

**What are support workers supposed to do?**

**How well will they realistically be able to do it?**

**What can I do to help them?**

[about me]

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- Employed 3.5 years by an autistic adult as her SW
- I've helped recruit and train Sws
- Before that I was self employed as a builder and handyman
- Before that and electrician
- Philosophy degree

[main point – summary ]

Two things that should constantly be in the support worker's mind:

- INDEPENDENCE
- AUTONOMY

Of these two, I think AUTONOMY is the more important, but I'll talk about INDEPENDENCE first.

### **INEPENDENCE**

**Support worker should help set up and maintain systems and routines**

**Is it always worth it?**

[independence]

Definition: Being able to do something without a support worker with you.

- It may not immediately be clear to a support worker why independence is a good thing, after all, wouldn't it be nice to have someone doing stuff for you all the time? Explain there is a cost to having support workers around:

it's stressful, they overload you, it's an invasion of privacy, they mess up your systems for coping, reduces your sense of security (because you don't know when the support might be taken away).

SW needs to understand the importance of SYSTEMS and ROUTINES for independence.

## SYSTEMS

Example: Catching a bus. An NT only needs to know a couple of bits of information: where they want to get to and the nearest bus stop on the right bus route. They can probably improvise the rest.

An autistic person will need to know a lot more in advance and have a clear and explicit SYSTEM if they are going to manage to do the same thing independently. Systemising this may involve not just knowing timetable information but also having scripts for what to say to the bus driver, and other encounters with people on the bus. It may involve making sure you have exactly the right change because sometimes bus drivers can't change paper notes. Also contingency plans in case there are no seats available, or if you get stuck on the bus and miss your stop. All of this together constitutes a SYSTEM for catching the bus.

A major part of the support workers job is HELPING SET UP AND MAINTAIN SYSTEMS.

## ROUTINES

If a support worker is not around to prompt you to do something, you might FORGET to do it. Even if you do remember to do it, you might still have trouble getting started due to INERTIA.

Routines can help with both of these. If you get into the habit (perhaps by using alarms or reminder systems) of doing the same thing at the same time every day, you are more likely to both REMEMBER to do it, and to be able to overcome your INERTIA.

A major part of a support worker's job is HELPING SET UP AND MAINTAIN ROUTINES.

To an extent, having good systems and routines can reduce your dependence on support workers.

### **Is it WORTH trying to be independent with X activity?**

Sometimes it may not be worth trying to be independent at an activity.

Example: catching a bus. Yes, especially if you're likely to want to do it regularly, like a regular trip to college or to the shops or something.

Example: going out on bike ride for fun? Yes. It's important to be able to do fun things by yourself.

Example: sewing up trouser rip. Probably not. You could manage easily enough with ripped trousers until the next support worker comes anyway, so there is no pressing need for independence with this. You could waste a lot of time getting a support worker to help create a workable system for doing this independently when they could just do it in ten minutes.

## **AUTONOMY**

Definition: 'Autonomy' means being able to make decisions for yourself. It means being able to live the life you choose for yourself, not the life other people choose for you.

[next slide]

The Mental Capacity Act 2005 is all about this and well worth looking at. Also get support workers to google it. The NHS site's wording seems particularly relevant to supporting autistics, so I have printed it out and put it on a handout.

Talking about these four bullet points could be a presentation in itself, but I'll just whizz through them for now.

***A person is unable to make a decision if they cannot:***

- ***understand the information relevant to the decision,***

SW can help translate 'NTspeak', fill in context, make explicit implicit assumptions

- ***retain that information,***

SW can help develop information storage systems, memory aids such as constructing narratives

- ***use or weigh that information as part of the process of making the decision,***

SW can help with this by constructing lists of options, taking care not to exert undue influence or pressure. The act says people should be allowed to make decisions that others regard as 'unwise'.

- ***or communicate the decision.***

SW can help autistic person work out who needs to know and help create suitable 'NTspeak' etc

OVERLOADING - Key concept SW needs to understand, as it can profoundly affect all four of these things and therefore your autonomy.

- A definition of overloading: exposure to more information and sensory stimulation than you can comfortably process.

The more overloaded you are the less you are able to:

- take in and understand new information
- retain that information
- evaluate that information
- communicate a decision

The SW can play a very significant role in OVERLOAD PREVENTION by managing environment and interactions with people, slowing them down, asking clarificatory questions etc.

**Realistically, how well will they be able to support me?**

**Family and friends**

**Agency workers**

## Employees

[informal support]

Pros:

- Friends and family will have a familiarity with your disability (not necessarily understanding).
- They might be more committed to helping you because they are already emotionally engaged.

Cons:

- A lot of work for unpaid people to do. You may feel uncomfortable asking for help from them.
- It may be particularly difficult for friends and family to avoid trying to influence your decision and therefore compromise your AUTONOMY. They may want to protect you from making 'unwise' decisions.
- Inappropriate to 'discipline' informal support workers. **They're not accountable to you.** I would love to have a disciplinary procedure for my friends and family, but it would compromise our relationship.

