

How to help support workers support you

1) I suspect the main reason support workers may not do a very good job is simply because they haven't been given the right information about what they are supposed to do. So the first thing to do is give them that information. You could start with giving them the materials I have given you. You may wish to adapt them first to your particular circumstances. If you can't manage to adapt them, perhaps say "These materials were not made specifically with my needs in mind, so while they are better than nothing, they are not a perfect match with my individual needs."

If you are able, it would be a good idea to go through the training materials face-to-face. NTs seem to take in information much better if it is given to them face-to-face. They will also take it more seriously and not think of it as just 'blurb'.

I am in the process of writing training emails which are basically just comprehension exercises designed to force employees to read the training materials. When these are ready I will make them available online somehow, perhaps on the Autscope website.

2) If you can tolerate the lack of privacy, consider telling your support workers stories about your disability. It may be helpful if you write them down first. If you don't want to tell these stories verbally you could get the support worker to read the written version. This will help support workers:

- understand your disability better. This will make them more effective.
- identify with you - so they are 'on your side' and don't think of you as 'other'. This will make them more committed and less scared of you.
- know the consequences of them not doing their job properly. If they know their actions could screw your life up, they will be more careful.

Here are some examples of the things you might want to talk about:

- a occasion when you get very overloaded and the consequences of that
- a time you were completely misunderstood and the consequences of that
- a time when an unexpected change caused you problems
- a time you didn't have enough information to be able to handle a situation
- someone tried to be helpful but ended up making things worse
- a support worker screwed up
- someone messed up one of your systems for coping, and the effects this had
- someone made a decision for you which you would have liked to have made for yourself
- a time when you were treated unjustly because others didn't understand your disability
- any times when someone made a big positive difference to your life

There may be episodes you would prefer to keep private for whatever reason.

Include plenty of details (if you can remember them) so that it is easy for the support worker to imagine it actually happening. Where did it happen? Who was involved (you may wish to protect identities)? What did they say? What did you say? How did you feel at each point in the story?

Then, maybe once a fortnight or something, show one of these to the support worker, or read one out, or retell it from memory. You may like to tell them it is training to help them understand your

disability and needs.

3) Give the support worker feedback. Timetable regular sessions, maybe once every two months or so. Don't just tell them what they are doing wrong. Make an effort to think of some things they are doing right, even if that is hard!

On a day-to-day basis, if you can, thank them for the things they do. You shouldn't have to do this - their reward for working for you is money (unless they are informal support), not psychological affirmation. But people are not robots and, realistically, people need to know that they are valued if they are to do their job confidently. The better a support worker feels about supporting you, the longer they will stay, the more willing they will be to communicate with you. If all you ever do is give them a list of things they are doing wrong, they will begin to dread coming in to work and will start avoiding you.

If you keep forgetting to give support workers this kind of moral boost, at least explain to them occasionally (or even just once) that you find it difficult to give supportive feedback, and that this does not mean that you don't appreciate the work a support worker does.

4) Ask the support worker to help you solve some problem you have been struggling with and which is important to you. Maybe an ongoing communication issue with an NT or institution. Maybe a practical problem about organising something in your house. Maybe get the support worker to develop a system for you to do something independently - like catch a bus by yourself or something – perhaps including written instructions on laminated cards that you can take with you in case you get stuck, and scripts to manage conversations that might happen etc.

As well as being useful for you, this has great psychological benefits for the support worker. You are inviting the support worker to see things from your perspective and and to 'cross the dividing line' between the NT world and the autistic world. The support worker will hopefully feel a sense of pride if they have actually managed to help you solve a problem. If the support worker does even a half-decent job of helping you, be sure to say so: "Thank you. You've helped me with that. I am now more independent than I was." Then the support worker will hopefully be motivated to do it again, and do it better.