

**The Capability Framework for Autism Peer Support Workers**



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We work with partners to plan, recruit, educate and train the health workforce.

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# Foreword

All people have the right to live in an inclusive community where they are valued for who they are and appreciated for their individual role and contribution to society. Unfortunately, for some autistic people this has not always been the reality. Stigma and misunderstanding have impacted on their lives, disrupting their access to health and social care support with a poor quality of life, higher prevalence of mental ill health resulting in shortened lifespans and an increased number of early deaths.

The NHS long term plan and the governments national strategy for autistic children, young people and adults seeks to reverse these inequalities, improving health services, tackling stigma and increasing employment opportunities for autistic people.

The development of new autism peer support worker roles is an exciting opportunity for health service providers to harness the skills and lived experiences of autistic people, who, as part of the workforce will offer peer support to help other autistic people to maintain their wellbeing.

It is hoped that many commissioners and service providers who are developing new specialist autism teams will embrace these new roles and embed them within the fabric of future services and that this document will support them with their workforce development journey. Universities and training providers may also find this framework important and helpful in planning education and training.

The document has been fully co-produced and co-authored with the help and support of many autistic people to whom we are grateful and would like to convey our thanks for their invaluable contribution.

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**Introduction**

It is widely reported that about 1% of the UK population is autistic, however there are many studies that indicate that the figure is significantly higher than this. One study published in 2021 indicated that approximately one in 57 (1.76%) children in the UK is autistic.

Many autistic people will experience increased rates of physical and mental health conditions when compared to the general population, and there is a sustained national focus on reducing these health inequalities.

Since 2015, Health Education England’s National Autism Programme has been working to support NHS England to improve the lives of autistic people by facilitating significant workforce transformation across England. As Integrated Care Systems evolve across the country and health and social care providers consider how they will anticipate and meet the health and wellbeing needs of autistic people, new and emerging care pathways and services are under development. It is here that specialist autism peer support roles can contribute significantly to the quality and the reach of the services offered and enhance the workforce.

**Ref:** [https://www.ncl.ac.uk/press/articles/archive/2021/03/autismratesincrease](https://www.ncl.ac.uk/press/articles/archive/2021/03/autismratesincrease/)



* 1. **What do we mean by Autism Peer Support Worker?**

Peer support is generally understood to be a relationship of mutual support where people with similar life experiences offer each other support, especially as they move through difficult or challenging experiences.

Autism peer support roles in this document refer to developing paid roles within NHS funded autism services for autistic people to be employed to provide support through their own lived experience of autism to other autistic people using the service. The peer support roles will sit alongside other support roles and services, for example diagnostic services, psychological services, professional sensory assessments, employment services and benefits advice.

These roles would be connected to local services and be able to signpost to other skilled or specialist support. People should have a choice of peer support and service providers should pay attention to ensure they carefully match the peer support worker’s lived experiences with the needs of the person seeking support.

Autism peer support also extends to carers/parents of autistic people providing peer support to other carers/parents of autistic people. Carers may be employed to support family, friends and carers of autistic people using services. The positive impact of someone with their own lived experience of autism supporting other parents/carers are numerous and include benefits for the worker, the person being supported, the team in which they work and the organisation which employs them.



## Understanding the values of autism peer support and the principles that underpin its implementation

Core to peer support roles is the value that is placed on the use of lived experience of autism (including the experience of caring for someone with lived experience of autism) and recognition of this as a form of expertise. This means that the areas of knowledge described in this section are embedded in an autism peer support workers experience and are therefore applicable to all the other sections in this capability framework.

### **Values of autism peer support workers**

* An ability to understand that the peer support role is characterised by working alongside the person to develop an **equal and trusting relationship**, and that this is underpinned by:
  + **Respect** – being non-judgmental and not making assumptions about the person’s experiences or beliefs
  + **Reciprocity** – a willingness to give and receive support, and learn from difference, with both parties sharing their experiences and benefitting from this
  + **Mutuality** – a non-hierarchical relationship that is of equal value to both parties and is based on shared experience of autism

### **Principles of peer support**

* An ability to draw on experiential knowledge that peer support is based on the following principles:
* **building safe and trusting relationships** based on sharing lived experience of autism and neuro-diversity services, and using this to develop connections
* ensuring that relationships are built on the values of **mutuality** and **reciprocity**
* respecting the **diversity** of each person’s experience, and their particular background or cultural context
* recognising and placing value on peers’ personal **experiential knowledge and lived experience of autism including the diversity between different autistic presentations** which can complement, or provide alternatives to, traditional models of thinking about autism



* enabling people who are supported to **exercise choice** about the way in which peer support is given and received, both directly and at an organisational level (influencing the ways in which peer support is integrated with and offered through teams)
* enabling people who are supported to make use of their own **strengths, skills and strategies**
* **working progressively** to help people learn from their experience and better equip themselves for living well
* understanding and recognising the **communities** that people come from, the communities they choose to be a part of, and the ways in which these have and will shape their experiences
* **working inclusively** by helping people to become (re)integrated into their communities or to overcome the challenges they may face around this, by building and strengthening **connections** with their families, friends, support networks and wider communities
* Using **active listening** and **demonstrating empathy**
* An ability to draw on knowledge that peer support is:
  + **Direct guidance** – Enable people to make decisions by presenting options and information so they can make informed choices.
  + **Strengths-based** – focusing on and building a person’s strengths and their ability to make use of the resources available to them
  + **Promotes personalised and person-centred support** – This means holding the individual at the centre of the support process, working with them to identify their unique abilities and challenges, and working alongside them to achieve their (self) identified needs

As is the case with other examples of peer support roles in healthcare, autism peer support worker roles should not replace other professional or clinical roles.