So, realistically, are family and friends going to be able to give you the support you might need? I think the odds are stacked against it.

[agency workers]

Pros:

- They are paid, so you can feel OK about asking them to do stuff for you
- You don't have the administrative burden of employing them yourself
- Security – they will reliably deliver someone to you without you having to put in much effort

Cons:

- They are not accountable to you. If there is a problem you have to go through their management structure, which involves all kinds of problems: communicating the issue successfully and then them actually taking some

useful action. You have little control over this process. May involve a social worker as well.

- They are unlikely to have the time or inclination to think about the job in as much depth as they need to. They will be under time pressures, probably on minimum wage, quite possibly treated badly by their employer. They are unlikely to be willing and able to take on board difficult in depth training about how to support you well.

So, realistically, are agency workers going to be able to give you the support you might need? Again, I think it's unlikely.

[Employed support workers]

Pros:

- You can advertise for whomever you like (without breaking the law). That means you can seek to recruit from **outside the care sector**. I would suggest that being a support worker (especially for autistics) is not really a **caring** job at all, but a somewhat **technical** job, considering all this stuff about creating and maintaining systems, information processing and so on. So you can look for people from technical and practical backgrounds such as builders, electricians, engineers, mechanics, computer programmers, whatever. That way you can start off with the right kind of person in the first place, rather than be stuck trying to train the wrong kinds of person. Recruitment is probably another presentation in itself, so I'll stop there.

- You can deliver your own course of training

- You can send employees of training courses chosen by you (I went on a useful "Safeguarding Vulnerable Adults" course)

- You can communicate between shifts. Greater flexibility in managing support.

- **You are the boss and SW is answerable to you.** You can put disciplinary and management systems in place that work for you without having to go through an agency's management structures.

- You get to write the JOB DESCRIPTION. This is good because:

- You get to define what the job is, not have the agency do it

- The job description is a standard you can hold the SW to. Useful to structure supervision sessions.

- It forces you to think carefully about what it is you need for a SW, and will help you to articulate to a SW what your needs are.

Cons:

- And it's a biggie: Much greater administrative burden. But the benefits are so huge it may be worth getting your existing support to help you access funding with which you can employ your own support workers.
- Less security. If you have a bad run, and people leave, you might be left without any support at all for a while, and then you may struggle to get organised enough to recruit new people.

So, realistically, are family and friends going to be able to give you the support you might need? Well, IF you can manage to recruit the right kind of person, then, quite possibly, YES!

### **What can I do to help them?**

1) **Train them.** *I think the #1 reason support workers of any kind might not do the things I've been talking about, is that nobody's actually told them that's what they're supposed to do. If you tell them, and tell them again, they may actually start doing it.*

- Adapt and use the training materials I've given you. Give them to the support workers and, ideally, go through them with the support workers face-to-face. NT's take face-to-face information more seriously. I've given you something for each of the categories of support worker. I'm fairly happy with the one for employees, fairly happy with the one for agency workers, but I'm not at all sure about the one for family and friends.
- Send them on short free courses, e.g. "Safeguarding Vulnerable Adults"

2) NT support workers are likely to be scared of you because you are disabled and therefore 'other' and 'weird'. They won't immediately identify with you, and it might be hard for them to start seeing things from your point of view. They may be reluctant to communicate with you.

Tell them stories illustrating your disability. Use example of moving house. "I suggested my employer move house to solve some problems. She told me what happened last time she moved house. It was a MAJOR insight into her disability and helped me do my job better."

You could tell them about:

- a time when an unexpected change caused you problems
- 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
- any times when someone made a big positive difference to your life

These stories will hopefully help them identify with you and see things from your point of view. This will make you less scary.

3) Give them a problem to solve. Something that matters to you. “There's something that's been bugging me for ages. I keep bumping into this person and they keep trying to talk to me and I don't want to talk to them. But I don't know how to get them to stop talking to me without being rude. Can you use your NT knowledge to help me out with this?” If the support worker can see that this is something that really bothers you then it will give the SW a great sense of achievement if they actually manage to help you with it. Be sure to express your appreciation. This will give the SW confidence that they can actually make a difference to your life.

4) Give them feedback and understand that they need to know that they are helping you. People don't work for money alone. Schedule regular feedback sessions. These give you a chance to have a proper think about how the SW is doing and give balanced feedback. Otherwise there is a danger that the SW will only ever hear lists of things they are screwing up, which will demoralise them. If you can, remember to say 'thanks' when they do something well.

## **Summary**

Support worker should promote independence by helping create and maintain systems and routines

Support worker should promote autonomy by helping manage overload, information and communication

Employ your support directly if you can manage it

Train your support workers

Tell them stories

Give them a problem to solve

Give them balanced feedback and say 'Thanks'