



National Autistic Taskforce
Bolder Voices, Better Practice

An independent guide to quality care for autistic people

Easy Read
Version



Introduction



This guide is written by autistic people with experience of giving and getting support. The main people involved were: Kabie Brook, Leneh Buckle, Yo Dunn and Damian Milton.



This guide is about the whole autism spectrum, both children and adults, autistic people with and without learning disabilities. The guide is meant to be used in all care settings.



This guide has been written for people who provide care, people who decide which care to pay for and people who check if care is good.



In this guide we think it is important to get information from autistic people ourselves.

Background



National Autistic Taskforce
Bolder Voices, Better Practice

The National Autistic taskforce started in January 2018 to make government and local communities give autistic people the support and services they are supposed to have. NAT is completely controlled by autistic people.



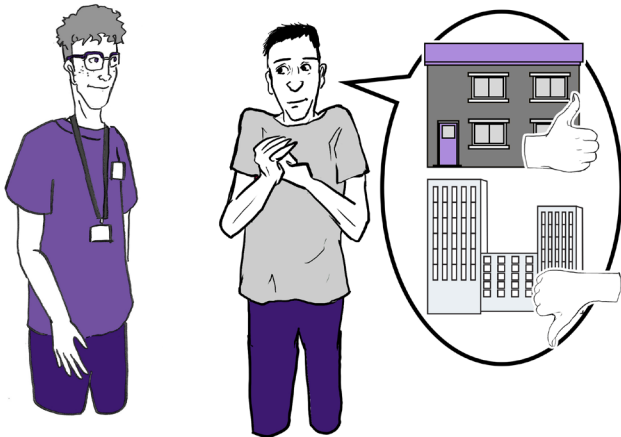
We try to use the knowledge and experience of autistic adults to improve care and support, especially for autistic adults who are not able to say what they want.

1. Respecting choices

Care Providers should:



- Make sure autistic people's choices are protected. This is very important



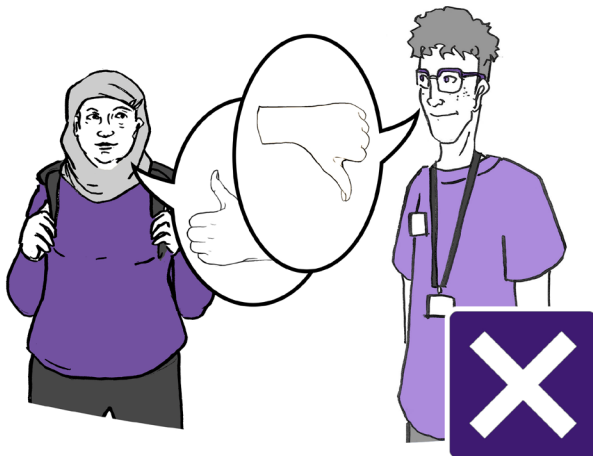
- Help autistic people to choose and control important choices in their lives, not just everyday choices



- Support people to make their own decisions. They need to do this whenever they can



- Be honest and open with autistic people about their own lives even when that information might upset them



- Avoid controlling people



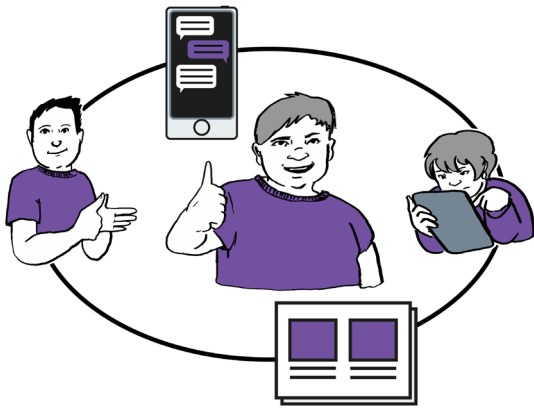
- Make sure staff follow care and support plans



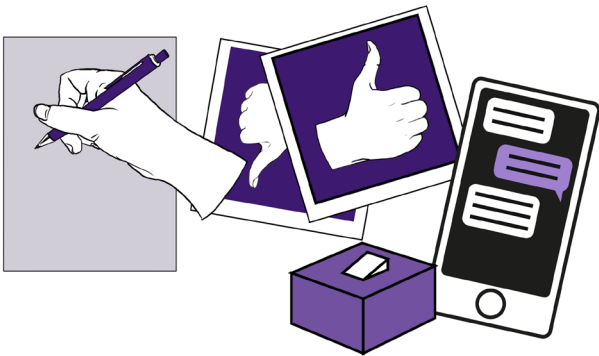
Good care is when autistic people have power and responsibility and are supported to be able to control their own lives