Instead, there is an opportunity for these new roles to be deployed to work alongside other professionals in teams that offer specialist healthcare support to autistic people. Postholders would bring their skill in using their own experience to work alongside people, supporting them to pursue their self-directed outcomes.



These roles can offer emotional and practical support to people who have had similar life experiences. They can use their own lived experience to connect with people and help them, by:

* giving them a sense of wellbeing
* supporting them to gain a sense of control over their lives
* helping them engage with, and build connections and a sense of belonging to, their local communities
* helping them gain satisfaction in different parts of their lives which may impact on their health and wellbeing

In all peer support relationships, the relationship between the peer support worker and the person they are supporting is key. It is based on people learning together in a relationship that is mutual, trusting, safe, non-judgmental, and respectful using a person-centred approach.

The focus of peer support should be empowerment, autonomy, and agency, supporting that person to understand themselves and be as authentic as they can be. Autism peer support workers should be empowered to explore alternative methods of communication, learning/ teaching tools, and encourage unique approaches to meet case-by-case profiles.

Autism peer support workers may work in public, private and voluntary sector organisations, in a range of specialist autism services or potentially as part of other teams that deliver mental or physical health services.

The roles may involve working with people by meeting with them face to face, talking to them on the telephone, or via email/messaging and other internet- based support. The way in which these roles will be deployed will be largely determined by the service that is being provided and the needs of the person who is accessing peer support.



## The Framework

This framework has been commissioned to assist health and care organisations who are developing new NHS autism services to understand how these emerging roles can add value and enhance their teams and services. In particular, the document seeks to: -

* + - support discussions about the development of autism services, team development and the role of specialist autism peer support workers
    - provide a framework for a minimum set of capabilities for the autism peer support worker roles
    - support conversations about workforce development and training for autism peer support roles and should be read in conjunction with the associated autism peer support worker curriculum document.
    - recognise that neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one “right” way of thinking, learning, and behaving, and differences should not be viewed as deficits.

It is hoped that the publication of this document will assist in protecting people working in autism peer support worker roles from being asked to work in inappropriate ways, which are either outside of their capabilities, or in ways that do not reflect the skills and limitations of the role.

The framework applies principally to formal paid autism peer support worker roles that deliver NHS autism services, but it will also be helpful to organisations in the voluntary, community and social enterprise sector that want to offer high quality autism peer support services.

This framework is not a mandate. It aims to be flexible and adaptable, and to steer away from over professionalising a role which, centres on fostering human connection and relationships. It is recognised that the framework may need to be adapted for specialist contexts, such as children, and young people’s services.

At the outset of the project, it was agreed that the framework for the autism peer support worker should be a capability framework, rather than a competency framework. This approach has been taken as a reflection of the level of the role, and expectation that new entrants are likely to be required to undergo a programme of training before commencing in these roles.



### **Specialist autism teams**

It is expected that these roles will be able to make a key contribution to the work of wider specialist autism teams that provide community services, including those teams that offer pre and post diagnostic support to people who are awaiting any formal diagnosis.

Some autism service providers may see a role for specialist autism peer support workers to reach into mental health teams to work alongside mental health peer support workers to strengthen the support to autistic people, and to offer wider access to autism information/training for wider members of the workforce.

It is also recognised that these roles may be of interest to mental health service providers who may consider their development alongside, or as part of their wider peer support team.



## How this framework was developed

This publication has been developed and produced in partnership with autistic people. It is the result of multiple layers of work that have been brought together to ensure that the voices and thoughts of autistic people are reflected as much as possible throughout the development of these roles.

During the process to create the document we have engaged with a wide range of autistic people. We have heard from more than 240 individuals, who have been kind enough to share their thoughts and views with us about what needed to be included in the framework. People have given their time to participate in various workshops and surveys hosted by Skills for Care to help us to develop and refine this publication.

The project delivery group that developed the framework was led on behalf of Health Education England by Oxford Health NHS Foundation Trust which has an established track record of developing peer support. The delivery team worked collaboratively with a partnership of autistic people from five organisations to draw in expertise from a wide base which included:

* Autism Oxford UK
* Autism Champions
* Sussex Ehlers-Danlos Syndromes Hypermobility Disorders (SEDS) community interest company
* Resolve
* National Autistic Society

The co-production of the framework was facilitated by an autistic project manager from Autism Oxford who brought together weekly coproduction groups to discuss and amend drafts with autistic representatives from the organisations above.

The whole project has been overseen by a separate group which includes autistic representatives who are independent of those involved in the delivery team. This group was able to provide another layer of lived expertise of autism, and knowledge of peer support roles to the process.

Throughout the work, it has been imperative to listen to autistic voices during the creation of the autism peer support worker capability framework and include a diverse range of individuals and organisations in the process. HEE and Oxford Health would thank everybody for their input into this document.





