

Module 10 : Ethical Considerations and Legal Obligations

1. The important ethical considerations for working effectively with autistic people
2. Examples of some unethical approaches in working with autistic individuals
3. Why strict ethical parameters must be maintained when working with people on the autism spectrum
4. The legal obligations that must be recognised and adhered to at all times
5. Autism-related regulations and guidelines.

In this module, we will take a look at:

- The important ethical considerations for working effectively with autistic people
- Examples of some unethical approaches in working with autistic individuals
- Why strict ethical parameters must be maintained when working with people on the autism spectrum
- The legal obligations that must be recognised and adhered to at all times
- Autism-related regulations and guidelines.

10.1 Ethical Considerations

Some of the essential practices that must be observed when working with people on the autism spectrum include the avoidance of: (a) any practice that can cause pain, harm, or hazard, (b) making claims for achieving unrealistic outcomes, and (c) any negative or punitive actions.

Demeaning attitudes and negative behaviours, language, and imagery must always be avoided as, at their best, they will not be helpful or understood, and at their worst, they can cause confusion, upset, and lasting hurt and damage. Remember that the world can be a confusing and unfamiliar place to people on the autism spectrum; damaging, punitive actions, promises that can't be kept, and negative behaviours make life even more difficult for autistic people and their families.

In fact, no form of abuse is ever acceptable when working with an autistic person, whether it's pharmacological, behavioural, environmental, or societal. An inclusive, positive approach is the only way to support individuals when working alongside them.

It is also incredibly important to recognise that people on the autism spectrum are not all the same; each individual demands a flexible and personal approach to their unique condition and needs. It is important to recognise the humanity, diversity and individuality among autistic people. Personalisation is key to working successfully and ethically, and a "one-size-fits-all" policy will rarely be effective, and indeed, may even be damaging.

Instead, it is essential to recognise the complex needs of autistic people and take a multidisciplinary approach to looking after their wellbeing. Remember, this is a condition with a highly sensitive nature.

Any actions taken when working with autistic people must always be in the best interests of their personal wellbeing and be considerate of their rights. Each individual must be respected, and their right to be different must be recognised and balanced with quality support and safeguarding measures.

A positive, can-do approach should always be taken when working with people on the autism spectrum; however, it should never make light of their condition or exploit family guilt or vulnerability. The difficulties faced by autistic people and their families must always be considered. This relates in part to making claims about cures or outcomes that can't be substantiated. Giving

false hope is an unethical and counterproductive approach.

Good communication is also vital when working with autistic people and their families. Be honest and employ best practices, recognise behaviour triggers, use visual prompts when appropriate, and speak in short, clear sentences without being patronising or demeaning. Remember how well many autistic people do with structure and use it to help them make sense of their day and achieve personal success.

Give effective support by being empathetic to those you are working with and make an effort to understand the world from the viewpoint of an autistic person. Ensure that, by supporting individuals on the autism spectrum, you are providing them with a calm and safe environment that respects their sensory sensitivity difficulties.

When developing a support plan for an autistic person, whether it's for dental care, progressing in the classroom or joining an after-school activity, always make sure to involve the people who know the autistic person best, such as family members, teachers, and support workers. They might have knowledge and insight that can help you work more successfully with the individual or help the autistic person feel more comfortable with a new activity, setting or challenge.

Healthcare professionals have further, highly specific considerations regarding the ethics of their practice when supporting people on the autism spectrum. It's essential to be as accommodating as possible with appointment times, for example, offering the first or last appointment of the day in order to reduce waiting and stress for the autistic person. It's also important to keep in mind that waiting in busy and noisy areas can increase stress levels for autistic people who are already feeling anxious.

Family members or support workers may wish to have each person in their care complete a Hospital Passport, or have one completed by a parent or legal guardian on their behalf. This can help communicate current or ongoing needs to health professionals if the autistic person is non-verbal or struggles to explain their needs.

When attending medical or dental appointments, a clear explanation of medical outcomes or recommendations is imperative; if possible, use pictures, dolls or Social Stories, as appropriate for each individual.

Remember, people on the autism spectrum tend to take things literally, so concrete language that avoids expressions, jokes or idioms is always recommended. Furthermore, avoid using body language, gestures or facial expressions as a means of communication without also supplying clear, verbal instructions. The gestures themselves won't be understood on their own.

Giving direct requests will help alleviate much confusion, as will checking for understanding before

procedures are conducted.

