

**Learning Disability Wales Response to the
Autistic Spectrum Disorder (ASD) Strategic
Action Plan for Wales**

Our response is provided within the framework provided by the consultation document questions:

1. Are the areas covered by the draft Autistic Spectrum Disorder (ASD) Strategic Action Plan comprehensive and pertinent? Are any critical issues not covered?

Learning Disability Wales is very disappointed by this plan. It fails to be strategic in that it is not appropriately tied into other pre-existing Welsh Assembly Government policy and fails to assign identifiable leadership roles at county level. It fails to provide an appropriate action plan. Most of the actions identified only relate to children and are not new.

Even the branding and ownership of the Plan is unclear. While the content relates to children and adults, the cover refers to “Children and Young People – Rights to Action”. Unusually the membership of the working groups that contributed to the Plan are not identified, so we have no knowledge of the expertise that informed its preparation. Again, unusually, there is no description of the process that resulted in the production of the Plan.

These shortcomings are all the more disappointing in that this Plan has been in preparation for several years, and we know that many children and adults with ASD do not receive appropriate help and support. The isolation of parents, and the extent to which they are reliant on voluntary sector assistance, in the absence of any alternatives, is one of the few highlights of the Plan.

2. Should any part of the draft document be changed, and if so, how?

Learning Disability Wales recognises that there is a significant policy gap, and a gap in service provision for children and adults with ASD, who do not have a learning disability. As a distinct group, they appear to be no ones responsibility. We would have wanted the Plan to tackle this key issue.

Research indicates that some 70% of children and adults with ASD also have a learning disability. The last Welsh Assembly Government administration, as one of its final acts, issued a new comprehensive policy statement on learning disabilities. We are told that this policy covers and includes all individuals with a learning disability. It must therefore cover those 70% of individuals with ASD who also have a learning disability. The Welsh Assembly Government policy on learning disability, with its emphasis on meeting individual needs, and doing so as ‘locally as possible’ has evolved over some twenty-five years, and is entirely consistent with policy in the rest of the UK and the

European Union. The latest Ministerial policy statement has also benefited from the substantial input and advice received from the Ministers own Implementation Advisory Group over some five years.

In this context, it is surprising that the Plan was not subject to detailed discussion during the drafting phase, with the LDiAG and that the relationship with the policy statement on learning disability is not fully explored, or any rationale for departing from its approach provided.

Any final plan could and should tackle the highly contentious issue of intensive early intervention programmes. Hearing about these approaches, parents frequently go to extraordinary lengths to raise funds and gain access to these programmes. A plan must provide leadership and advice on this issue to local authorities and education authorities. If research can assist in considering these matters, it should be commissioned (pp12-18). We also note that there is an assumption that all children with ASD have a key worker. While this is a standard in the National Service Framework for Children, Young People and Maternity Services, it is not a priority for implementation (p.18).

We are disappointed with Chapter 4 on the commissioning of services. Rather than tackling the key issue of ensuring that there is local access to support and assistance for individuals with ASD who do not have a learning disability, the Plan appears to accept and encourage institutional services remote from the family home. In doing so, not only does the plan run counter to the Welsh Assembly Government policy statement on learning disability, but it undermines and runs counter to one of the central principles of the Welsh Assembly Government Ten Year Strategy for Social Care "Supported Lives, Fulfilled Communities".

Aside from the policy conflict, it is not clear why these remote institutional models for service are being encouraged. Out of county placements are known to be extremely expensive, and there is little evidence, and certainly none offered in the Plan, that congregating individuals with a similar diagnosis a long way from home leads to better outcomes for the individual. Children, in particular, require families and we reject the statement implying that 52 week care or residential placements in schools represents good practice (p.25).

On transition, we note that the references to standards in the NSF for Children, Young People and Maternity Services should make it clear that the standards have not, to date, been identified as a priority for actions (p.27). Given the importance of 'the transition period' to the young people concerned, and their parents, we are disappointed by the sketchy, vague way in which it has been addressed. The whole section now needs to be expanded and revised in the light of the two recent reports from Assembly Committees that relate to transition. That is the Education, Life Long Learning and Skills Committee review

of Special Educational Needs, Part 3, and the Equality of Opportunity Committee report “Why do disabled young people always get left to last”. We would welcome evidence that most young people with ASD in mainstream secondary schools “will be given the opportunity to undergo work experience”(p.29).

We would also note the following:

- We welcome the endorsement of person centred planning (p.31)
 - We support the statement that adults with ASD should be given opportunities to live as independently as possible (p.34). We would have expected the Action Plan to identify who will oversee this responsibility at county level, and who will be expected to deliver support to people with ASD who do not have learning disabilities.
 - We are pleased at the recognition of the role of parents, the extent to which they are left alone and unsupported, and the important work carried out by organisations like the National Autistic Society, Autism Cymru and local self help groups.
 - We note that at no point is there a discussion about funding.
3. Are the key actions proposed appropriate and relevant? Are there other key actions to be included?

Consistent with our general view, we find the key actions disappointing. We welcome the requirement for local mapping of needs and services, though we are surprised that this has not already been a long standing expectation. The actions are generally weak, containing too many ‘coulds’ and ‘shoulds’, and very few relate to adults.

Learning Disability Wales
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