**Knowledge for autism peer support workers**

## Knowledge of autism, its history and its key aspects regarding:

* Know basic facts about autism including, how common it is, that autism is neurodevelopmental and lifelong.
* To be aware of how an individual may be able to obtain a diagnosis and of the impact that may have on the individual, depending on when in the person’s lifetime that diagnosis was obtained.
* Be able to use respectful terminology and avoid terminology that may have been acceptable in the past but is no longer considered appropriate e.g., references to ‘disorders’, ‘functioning levels’ etc.
* Understand what common autistic characteristics may look like in real life situations e.g., at home, at work, in the classroom, in care settings, in the community.
* Recognise that each autistic person is different and that autistic individuals are as diverse as the rest of the population. That every autistic person has a different combination of traits, different sensory profiles from one another and is unique.
* Be aware how autistic people may become overwhelmed and need time and quiet space to process and understand information.
* Be aware that autistic people often take language literally, so it is important to use clear, unambiguous language, responding positively when autistic people use direct language and give direct feedback.
* Be aware of difficulties and differences in non-verbal communication e.g., facial expression; eye contact; and personal distance. To be aware of difficulties and differences in non-verbal communication e.g., facial expression; eye contact; (which some people prefer to avoid) and personal distance.
* Be aware of some key differences in social interaction e.g., processing time, difficulties with small talk, social rules, understanding and interpreting emotions.
* Understand how sensory issues can impact on autistic people
* Recognise the importance of passionate interests and hobbies.
* Don’t spring surprises and don’t touch without consent
* Know where to access resources and further information about autism.



## Communication

* Understand that effective communication, in all areas of life, is critical for supporting the autonomy, wellbeing and quality of life of autistic people and continue to support the development of functional communication throughout the lifespan.
* Understand and promote the role of non-verbal communication e.g., written information (including text and email), signing, symbol-based communication, assistive technology and the appropriate (and inappropriate) use of touch and provide access to non-verbal means of communicating whenever appropriate.
* Understand the provision of information that is specific and clear, and the importance of avoiding ambiguities.
* Understand the importance of providing time and space for autistic people to process and understand information and to make and communicate decisions.
* Recognise that behaviour can be a form of communication and avoid assumptions about the meanings that can be attached to behaviour.
* Understand the importance of being able to communicate basic needs to reduce frustration.
* To be able to use a range of communication techniques to convey information, according to the different abilities and preferences of autistic people, recognising that each autistic person may have a unique way of communicating.
* Recognise the impact of the environment and sensory needs on communication

– knowing how to find the right time, place and situation for important communications.

* Understand the importance of, and promote, effective communication with families and carers. Also, to recognise the expertise and insight that families and carers may be able to offer to support effective communication with the autistic person.
* Understand Double Empathy Theory and how it effects communication between autistic and neurotypical individuals due to the difference between how autistic and neurotypical people experience the world. Autistic people may struggle to interpret neurotypical people’s thoughts and feelings and neurotypical people may struggle to interpret autistic people’s thoughts and feelings.



## Sensory processing and the environment

* Recognise difference and understand that not every autistic person will have the same sensory profile, level of over or under sensory sensitivity, or indeed any sensory sensitivity in some areas and that each person’s tolerance of sensory stimuli will vary according to other factors and over time.
* Know how one might create environments to support autistic people and understand how to adjust environments to enable areas to be inclusive and welcoming to everyone.
* Recognise the importance of accessible quiet spaces and the autistic person’s right to take a break if that is their choice - and acceptance/provision of adaptations (such as noise cancelling headphones, sunglasses, dimmable lights etc.).
* Be able to identify sensory issues and in developing proactive approaches to the environment e.g., making sure that assessments, meetings, interviews, appointments are planned for, asking the question about any adjustments that might be required to the environment.
* Be able to recognise sensory overload and know how to respond.
* Acknowledge, understand, and reassure regarding the use of vestibular and sensory stimulation behaviours (e.g., ‘stimming’)



## Knowledge of how being autistic can affect a person’s mental health and wellbeing

* Understand that mental health conditions are common and can be overlooked in autistic people.
* Understand the role of trauma in the lives of autistic people which may lead to a wide range of mental health problems in later life and the importance of building trusting relationships and providing support to make choices to enable empowerment.
* Recognise when an autistic person may be experiencing mental distress, including suicidal thoughts and intentions.
* Recognise that autistic people have a right to equitable access to treatment, including appropriate medication, whilst also recognising the issue of overmedication of autistic people and know how to address this initially by asking their GP to review their medication and their psychiatrist if they have one.
* Understand that autistic people with mental health needs may display behaviours that indicate that they could be experiencing distress, masking and other difficulties such as with communication.
* Create opportunities for autistic people to express their feelings, including feelings of loss, grief and bereavement, and anger and frustration, in ways which are meaningful to them.
* Know the function of different mental health services that autistic people may need to access (such as occupational therapists, counsellors, speech and language therapists, psychologists, psychiatrists, and mental health nurses) and where to refer an autistic person with a suspected mental health condition.
* Know how to coordinate and communicate with key people and services in the life of the autistic person with a mental health condition.



## Knowledge of physical health issues more prevalent in the autistic population and to be able to promote health diet, exercise, and lifestyles

* Be aware that autistic people may live with other conditions or impairments that will also impact on their lives, for example, physical impairments, visual impairment, chromosome disorders, mental health conditions (including eating disorders), epilepsy, allergies, gastrointestinal conditions or other neurodevelopmental conditions such as ADHD, Dyslexia, Dyspraxia.
* Understand the benefits of pacing for autistic individuals living with other conditions.
* Understand the benefits and risks of prescribed medication (including psychotropic medication) on the physical and mental health and the choices and rights of patients – including the potential for autistic people to have atypical reactions to medication. Be able to identify and supporting with additional needs around taking medication (such as needing prompting).
* Understand the role of families and carers in supporting the health and wellbeing of autistic people.
* An ability to support the development of health action plans with autistic people, including identifying reasonable adjustments and unmet support needs.
* Be able to recognise the potential impact of sensory differences on the autistic person, being able to recognise themselves when they are feeling unwell, and the potential for differences in interpreting pain sensations being both hyper and hypo sensitive to pain and more likely to mask pain as a result.
* Understand that some autistic people may not report pain or seek help early due to a variety of factors such as Alexithymia, communication difficulties, anxiety, difficulties with initiative and/or their high pain threshold
* Be able to signpost autistic people to specialist healthcare services for assessment, diagnosis and support and ensure they are aware of any expected timeframes. Encourage them to persist in liaison with specialist services, providing support to do so when needed.
* Support autistic people to make healthcare decisions including advocating for reasonable adjustments such as provision of accessible information and processing time.
* Understanding the intersectional identities of autistic individuals who are asexual, bisexual, homosexual, or ‘other’ sexuality is key. It is particularly important that language that is affirming and accepting of all sexual orientations and gender identities is used. Peer support workers should challenge any barriers which prevent appropriate support for LGBTQ+ autistic people.