Finally, health professionals should remember to ask for further information from the patient, if needed, as it may not automatically be provided.

10.2 Unethical Approaches to Working with Autistic Individuals

At the beginning of this module, we covered several things to avoid when working with autistic people, namely:

- Any practice that can cause pain, harm, or hazard to the individual
- Making claims for achieving outcomes that can't be substantiated
- Using any negative or punitive actions when dealing with people on the spectrum
- Having a demeaning attitude or displaying negative behaviour, language, and imagery towards autistic people
- Any form of abuse, whether it's pharmacological, behavioural, environmental, or societal

Other unethical approaches include promising unrealisable results, such as cures or complete recoveries, cherry-picking examples based purely on anecdotal evidence, being inconsiderate of the adverse effects of intervention, and failing to mention best possible practices or other available evidence for autism-related issues.

It's also inappropriate to use punishments such as physical or emotional confrontations and the removal of possessions or privileges when, in most cases, people on the autism spectrum do not intend to act with malice and may not comprehend the potential consequences of their actions.

The following behaviours are also unacceptable:

- Acting beyond the area of your expertise
- Disregarding the potential health and safety risks
- Ignoring, patronising or oversimplifying the perspectives of autistic people
- Profiting without thought for the quality or outcome of the service provided

10.3 Why Strict Ethical Considerations must be Observed

Some people may wonder why such strict and detailed ethical considerations must be observed for people on the autism spectrum.

Research has shown that children and young people with disabilities are at a far higher risk of abuse and neglect than their typically developing peers. They are also less likely to be the subject of child protection plans designed to keep them safe. There must be safeguards in place to protect autistic people from violence, sexual and emotional abuse.

In many cases, unlike their typically developing peers, a person on the autism spectrum is unable to comprehend the abuse they are experiencing or communicate to a trusted person what has happened to them.

Autism is a compelling, complex, and often controversial condition, which is why there are so many ethical factors to keep in mind. It raises many questions about Theory of Mind, cognitive science, and language skills, not to mention the theories about the causes of autism.

While there are still many questions that should be answered in order to improve services and support for individuals on the autism spectrum, there are also concerns about the ethics of how the answers can be found.

There are also ethical questions about: how autism can affect the nature of human consciousness and the ability to perceive the consciousness of others; the value placed on the lives of autistic people; gene editing developments, and the quest to alter this condition.

While it is natural and even beneficial for scientists and medical professionals to ask such questions,

exploring the answers may be a different story. In fact, it may even relate to potentially unethical practices when working with autistic people.

10.4 Legal Obligations

In addition to the many ethical considerations, there are also a number of legal obligations to be aware of when working with autistic individuals.

In fact, many ethical and legal requirements overlap.

Autistic children have a legal right to receive the right support at the right time, and in order to better guarantee that, improved training must be undertaken - particularly in schools. While progress has been made in recent years, the overall expertise across schools and local councils in the United Kingdom remains sporadic.

Children on the autism spectrum also have the right to certain adjustments, including a better understanding of their difficulties, more time to finish schoolwork, quiet spaces they can go to if feeling overwhelmed, and help whenever they feel upset.

Every child also has a right to an education, whether they're integrated into a mainstream school or attend a school for children with special educational needs. There must also be an understanding of the support needed for autistic children within the UK school system, and remove any inconsistencies across education.

10.5 Laws and Regulations Relating to Autism

The Autism Act of 2009 (published in 2010) was the first ever disability-specific law in England.

Its existence places a duty on the government to produce strategies specifically for autistic adults, as well as statutory guidance for local councils and healthcare bodies on how to implement autism-friendly strategies.

The Autism Act was designed to help develop strategies that ensure autistic adults continue to receive the help they need, whether at home, in the community or in the workplace. It lays out what local councils and NHS health services can do to assist people on the autism spectrum once they become adults.

This statutory guidance also tells local authorities, the NHS, and NHS Foundation Trusts what actions should be taken to meet the specific health and wellbeing needs of autistic individuals in their area.

In 2014, the government launched the 'Think Autism' strategy, which named several key proposals designed to make significant differences to the lives of autistic people and the services and support available for adults. It focused on developing more autism-aware communities, establishing autism innovation funds for innovative projects and lower-level support, improving data collection, creating a more joined-up approach regarding advice and information services, and setting up new ways that social care staff record autism-related conditions.

