

THE NATIONAL AUTISM PROGRAMME BOARD

NO. 7 IN THE AUTISTIC UK “NEED TO KNOW” SERIES

The National Autism Programme Board has been meeting since March 2010. After all this time there is still NO INVOLVEMENT OF THE AUTISTIC COMMUNITY

The touchstone of Autistic UK and its member organisations is the central principle of the Madrid Declaration of 2002;

NOTHING ABOUT DISABLED PEOPLE WITHOUT DISABLED PEOPLE
Successive British governments have failed to understand the importance of this principle. Andrew Lansley’s hijacking of the phrase, twisting it into “nothing about me without me” is crass and offensive, a Tory perversion of a universal principle into personal self-interest.

The Declaration goes on to say;

A strong alliance between Governments and disability organisations is the basic requisite to progress most effectively the equal opportunities and social participation of disabled people.

Successive British governments have failed to understand (or have wilfully refused to understand) the importance of Disabled People’s Organisations (DPOs) – organisations of disabled people not organisations for disabled people

The UK government signed up to the United Nations Convention on the Rights of Persons with Disabilities on June 9th, 2009.

The Convention says;

In...decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

The United Nations Convention on the Rights of Persons with Disabilities, Article 4.3

Successive British governments have failed to understand the importance of this Article.

Autistic UK is the first national campaigning Autistic People’s Organisation (APO) and as such it is essential that Autistic UK is included in the work of the Autism Programme Board (APB)

In the drafting and in the implementation of the “Strategy for Adults with Autism in England” the government and the Department of Health (both “State Parties” under the terms of the UN Convention) have blatantly failed to abide by this Article.

The Autism Strategy says of itself (at 1.36) that, “it has been developed using the core principles of inclusivity and co-production, with extensive public consultation”.

This was not the case.

The lengthy “consultation” period was in fact nothing more than a broad survey of opinions regarding autism.

No proposals were submitted for public consideration.

No draft version of the published Autism Strategy was put out for public consultation.

The first year delivery plan to the Strategy (April 2nd, 2010) stated that “organisations that represent adults with autism have been invited to join the national Adult Autism Strategy Programme Board”.

This was not the case.

The only voluntary sector organisation that has been invited to join the Autism Programme Board (APB) is the National Autistic Society (NAS).

The NAS is not a Disabled People’s Organisation nor is it in any sense “user-led”.

The NAS cannot be said to “represent adults with autism”.

The NAS can only legitimately represent its members.

Of the 17,400 members of the NAS less than 500 identify themselves as autistic.

The overwhelming majority of NAS members are parents of autistic people.

In October 2010 the DH appointed two autistic people and two carers to the APB.

These people represent no-one but themselves.

The general public has no clear means of contacting or lobbying them.

This is the sort of tokenistic “representation” that ARM UK and other DPOs oppose and which must be addressed in the forthcoming government disability strategy.

Quite clearly, the government and the DH have not only failed to “closely consult with and actively involve” autistic people “through their representative organizations”, they have made no serious attempt to do so.

The Autism Act 2009 states that;

The Secretary of State must prepare and publish a document setting out a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts.

It seems that the implementation of the Autism Strategy as currently written is not leading to any significant improvement in provision of services for anyone. Levels of unmet need remain massive.

As it stands the Autism Strategy is something that we didn’t ask for being imposed upon us without our consent.

With the appropriate involvement of autistic people, carers and the voluntary sector it could be transformed into a blueprint for a better future.

Published by AUTISTIC UK

Nothing about Autism
without Autistics



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