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## Knowledge of local services and sources of autism support

* Know the function of different healthcare services that autistic people may need to access, such as psychologists, speech and language therapists, optometrists, occupational therapists, dietitians and physiotherapists - and the barriers autistic people may face in accessing them.
* Have an ability to draw on a working knowledge of the local statutory and non-statutory autistic support options, (as well as local community organisations, activities and resources) with which autism peer support workers will be engaging to help people achieve their personal goals, including: - what each organisation, service or resource is able to offer, how to access each organisation or service, whether services apply criteria that restrict access, and any limits (or gaps) in the services being provided.



## Knowledge of professional, legal and ethical frameworks for autism peer support workers

* An ability to draw on knowledge of the professional guidelines and principles that need to be applied to specific situations.
* An ability to draw on knowledge of the local codes of ethics and conduct that apply to all professionals in the service, and how these are implemented in relation to: capacity and consent, confidentiality, information sharing, and data protection.
* An ability to maintain boundaries, for example by communicating the limits and boundaries of the role with the people they support, maintaining clear and appropriate personal and sexual boundaries with people they support, as well as their families and carers. Not accepting gifts, hospitality or loans that may be interpreted as attempting to gain preferential treatment. To be able to identify when a boundary has been crossed and knowing what action to take.
* An ability to recognise and work within the limits of their qualifications, knowledge, skills and experience, and only offer support to individuals that is within the scope and limits of the role and to know when to refer to colleagues within the wider team when clinical or medical input is necessary to support an individuals wellbeing.
* An ability to maintain and update skills and knowledge through participation in continuing learning and development and an ability to seek opportunities to increase knowledge and skills.



## Knowledge of, and ability to work with, issues of confidentiality, consent and information sharing

* Knowledge of policies and legislation. An ability to draw on knowledge of local policies on confidentiality and information sharing, and the ways these are applied when working within and between teams or organisations.
* Ability to gain informed consent. An ability to give people being supported the information they need to decide whether to proceed with meetings with an autism peer support worker, for example: what these meetings and support would involve, the potential benefits of these meetings.
* An ability to invite, explain and to actively respond to questions regarding peer support.
* To know that individuals have a right to withdraw or limit consent at any time: NB In the event of consent being declined or withdrawn, an ability to respect the individual’s right to make this decision and the ability to seek advice from senior colleagues or a supervisor as required
* Knowledge of confidentiality and information sharing protocols and legislation. To draw on knowledge that a duty of confidentiality is owed to the person to whom the information relates.
* To have an ability to ensure that a person’s information is treated as confidential and used only for the purpose for which it was provided.
* An ability to draw on knowledge that confidentiality is breached where the sharing of confidential information is not authorised by the person who provided it, or to whom it relates.
* Also, an ability to draw on knowledge that there is no breach of confidentiality if information was provided on the understanding that it would be shared with a limited range of people, or for limited purposes, and information has been shared in line with that understanding. Or where there is explicit consent to the sharing of information.
* An ability to draw on knowledge that it is appropriate to breach confidentiality when withholding information could; place the person, or family members or carers, the autism peer support worker, mental health professionals or members of the public, at risk of significant harm, or, prejudice the prevention, detection or prosecution of a serious crime, or lead to an unjustified delay in making enquiries about allegations of significant harm to others.
* An ability to draw on knowledge that safeguarding needs usually take precedence over issues of consent and confidentiality.



## Knowledge of safeguarding procedures

* An ability to draw on knowledge of local and national safeguarding policies.
* An ability to draw on knowledge that safeguarding concerns can arise across the lifespan, from infancy through to old age.
* An ability to draw on knowledge of the types of abuse and neglect that could trigger a safeguarding concern, such as: physical abuse, domestic violence, psychological abuse, financial or material abuse or exploitation, sexual abuse or exploitation, neglect, abuse in an organisational context.
* Able to identify signs or indicators that could flag the need to instigate safeguarding procedures. Where neglect, abuse or exploitation is suspected, an ability to respond appropriately by discussing these concerns with the person being supported and explaining (and agreeing) what actions need to be taken, raising and escalating concerns in line with local safeguarding procedures.



## Knowledge of self-harm and suicide prevention, and procedures for maintaining safety

* An ability to draw on knowledge of the factors that contribute to, and increase the risk of, self-harm, self-neglect and harm to others.
* An ability to recognise and respond to expressions of distress and self-harm, and to acknowledge and discuss these feelings with the person in an open and non-judgmental way.
* An ability to determine whether there are any immediately applicable strategies that may be helpful when a person may present as a significant risk of harm to themselves or others and if the person has the resources to implement them.
* An ability to discuss and agree next steps, (whilst drawing on knowledge of local policies and procedures for responding to risk), with the person if the current strategies to reduce risk are ineffective.



