



Consultation Response to the LDIAG Proposed Action Plan for Adults with Learning Disabilities; All Wales Forum of Parents and Carers, All Wales People First, Learning Disability Wales and Mencap Cymru

Our response to the consultation reflects, and is based upon, the findings of three consultation events that were held across Wales in partnership with All Wales Forum of Parents and Carers, All Wales People First and Mencap Cymru;

- **Llandudno Junction 11th December 2008**
20 people attended including 6 people with learning disabilities.
- **Blackwood 15th December 2008**
31 people attended including 5 people with learning disabilities.
- **Carmarthen 16th December 2008**
27 people attended including 2 people with learning disabilities.

We would wish to acknowledge and thank the Welsh Assembly Government for their financial assistance in making these events possible.

A copy of the report from the events is attached.

The consultation process initiated by the Welsh Assembly Government asked two questions.

1. Is there a need for the Welsh Assembly Government to issue an Action Plan to accompany the ‘Statement on Policy and Practice for Adults with a Learning Disability’?”

We want to acknowledge and welcome the work that has been undertaken by the Ministers Learning Disability Implementation Advisory Group (LDIAG) and by officials to prepare the draft Action Plan for consultation. The Group continues to be the only route for voluntary organisations, people with learning disabilities and carers to influence the review and development of policy and services. Most critically it allows examination of all relevant services, ranging across education, health, lifelong learning, social care and vocational training in a holistic and joined up manner.

We want the Welsh Assembly Government to give higher priority to securing services and support for adults with learning disability that fulfil the principles set out in the original 1984 All Wales Learning Disability Strategy .

While several subsequent policy statements have been developed and issued since 1984, there is still a very substantial gap between stated all Wales policy intentions and the reality

of life as experienced by adults with learning disabilities and their carers. Our very strong view is that the intentions set out by the Welsh Office over 20 years ago, and regularly re-endorsed by successive Welsh Assembly Government administrations have still not been fulfilled.

Services should be developed for the individual through a person centred approach, and designed to help the individual overcome the discrimination and barriers to an inclusive life in the community that they frequently face.

There is anecdotal evidence that for some individuals a combination of ever tightening eligibility criteria, adverse changes in commissioning practice and service reviews have resulted in inappropriate cuts in the services they have received and a widening gap between the rhetoric of the strategy principles and the reality of individual experience.

Detailed points about how the format and content of the Action Plan could be strengthened follow. In its current form, however, we are not convinced that the combination of the Action Plan with the 2007 Policy Statement and the Service Principles/Service Responses document will be sufficiently robust to transform the experiences of individuals in their everyday lives.

Alongside these points about how the Action Plan could be effectively strengthened, we would wish to restate the call that we originally made nearly 10 years ago for consideration to be given to the issuing of a National Service Framework for learning disabilities. An initiative of this nature would give a status and priority to learning disability provision at local level that has plainly been absent. It could also usefully gather together and rationalise the guidance that is currently distributed across the Policy Statement, Service Principles/Responses and the Action Plan.

The Action Plan in its current form is more a reworked statement of principles and policy. We support many of the points made in its narrative sections but they do frequently repeat and rework ground covered by the 2007 Policy Statement. We are concerned that key decision makers and stakeholders alike may be confused and unclear about the relationship between the three documents. Our dilemma in commenting on the action plan is that suggesting that further points be added to the narrative will merely add to the duplication and repetition across the three policy documents without any improvement in local delivery.

We would like the Action Plan to be a much more concise document which spells out how it relates to the other two policy documents, focuses on actions that are specific to the learning disability field and highlights and groups together all proposed action points.

We would like to see the action plan identify;

- SMART targets (Specific, Measurable, Achievable, Relevant, Time related) that are more outcome than output based
- clearly defined actions – what will be done to reach targets
- the organisations and agencies responsible/accountable for actions.

So that the action plan is effective, has an impact upon policy and practice and meaningfully benefits the lives of adults with learning disabilities we would recommend;

- the plan should be reviewed and reported upon on an annual basis

- an implementation taskforce is established which could work with local authorities to encourage, assist with and monitor change
- a civil service post within WAG, dedicated to learning disability policy and practice should be created
- consideration should be given to establishing a Learning Disability Commissioner for Wales.

Before the Action Plan is finalised and published it should be revised and amended to reflect the impact of;

- the reorganisation of Local Health Boards and NHS trusts
- the review of Health Commission Wales and any consequences for the commissioning of continuing health care and/or special/forensic care commissioning
- the increasing adoption of outcome based commissioning
- the increase in provision of individual budgets by local authorities
- the introduction of self directed support by some local authorities
- the rise of shared home ownership schemes
- any decisions arising from the 'Who Pays for Care' consultation
- workforce planning and training initiatives arising from the 'Fulfilled Lives, Supportive Communities' ten year social care agenda
- the implementation of the ASD Action Plan.

