to an unfamiliar situation. Therefore concrete knowledge about the experimental framework (place, time, people, requirements) is necessary and provides security.</p> <p>Changing testing conditions, such as unannounced events and deviations from previously announced procedures, elicit stress in people on the AS, which may not be directly visible to you.</p> <p>Meeting and interacting with strangers triggers tension and stress in autistic people¹. Fixed contacts, on the other hand, provide stability and security. Additionally, knowing the number of people present in advance (., lab assistants) creates predictability.</p>	<p>Offer your participants the highest possible predictability.</p>
<p>Few, consistent contacts</p> <p>From the first contact onwards, try to keep the number of contact persons as small and consistent as possible:</p> <p>e.g. appointment scheduling → not through a secretary/ assistant/ representative/ unknown person, etc.</p> <p>e.g. experiment subcomponents, such as questionnaire completion or experiment explanation → carried out by the same person</p>	<p>Offer consistent reference person</p>
<p>Getting to know the facilities beforehand (e.g. a visit, photos, description)</p> <p>Is it possible to visit the facilities beforehand? Is it possible to send photos and room layouts in advance (e.g. along with the participant's information sheet)?</p>	<p>Allow participants to get acquainted with the facilities</p>
<p>Timely communication about changes in the experimental procedure that deviate from previous information</p> <p>Plan the participation procedure in a way that you can adhere to previously given information and agreements. For people on the AS, 'agreements' include any written or verbal information given in advance. People on the AS do not naturally assume that these 'agreements' are approximate descriptions still subject to change.</p> <p>If changes are nevertheless unavoidable (e.g. change of location or presence of additional people), let the participant know as early as possible. If changes can only be communicated on-site, do so calmly and not in passing. It takes them some time to mentally re-adjust.</p>	<p>Adhere to previously given information</p> <p>Mention changes as early as possible</p>

¹ Identity-first language has been employed in this document in order to recognize, affirm and validate the individual's identity.

<p>Do not plan on asking the subjects to participate in any additional tasks or experiments once they are on site. Adhere to the previously agreed duration of the experiment.</p>	<p>No changes in the scope of the tasks</p>
<p>Communication of special needs and anticipated difficulties in advance and on-site</p> <p>Provide the participants with the opportunity to communicate their own needs and difficulties in advance (e.g. via email). Which aspect of participation could be the most exhausting or stressful for them and which adjustments would help?</p> <p>Ask again about needs and potential difficulties on-site.</p> <p>Needs and anticipated difficulties are most likely highly individual. The stress factors mentioned may be difficult for you to comprehend. Show understanding for participants' individual needs and difficulties and take them seriously.</p>	
<p>Take individual needs seriously</p>	

<h2>II Communication</h2>	<h2>Please note!</h2>
<p>Many expressions in our communication are ambiguous. Most of the time this goes unnoticed. People on the AS often notice these ambiguities and are irritated by them. Unclear communication can lead to tension.</p> <p>Most of the time, small talk is exhausting for people on the AS. However, they are usually very interested in fact-based information.</p> <p>Often, people on the AS make little or no eye contact, because this is perceived as unpleasant. However, this does not mean that they are absent-minded. You do not need to change your own behaviour, but accept the different preference – similar to a different culture – and do not insist upon eye contact.</p>	<p>Take autism-typical features in communication into account.</p>
<p>Clear communication without jokes and irony</p> <p>Try to avoid ambiguous language when communicating with the participant.</p> <p>e.g. “Can you press the space bar on the keyboard?” Questions like this could be understood as a question about their ability rather than as an instruction. Better → “Please press the space bar on the keyboard”.</p> <p>e.g. “Please don’t sit down”. This tells the participant what he/she should not do; however, it does not imply what should be done instead. Better → “Please remain standing precisely where you are for a moment”.</p> <p>e.g. “We’ll meet downstairs in the entrance area”. Better → “There is a sign in the entrance area that says ‘meeting point for participants’. I will pick you up from there at ... o’clock”.</p> <p>People with AS also have a sense of humor. However, you should not assume that they understand irony or puns and jokes! Try to stay on the factual level.</p>	
<p>Avoid ambiguous questions and statements</p>	

Minimizing Small-Talk

Try to use content-related communication.

Stick to facts

e.g. "It's such beautiful weather, it would be nice to go outside, but we have to go to the lab now".

Better → "Let's go to the lab now".

Content-related language does not rule out a friendly tone of voice. A friendly approach is the basis for successful contact.

III Sensory differences

Please note!

People on the AS often have sensory differences. These refer to a more intense (or lower) perception of stimuli, such as light, sound, smell or taste or pain, than in non-autistic individuals. This can cause concentration problems, nausea, dizziness, headaches and almost always exertion. However, previous negative experiences mean people on the AS often do not feel comfortable talking about these things with strangers

Participants usually perceive surrounding stimuli more intensely and cannot disregard them.

Physical contact and even light touch are perceived as extremely unpleasant by the vast majority of people on the AS. The concomitant stress can be largely decreased if the touch is announced (and permitted) beforehand.