**Supporting people as an autism peer support worker**

## Being able to support people’s choice, autonomy and independence

* Personalised support is centred on the needs, preferences, and aspirations of autistic people and should promote the autonomy of the autistic person. Personalised support includes supporting autistic people who may display behaviours that indicate that they could be experiencing distress, avoiding assumptions that this is an inevitable part of autism and seeking to identify underlying causes and meet needs. Gain a sense of autonomy and choice over decisions that impact on their lives; therefore, the autism peer support worker needs to know how to enable an individual to be able to demonstrate positivity, recognising the strengths and abilities of autistic people.
* An ability to act with integrity, honesty, and openness, seeking to develop mutual trust in all interactions with autistic people, their families, carers and communities.
* An ability to recognise the presentation, behaviour, and identity of autistic people – and respond with respect and compassion, without judging them or labelling their behaviour in unhelpful ways.
* An ability to know how to help people to identify and connect with the communities they are part of and those they wish to belong to
* An ability to enable the autistic person to develop and maintain positive relationships
* An ability to enable the autistic person to identify their strengths, values and

aspirations

* An ability to share, appropriately, their own experiences and feelings, and make sense of these (and the impact of cultural beliefs and interpretations on their ways of understanding)
* An ability to support the autistic person to engage in actions that can lead to personal growth and development, even if these may be seen by other people as potentially challenging or involving a considered risk
* An ability to help people identify and prioritise their own personal goals and to work with people to develop their skills to manage difficult situations or challenges
* An ability to support the person to make their own decisions and empower them to build autonomy



## Enable choice, control and empowerment over one’s own life

* Facilitate and seek to increase an autistic person’s choice, control and empowerment over major life decisions in addition to everyday choices, whenever possible, and recognising difficulties autistic people may have with choice. A collaborative approach to change ensuring empowerment.
* An ability for the autism peer support worker to maintain a focus on encouraging the person to arrive at their own solutions (rather than making suggestions as to what these might be and so risking imposing these on the person)

## Self-determination, self-management and wellbeing

* An ability to help people develop self-determination and self-management skills. Recognising that each person will find their own approach to wellbeing. Having the ability to explore, create and implement a wellbeing plan.



## Able to help autistic people to engage in activities that are meaningful for them

* The autism peer support worker needs to be aware that autistic people have the right to the same opportunities as anyone to develop and maintain safe relationships and get the support they need to develop and continue their interests, social life and community involvement. This includes the recognition and encouragement of passionate interests and hobbies. Support to gain and maintain employment commensurate with their strengths and abilities as well as social isolation and loneliness.
* The autism peer support worker needs to know how to work with the autistic person and other people to identify and connect with local groups, activities or programmes. To be able to recognise and encourage the importance of passionate interests and hobbies.
* To be able to support autistic people to develop and retain skills for everyday life, including practical tasks, decision making and positive risk taking, accounting for age. To be aware of how everyday technology such as Google Maps, Skype and apps for task planning, calendars, online shopping etc. can be used to enable autistic people to choose and use the full range of social interaction available in a way which works for them.
* To be able to support autistic people to communicate what reasonable adjustments could be made when engaging with educational, recreational, employment, justice and public services which would create autism friendly environments. If requested, to go with people to groups, activities, or programmes that they are interested in joining or alternatively, supporting them to go on their own.
* Know how to help people to rebuild social and community networks, or to get involved again with their chosen communities. Have an ability to help people to identify (and problem solve) issues or concerns that make it difficult for them to access and engage in activities that are meaningful to them.
* To be able to draw on knowledge that, for many people, engaging in activities that have meaning and purpose can help:
  + improve their sense of wellbeing
  + improve their sense of identity, confidence and self-esteem
  + them interact with others and build their social and community networks
  + encourage them to acquire or develop new skills
  + provide a sense of structure or routine to their day



* Also, to have an ability to help people identify activities that are meaningful to them, for example:
  + hobbies
  + exercise
  + sport and other leisure activities
  + educational and vocational courses
  + creative programmes
  + volunteering
  + being involved in health and wellbeing initiatives or programmes
* Recognise that whilst encouraging new experiences that an autistic person might like based on their preferences is advocated, they may prefer repetition and routine rather than unpredictability.



## Problem solving

* An ability to explain the rationale for problem solving.
* An ability to help the person select problems, on the basis that these are both relevant and important for them and are ones for which achievable goals can be set.
* An ability to help the person specify the problem(s) and break down larger problems into smaller (more manageable) parts.
* An ability to identify achievable goals with the person, bearing in mind their resources and likely obstacles.
* An ability to help the person:
  + generate possible solutions
  + select their preferred solution
  + plan and implement preferred solutions
  + evaluate the outcome of implementation, whether positive or negative
  + test beliefs or assumptions that might get in the way of problem solving



## Able to collaboratively discuss support options

* Ensure they and others use respectful terminology. An ability to explore with the person how they might discuss issues or concerns they have regarding support. Understand how to use and adapt support approaches in a person-centred way to meet the needs of autistic people.
* Be able to identify simple adjustments which can be made to meet the communication needs and preferences of autistic people, including using visual information (photos, diagrams, symbols), use of IT, autism alert cards and written information (e.g., text or email) when this works for the individual.
* Support access to diagnosis of any physical and mental health issues. Person-centred support, inclusive and accessible communication. Engage the person in a collaborative discussion of the support options or choices open to them.
* An ability to give information about support options in a way that:
  + helps the person to have a clear understanding of the support options open to them (that is, the organisations, services and support available to them, and the way these are usually accessed)
  + helps the person raise and discuss queries or concerns
  + helps the person decide what is best for them
* An ability to work collaboratively with the person when making decisions about them, allowing them choice.