Through this initiative, a commitment was demonstrated to make it easier for autistic people to access information, especially online, about how local authorities are performing in regard to services tailored for them.

2015 Revision

In 2015, the Autism Act 2009 was revised with new statutory guidance regarding people who work with autistic individuals. Specifically, the new guidance states that people assessing autistic

individuals must have a sufficient level of related skills, plus access to ongoing specialist training.

The 2015 revision also places more responsibility on local councils throughout the UK to ensure people who are carrying out assessments of autistic adults understand the key aspects of the condition. This includes how it typically presents throughout the lifetime of a person and what the various levels of ability may be.

2021 Review

In 2021, the government reviewed the Think Autism strategy and extended it to cover children and young people as well as adults.

Autistic people, their families and carers were surveyed about their experiences of care and support, and professionals were surveyed about the care and support they provide to people on the autism spectrum.

The surveys were reviewed to understand where progress has been made and where more needs to be done in the future.

From this consultation, the government has implemented the [national strategy for autistic children, young people and adults: 2021 to 2026](#).

The new strategy aligns with the existing [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(2015\)](#).

The new national strategy will look at six key areas and three enablers.

Six Key Areas:

1. Improving understanding and acceptance of autism within society
2. Improving autistic children and young people's access to education and supporting positive transitions into adulthood
3. Supporting more autistic people into employment
4. Tackling health and care inequalities for autistic people

5. Building the right support in the community and supporting people in inpatient care
6. Improving support within the criminal and youth justice systems

Three Enablers (required to deliver the strategy and demonstrate progress):

1. Improving research, innovation and examples of best practice
2. Improved data collection and reporting to drive system improvement
3. Strengthened governance, leadership and accountability

SEND Code of Practice

The government's [Special Educational Needs and Disability Code of Practice](#) provides statutory guidance for all organisations in England that work with and support children and young people who have special educational needs or disabilities, including autism.

It outlines the duties of local authorities, schools and colleges, to provide for those with special educational needs as set out in the Children and Families Act 2014.

It states that: "All children and young people are entitled to an appropriate education, one that is appropriate to their needs, promotes high standards and the fulfilment of potential."

The guidance covers provision for children aged 0 to 25 years and underlines four broad areas that should be considered:

1. Communication and interaction
2. Cognition and learning

3. Social, emotional and mental health
4. Sensory and/or physical needs

However, the code explains that "the special educational provision made for a child should always be based on an understanding of their particular strengths and needs and should seek to address them all, and that their needs may change over time".

Legal Rights in the Workplace

There are also specific legal rights regarding autistic individuals who enter the workplace in the UK. The National Autism Society offers examples of the challenges autistic adults may face in a work environment, including how to increase awareness and avoid potential misunderstandings. It also offers reasonable adjustments that can be made, which fall in line with the Equality Act 2010.

[The National Autism Society's guide for autistic people in the workplace](#)

[The National Autism Society's guide for employers on the benefits of employing an autistic person](#)

Equality Act 2010

The Equality Act 2010 also covers information on whether individuals decide to disclose their diagnosis to an employer. If an autistic person does inform their employer of their diagnosis, they will be protected from discrimination on that basis.

The Equality Act 2010 protects people on the autism spectrum and other vulnerable people, by stating that public bodies are required to promote equal opportunities for disabled people. Protection under this law means that autistic people should be treated fairly and equally in the workplace, and not discriminated against because of their condition. It also requires employers to make reasonable adjustments for autistic individuals.

Take a Quick Recap Test

[viralQuiz id=98]

10.6 What We've Learned

In this module, we reviewed the important ethical and legal considerations to be observed when working with people on the autism spectrum.

We also looked at why it's important for people in medical and health professions to think about ethical considerations when treating autistic patients, and explained why it's so imperative to adhere to strict ethical standards.

Next, we discussed the laws and regulations that affect autistic individuals in the UK, including the Autism Act 2009, the Equality Act 2010, and the latest government strategies.

Summary

After completing this module, it should be clear how we characterise good ethics regarding supporting or working with autistic individuals. You should know what not to do and what is expected of highly professional individuals who work with people on the autism spectrum in a variety of capacities.

You should also be aware of the laws regarding working with autistic people, and what measures are in place specifically to protect children and adults in the United Kingdom.

In the next module, we will take a look at raising awareness about autism and how to encourage more people to get involved in the cause.
