

KNOW YOUR RIGHTS, OWN YOUR LIFE

Rights exist to protect and guide people. When we know how and when to use them, we gain the clarity to make decisions with confidence and the strength to act when it matters.

Knowing our rights can change our lives. It gives us the tools to make decisions that define our future.

THE AUTISM ACT 2009

What You Need to Know and How It Can Help You

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OVERVIEW

The Autism Act 2009 (c.15) is “An Act to make provision about meeting the needs of adults with autistic spectrum conditions; and for connected purposes” and received Royal Assent on 12 November 2009.

The Act places a duty on the Secretary of State to prepare and publish a document setting out a strategy to meet the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services by local authorities, NHS bodies, and NHS foundation trusts. This document, referred to as “the autism strategy,” had to be published no later than **1 April 2010**.

The Autism Strategy

The autism strategy must be kept under review and may be revised, with any revised version being published. The Secretary of State must consult and seek the participation of autistic people as they consider appropriate when preparing or revising the autism strategy in a way that would result in a substantial change to the strategy.

Statutory Guidance to Support Implementation

The Act requires the Secretary of State to issue guidance, no later than **31 December 2010**, to local authorities, NHS bodies, and NHS foundation trusts to secure the implementation of the autism strategy. This guidance must also be kept under review, and the Secretary of State must consider the extent to which it has been effective in securing implementation.

Structure and Scope of the Act

Sections 1 to 3 contain the substantive provisions of the Act. Section 1 concerns the autism strategy, section 2 concerns statutory guidance, and section 3 establishes the duty on local authorities and NHS bodies to act in accordance with that guidance. Sections 4, 5 and 6 deal with interpretation, expenses, and extent, commencement and short title, respectively.

The Act applies only in relation to England, although it extends to England and Wales. It defines “adult” as a person aged 18 or over, and “child” as a person under 18. It also defines “local authority”, “NHS body”, and “relevant services”, with relevant services meaning health services in relation to NHS bodies and social services functions in relation to local authorities.

Autistic spectrum conditions are lifelong conditions that affect how a person communicates and relates to others and to the world around them. The Act itself does not include a formal definition, with the intention that definitional issues will be dealt with in the autism strategy, allowing changes to be made more quickly than through primary legislation.

GUIDANCE FOR CHILDREN, YOUNG PEOPLE, ADULTS AND THEIR FAMILIES

Although the Act focuses on adults, it explicitly includes planning for children and young people as they move into adulthood. Guidance issued under the Act must include planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults.

The statutory guidance must, in particular, cover:

- the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- the identification of adults with such conditions;
- the assessment of the needs of adults with such conditions for relevant services;
- planning in relation to transition arrangements for children with autistic spectrum conditions as they move into adulthood;
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- the training of staff who provide relevant services to adults with such conditions; and
- local arrangements for leadership in relation to the provision of relevant services.

Planning of Services and Workforce Development

The guidance may also cover collecting information on the number of adults requiring services and the types of services they need, supporting more informed planning and service development.

For individuals and families, this means the Act establishes a national framework requiring:

- access to diagnostic services for adults;
- systems for identifying autistic adults;

- formal assessment of needs for relevant services;
- structured transition planning from childhood to adulthood;
- trained staff delivering services; and
- clear local leadership arrangements.

Participation in Strategy and Guidance Development

The Secretary of State must consult and seek the participation of appropriate persons when preparing or substantially revising both the autism strategy and the guidance. This establishes participation as part of the statutory process, ensuring that people affected by the strategy can be actively involved in its development rather than only responding through consultation.

The Act also ensures that where services are arranged through third parties (commissioning), they are treated in the same way as services provided directly by local authorities or NHS bodies. References to the provision of services include references to arranging for the provision of services.

This is how knowing our rights can change lives.

When families and young people understand what support they're entitled to, they can make informed choices, access the right services, and create new possibilities for their future. Now, **meet Ben**, who is autistic and living with a PDA. Because of a lack of additional support, he couldn't find joy in the outside world, but today Ben is an active member of his community, loves trying new things, and lives more freely.

MORE



OBLIGATIONS AND DUTIES FOR COMMISSIONERS, PUBLIC BODIES AND LOCAL AUTHORITIES

The Act creates clear legal duties for public bodies.

The Secretary of State must:

- prepare and publish the autism strategy;
- keep the strategy under review and revise it as necessary;

- **issue guidance to local authorities, NHS bodies and NHS foundation trusts;**
- **keep the guidance under review; and**
- **consult and seek participation before issuing or substantially**

Local authorities and NHS bodies are under a duty to act in accordance with guidance issued by the Secretary of State.

Legal Duty on Local Authorities

Guidance issued under section 2 is treated as if it were general guidance under section 7 of the Local Authority Social Services Act 1970. Case law establishes that this means **authorities must “follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course”**. Failure to comply without a compelling reason would be unlawful and could lead to judicial review or default action by the Secretary of State.

Legal Duty on NHS Bodies

For NHS bodies, **the Act gives the same legal effect by treating them as local authorities for the purposes of the guidance and treating their relevant functions as social services functions**. This means NHS bodies are bound by the guidance to the same extent as local authorities.

NHS foundation trusts, while receiving guidance, are not subject to the same statutory duty to act under it. They are expected to take the guidance into account, reflecting their greater autonomy.

The guidance must address diagnosis, identification, needs assessment, transition planning, service planning, staff training, and local leadership. These requirements place obligations on commissioners and service planners to ensure coordinated, informed, and adequately trained provision of services for adults with autistic spectrum conditions.

Commissioning Responsibilities

Where services are arranged through third parties, those services remain within the scope of the Act. Commissioners retain responsibility for ensuring compliance with statutory guidance.

HOW INDIVIDUALS AND FAMILIES CAN TAKE PART AND BENEFIT FROM THE ACT

The Act establishes several mechanisms through which individuals and families can understand, engage with, and benefit from its provisions.

Participation in Strategy and Guidance

First, the Secretary of State must consult and seek participation in the preparation and substantial revision of both the autism strategy and the statutory guidance. Participation means people and organisations may be actively involved in development, not only consulted after decisions are drafted.

Second, the statutory guidance requires provision for:

- diagnosis of autistic spectrum conditions in adults;
- identification of adults with such conditions;
- assessment of needs for relevant services; and
- transition planning from childhood to adulthood.

This enables individuals and families to seek diagnostic services, request needs assessments, and expect structured transition arrangements, supported by trained staff and local leadership.

Third, because local authorities and NHS bodies must act under the guidance, individuals and families can rely on the guidance as a legal framework. Public bodies are required to follow it unless there is a compelling reason not to do so, and failure to comply may be challenged.

Fourth, the Act ensures that commissioned services are treated the same as directly provided services. This means that **individuals and families retain the same expectations regarding quality and compliance, even when services are delivered by external providers.**

Finally, the requirement for ongoing review of both the autism strategy and the guidance means the system must remain responsive to emerging needs, evidence, and lived experience. Revisions must be published, and substantial changes must involve consultation and participation.

Through these provisions, **the Act enables individuals and families to:**

- engage in consultations and participation processes;
- seek diagnosis and identification;
- request assessment of needs;
- expect transition planning from childhood to adulthood;
- rely on trained staff and local leadership; and
- hold local authorities and NHS bodies accountable to statutory guidance.

Original Source:

https://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf

Introduced by :

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