## Able to contribute to co-production of individual support plans

* Autism peer support workers do not have formal responsibility for drawing up and monitoring support plans but can contribute to their development and use, depending on the service they work in.
* An ability to work with people collaboratively, to participate in the development of their support plans.
* An ability to discuss a person’s support plan with them, including any personal goals or objectives that would benefit from input from the autism peer support worker.
* An ability to help people develop an advance directive or statement (where appropriate) as part of their support plan.



## Able to facilitate access to sources of support

* For the autism peer support worker to be aware of the key differences between learning disability, autism, mental health conditions and learning difficulties – and understand that individuals may experience more than one of these, or other neurodevelopmental conditions at the same time.
* For the autism peer support worker to be able to promote equal access to autism diagnostic assessment, recognising that there may be some girls and women who present with less traditionally obvious characteristics, leading to them historically being excluded from assessment and diagnosis.
* To be able to recognise that autistic people can be misdiagnosed and those who display less traditionally obvious characteristics may be masking their difficulties, which can be a barrier to diagnosis and that masking is not gender specific and may occur in relation to women and girls, men and boys, as well as those who are gender fluid or non-binary.
* For the autism peer support to know why timely identification of autism is important and the likely outcomes if assessment for diagnosis is delayed.
* To be able to explain the benefits of an assessment for diagnosis of autism with sensitivity and in a way that is appropriate to the autistic person and their families and carers. To be alert to the need for timely informed and adaptable support for autistic people and their families.
* To know how to access further support within one’s own organisation to ensure the needs of autistic people are met.
* To know how to identify, advocate and enable the implementation of ‘reasonable adjustments’ to improve access to health care and other services.
* To be able to help people to keep on using organisations or services (this may include working with the person to overcome any barriers to access).
* For the autism peer support worker to be aware of relevant specialist services and support networks locally and nationally and appropriately signpost autistic people to them. Therefore, they will need:
* An ability to draw on knowledge of available sources of support, for example:
  + local voluntary and community sector organisations or groups
  + national websites and helplines



* An ability to ensure that information about these sources of support:
  + is up to date
  + accurately describes the type of support that is on offer
* An ability to draw on knowledge of social activities, resources or programmes within local communities and to help people access and engage in them
* An ability to convey information about organisations and services, to help the person make informed choices about the options they wish to pursue
* An ability to identify organisations and services that are accessible to a person
* An ability to draw on knowledge that signposting aims to help a person independently access sources of support that are relevant to their circumstances and goals, and of which they may not be aware
* An ability to help the person consider the type of support that matches their needs and situation, based (for example) on:
  + their goals
  + their expressed preferences
  + their willingness to access services
* An ability to discuss with a person the reach, responsibilities, and limits of organisations and services, to identify those that are both suited to their needs and acceptable to them.



## Signposting

* An ability to draw on knowledge that signposting aims to help a person independently access sources of support that are relevant to their circumstances and goals, and of which they may not be aware.
* An ability to pass on contact information in a way that makes it likely to be remembered and used, for example:
  + written rather than verbal
  + using the medium most likely to be accessed by the person (for example electronically via social media or an app, or printed media)
* An ability to establish that a person is willing and able to access the organisation, service or support. An ability to follow up with the person to see whether they have accessed the organisation, service, group, activity or programme, or whether they need a different type or level of support.



**Working with teams and promoting autistic people’s rights**

## Able to work as part of a team

* This includes the ability to manage change, be adaptable, deal with situations which may be unpredictable and continue to improve performance.
* An ability to draw on knowledge that working effectively as a team is important as it can have a positive impact on the experience of people using services.
* Have an understanding of the knowledge of the roles and responsibilities of other team members including the team’s remit, shared goals, values, culture and practice.
* An ability to work as part of the service or organisation while retaining the perspective and ethos of peer support.
* An ability to work effectively with colleagues to enhance:
  + existing services and the support they offer
  + identify and resolve potential conflict or disagreement regarding the support provided to a person
  + their knowledge and understanding of the autism peer support worker role, how they fit within the team, the values and principles underpinning peer support
* An ability to be aware of team dynamics that challenge effective working within the team, for example, when:
  + there are unhelpful power relationships
  + the autism peer support worker role is not recognised as a distinct and valued position
  + autism peer support workers are not given the same status as those of other members of the team
  + tensions develop because of the autism peer support workers dual role (being a member of the team and having a professional relationship with the person being supported)



## Communication with others in the team

* An ability to discuss challenges to team communication (with a supervisor) and to consider how these can be best managed, for example by:
  + identifying when (and when not) to challenge problematic team behaviours
  + presenting a case calmly and clearly
  + focusing on the problem (rather than on personal issues)
  + focusing on the future rather than the past
  + listening to the point of view of other team members
  + problem solving (identifying potential strategies for resolving the issues)



## Documentation

* An ability to understand how work is documented in the setting in which the autism peer support worker is working, and to maintain a record of contacts with the people they support (in line with service guidelines and policies)
* Understand that in statutory (and many other) settings an up-to-date record of progress for each person being supported should be entered into the person’s clinical record (usually after each contact with the person being supported)
* Ability to write a record of progress that:
* is person-centred, providing a sense of the person or their experience
* reflects on the person’s wellbeing
* addresses the goals and objectives set out in the person’s support plan (where possible)
* is concise, legible, written in a style that is accessible, and signed and dated
* summarises the activities that have taken place to date with each person being supported
* identifies any significant issues or concerns that have arisen