2. Helping people with communication

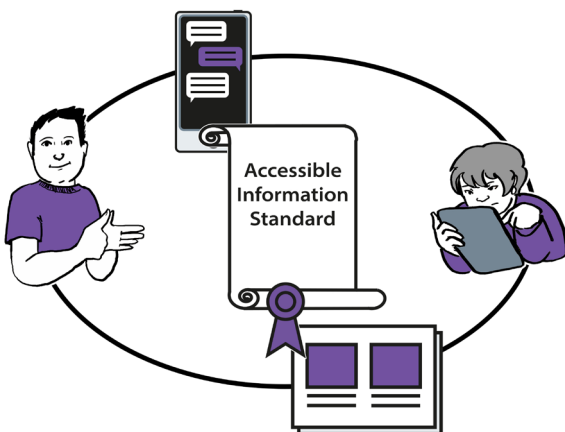
Care Providers should:



- Use and offer different ways to communicate



- These can be ways like: pictures, signs, apps, switches, objects to touch or smell, and writing, emails, or texts. Use these all the time.



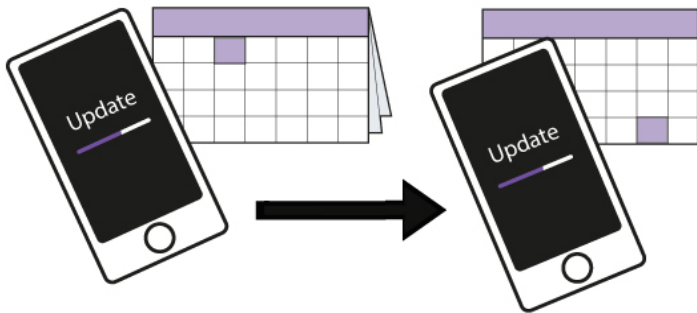
- Meet the Accessible Information Standard



- Make sure everyone can easily get their own phone, tablet or assistive technology to help them communicate



- Put a member of staff in charge of finding the best way to help people communicate and help them to keep in touch with friends and family



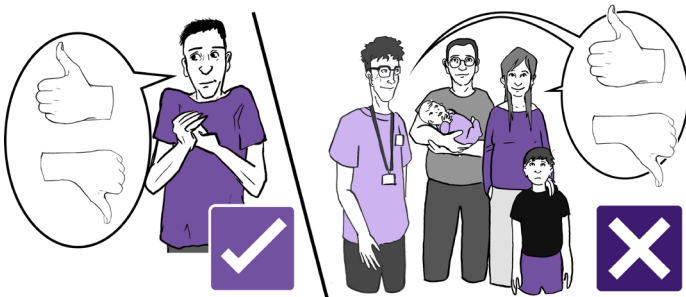
- Look after assistive technology and keep it up to date



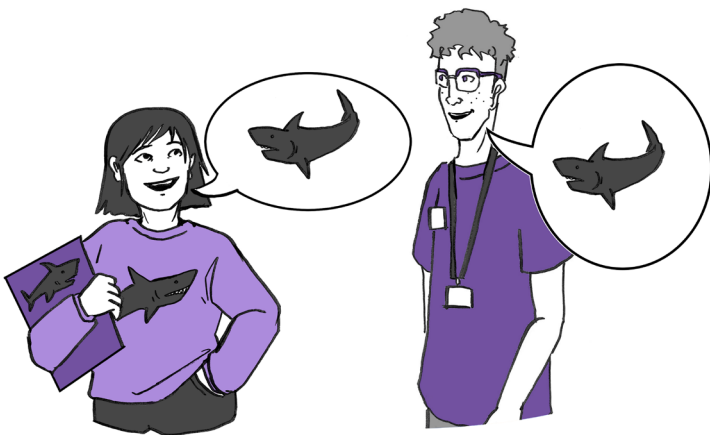
- Make sure staff have the right training and skills to help people communicate.

