



Department
of Health &
Social Care



**Easy
Read**

Core Capabilities Framework for Supporting Autistic People



Royal College of
General Practitioners



National Autistic Taskforce
Bolder Voices. Better Practice

Introduction



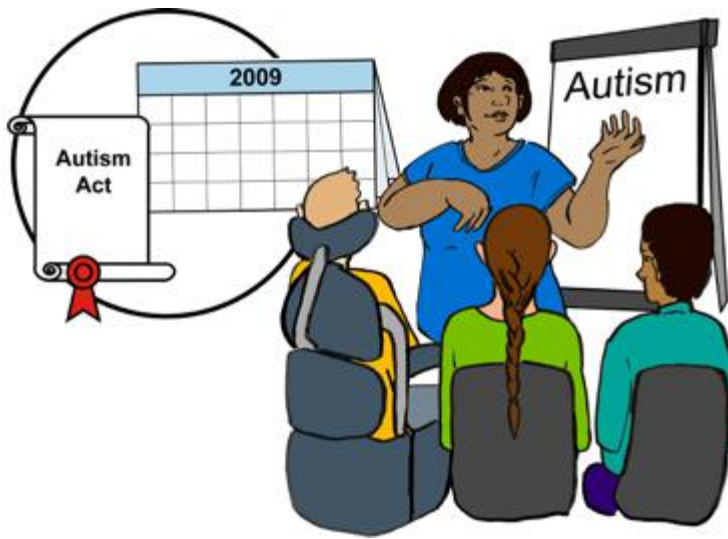
At least 1 in every 100 people in England is autistic.



Many of these people struggle to get the right information, support and care.



These problems can be made worse by a lack of skills and knowledge in the people who work to support autistic people.



In 2009 The Autism Act said all public service staff must have autism training.



This framework is made to explain what these staff need to know and do to support autistic people.



When we talk about autistic people in this framework we mean children and adults of all ages.

About this framework



This framework starts with a description of how staff need to act towards autistic people.



After this it is split up into 5 parts.



A: Understanding Autism
This part is about what autism is and how it affects autistic people.



It also contains information people need to know if their job is to tell if people are autistic.



B: Personalised Support

This part is about how to support and care for autistic people properly.



It is the most important part for care staff and support workers.



C: Physical and Mental Health

This part is about autistic people's health needs.



It is the most important part for doctors and other people whose jobs are to do with health.



D: Risk, Legislation and Safeguarding

This part is about the law and autistic people's human rights.



E: Leadership and Management, Education and Research.

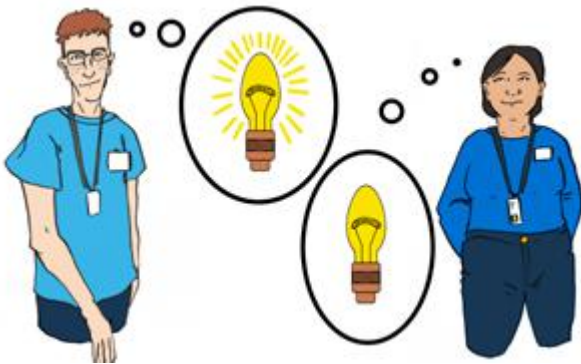
This part is for people who run organisations that autistic people use, people who run training about autism and people who do research about autism.



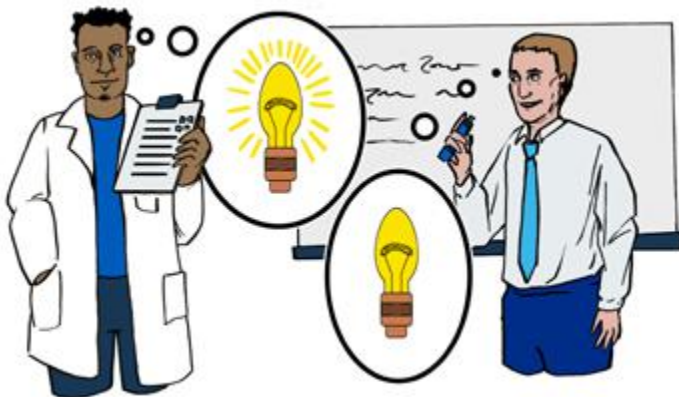
It is about how to do all these things in the best way for autistic people.



Not everyone will need to know everything in these 5 parts but any team or service should cover all of them.



