

How to support autistic adults – a brief guide for employees of an autistic adult

Aim of support

The aim is to maximise my **autonomy** and **independence**.

'Autonomy' means being able to make decisions for myself. It means being able to live the life I choose for myself, not the life others would choose for me.

'Independence' means being able to do things without a support worker. Often this involves supporting me to be sufficiently prepared for a task or activity so that when you leave I can do it without you there. The cost of exposure to support workers is: stress, overload, lack of privacy, financial cost (paying them), insecurity (you don't know when you are going to lose support), institutionalisation.

Change, surprises, expectations

I need the world to be as predictable and regular as possible. I find it very hard to cope with change of any sort, even change that is fairly well-managed and I know is coming. Sudden surprises and unexpected events, even if they are supposed to be pleasant, I find even harder. If I have to make too many changes or transitions too quickly I will may become non-functional and lose my capacity to make decisions (autonomy) and be unable to do things for myself (independence). I need to know as much as possible about what is going to happen in the future to give me time to get used to the idea and also to prepare anything I need to prepare in order to help me cope with the change.

*It is your job to think ahead all the time about what things are going to happen to me and that I am aware of them and have prepared for them. Please be neither late nor early for shifts. **Don't make changes to my systems, routines, environment or any aspect of my life without consulting me first and making sure I am OK with it.***

Sensory sensitivities

Find out from me what my particular sensitivities are and avoid triggering them. Examples might be:

Hearing: loud unexpected noises, e.g. bells, alarms, banging, drilling etc

Smell: perfumes, cleaning fluids

Touch: unexpected and accidental touch

Sight: rapid presentation of complex images can be very difficult, flickering lights, bright lights

Vestibular: I might get dizzy easily and feel sick

It is your job to help me manage environments to minimise the negative impact of sensory stimulation. This means helping me take permanent steps to minimise problems in my own home, and, when out of my own home, help me make choices that will result in minimal sensory overload (e.g. choosing a quiet street to walk along, choosing shops without loud incidental music and strong smells) and to adapt my environment to my needs (e.g. being a barrier between me and other people so they don't bump into me).

Sensory discrimination

I may have difficulty 'filtering out' irrelevant sensory information. For example, if I am trying to have a conversation, and there is another conversation going on in the background, I may not be able to filter out the other conversation and I may be unable to follow the conversation I am interested in.

Your job is to help me manage this, for example, lead me somewhere out of earshot of other conversations.

A similar thing can occur with sight. Attempting to find an object in a cluttered room can be impossible as I may be unable to 'filter out' irrelevant shapes and colours.

Overload

Overloading just means: **taking in more information than can be comfortably processed**. It is related to sensory discrimination. You can think of overloading in terms of a traffic jam. Too much traffic (information) clogs up the system, and slows everything down. The way to fix it is to give it time for the jam to clear and not to add more traffic.

I get overloaded much much more easily than NTs (NT = neuro-typical, non autistic people) with much more debilitating results. The main result is a big slowdown in what I can cope with, a reduced ability to function generally, and a reduced ability to make decisions. In extreme cases I can become non-vocal and even immobile. These effects have a direct negative impact on *autonomy* and *independence*. Therefore:

It is your job to help reduce the risk of overloading at all times as much as possible.

Overloading can happen in many many ways:

- People talking too fast (*slow them down, ask them questions, get them to repeat themselves*)
- Lots of noise (*shut intervening doors, lead away from sources*)
- Lots of visual stimulation (*stay away from it*)
- Having to make lots of decisions in a short time, even decisions about trivial matters
- Coping with anything new (*plan well in advance for new things, or changes to existing routines and systems*)
- Coping with anything unexpected (*slow things down. Jettison non-essential demands on my resources. Don't add to the problem by talking unnecessarily or asking me to make lots of trivial decisions. Save my decision making resources for the more major decisions. **You may often find yourself in a difficult position where you have to balance my need for autonomy with the negative overloading effects of asking me what I want to do all the time.** Use your judgement. If I am significantly overloaded, it may actually be better to take over some minor decision-making on my behalf. Check with me after I have recovered to see if you did the right thing.*)

Signs of overload and other forms of stress might include:

- Slowed speech
- Rocking
- Finger waggling
- Other things which may look weird (let me do them, even if other people find it uncomfortable)

Inertia

I can have difficulty starting a particular activity, and also changing from one activity to another. This is called inertia. Just because I'm not doing something, it doesn't mean I don't want to.

It is your job to help me get started, by prompting me to do the things I want to do. Just make sure I really do want to do them, though.