3. Put the autistic person at the centre of their care

Care Providers should:



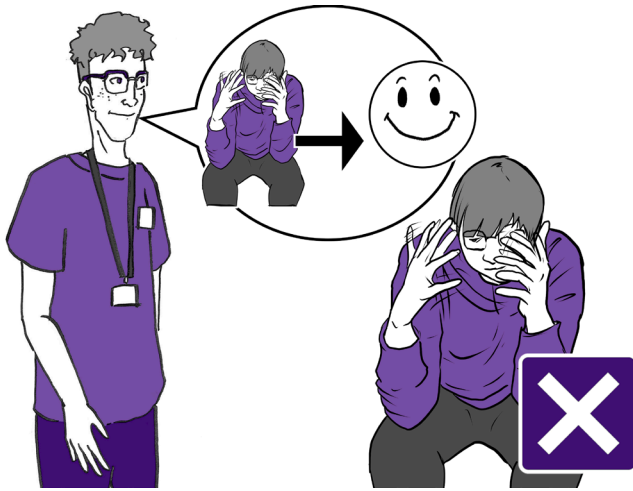
Make sure that autistic people are in control of their own lives instead of family and professionals



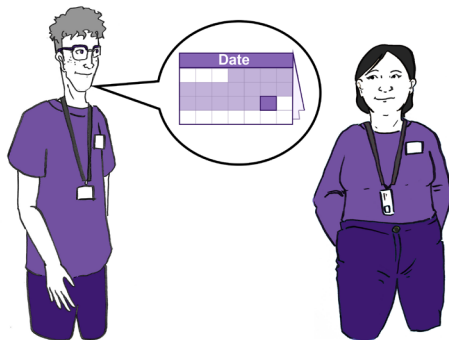
Try to use the same staff and make sure they share interests with the person they support where possible



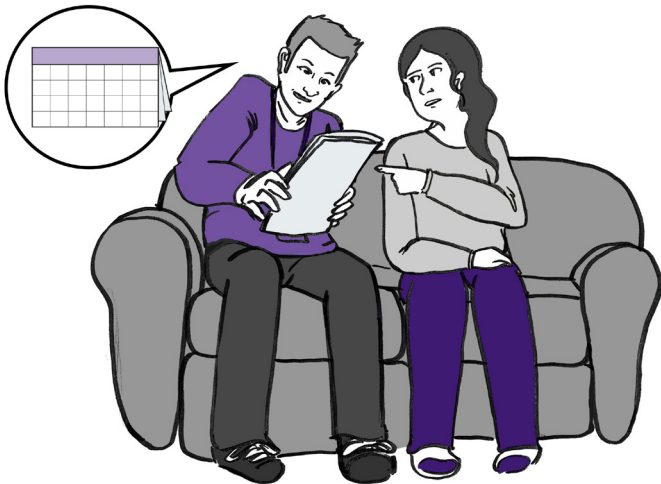
Think about why they are doing what they're doing. This is very important when they are supporting someone with their behaviour.



- Ask themselves if they are trying to help the autistic person to sort out what is making them upset or trying to stop them looking upset and get them to act normally



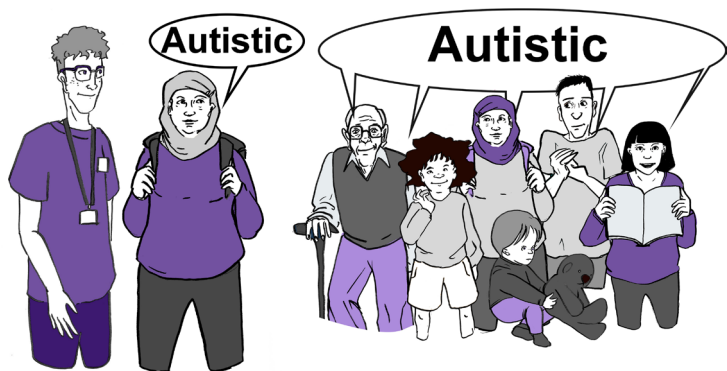
- Plan changes ahead of time wherever they can and try very hard to do this.