Some people will need more in-depth knowledge than others.



For instance, someone who diagnoses people with autism will need to know a lot more than a doctor's receptionist or a teacher.



People will have to think about what level of training they need. The full framework will help them to do that.

Who is this framework for?



Workers and teams can use this framework to know what autism training they should have.



Managers can use this framework to know what training they need to give to their staff.



They can also use the framework to plan the training their staff may need in the future.



Commissioners can use this framework to know what services for autistic people need to include.



Commissioners are people who put together services.



This framework helps people who design training to know what they need to train people about autism.



This framework can help universities and colleges design courses about health and care to include autism.



This framework means that services all over the country will be giving people the same training and making sure that staff everywhere know the things they need to.



Autistic people and their families, friends and carers can use this framework to know what skills and knowledge staff they meet should have.



This can help them choose good care and recognise when people need to do more.

Values and behaviours



By values and behaviours we mean how staff need to act towards autistic people.



Staff don't just need to know about autism, but how they need to treat autistic people.



They need to follow these values and behaviours through every part of this framework.



We decided on these with the help of autistic people from across the country who told us what they would like to see from staff and professionals.

The staff member or other person will:



a: Recognise the strengths and abilities of autistic people



b: Work to understand what each autistic person they are working with prefers



c: Be patient and really listen to what autistic people say to them no matter how the autistic person communicates



d: Understand how autistic people might act, appear and describe themselves – and respond with respect and kindness



They should not judge autistic people or label their behaviour in unhelpful ways



e: Know that autistic people, their families and support networks are experts in their own lives



They should protect people's human rights and help autistic people make their own choices and decisions.



f: Act with honesty and openness, working towards trust on both sides when speaking or working with autistic people, their families, carers and communities.



g: Work in partnership with autistic people, teams, communities and organisations



h: Work with autistic people to make services better and more person-centred



i: Understand and respect autistic people's differences and challenge bad stereotypes



j: Take responsibility for their own learning and help other people to learn.



There will be a logic to what I do, it just might not be your logic...

I like being different
I'd rather be weird
than have a beard.



I can hide my autism,
but I can't switch it off.



Tell me what it is you
are going to do.



Quotes have been taken from
the coproduction workshops

Domain A: Understanding Autism



This part of the framework is about understanding what autism is, how it affects people and how many autistic people there are.



Everyone who works with autistic people needs to understand these things.



Autistic people have the same human rights as everyone else.



They have the right to live the life that they choose, in the place they choose.



They have the right to have the support they need to do this.



They have the right to be treated with respect.



If someone is working with autistic people they should treat each of them as their own person.



Every autistic person is different because every person is different.



It is also important that autistic people are able to get a diagnosis.



A diagnosis is when a doctor or professional tells you if you have a condition or not.



It is important autistic people can get a diagnosis at the right time and from someone who knows a lot about autism so they can get the right support.

About Capability 1, Tier 1



Understanding autism at tier 1 is for people who need to know general facts about autism and the support autistic people may need.



People who are taking basic autism training should know these things at the end of the course.

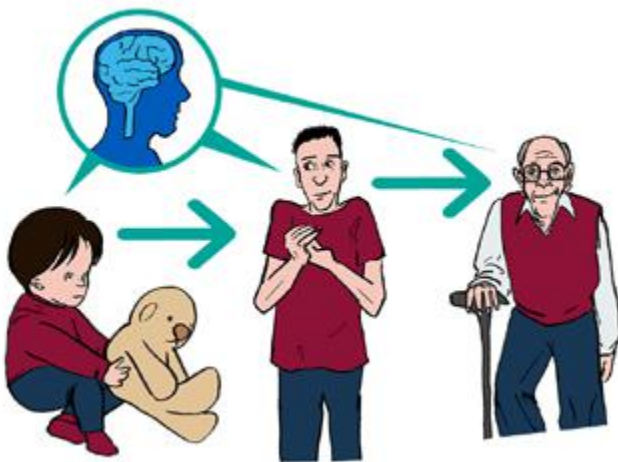
At Tier 1, the staff member or other person will:



a: Know basic facts about autism including:



i: how common autism is



ii: that autistic people have autism all their lives and that autism is caused by differences in people's brains.



iii: that every autistic person is different and autism affects everyone differently.



b: Be able to talk about autism in a respectful way.



c: Understand what common signs and traits of autism may look like in real life, for instance, at home, in the classroom, in care settings and in the community.



d: Take responsibility for communicating with and giving information to autistic people in a way they can understand.



i: understand that communication is about both giving and being given information and the importance of including autistic people in conversations about them



ii: Know how autistic people may become overwhelmed and need time and quiet space to think about and understand information.