We would ask that in taking forward policy development at an all Wales level special consideration is given to the more effective input and participation of adults with learning disability. Though the reasons for this are self evident they should be highlighted;

- it will provide a powerful indication that the implications of the strategy principles are being reflected at an all Wales level and that real progress in the status accorded to people with learning disability in Wales is being made
- it will reflect the spirit and content of the UN Convention on the Rights of Disabled People and the All Wales People First Manifesto
- it will demonstrate that the emphasis on inclusion and participation in the Policy Statement and Action Plan is being practised at an all Wales level, 'do as we do' not merely 'do as we say'.
- It could provide a best practice example that county and local agencies could learn from
- It will ensure that policy- making work at national level is more fully informed by the realities experienced at local level.

Discussions should take place with All Wales People First and other interested parties to consider this proposal.

Finally we would note that the Action Plan includes some very specific targets that have major funding/capacity/resource implications, but these implications have not been addressed.

Without strong leadership and additional resources we are not convinced that the Action Plan and Policy Statement will have the required substantial impact.

2. If the answer is yes to Question 1 are:

- **the areas covered by the proposed Action Plan comprehensive and appropriate?**
- **should any part of the proposed Action Plan text be amended? If so how?**

We shall first respond to those sections of the Action Plan that directly impact upon adults with learning disability and their carers, and are identified in the plan as 'Implementation Priorities'. We then look at the sections on 'Investing in Continuous Improvement', 'Moving Towards Effective Services' and 'New Investment Priorities'.

Implementation Priorities

Person Centred Planning

We support the points made about;

- the review of the Unified Assessment Process ,
- people being at the centre of any planning process and the objectives of planning activity
- having a named care co-ordinator
- plans being subject to a minimum annual review
- plans being capable of evaluation

The target date of 2009 will need to be revised and we are not clear how achievable the target is and who will monitor progress at county level and when. We are not confident that there are sufficient people skilled in PCP work available at this point to allow substantial progress towards the targets identified.

Individuals may not want a PCP and this should be recognised.

Transition

We support the points made in the narrative and the target. PCPs and arrangements should also apply at other times of transition.

Accessible information

We find the narrative weak and are disappointed that no target is identified. The absence of relevant and accessible information provided in an appropriate way is a major barrier for people with learning disabilities, many of whom cannot read or write.

Advocacy

We support the points made in the narrative and welcome the commitment to consider developing an advocacy strategy. Our sole concern is about the suggestion that local advocacy groups merge into larger geographical agencies as this could lose the local, grass roots benefit that the current system promotes.

It is essential that the independence of advocacy is preserved and considered in any future arrangements for funding.

We would like to see a particular policy focus on addressing the advocacy needs of individuals with more substantial disabilities and individuals placed out of county.

Community Living

We support the points made in the narrative about;

- the development of joint strategic plans for accommodation
- the review of Circular 1/91
- the importance of friendships in transition
- the importance of individuals being able to live in their own locality
- encouraging new models of support that further independence
- commissioning accommodation locally for people with more substantial support needs
- out of home health treatments
- the review of private and voluntary healthcare
- the participation of service users in the recruitment of staff that will work with them.

We also cautiously welcome the interest in reviewing expenditure and seeking to reinvest savings. We trust that the forthcoming commissioning guidance will put in place sufficient quality safeguards so that this will not just be seen as a further cost stripping opportunity by commissioners. We note voluntary sector providers have been required to meet challenging cost savings year on year for many years now, and this environment has not encouraged a confident approach to innovation.

We would like a stronger commitment to recognising the tenancy rights of people and their right to be consulted about any changes in people sharing their accommodation.

We would like to see additional targets that progress beyond the initial requirement to have a plan in place.

We would like the action plan to seek engagement with and address some of the generic providers of service which are frequently paid for by WAG and can have an important bearing on furthering the inclusion of people with learning disabilities in their local community. Public transport and services provided by local authorities like leisure centres are examples.

Better support and transport to help people better engage in mainstream community life will promote further independence, community inclusion and the development of natural support networks.

Health Needs

We support the points made in the narrative about;

- the right to an annual health check
- health needs being met at home, including for those people with more complex physical or mental health needs
- monitoring by the National Public Health Service
- access to all public health screenings and initiatives
- access to dentists
- full access to appropriate mental health services
- training for generic health care staff
- support to carers
- joint and pooled budgets.

We support the targets identified.

We would ask that all people with learning disabilities should have a Discharge Planning Meeting prior to any discharge from hospital and that targets should be placed on providing additional home care on discharge from hospital where needed. It is also suggested that Wales adopt a system of Liaison/Link nurses in hospitals as is the case in England.