- Support autistic people by giving them information about changes coming up using written words and pictures as well as speaking to them



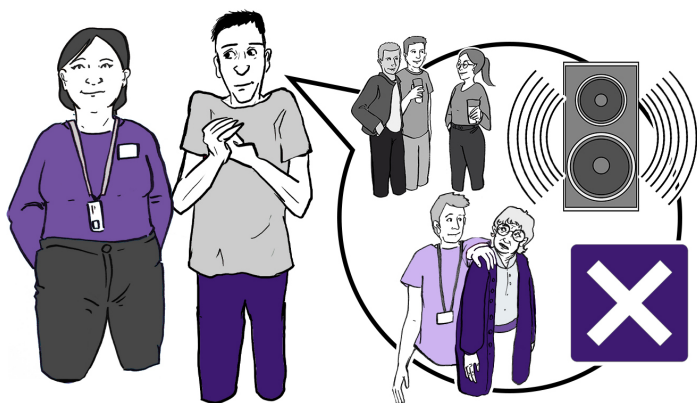
- Support people to try things they might like



- Support autistic people to meet other autistic people and find out from them about being autistic

4. Making services less stressful

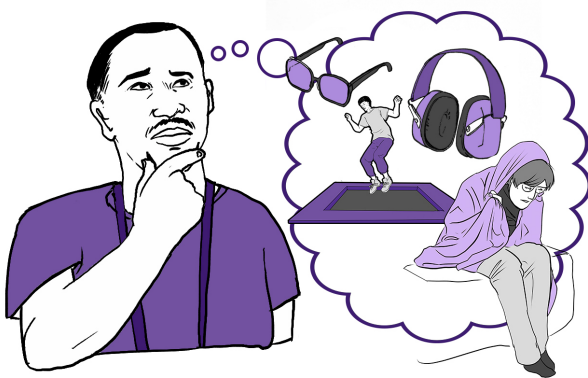
Care Providers should:



- Look at spaces often to make sure they are right for autistic people. They need to have help from autistic people to do this.



- Give autistic people things to help them with their sensory needs like noise cancelling headphones and accessibility settings on technology



- Make sure staff know how important autistic people's sensory needs are and give autistic people safe ways to meet their sensory needs



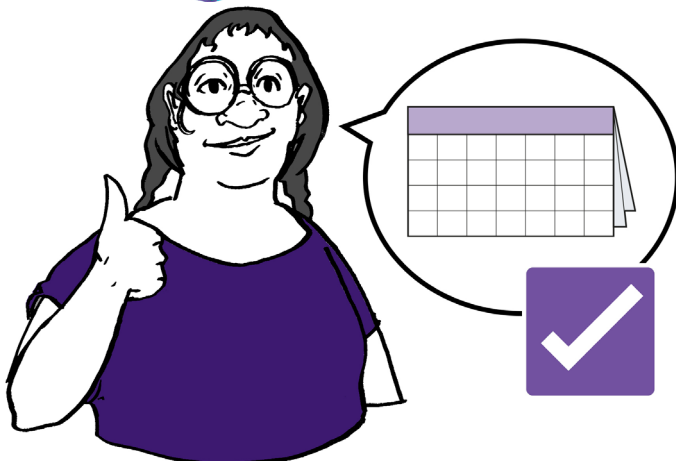
- Accept stimming, and only try to stop it if it is upsetting the autistic person or causing harm and if they have agreed this with you



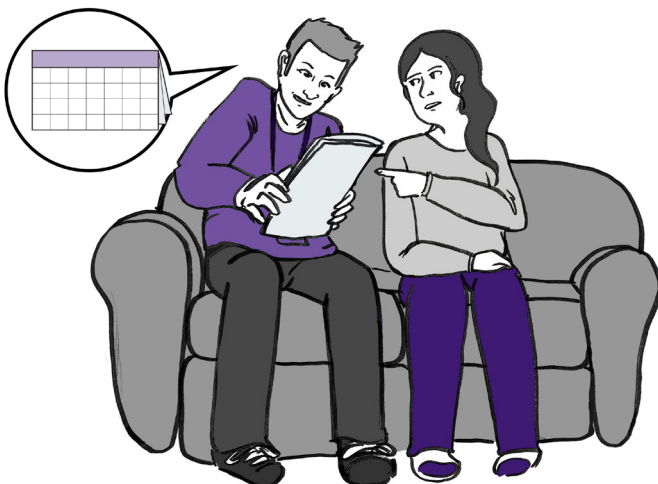
- Make rules for staff which make clear autistic people need:



True and clear information



Routines and to know
and understand what is
happening



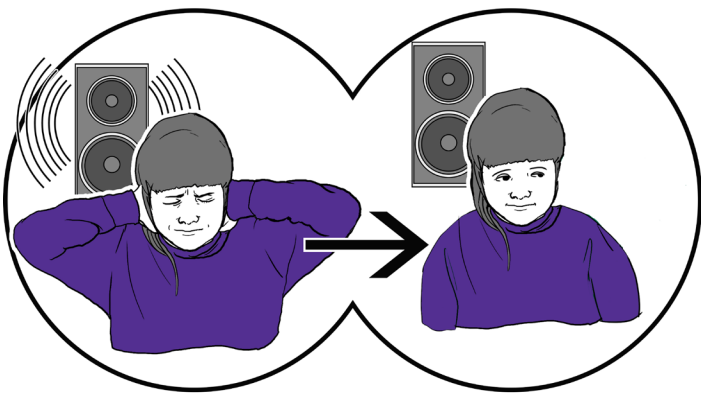
Support and time to get
ready for changes



- People who provide support
must be honest and open.



See distressed behaviour as a sign that people are upset



Concentrate on getting the things around the autistic person right instead of changing their behaviour



Distressed behaviour is behaviour that is worrying or dangerous. It is sometimes also called challenging behaviour

5. Helping people get equal access to the community

Care Providers should:



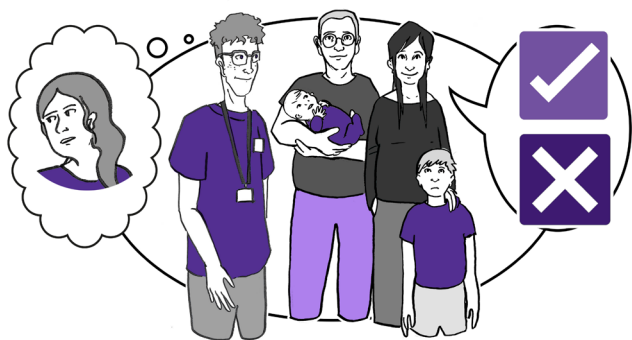
- Make sure people can get an advocate when they need one.



- Make sure that autistic people are fully involved in best interest decisions about their lives



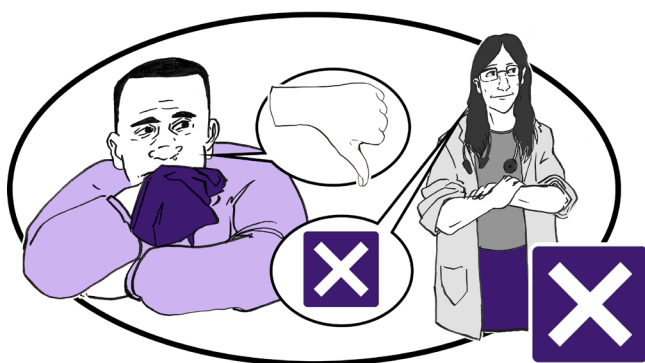
- Best interest decision making is when someone cannot make their own decisions about certain things



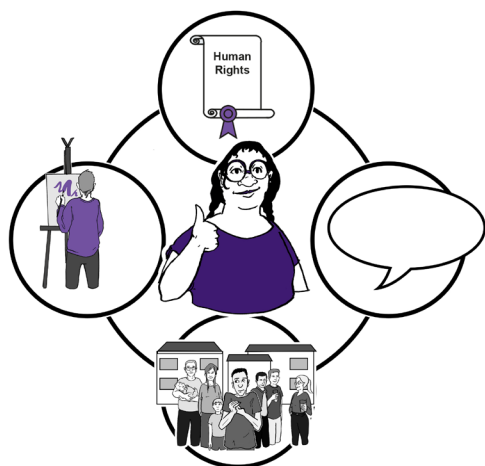
Family, friends and professionals will be involved in making decisions for them. They must listen to the autistic person and try to make decisions that are right for that person.



- Understand that autistic people do not always get good healthcare. Support autistic people to get health checks and tests.



- Speak up if autistic people are treated unfairly in the community or by health and care services



- Support autistic people to use all their rights, have their say and do things they think are important.