Even if it is not apparent to others, many people in the AS perceive flickering light and screens more intensely. Under certain circumstances, either can trigger epileptic seizures.

Optimal consideration of sensory needs

Ask about individual sensory differences beforehand. Offer solutions.

Ask about and deal gently with (individual) sensory differences in perception

Reduce sensory stimuli, such as street noise coming through open windows or of colleagues' loud conversations in the room next door. Also, reverberation is often experienced as unpleasant or hinders speech comprehension

There should not be any strong smells in the room (e.g. cleaning products, new carpet). This also applies to food/meals/perfume.

If the person says, for instance, that the room is too bright, then this is indeed the case. Take this seriously, even if your perception is different, and be sensitive to individual perceptual differences.

Always give advance notice of any touching necessary, even if there is only little physical contact. Always announce beforehand what will be done, even upon agreement with the participant and especially when it comes to physical contact. If you are unsure, ask!

Avoid touch or announce it beforehand

→ "I will touch your shoulder now. Is that ok?"

Establishing soft light in the experiment facilities (e.g. through indirect lighting)

Make sure the light in the room is soft! Glaring light (e.g. neon tubes) or flickering lamps can be very unpleasant and cause physical discomfort.

Adjust the lighting

→ Ask if the lighting is ok!

<p>Avoid backlighting</p> <p>Any backlighting, for example, from windows, lamps or screens that are set too brightly can be perceived so intensely that it might be hurtful to the participant. Check for backlighting in advance and offer to adjust the brightness of screens individually.</p>	<p>Avoid backlighting</p>
<p>Avoid flickering screens</p> <p>Take comments about flickering screens seriously and try to find a solution. “Unfortunately, I can’t change that right now” is not dealing adequately with autistic-perception differences.</p> <p>Moreover, the experiments should avoid flickering or blinking elements, if possible. Except if the presence of epilepsy has been ruled out.</p> <p>Either way, experiment elements such as these should be announced and their necessity explained.</p>	<p>Check the screens</p>

<h2>IV Stress reduction</h2>	<h2>Please note!</h2>
<p>Interaction with other people (even when positive) is a consistent effort for autistic individuals. While some people remain silent and respond only to questions, there are other people who talk a lot.</p> <p>Neither behaviour is intended as an impolite response, but rather as a way of dealing with tension triggered by the situation.</p> <p>People on the AS can also be overwhelmed by trivialities. This results from a different way of processing information.</p> <p>Switching from one activity to another is often difficult for people on the AS. Being able to keep their own pace can help to reduce stress.</p> <p>Having a familiar and trusted person as a companion or bringing personal objects and adhering to routines can reduce stress.</p>	<p>Take your participants’ stress level seriously and try to keep it as low as possible.</p>
<p>Bringing important, personal objects (e.g. for reassurance)</p> <p>Some people on the AS may want to bring personal objects into the room or to the computer, e.g. a figurine, fidget-toys or a special item of clothing. This helps them feel safe and comfortable.</p> <p>Facilitate this as much as you can. For some participants this may even be a requirement for participation. Offer this possibility in advance.</p> <p>For many people on the AS, the companionship of a close person (e.g. a friend, family member) can be helpful for support. Participation could also depend on this. Discuss the possibility of bringing a companion in advance.</p>	<p>Facilitate bringing reassuring objects or a companion</p>
<p>Adhering to personal routines</p> <p>Routines and everything that is considered familiar make things easier for people on the AS. If tests or interviews take place at several time points, try to offer the same time of day for each appointment, use the same facilities and keep the procedure as similar as possible.</p>	<p>Facilitate and create routines</p>