## Working with other organisations or services

* For the autism peer support worker to be aware of the value of collaborative involvement and co-production with autistic people to improve person- centred design and quality of services. They will need an ability to hold other organisations to account and knowing how to do this diplomatically in a collaborative, values based and solution focused way. For example, if someone needs a health assessment and this does not take place.
* For the autism peer support worker to be aware of the value of integrated, current and future support, through working in partnership with autistic people, teams, communities and organisations. To be able to draw on knowledge of how collaborating with other organisations or services will directly benefit the person’s support and wellbeing.
* To be able to identify and connect with organisations or services that are already involved with a person, or their family members or carers. To also to be able to contribute to meetings with other organisations or services to support the planning and coordination of a person’s support to be able to recognise challenges when working with other organisations and services (including those that reflect differences in values and principles), and to work with colleagues, a supervisor or team leader to plan how these challenges can be managed



## Communication with other organisations and services

* For the autism peer support worker to be able to identify when it is appropriate to share information with other organisations or services. They must also, maintain effective communication (both written and verbal) with professionals in other organisations when it is relevant to the person’s support. The autism peer support worker needs to be able to identify potential barriers to effective communication and, where possible, to develop strategies to overcome these.
* The autism peer support worker needs to know how to link and work with all staff to enable them to:
* understand the autism peer support worker’s role and remit
* improve their awareness of the importance of treating people with dignity, respect, kindness, and consideration
* discuss (and possibly challenge) their attitudes and perceptions about autism
* help them avoid unhelpfully technical language or jargon
* understand the importance of co-production (involving people with lived experience of autism in planning, developing, delivering, and evaluating services), social inclusion and equality
* An ability to support co-production in service development and evaluation
* An ability to work with staff to make reasonable adjustments and sure that environments are culturally sensitive and free from discrimination



## Able to offer a personalised support

* The autism peer support worker needs to be aware and understand that personalised support is centred on the needs, preferences and aspirations of autistic children, young people, and adults and should genuinely promote the autonomy of the autistic person. This includes effective communication and interaction to meet the different needs, abilities and preferences of autistic people and recognising the sensory processing differences of individuals and the adaptations which may be required. It includes understanding the significance and value of families, carers, and social networks, including when and how the autistic person would like them to be involved and the support autistic people may need at times of change and transitions throughout life.
* The autism peer support worker also needs to understand that personalised support includes supporting autistic people who may display behaviours that indicate that they could be experiencing distress and avoiding assumptions that this is an unavoidable part of autism and seeking to identify underlying causes and meet needs.



## Able to promote the rights of autistic people being supported

* The autism peer support worker should know how to value and acknowledge the experience and expertise of autistic people, their families and support networks, enabling choice and autonomy and protecting people’s human rights.
* An autism peer support worker should always ask a person what they think/ feel and act on this information. The role of the autism peer support worker is to work for the individual and to understand that their needs are not always congruent with the needs of their family/carers.
* They must also understand the importance of working with others, including the role that family carers and supporters may play in the lives of autistic people.
* The autism peer support worker needs to understand how health inequality affects autistic people and be aware of the main causes of health inequality for autistic people. To be aware of a person’s statutory rights to independent advocacy and to make or support referrals as appropriate. They should recognise, respect and value autistic people’s differences and challenge negative stereotyping.
* The autism peer support worker needs to be aware of how views and attitudes of others can impact on the lives of autistic people and their families and carers, such as through social isolation, bullying and social misunderstandings. They also need to be aware of the rights and understand the policies, processes or legal structures that might affect the autistic person.
* The autism peer support worker needs to know how to amplify the voice of the person they are supporting. They can do this by raising and discussing questions and concerns about the person’s support. They may find that they need to speak on a person’s behalf, with their consent, to promote their inclusion and rights in situations such as treatment team meetings, with organisations and services, and with family members (where necessary). The autism peer support worker will also need to be able to work with people being supported to address challenges with, or barriers to, accessing organisations and services, or infringements of their rights.



* The autism peer support worker needs to understand how to listen to a person’s feedback and concerns about their support and respond in a prompt, open and constructive way by:
  + helping them to think about possible next steps, and what actions they would like to take
  + seeking advice or support from a supervisor or team leader regarding the appropriate next steps
  + following the service’s complaints procedures (for example, referring concerns to independent mediators where appropriate)
* The autism peer support worker needs to understand the key aspects of the Equality Act 2010, Human Rights Act 1998 and Mental Capacity Act 2005.
* The autism peer support worker must also be aware of and understand the statutory rights to independent advocacy that a person has and be able to support them to make any such referrals, as appropriate.
* The autism peer support worker needs to understand how to support and facilitate the development of a person’s autistic identity, including gender identity and access to autistic culture and autistic space.





**Meta capabilities for autism peer support workers**

* An ability to balance the various roles of an autism peer support worker (for example providing support, promoting people’s rights, facilitator, providing interventions)
* Ability to develop plans with the autistic person around their individual behaviours that occur when distressed or in a crisis and how they would like to be supported.
* An ability for autism peer support workers to be aware of their own values and the needs of neurodivergent individuals, and to reflect on the ways that these values and neurodivergent needs might affect (positively and negatively) the

people they work with.