- Make sure autistic people can use the internet when they want to and support them to keep themselves safe

6: Fighting discrimination

Care Providers should:



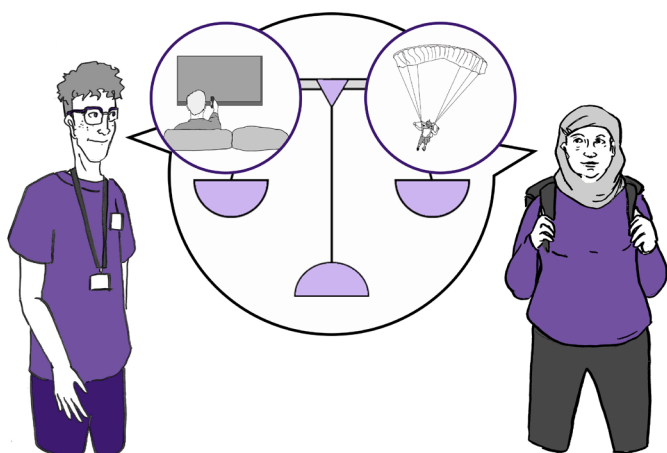
- Make sure the way they provide care to autistic people is based on people's human rights



- Support the right of autistic people to choose where they live and who they live with



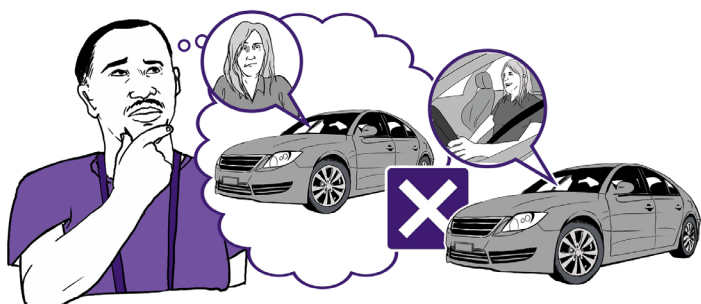
- Agree that autistic people should live in the community and work against autistic people having to live in institutions for a long time



- Help people take risks



- Be positive about autistic people's differences and identity



- Not assume people can or can't do things



- Recognise and challenge bullying

7: Know when people are upset

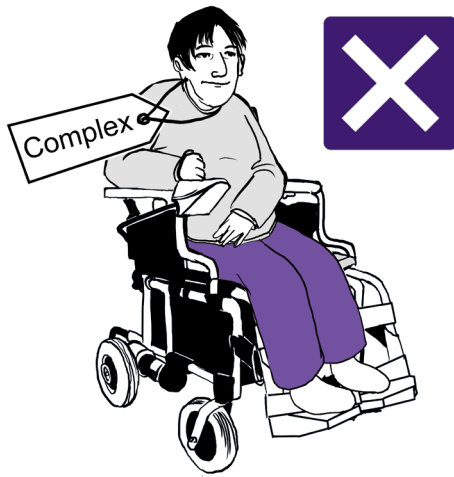
Care Providers should:



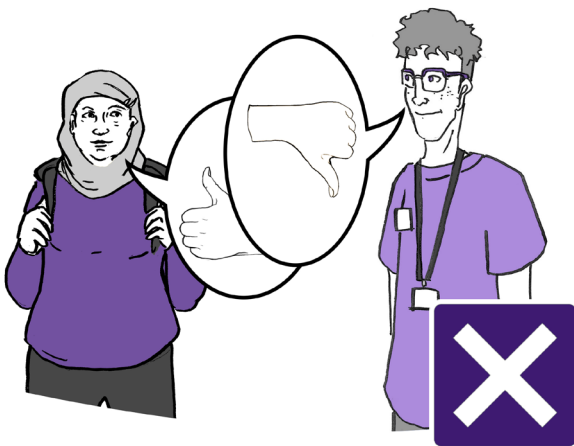
- Treat the use of restraint as a failure and try not to use it at all