<p>Ask your participant if he/she has a specific daily routine (e.g. meals, breaks). Keep this in mind when scheduling. Ask about routines: 'What do you usually do at ... o'clock?' (e.g. eat a banana every day at 10am). Try to facilitate routines and emphasize that it is alright to adhere to these routines on site.</p>	
<p>Consideration of individual limits regarding, for example, resilience or sensory stress</p> <p>Information can be perceived faster, slower or in an altered way. Allow more time to work through questions and tasks, if necessary.</p> <p>Offer time for breaks. Let the participant decide, whether these should be scheduled or used spontaneously.</p> <p>Try to not to engage in small talk during breaks, as interaction prevents recovery. Unless, of course, the participant asks questions him/herself.</p> <p>Do not force breaks. Some people on the AS do not like them and the waiting that comes with them.</p> <p>The duration of individual tasks and the whole experiment should be clearly defined.</p> <p>Whenever possible, offer headphones/earplugs or the possibility to close their eyes.</p> <p>Pay attention to hygiene! Knowing that something is being used for the first time or has been cleaned beforehand (e.g. headphones) is important to many. Mention this.</p> <p>People on the AS experience stress due to circumstances that other people would never consider. Therefore ask (e.g. "Is there anything that we could change?") and take the individual stress levels seriously, even if the person does not appear to be affected to you (e.g. smiling participant: "One can get very dizzy from the fast display of images" – Experimenter: "What could help make it better? Take your time").</p>	<p>Offer sufficient time for tasks</p> <p>Allow individual breaks</p> <p>Maintain a limited duration of testing</p> <p>Ask!</p>
<p>Provision of a rest area (e.g. for longer breaks or in case of overstimulation)</p> <p>Plan for the availability of a (quiet) room, in which the participant can be undisturbed if needed. Inform the participant about this option.</p> <p>Offer this room also for breaks, especially for longer ones like lunch breaks.</p>	<p>Offer a quiet room with no other people</p>
<p>Sufficient time to prepare for the next task of the day (e.g. the way home)</p> <p>Everyone has their own pace. Always give your participants enough time (e.g. when packing up/dressing). (Subliminal) time pressure, e.g. signalling that your colleagues are about to go to the canteen/cafeteria soon, can lead to a disruption of individual processes and the successful transition from the current task (e.g. experiment participation) to the next task (e.g. shopping, trip home). Often for people on the AS, this messes up their whole day and the next tasks cannot take place.</p> <p>Show the participant a place where they can stay comfortably for a while after the experiment, until they feel ready to leave (e.g. at the initial meeting point).</p>	<p>No being rushed after the experiment</p>
<p>Consideration of special interests during the experiment</p> <p>Often, people on the AS have interests which they like to talk about. A short conversation about this with the participant, e.g. as a substitute for small talk, can build trust and lead to relaxation.</p>	<p>Special interests can be a good conversation topic</p>

V Time perception and information processing	Please note!
<p>Many people on the AS do not have a particularly good sense of time intervals. It can be challenging to remain orientated concerning the time elapsed during testing. A lack of orientation regarding the remaining participation time can cause stress and overload.</p> <p>A clear structure is important to facilitate orientation and predictability. Visual support is particularly helpful.</p> <p>Because of a different way of processing information, simultaneously occurring stimuli and demands are exhausting and overwhelming for people on the AS. By avoiding such situations, you can reduce stress for the participants.</p>	<p>Support individual orientation regarding procedural timing and design the tasks sequentially.</p>
<p>Visualization/Verbalization of the experimental procedure</p> <p>Provide a daily plan or schedule in written form (e.g. list, table, timeline). Provide assistance with the participants' schedule orientation/understanding</p> <p>Clearly signal the beginning and end of a task, as well as where in the process they are currently at.</p> <p>e.g. "There will be 2 blocks of 5 exercises each. We will start with block 1, exercise 1 now", "We have now finished exercise 1 of block 1".</p> <p>While working on a task, time visualization is helpful, e.g. a display or an hourglass.</p> <p>Refrain from using adverbs like soon, immediately, shortly, if you cannot accurately estimate the time.</p>	<p>Support schedule understanding</p> <p>Avoid imprecise adverbs of time</p>
<p>Setting only one task at a time</p> <p>Even if there is no intelligence impairment, multitasking can overwhelm people on the AS. Do not say anything in passing, such as explaining something while you walk.</p> <p>Too many choices can also cause stress, e.g. "Do you want to fill in the questionnaire now or go to the lab first, or do it at the end, or ...".</p> <p>Better → "Now, we're going to the lab together. When we are there you will get time to fill in the questionnaire".</p>	<p>Only one thing at a time, avoid multitasking</p>

VI Inclusion/Contribution	Please note!
<p>Financial incentives do not provide as much motivation for people on the AS to participate in studies as their scientific interest and the wish to support the research. Answering questions about the experiment or study, as well as giving explanations about its bigger scope, can help to make participation more purposeful and to satisfy curiosity.</p> <p>Since they are the most important part of a study, the participants should be involved in the project by receiving the study results and publications.</p>	<p>Acknowledge the intrinsic motivation of your participants.</p>

Offering the possibility to ask questions or remark on the experiment after participation

After the experiment, offer to answer questions and give explanations. Allow enough time for this, as for many participants, this is the actual “compensation”.

Facilitate the evaluation of thoughts and impressions regarding the participant’s experience of the experiment (e.g. in conversation or in a questionnaire). This way, participants can (and often want to) actively contribute to the study. Often, you will receive valuable proposals and suggestions that can be very helpful for your study.

If you have posted your study announcement in a forum for people with AS, check the forum every now and then to see if there are any questions or feedback.

Allow time for questions, feedback and explanations

Information about the results of the study

Offer the participants to take a look at the monitors, etc.

Offer the participants to sign up to receive the results of the study.

Once the evaluation of the study is complete, send a summary in comprehensible language.

Share the results of the study

Providing study publications

Send your participants publications pertaining to the study. This is a sign of appreciation, which strengthens their feeling of belonging and increases the chance of another future participation.

Send publications



If the checklist is used in a study, researchers can download the checklist label and place it on their study information.

Find the checklist, the label and more about our work under:

<https://www.autismus-forschungs-kooperation.de>