Conversely, just because I am doing something, it doesn't mean I want to continue doing it. This will happen less often, but it may be your job to:

Help me disengage from what I am doing and perhaps help me focus my mind on the next thing I need to be thinking about or doing.

You must take care here and be sensitive. I need to stay in control of this whole process. I don't want to be pushed into doing things I don't want to do, nor be stopped from doing things I do need to do!

Sometimes a single prompt may not be enough. You may have to stand there and wait a moment for your presence to have sufficient effect for me to get started on something. And then you may have to prompt again. If you go away, you may have to come back a few minutes later to check I have got started. But be sensitive about this and mindful of the next section.

Have a talk with me about my inertia and how significant it is. Autistic people vary on this.

Other reasons I may not be doing something I want to do

Although inertia is often the reason I'm struggling to do something, there are other reasons as well which you need to be aware of. Don't assume it is always inertia. If you prompt me to do something a couple of times, and I'm still not doing it, check the following:

- 1) Do I really still want to do it?
- 2) Am I confused about what is involved?
- 3) Am I 'stuck' because the activity involves a lot of different processes? *(if so, break the activity down into smaller, simpler components and prompt me to do each smaller activity)*
- 4) Does the activity involve a lot of decisions?
- 5) Does it involve something I'm scared of?
- 6) Are there other higher priorities? *(if so, help me get those done first)*
- 7) Am I too overloaded? *(if so, help me decide how important the job is and whether it can be left until I am less overloaded)*
- 8) Am I too tired? *(if so, help me decide how important the job is and whether it can be left until I am less tired)*

Important: if I'm not doing something, it is entirely inappropriate to tell me off or think of me as lazy or stupid. I can and I will do what I need to do provided that (1) I genuinely want/need to do it and (2) conditions are favourable. And (2) is, to a large extent, dependent on my support worker helping me create the right conditions.

Inertia, independence and routines

Clearly, needing a support worker to help me overcome my inertia is a major barrier to independence. **Routines** can be of great help in overcoming inertia when a support worker is not around. If I get used to doing something every day at 11:00am then I am much more likely to be able to do it without a support worker present.

*Helping me to establishing and maintain **routines** is a key way to support my independence.*

Systems and independence

One of the barriers to doing things independently is '**getting stuck**'. I might successfully **decide** I need to process some laundry, and furthermore, I might successfully **overcome my inertia** (perhaps because of a **prompt** or a **routine** I have set up with your help) and go to the washing machine ready to do so, but completely fail to get started because:

- (a) all my dirty laundry is still upstairs
- (b) I can't find the laundry powder
- (c) the support worker has put the laundry baskets somewhere and I don't know where
- (d) I haven't got anywhere to hang it once it's washed
- (e) There's a big cardboard box in front of the washing machine and I have no idea what to do with it etc etc

Problems like this can completely scupper my ability to do things independently. The solution to these kinds of problems are **SYSTEMS**. They are vital for my independence.

To do the laundry independently, I need a system to follow, which may include a detailed list of instructions until I have learned it by heart. For example:

- (1) Check there is enough drying space to hang out clothes once they are washed.
 - (2) Put all clothes on the floor in your bedroom in the basket.
 - (3) Put all clothes and towels from the floor of the bathroom in the basket.
 - (4) Take full basket downstairs to the washing machine.
 - (5) Bung it all in the machine
 - (6) Close the door until it 'clicks'.
 - (7) Add the powder using the measuring cup
 - (8) Turn the dial to cottons, 60 degree wash
 - (9) Press 'START'
 - (10) If nothing happens, check a support worker hasn't turned it off at the plug. If so switch it back on.
 - (11) Leave the washing to wash. It will take two hours, after which time it will start beeping.
 - (12) When the washing machine has started beeping check the display says 'wash complete'
 - (13) Get the basket you used to bring the washing down.
 - (14) Empty washing machine into the basket.
 - (15) Go to the small clothes horse in the living room and put any laundry smaller than a bath towel on there.
 - (16) then put any laundry larger than a bath towel on the pulley drying rack
- etc etc.

These lists of instructions may need to be extremely detailed, especially if I am unfamiliar with a particular task.

These systems may not work first time. You can do your best to help me set them up and you can write me lists of instructions, but I may well still get stuck at some point. This is where you use your practical analytical skills to talk to me and, with me, figure out what went wrong and how to fix it ready for next time. Then we try again, and if it fails again, we analyse the problems again and find solutions. Eventually, we will have set up a system that works and which I can manage independently. You may still be needed to keep it running (for example, making sure there is always some washing powder in the right place) but your involvement will hopefully be reduced to a minimum.

Is it worth trying to be independent at such-and-such?