- Not blame the way people act on their autism



- Not label people as complex but try to understand what life looks like to them



- Not take away choices and control from an autistic person



- Speak up against taking autistic people away from their local communities



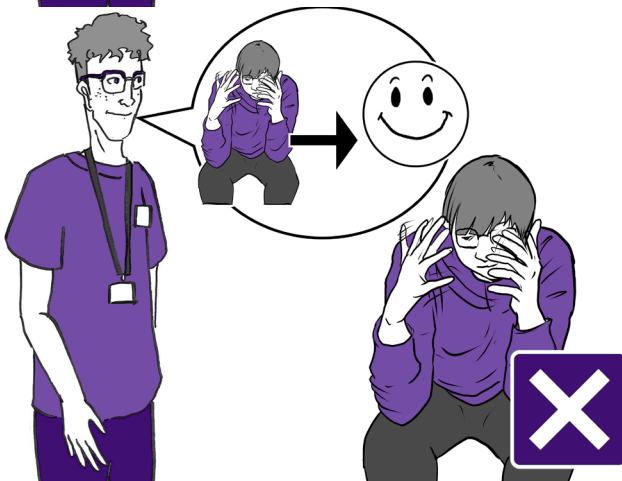
- Change spaces to meet the needs of autistic people and look at why places might not be right for autistic people



- Change the way staff act to meet the needs of autistic people. Understand that ways of doing things that are ok for other people might not be right for autistic people.



- Work with autistic people and support them to cope with stress and help them if they get upset



- Think about autistic people's needs and not just try to stop them behaving in ways other people don't like



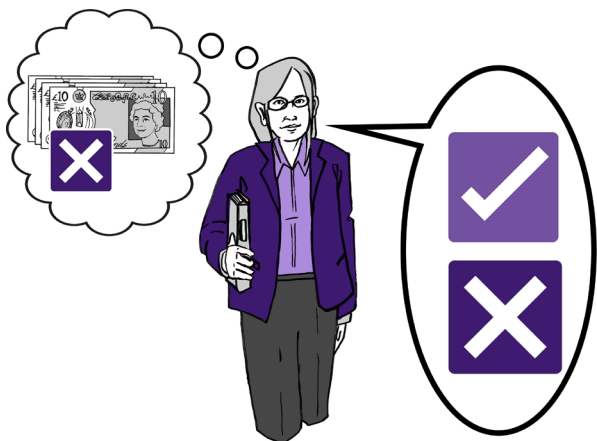
- Accept the way autistic people behave if it doesn't harm other people



- Support autistic people to find ways to meet their own needs that do not harm themselves or others



- Notice when services or staff are not the right match for an autistic person

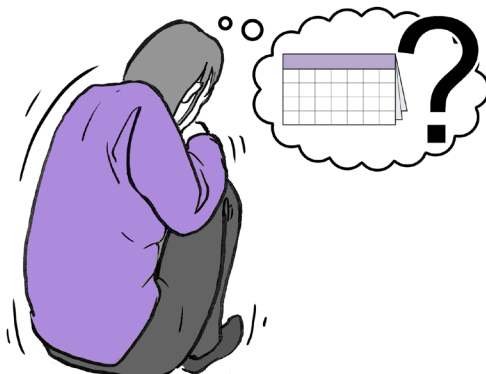
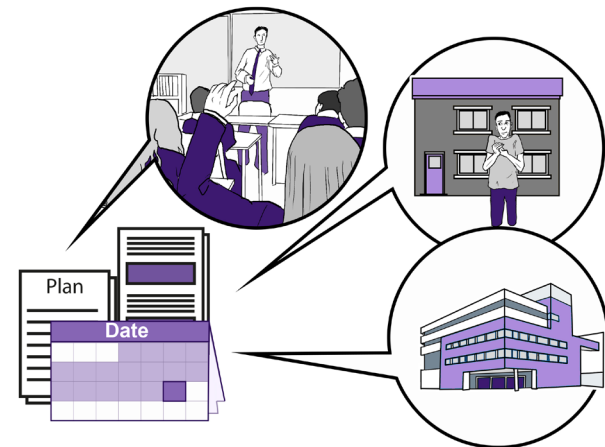


- Know when decisions are taken because of a lack of money and when those decisions might cost more in the future



- Don't use medicine to control how people behave.

