

# **THE STRATEGY FOR ADULTS WITH AUTISM IN ENGLAND**

## **ARM UK RESPONSE**

**Press release March 3rd 2010**

**With today's publication of "Fulfilling and rewarding lives: the strategy for adults with autism in England" the government has condemned autistic people to three more years in the wilderness of unmet needs.**

The Autistic Rights Movement UK (ARM UK) welcomes the fact that we now have a Strategy for Adults with Autism.

We welcome the fact that the government has finally made an attempt to address the unmet needs of autistic people.

Unfortunately, it is a failed attempt.

Autistic people are often misunderstood, excluded and discriminated against.

Our access and support needs are poorly understood and are often unmet or ignored.

This makes it impossible for most of us to be fully accepted and appreciated as equal members of society.

As Andy Burnham, Secretary of State for Health says: "profound change is long overdue".

However, this strategy is not the vehicle to deliver that profound change.

ARM UK regrets that it cannot support this strategy.

Even if fully implemented, it is insufficient to meet the needs of the majority of the autistic population.

Moreover, we do not believe that it will be more than partially implemented as there is almost nothing in it which constitutes an actual directive to local service providers and commissioners.

If Local Authorities and NHS Trusts are not instructed to provide they are unlikely to provide.

Furthermore, the strategy is incomplete.

The forthcoming "delivery plan", which is not to be published until later this month, will obviously form a key element of the strategy and it is difficult to comment in the absence of it.

It might be that the delivery plan is the "missing part" without which the part that we have fails to make sense.

We certainly hope so.

We find ourselves not only bitterly disappointed but frankly baffled by the language used throughout.

There is an abundance of phrases containing words such as "may", "might", instead of the "must" and "will" that is needed.

As one parent of two young autistic adults commented today, "There's not much

chance of having a fulfilling and rewarding life when Local Authorities and PCTs are being handed a strategy with words like “encourage”, “recommend” and “seek ways” in it is there. It is a heap of steaming b\*\*\*s\*\*\*!”

Where the strategy contains as statement such as “local partners may also want to consider establishing a local autism partnership board” the outcome of those considerations are all too predictable.

Much will depend upon the forthcoming guidance which we understand will be issued under the Local Government and Social Services Act 1970 and will be binding upon local authorities.

In addition NHS trusts will be treated “as though they were local authorities” for the purpose of the guidance.

This unique and innovative arrangement is to be applauded as recognition that local and regional statutory sector bodies are unlikely to meet the needs of autistic people unless there are legal sanctions in place.

However, it is difficult to imagine how even the most stringently binding guidance can have any effect upon the implementation of a strategy which contains so little that is compulsory.

We suggest that the lack of understanding of autism on the part of “frontline staff” of various types that is referred to throughout the strategy also applies to staff within the Department of Health.

We suggest that this lack of understanding goes some way to explaining the shortcomings of the strategy as written.

**A strategy as weak and equivocal as this one makes the Autism Act meaningless.**

It seemed to us that the government supported the Autism Bill only when it became clear that there was sufficient cross party support to make the enactment of the Bill likely.

When the Autism Bill gained government support the Bill was then eviscerated, emptied of content other than the duty to deliver a strategy and guidance to underpin that strategy.

We argue that this strategy has betrayed the faith put in government by those MPs and peers who are sincerely concerned about the plight of adults with autism.

ARM UK suggests that Phil Hope and his ministerial colleagues ought to consider the potential consequences of that betrayal of faith.

The only new money that has been committed to is the proposed £500,000 to be spent on a national training programme.

This is derisory.

The recent National Audit Office report on Autism, referred to in the strategy, indicates that by investing in services for people with autism there would be significant savings in order to save the taxpayer money.

“Increasing the identification rate further could result in greater financial benefits over time....A six per cent identification rate could lead to potential savings of £38 million per year, and an eight per cent rate to savings of £67 million”.

There seems to be no real commitment to providing such services.

The assertion that “the strategy....has been developed using the core principles of inclusivity and co-production” is fallacious.

The strategy was written entirely by Department of Health staff members.

In 2008 the Cabinet Office defined co-production as, “a partnership between citizens and public services to achieve a valued outcome”.

ARM UK would welcome an opportunity to work in partnership with the Department of Health and other agencies to achieve the valued outcome of the needs of autistic people being met by the statutory sector in all local authority areas.

If the government is truly committed to the vision that “all adults with autism are able to live fulfilling and rewarding lives”, they must see that this can only be achieved if autistic people have significant involvement and influence in shaping the changes that are so urgently needed to achieve true equality.

As one autistic person commented, “Users and carers expend a lot of energy battling with service providers. Meanwhile the commissioners hide in the shadows. They have no idea what we need. They need to talk to us so that they know what to commission”.

The “extensive public consultation” it refers to was, in essence, a survey of opinion. This survey produced much that is relevant some of which is reflected in the strategy.

However, the strategy itself has not been put out for public consultation.

It is within the Minister of State’s (Phil Hope MP) power to do this and this must now happen.

We cannot wait for three years for this strategy to be reviewed.

It needs to be reviewed now by putting it out for public consultation in the usual manner before the end of the year.

It is within the power of the Minister of State (Phil Hope MP) to do this and this must now happen.

The strategy says that “it is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally” but provides no guidance as to how this is to happen.

It is of paramount importance that mechanisms and processes are introduced which will enable autistic people to become involved in the development of services at a local level.

We need structures equivalent to those which came out of the "Valuing People" White Paper and other initiatives for people with learning disabilities; comprehensive and fully funded structures at local, regional and national levels (such as a National Forum for Autistic People, Regional Autism Forums and local Autism Partnership Boards).

We also need the funding and support given to such organisations as People First to enable our participation in these (and European and international) structures.

It is imperative that autistic adults (and autistic-led Disabled Peoples’ Organisations) are fully involved in all areas of the implementation and reviewing of this strategy.

One of the few elements of the strategy that we are able to welcome is the establishment of an Autism Programme Board within the Department of Health.

We look forward to ARM UK (and other autism-specific DPOs) being able to work in partnership with the Department of Health and other government agencies as part of this bold initiative.

March 3rd 2010.

**The Autism Strategy remains fundamentally flawed.  
We will continue to argue that user-led organisations ought to be  
involved in revising it in the true spirit of “inclusivity and co-  
production” and of course the spirit of the Madrid Declaration  
NOTHING ABOUT US WITHOUT US**

**The Autistic Rights Movement UK (ARM UK)  
held its second Annual General Meeting in November 2012 and at that meeting  
the name was changed to  
Autistic UK (A-UK)**

Autistic UK works to promote the involvement of autistic people in statutory sector strategic planning at all levels and in all areas.

Autistic UK does not seek to represent autistic people. It aims to ensure that autistic people have the opportunity to represent themselves. We need the mechanisms and processes which will empower autistic people and enable them to represent themselves. As part of this, A-UK envisions autistic-led organisations in every locality in the UK, independent autonomous groups able to use the umbrella of A-UK to come together into a national network.

Autistic UK recognises that many autistic people are unable to represent themselves or experience great difficulty in representing themselves. Consequently, we recognise the importance of carers, family members, friends and supporters of autistic people and welcome these non-autistic people as associate members. A-UK believes in strength through unity and that there is much common ground to be agreed upon in the factionalised world of autism.

**Join us  
and help to explain what it is to be autistic  
to those in power who need to know**

**AUTISTIC UK**

**Nothing about Autism  
without Autistics**



**The National Autistic Peoples' Organisation**

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