Challenging Behaviours

We support the points made in the narrative about;

- joint planning
- early identification and assessment
- availability of expertise
- availability of specialist psychiatric services
- better coordination between agencies about offenders
- availability of local care and support
- reviewing out of county spending and outcomes achieved for the individuals concerned.

We particularly welcome the proposal to review the working of the continuing health care guidance.

We support the targets identified.

Families and carers

We support the points made in the narrative about;

- developing procedures to inform carers about carer assessments
- Carer Information Packs
- Recognising their role in PCP and decision making and strategic planning
- Access to short breaks
- Family friendly employment policies.

We are disappointed that there are no specific targets in the Action Plan that will benefit carers.

Employment & Day Services

We support the points made in the narrative about;

- improving vocational training
- assessment about appropriateness of vocational training as part of transition plan
- greater co-ordination
- provision of locally available range of employment and day time occupation options
- recognition of usefulness of supported employment
- priority for replacing traditional large day centres
- meeting individual interests and ambition.

We note that benefits awareness and take up campaigns can help improve the financial viability of taking up employment and alleviate the problems for families if someone takes up employment. We would encourage WAG to consider the cost benefits of funding targeted take up campaigns and access the skills of organisations like Mencap Cymru.

We would ask that better statistics be kept on all aspects of employment and day services, including numbers of people in different options.

We would note that F.E. college courses should be relevant to jobs available, not merely contribute to perpetual training and suggest that college funding could be related to outcomes achieved by people. We would also note that there should be a reasonable prospect of employment before someone is placed on a job-taster scheme.

We would ask that local authorities be required to set a better example on employing people with learning disabilities by setting a target.

We welcome the targets identified.

We also welcome the statement in the narrative that WAG will develop an all Wales Supported Employment Strategy but are not clear why there is no associated target.

We are convinced that as in the development of new models of supported living, the Supported Employment Strategy will only blossom if the creativity and flexibility of voluntary sector providers is fully encouraged and utilised. Current voluntary sector provision is largely dependent on a rag-bag of piecemeal and short term funding or European project funding.

Investing in Continuous Improvement

Performance Monitoring and Management

We welcome the initiatives being taken by WAG on a Charter for service users and carers and on minimum data sets. However, it is not clear whether these actions are an integral part of the action plan or whether they are merely being reported on for information and therefore whether they then need to be described in such detail.

Workforce Planning

The initiatives described here are welcome but have a wider scope than just learning disability. Again it is not clear whether they should be described so fully in this action plan.

More sophisticated Commissioning

We support the points made in the narrative but are disappointed that there are no actions or targets identified.

Maximising Developmental Learning

We strongly support the points made in the narrative. We recognise that, while the 22 local authorities have the lead role for learning disabilities, they range enormously in their size, level of resources, and the staff skill mix they have to plan, commission and deliver services. We think it essential that in a relatively small country the skills, knowledge, expertise and enthusiasm that are present amongst many professionals working in the range of organisations active in the field of learning disability must be far more effectively shared and networked.

In line with the 'Making Connections' agenda this networking activity must work across agencies and organisations and include the valuable perspective of citizens, people with learning disabilities and their carers.

We would suggest that, in the light of our track record in networking, facilitating, information dissemination and developing training programmes, Learning Disability Wales would be well placed to coordinate a Learning Network.

External Advisory Group

We support the proposal in the narrative to establish a new Advisory Group. Membership should be kept to a small number and members be required to make an active contribution to the work of the group.

Implementation Task Force

We support this proposal.

Research

We fully support the initiative to develop the Learning Disability and Autism Research network and would wish to see the expertise of the Welsh Centre and the other Welsh research centres more fully utilised.

Moving Towards More Cost Effective Services

Reducing Reliance on Staff in Supported Accommodation

We fully support the points made in the narrative but believe that they do not sit well in an Action Plan and should be in a National Service Framework or revised Policy Statement

Resettling People in Out of Area Placements

We fully support the points made in the narrative but would again note that they do not sit well in an Action Plan.

Expansion of Supported Employment

We fully support the points made in the narrative but note that they repeat points made in the 'Implementation Priorities' section and again do not sit well in an Action Plan.

New Investment Priorities

We are very pleased that, despite the difficult economic future facing the U.K., the Action Plan proposes targeted additional funding. We support the compelling case that a review of the statistical information makes for additional funding for supported accommodation. The certainty of securing a home that an individual with a learning disability can call their own has to be the most pressing concern for all, whether they be the individual, their relatives, advocates or professionals.

We also support the second priority for funding being on day opportunities and supported employment.

All Wales Forum of Parents and Carers/ All Wales People First/ Learning Disability Wales/ Mencap Cymru

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