For example when overwhelmed some people may 'shutdown' or simply say yes to anything said so they can get what is happening to stop; that means you will not get good information and they will not remember what you have said.



iii: Know about and respect the different ways of communication that an autistic person may use, such as visual techniques.



iv: Actively listen to what autistic people are saying and be prepared to use patience – including being silent to allow thinking time.



v: Know that some autistic people can find it very difficult to understand speech.



vi: Use clear language and know and understand that many autistic people are very direct when they talk.



vii: Know that autistic people can find normal body language difficult.



viii: Understand that stress and anxiety can make communication more difficult for autistic people.



e: Know that when autistic people behave oddly or in a scary way it may be because they are upset or trying to tell people something they can not say another way.



f: Recognise some of differences and difficulties autistic people have being social, like difficulties with small talk, social rules, understanding emotions and needing more time.



g: Know that autistic people can have other disabilities or health problems that affect them in their lives.



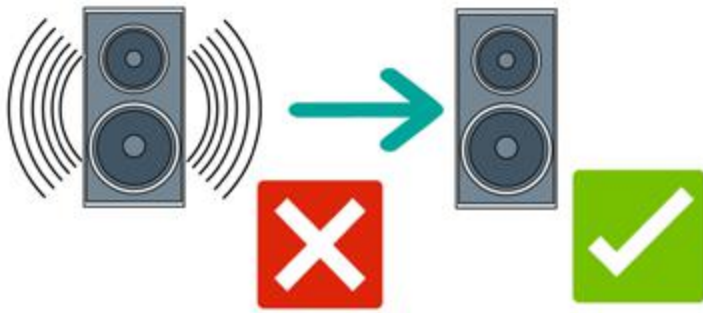
h: Understand that many autistic people have been through struggles in their life that can cause a lot of different mental health issues later on.



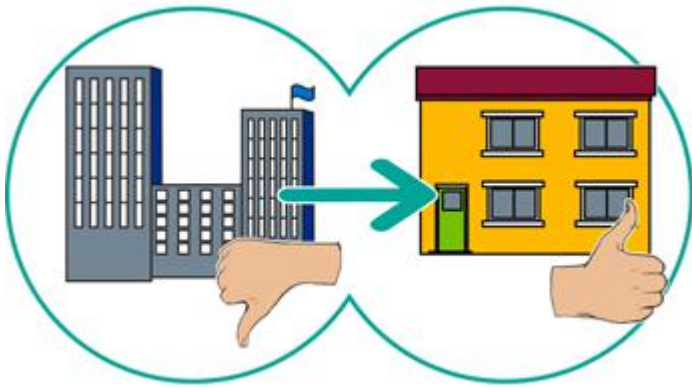
i: Understand how sensory issues can effect autistic people - for instance, over-sensitivity or under-sensitivity to light, sound, temperature, touch or smell



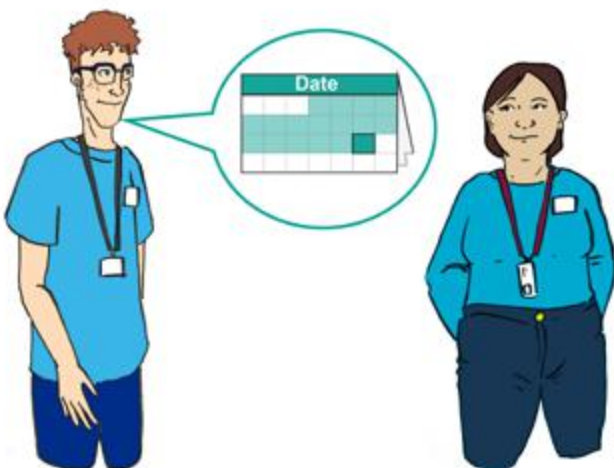
Understand how anxiety and stress can affect sensory needs.



j: Be able to make simple changes to make sure places are accessible to autistic people, including ways to avoid sensory overload.



Use somewhere else if places can not be made accessible.



k: Always plan changes early if possible.



Help people prepare and give them information about upcoming events in ways they can understand.