## Engagement

* An ability to judge when it is best to refocus on goals that are seen as personally relevant or manageable/achievable by the person they are supporting, rather than continuing to explore other issues, which could lead to disengagement
* An ability to judge when social, cultural and neuro-diverse barriers to engagement may be relevant and need to be taken into consideration
* An ability to judge when to continue focusing on working with difficulties and when to step back, based on the level of engagement with a person
* An ability to identify and respond to implicit or explicit indicators that a person is at risk of disengaging from the interaction, for example by:
  + responding to and openly discussing explicit feedback that expresses concerns about important aspects of the conversation or proposed course of action
* Taking actions in response to implicit feedback that indicates concerns about important aspects of the discussion (such as comments, non-verbal behaviour, or significant alterations in responsiveness).
  + identifying when it seems difficult for people to give honest feedback (that is, responding with what they think the autism peer support worker wishes to hear, rather than expressing their own view) and discussing it with them.
* An ability to balance flexibility and consistency when providing support, and delivering support to ensure a truly person-centred approach
* An ability to judge when to offer self-disclosure and to decide what would be helpful to disclose and what should be held back



## Support

* An ability to match the level of input needed and how often they are seen for support to the person’s needs, and to judge whether and when to increase or decrease the levels of input and support.
* An ability to judge when to offer support to the person or when to promote the persons own independence and their ability to self-manage in line with service and supervision.

## An ability to facilitate wellbeing

* The autism peer support worker will need to be able to judge when they have reached the limits of their responsibility and capabilities and when to seek advice, management or supervisory support, or assistance from others.
* The autism peer support worker will need to be able to identify when they personally are experiencing unhelpful levels of stress and to prioritise taking appropriate steps to relieve this which includes recognising the symptoms of their own mental/emotional wellbeing
* The autism peer support worker will need to know how to maintain and manage the boundaries in their professional relationships.
* Knowledge of how working with people who are distressed can impact on a workers own mental and emotional wellbeing.
* Know how and where to access support within the wider team to manage own wellbeing.



**Additional areas of awareness and signposting: Understanding and working with conditions that affect autistic people.**

## Able to support autistic people with mental distress

* The autism peer support worker must know what to do to support autistic people who are struggling with mental health difficulties. Thus, they will need to have knowledge and awareness of how autistic people may have problems with their mental health which they may need to be supported with. These problems may include:
  + Common mental health difficulties include:
  + Feeling worried a lot of the time (anxiety)
  + Feeling unhappy, irritable, or hopeless (depression)
  + a need to keep doing certain actions repeatedly (obsessive compulsive disorder, (OCD)
* Autism peer support workers may need to have awareness of different types of treatments available for autistic people with mental health difficulties, including medicines or talking therapies e.g., cognitive behavioural therapy
* The autism peer support worker will require an ability to maintain the core support element of the role of the autism peer support work while also encouraging people to make use of psychological approaches to help them better manage their own mental health. This may include supporting behavioural activation under the guidance of clinical professionals.
* Autism peer support workers need to have a knowledge of how symptoms of mental disorders such as anxiety can present as a physical symptom.



## Able to support autistic people who have attention deficit hyperactivity disorder (ADHD)

* For the autism peer support workers to recognise and have knowledge of how to support autistic people who have attention deficit hyperactivity disorder (ADHD)
* For autism peer support workers to understand that symptoms of ADHD may include:
  + Finding it hard to concentrate and getting distracted easily
  + Acting impulsively
  + Finding it hard to sit still
* For autism peer support workers to have awareness of how autistic people with ADHD may need extra support in education or work and may need to take medicine for their ADHD.

## Able to support autistic people who have dyslexia and dyspraxia

* For autism peer support workers to have knowledge and awareness of how to be able to support autistic people with other neurodevelopmental conditions, e.g., dyslexia, dyspraxia, dyscalculia, dysgraphia, and others:
  + Autism peer support workers to be able to work with autistic people with these conditions in a person centred and empowering way to support with the impact on the individual.
  + Autism peer support workers to have knowledge and awareness of how extra support in education and work can often help.
  + Autism peer support workers to have an awareness that recent research indicates that there may be a link between autism and hypermobility and related syndromes such as Ehlers Danlos syndrome (EDS).



## Problematic sleeping

* Autism peer support workers to have an awareness and knowledge of how to support autistic people with problems sleeping (insomnia) and non-restorative sleep
* For autism peer support workers to have and awareness of the symptoms and impact of insomnia which may include
* finding it hard to go to sleep
* waking up several times during the night
* not needing much sleep, which can impact on others, and the persons functioning
* For autism peer support workers to develop the knowledge and the ability to support individuals to consider changes to bedtime routine and sleep hygiene which may help.
* For autism peer support workers to be aware that in autistic people there may be other underlying physical reasons for their sleep difficulties.

## Learning disabilities

* For autism peer support workers to have knowledge and awareness of how learning disabilities may impact on autistic people
* For autism peer support workers to have knowledge and awareness that a person with a learning disability may find it hard to:
  + Understand new or complex information
  + Learn new skills
  + Look after themselves and manage activities of daily living



## Problems with joints and other parts of the body

* For autism peer support workers to have knowledge and awareness of how to support autistic people who may also have physical health issues.
* Autism peer support workers to have knowledge and awareness that the following physical health issues are more likely to be present with autistic people and that they may be required to develop additional skills to support people with these issues. These include:
* Symptomatic hypermobility, Ehlers Danlos syndrome, hypermobility spectrum disorders
* Complex symptoms that can affect the whole body/brain systems
* Laxity of the joints, soft tissues
* Pain (incl. fibromyalgia pain)
* Chronic tiredness (Chronic Fatigue Syndrome/M.E.)
* Dizziness/clumsiness/confusion (may be present with autistic people with dyspraxia)
* Eating issues like swallowing, reflux, stomach pains, bloating and bowel/ bladder issues
* Vascular issues
* Skin differences some leading to thin, easily bruised skin
* Headaches or migraines
* Epilepsy
* Alexithymia
* For autism peer support workers to have awareness that due to there being an array of issues that there may also be a range of specialist practitioners and expert groups that an autism peer support workers could signpost people to.
* Autism peer support workers to have knowledge and awareness of how autistic people may mask pain.