

Autonomy and the Mental Capacity Act 2005

There is lots of good information about this legislation on the web. From what I have seen, the Act articulates very well issues surrounding autonomy. I have snipped a couple of bits from the NHS website:

<http://www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/MentalCapacityAct.aspx>

I haven't quoted the whole web page below, only the bits that I think are particularly relevant to supporting autistic people:

“The act's purpose is:

- ***To allow adults to make as many decisions as they can for themselves.***

...

Incapacity is not based on the ability to make a wise or sensible decision.

...

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

- ***understand the information relevant to the decision,***
- ***retain that information,***
- ***use or weigh that information as part of the process of making the decision,***
- ***or communicate the decision.”***

It seems to me that supporting an autistic person to be autonomous is very much about helping them with these last four bullet points.

What SW can do to help with the four bullet points.

[These are just my presentation notes which I cut out of the presentation because I didn't have time to talk about them in detail and I thought you may as well have them in case they are useful to train SWs.]

- **All four bullet points:** prevent/manage overload:

SW needs to:

- Know what overloading is
- Not overload you by talking all the time and saying vague NT stuff
- Control sensory environment (lawnmowers, flickery lights, strong smells, relocating)
- Control interactions with others: slowing them down
- Avoid surprises and sudden changes (which may carry a big sudden information processing burden)

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

Barriers to understanding information:

- Speed of presentation SW ACTION: slow things down. Interrupt. Chit chat. Ask clarificatory questions. Ask to repeat.
- Vagueness. "Oh just go to reception, sign in and then go to the conference room." SW ACTION: gather way more details
- Hidden assumptions. SW ACTION: explicate them
- Context. Not understanding why things are the way they are. SW ACTION: supply context. Explain a person's motivation in a given situation (e.g. motivations of support workers), explain why a rule is the way it is (e.g. no watches in a swimming pool)
- Sensory distractions: lawnmowers, smells, flickering lights, others talking SW ACTION: manage these

- ***retain that information,***

Obviously, retaining information relevant to a decision is crucial for making a decision. E.g. information about past events which you need to use as evidence as the basis of a complaint. But you can't remember the date, nor who said what, and your complaint collapses for want of evidence. Memory is also important for other things – sense of security (knowing that yesterday was like today, and tomorrow will also conform to patterns established in the past), identity, being able to learn from past mistakes.

SW action:

- understand the importance of memory
- believe you really can't remember things (tell a story about when you couldn't remember something)
- assist in memory formation: post mortems, prompt to keep a diary, repeatedly recount an event soon after it has happened in order to construct a narrative which is hopefully fairly accurate (in place of a genuine memory of an experience), take photographs and annotate them
- help store information in the right place: filing cabinet, in an email,

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

- What other people want you to do. SW action: avoid giving advice "If I were you I'd..." "I think you should..."; help autistic person understand what other people's interests might be; give information not opinions; SW should be self-aware (check for this at selection stage) so SW knows when s/he is trying to influence. This is a problem with all support, but it will likely be more of a factor with INFORMAL SUPPORT – family and friends tend to think it's OK to try and control each other. Support workers need to watch out for selective presentation of information to influence a decision.
- Connecting the dots: SW needs to think laterally about what the effects of the decision is likely to be and inform the autistic person of possible consequences and problems
- Gets stuck. Too many contingencies. SW may just need to SHUT UP while the autistic slowly works through the problem verbally. SW may help by asking questions to help the autistic work out what s/he thinks.
- Trouble working out the options. SW can help by generating a list

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

- Figure out who needs to know – SW can help by making suggestions and asking questions
- Can they be told bluntly or does it need to be NT-ised? SW can help NT-ise.
- Should communication be verbal or written? Does SW need to be present for verbal communication? Is it helpful for SW to draft an email or letter?