I: Understand that hobbies and interests are important.



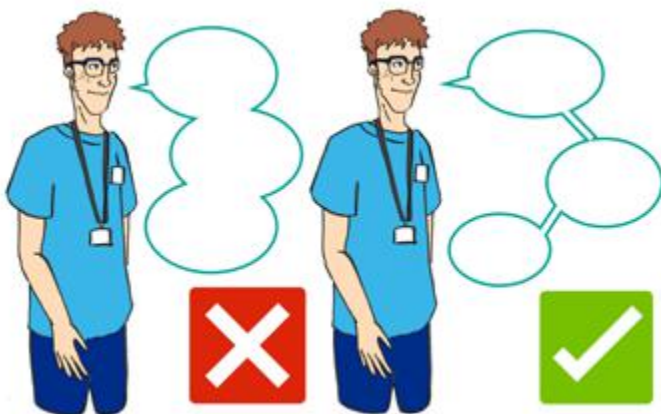
m: Be able to make changes in how they work, for example:



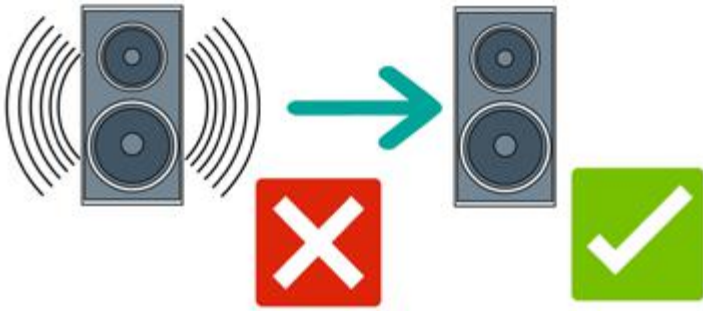
i: Don't give people surprises.



ii: Don't touch people unless they say you can.



iii: Slow down and pause.



iv: Make or find a calm, quiet environment.



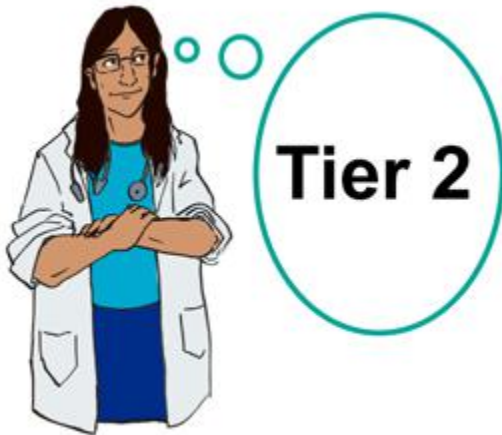
v: Explain what they're doing before they do it.



n: Know where to find more information about autism.



Some people will need to know more about autism, how autistic people communicate and how their health can be affected.



These people will also need to study the topics under Tier 2.



Experts will need to know about the science behind autism and how laws affect disabled people.



They will need to know the topics under Tier 3.



The full framework has the full list for Tier 2 and Tier 3 as well as more detail about what people need to learn about Understanding Autism.



You can find it here:
<http://www.skillsforhealth.org.uk/learningdisabilityandautismframeworks>

About Capability 2



If part of a person's job is diagnosing people with autism, there are other things they will need to learn.



They will need to know what autism can look like in different people.



They will need to know about other conditions that can look like autism.



They will need to know about other conditions autistic people can have at the same time as being autistic.



2

These, as well as other things they will need to know, are described in Capability 2 of the full framework.



You can find it here:
<http://www.skillsforhealth.org.uk/learningdisabilityandautismframeworks>

Personalised Support

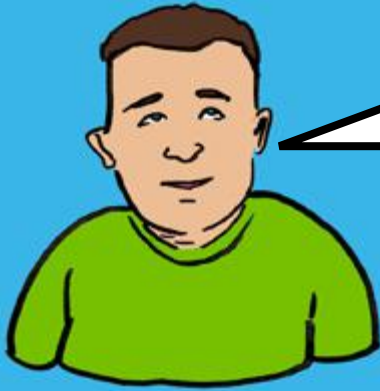
Don't assume you know what a good outcome is work it out with the person, measure it with them.



I like things in a routine, it's difficult for me if I expect something and don't get it.

Know things that make me comfortable, so I don't get upset.





