

AUTISTIC UK'S MESSAGE TO GOVERNMENT

**Nothing about Autism without Autistics
Let us contribute to a workable Autism Strategy**

The Autism Act was introduced in 2009

The aim of the Act was for the Government to produce a strategy for 'adults with autism'. The second aim was for the Government to produce statutory guidance for local councils and local health bodies on implementing the adult autism strategy. The subsequent strategy "*Fulfilling and Rewarding Lives; the Strategy for Adults with Autism in England*" (2010) has had little appreciable effect on the lives of the majority of English autistic people. This is largely because government has failed to ensure that local-level strategic-planning structures are in place.

The Strategy was reviewed in 2013

On April 2nd 2014 Norman Lamb MP announced that the Strategy is fundamentally sound and will be reviewed again in five years' time.

The Strategy is fundamentally flawed

It will not meet the requirement of the Autism Act – "meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services" - unless it is revised.

Three things are needed:

- The Strategy must require Strategic Planning Groups in every Local Authority area. Government must issue binding guidance detailing how Clinical Commissioning Groups (CCGs) and Local Authorities will establish such groups (with meaningful representation of the autistic population).
- The autistic population is extremely diverse. Our needs vary greatly but the service we all require is **a diagnostic service**. Those without a diagnosis are not (in any legal sense) "adults with autism" and the Strategy does not apply. No-one receives post-diagnostic support without a diagnosis. Existing diagnostic services are log-jammed, waiting-times measured in years rather than months. Government must direct CCGs to commission local diagnostics.
- Local Autism Teams must be a requirement, not a suggestion. NICE guidelines recommend that every area has a "community-based multidisciplinary team for adults with autism". The membership should include psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists and support staff (e.g. staff supporting access to housing, educational and employment services, financial advice). Such a team obviously requires NHS funding.

All CCGs and Local Authorities must joint-commission an Autism Team (however modest) and give it the broad remit of meeting the unmet needs of autistic people.

Detailed analysis of need ought to be on an individual basis.

The needs of the local autistic population will emerge by meeting individual need over time. Government must provide additional funding to facilitate this. However it will save money in the long run.

In addition:

- Autistic UK and other Autistic-led organisations must be represented on the national Autism Programme Board (APB)
- The Department of Health provides £150,000 annually to support the National Forum of People with Learning Difficulties. Government must commit to this modest funding to establish a National Forum for Autistic People.
- “Autism” is not a “mental illness” but it remains so in British law. Illness can stem from a lack of adequate support but we are not ill; we are neurologically different. Government must address this legal anomaly.
- The Autism Act should be amended as it gives the erroneous impression that all is well for autistic children. We need a Strategy for autistic children.
- The majority of us should be diagnosed in childhood. Too many are not. The Child and Adolescent Mental Health Service must be directed to address this.

A fundamental misconception is that most of us will qualify for and benefit from traditional Social Services. This is not so; but most of us have significant “unmet needs”.

We need the “low-level preventative services” recommended by the National Audit Office (“Supporting People with Autism through Adulthood”, June 2009).

This report, applauded by the Public Accounts Committee, argues that **if such services supported four per cent of the autistic population they could “become cost-neutral for overall public expenditure”**.

These services will never be established without central government taking a lead.

We are not “adults with autism”. We are autistic people

This is the most fundamental misunderstanding of all.

We do not have anything.

We are autistic.

Government has failed to understand what we are and the lives we lead. It must initiate a meaningful dialogue with us and our organisations.

Talking only with parent/carer-led and service-providing organisations such as the National Autistic Society and the Autism Alliance (both represented on the APB) has resulted in the current misunderstandings.

We know how to construct a Strategy that would not only help people live “fulfilling and rewarding” lives but which will also save money.

All we need is for government to listen.

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