There are things which may be extremely useful to be able to do independently. Processing my laundry might be one of them. Cooking my own meals might be another. There are other things which may be less useful but extremely desirable for me to be able to do independently, for example, going for a bike ride by myself purely for fun.

However, there are other things where it probably isn't worth it. I have poor manual dexterity and will never be able to sew easily. So if I rip my trousers, we could either spend two hours with you coaching me and guiding me through the process of sewing a patch on, OR, I could just let you do it for me which you could do in twenty minutes. This skill is not crucial to my survival – I can live with a pair of ripped trousers until a support worker arrives. It's not something it is worth me putting a great deal of time and effort learning how to be independent at. So it may just be better to let my support workers do it for me.

You may help me evaluate which things are worth trying to be independent with, and which are not, by informing me of the processes involved in an activity, and helping me work out the benefits of independence and the consequences of not being independent at a particular thing.

Reminders

Reminders are an important tool in maintaining my independence. You will probably spend quite a lot of time **figuring out where to put reminders** so I find them at exactly the moment that I need them. It is pointless to put a reminder to send an important email in the kitchen, when I am likely to be cooking. A reminder to send an email should go on my computer. A reminder to take a piece of paper to an appointment should probably go in several places: on the bag I am going to pack, on the paperwork pile, on the inside of the front door. That way I have several chances to remember it.

Supporting me to make my own decisions

This is largely about information management. You may like to look up on the web the **Mental Capacity Act 2005** which contains useful guidance on what is involved in making a decision and supporting someone to make decisions for themselves.

The main point to remember is to **allow me to make my own decisions**. Your job is not to advise me or influence my decision. Do not say things like “If I were you I would...” or “I think you should...” as that is not allowing me to choose freely for myself. You must also allow me to do things you think are unwise.

Very often, **the best thing you can do is simply be quiet and listen** while I talk through a problem and then I will likely arrive at a decision with little or no input from you.

It is your job to **help me gather all information relevant to a decision**. Some of that information may be in your head, as you may have a better idea than I do about things which you have experienced and I have not. For example, you may know things about bicycles which would be useful for me to know when deciding which one to buy. So feel free to **inform me**, but **don't push me into a particular decision**. Also take care not to influence my decision by selective presentation of information.

Help me **retain information** relevant to a decision or future decisions. This might involve storing information in emails, files, cloud services, sticky notes, notebooks, memorabilia boxes, diaries etc.

Help me evaluate the information, consider it and make a decision. Help me figure out a **menu of options**. When writing this menu, include options you think are unwise simply so that I have the opportunity to evaluate them for myself. I may end up choosing something that you haven't thought of, but your helping me work out the options can often help me structure and clarify my thoughts. I am not very good at thinking laterally and working out the consequences of a decision, so you need to spend a little bit of time working out the implications for other areas of my life. A classic example of this is when making arrangements, double-booking things or failing to realise that someone won't be where they usually are at a certain time, or that there will be a delivery coming at the time you had planned to go out etc. Thoroughly check arrangements so plans are properly integrated with each other.

Clear communication

Please be as honest and straightforward as you can. I probably won't pick up on subtle meanings in what you are saying. If you (or anyone) requires me to make a lot of inferences, or makes oblique references to things, makes many invalid inferences, or makes use of a lot of hidden assumptions, or beats around the bush, or is highly ambiguous or ironic, or lies a lot (which results in inconsistencies), or says contradictory things, I will quickly become completely lost. I need communication to be **honest, straightforward, on-topic (relevant) and logically coherent**. This is asking a lot, I know, but please do your best!

Your job is not:

- to cure me of autism
- to make me socially acceptable (although at times I may ask your advice on how to appear so)
- to train me to fake being NT

- to do everything for me
- to decide what is best for me

We have a professional relationship

While it's important to be relaxed and friendly, it is very important to be aware of boundaries that a friend might cross, but you, as an employee, should not. Personal questions ("How are you feeling today?"), personal comments/judgements ("You look nice today,") unsolicited advice ("I wouldn't do that if I were you."), even jokes, are all best avoided.

Feedback and monitoring your performance in the job

I am not very good at saying the socially 'right' things. I may go days or weeks without giving you a single word of encouragement even though you may be doing a perfectly good job. You are more likely to hear lists of things you are doing wrong. I don't mean this to be discouraging, I would just be telling you so you can fix them. I will try to give you appropriate encouragement, but I will probably fail to remember, and even if I do remember I may still get stuck on exactly what to say and end up not saying anything. It is very important that we schedule regular sessions in which I give you and any other support workers planned feedback so I get a chance to give you a properly balanced and accurate picture of how you are performing overall. Please help me set these up as soon as possible.