Expertise in the subject
doesn't make
you an expert in every
person!



Let me take time to listen
and think.



I don't like bright lights
and loud noises, they hurt
me and then I can't
concentrate.

Non verbal doesn't
mean stupid; long
words doesn't
mean clever.

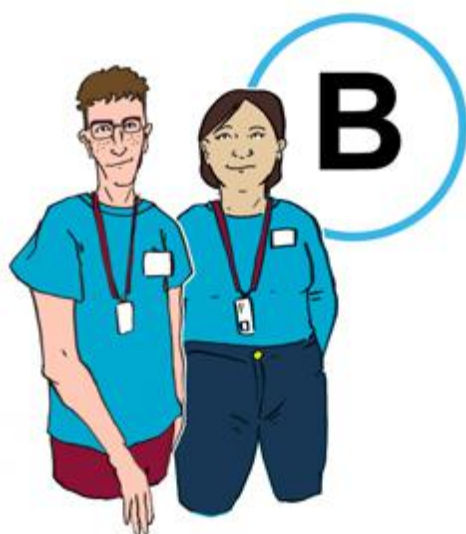


Quotes have been taken from
the coproduction workshops

Domain B: Personalised Support



This part of the framework is about understanding what personalised support is and how to apply it to working with autistic people.



This is very important for support workers and care providers to know.



Personalised support is support based around the autistic person in the centre.



It is support where the needs, likes and hopes of the autistic person are the most important.



The autistic person must be involved in making their own decisions and supported to make their own choices.



This means the person giving support must be able to communicate in a way the autistic person likes and understands.



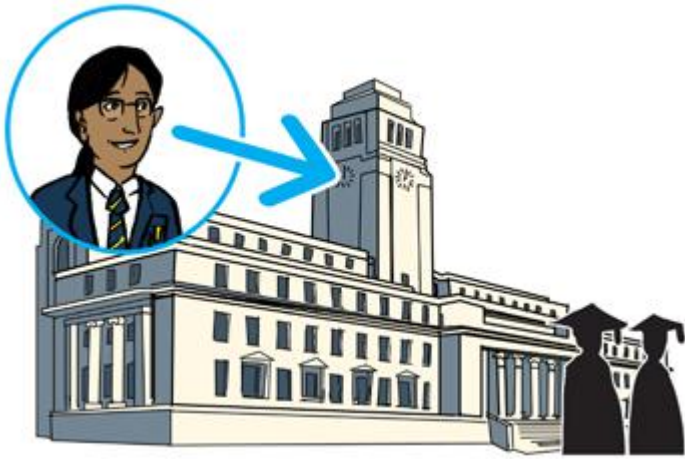
The person giving support must also understand the sensory needs of the person they are supporting and how to help them with these.



They must understand the importance of the people around the autistic person.



These people could be families, carers and friends.



Personalised support is even more important at times when the autistic person is going through changes in their life.



Personalised support means supporting autistic people when they behave oddly or in a scary way.



The person giving support should try to understand why they are behaving in that way and give them help if they need it.



Autistic people have the same rights as anyone else to make friendships and relationships with other people.



They should be able to get the support they need to do this.



They should also get the support they need to follow their hobbies and interests.



B

The details of what people need to know about personalised support are in the full framework.



You can find it here
:<http://www.skillsforhealth.org.uk/learningdisabilityandautismframeworks>



Doctors need to talk to me as well as my Mum and Dad.



You might not be able to tell when I'm in pain or distress.



Don't tell me something won't hurt if it will.



I make reasonable adjustments all the time for neurotypical people and it exhausts me.

Quotes have been taken from the coproduction workshops

Domain C: Physical and Mental Health



This part of the framework is about autistic people's health.



This includes both mental health and having a healthy body.



This is very important for doctors and other health professionals to know.



Autistic people have a right to good quality healthcare.



Autistic people generally have more health problems than other people.



They also have a higher risk of dying early.

