

# **NOTHING ABOUT AUTISM WITHOUT AUTISTICS**

## **NO.8 IN THE AUTISTIC UK “NEED TO KNOW” SERIES**

**About 1% of the population is autistic.**

**About 2.5% of the population has a learning disability.**

**In April, 2011 Andrew Lansley, the then Secretary of State for Health, committed £450,000 to support the National Forum of People with Learning Difficulties and £150,000 to support the National Valuing Families Forum for a further three years.**

**Andrew Lansley’s successor, Jeremy Hunt, must now commit a comparably modest level of funding to establish and support a National Forum for Autistic People and a National Forum for Carers of Autistic People**

The Valuing People White Paper has led to the learning disabled community having democratically elected representatives at local regional and national levels.

The autistic community has no such thing and

### **THIS MUST CHANGE**

The emergent regional autism partnerships must be recognised by central government as necessary in spite of the current localisation agenda. These regional structures must be supported and funded by central government. They are emerging because they are necessary. Without them the missing services needed to meet the staggering levels of un-met need cannot be established. These regional groupings must involve autistic people, carers, the voluntary and community sector and front-line workers. We need Regional Autistic People’s Forums and Regional Autism Carer Forums. We need an Autistic People’s Forum and Autism Carer Forum in every one of the 152 Local Authority areas in England.

**Central government must tell local government that this must happen.**

In future there ought to be no need to appoint autistic people and carers to the National Autism Programme Board (APB). Autistic people and carers ought to be elected at a local level, at a regional level and at a national level.

Those elected to a national position within the Autistic People’s National Forum and the carer equivalent will be able to sit on the APB.

This is what currently happens in the world of learning disability.

The Co-Chairs of the APB Jon Rouse (Director General of Social Care) and Norman Lamb MP (Minister for Social Care) know all about this; they are also Co-Chairs of the Learning Disability Programme Board.

**In addition Autistic UK suggests that the following ought to be considered**

Autistic UK must be given a place on the Autism Programme Board (APB).

The involvement of the National Autistic Society in the work of the National Autism Programme Board is perfectly legitimate and indeed desirable.

However, this is no substitute for the involvement of user-led Disabled People’s Organisations.

Autistic people must be appointed to the Equality 2025 Committee overseen by the Office of Disability Issues. Autistic people must be appointed to the Equality and Human Rights Commission’s Disability Committee **and to all comparable bodies.**

As 35% of the learning disabled population is autistic, these people ought to be represented and consequently;

- At least two autistic people who are learning disabled ought to be appointed to the APB
- At least two carers of autistic people who are learning disabled ought to be appointed to the APB
- The national user-led learning disability organisation, People First, must be given a place on the APB
- As a significant minority of the autistic population are learning disabled (about 10-30%), Autistic UK must be granted a place on the Learning Disability Programme Board
- Consideration must be given to involving other national autism organisations other than the NAS and Autistic UK.
- Consideration ought to be given to involving regional autism organisations (user-led, carer-led and otherwise).
- Consideration must be given to the involvement of “front-line” workers (those who know the shortcomings of current services first-hand) through their representative organisations

### **The Autism Strategy was never put out for public consultation**

This must now happen and it must be revised and re-drafted in light of public comment. It is within the power of Jeremy Hunt to do this at any time he so chooses.

The Autism Strategy indicates that all health care and social care professionals must receive autism awareness training. In addition it recommends such training for “all frontline public service staff”. Autistic UK welcomes this. However, there is currently no systematic monitoring of the quality and veracity of autism training. Consequently the quality of autism training is extremely variable. Some of the currently available training is of extremely poor quality. There needs to be a national autism training accrediting body established and funded by government and accountable to government. Autistic people and autism organisations must be involved in establishing such an accrediting body. If this does not happen then the training delivered concerning autistic people will continue to be misleading and the Autism Strategy training initiative will fail or become counter-productive.

**The majority of autistic people are not learning disabled.**

**The majority of autistic people do not have severe and enduring mental ill-health.**

**It is now 70 years since autism was recognised as a distinct condition; 50 years since it became a routine diagnosis in the UK; 30 years since Asperger Syndrome was recognised.**

**It is time for a UK government to commit to parity with learning disability services and mental health services.**

**At national, regional and local levels there must be an autism workforce of comparable numbers and with comparable funding to the learning disability and mental health equivalents.**

**Autistic people are being discriminated against by government by being treated less favourably than learning disabled people and other groups of disabled people and  
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**THE NATIONAL AUTISTIC PEOPLE'S ORGANISATION**

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