8. Supporting autistic people with big changes



Care Providers should:

- Plan very early for big changes through autistic people's lives

- Help autistic people to prepare for big changes

- Tell the truth to autistic people about big changes

- Know that not knowing about changes and not knowing what will happen will make autistic people stressed

9. Getting training right for staff

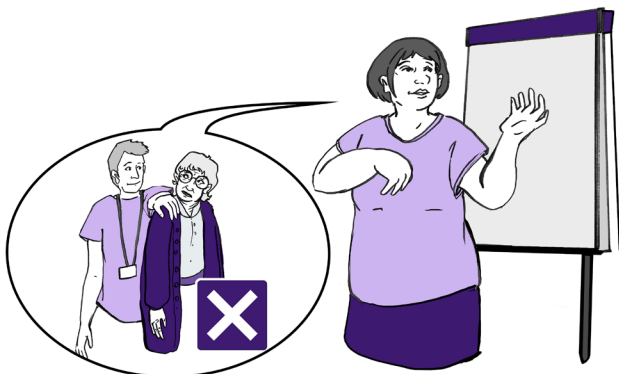
Care Providers should:



- Give all staff who might work with autistic people face to face training about working with autistic people. They should get this when they need it



- Make sure training gives useful knowledge about autistic people's support needs in day to day life



- Make sure training tells staff practical things to do to help autistic people



- Make sure that people in charge of assessments, care planning and safeguarding get training about autism



- Make sure that training is put together and led by autistic people



- Make sure that staff understand the law about human rights so they can speak up about bad support



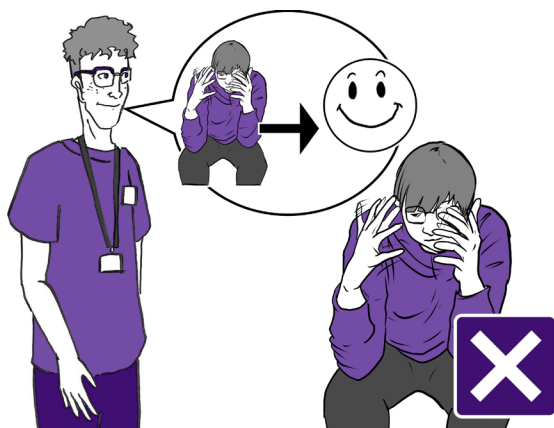
- Support their staff to keep learning, making sure they think about positive risk taking and human rights



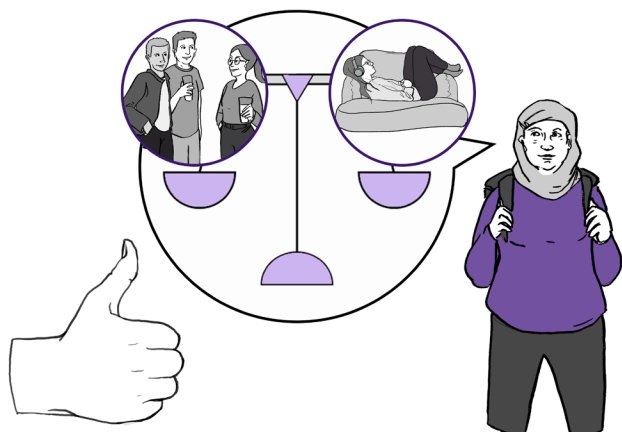
- Make sure their staff respect autistic people, think about boundaries and try to see things from the autistic person's point of view

10: Accepting difference

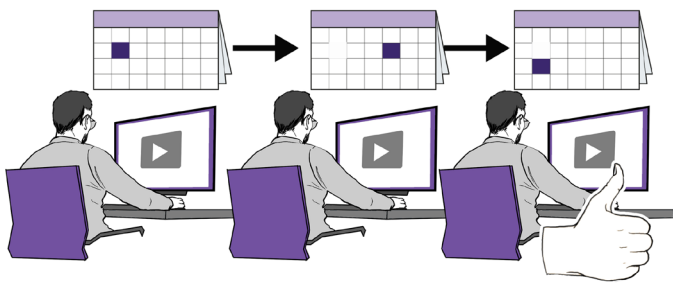
Care Providers should:



- Not try to make people 'normal'



- Be ok with autistic people's choices to be social or not social. Understand when autistic people want to be left alone.



- Be ok with autistic people keeping things the same in their lives. Staff need to know when to support autistic people with change and when to not change things.



- Support autistic people to meet other autistic people. Support autistic people to go to places where autistic people are in charge.



- Think about if someone might be autistic and help them to get a diagnosis.



- A diagnosis is when a doctor or a professional tells someone if they have a condition or not

This easy read document was
designed and illustrated by
Opening Minds Training and
Consultancy Ltd