There are many reasons for this, which include:



Autistic people are more likely to have other conditions as well as autism



Lack of understanding from health professionals



Some autistic people and the people who support them find it difficult to describe their health or get others to listen



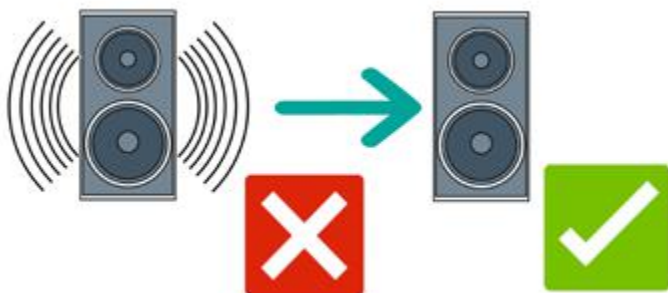
Lack of information



Autistic people are more likely to be poorer and to not have good connections with other people.



Health and care staff need the right training to support autistic people to have better health.



They need to put reasonable adjustments in place.



They need to make it easier for autistic people to access healthcare.



They need to make sure autistic people get good quality healthcare.



The details of what people need to know about physical and mental health are in the full framework.



You can find it here:
<http://www.skillsforhealth.org.uk/learningdisabilityandautismframeworks>



I can get bullied by people that don't understand why I do things; this makes me feel sad.

When I tell someone I'm being bullied I need adults to listen, take it seriously, I don't lie.



Trying to make the autistic normal' is one I face daily, my manager says I'm over sensitive and treats me different to everyone else. He is not interested in understanding only berating/shaming me.

Don't think I don't get upset when I'm bullied it makes me feel horrible.



Quotes have been taken from the coproduction workshops

Domain D: Risk, legislation and safeguarding



This part of the framework is about the law and autistic people's human rights.



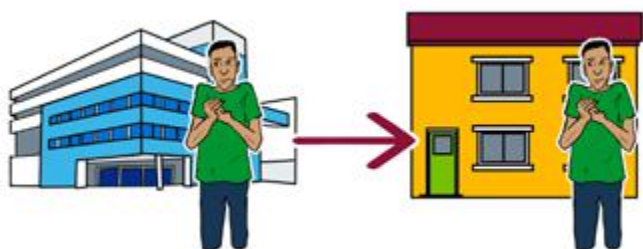
This is very important for people who give care and support to know.



Autistic people have a right to live the life that they choose.



They have the right to choose and control their support.



This might be because their needs have changed.



People giving autistic people support must know about autistic people's human rights.



They need to know about the importance of taking risks and the importance of being safe.



They should not try to make decisions for autistic people.



Autistic people should be given all possible help to make decisions before deciding they can't.



Autistic people might want different things from their families and carers.



They might also find it difficult to make choices sometimes.



It is still important they make their own decisions.



Organisations must put systems in place to protect autistic people from harm.



Autistic people might be treated badly because of their race and background.



They may also be treated badly by their families and people where they live because they are autistic.



People who give support must know what to do if they think an autistic person is being harmed.



People who support autistic people must know about the Equality Act and treat people fairly.



D

The details of what people need to know about risk, legislation and safeguarding are in the full framework.



You can find it here: <http://www.skillsforhealth.org.uk/learningdisabilityandautismframeworks>

Domain E: Leadership and management, education and research



E

This part of the framework is about how people who run services need to know how to support their staff to support autistic people well.

E



This is important for leaders, managers and people who run services to know.



Leaders and managers must take care of their staff so their services are good for autistic people.



They must make sure their staff follow the training in this framework.



They need to support their staff to do this.



Leaders should know about up to date research about autism.



Leaders should act in ways they want their staff to act.



Leaders in different organisations should work together.



If support for autistic people is going to get better new research has to be done.



Some of this research should be about seeing which services make a difference to autistic people's lives.



When autistic people are involved in research they must be treated well and fairly.



Research about autistic people should be made with the help of autistic people and their families.



The details of what people need to know about leadership and management, education and research are in the full framework.



You can find it here:
<http://www.skillsforhealth.org.uk/learningdisabilityandautismframeworks>

Appendix 1: How this framework was made



This framework was paid for by Health Education England.



The organisations Skills for Health, Skills for Care, the National Autistic Society and Opening Minds Training and Consultancy all worked together to make this framework.



The group who were in charge included autistic people and people with autistic family members.



It also included professionals from different backgrounds.



During January 2019, we ran ten workshops in different places across England so autistic people, the families and people who work with autistic people could have their say.



This was to find out what they wanted in the framework.



In May 2019 we also ran some workshops for autistic children and young people.



In June and July, an early version of the framework was put online so people could tell us what they thought about it.



All of this was put together to make the final framework in October 2019.

This easy read document was produced by
Opening Minds Training and Consultancy