

Evidence to the Independent Commission on Social Services in Wales submitted by Learning Disability Wales

Learning Disability Wales is the umbrella body for over 120 voluntary organisations in Wales active in supporting children and adults with learning disabilities and their carers. Our members include organisations large and small who provide services, advocacy organisations, parent carer groups and generic organisations. Particular contributions to this paper have been made by Cartrefi Cymru, Touch Trust and Mudiad Ysgolion Meithrin.

Summary

We have identified 8 key areas where we believe that substantial changes in social care and social services need to be made. As requested we set out existing strengths, barriers and actions that should be taken. For simplicities sake, most actions only identify WAG as the actor. In almost all of these actions the active participation of other stakeholders will be required if the action is to be successful.

1. Services for Disabled Children and Young People

Strengths;

The Welsh Assembly Government (W.A.G.) have acknowledged the very variable range and quality of services provided to disabled children and have made a commitment through 'We're on the Way' to improve them.

Partial funding has been provided to begin the creation of a network of transition key workers.

Specific Barriers;

Disabled children continue to be at the bottom of the list when local authorities self audit their performance against the National Service Framework standards. There is an increasing gulf between the services parents can access in England compared to Wales.

The transition years between being a child and an adult are a critical time when the correct support can ensure a decreasing reliance upon services and an increasing independence on the part of the individual. All too frequently young people with learning disabilities are funnelled into a lifelong dependence upon social care day services or an endless series of training courses at Further Education College that fail to foster independence.

Action;

- *Disabled children should be able to access integrated pre-school playgroups to the same frequency each week as their non-disabled peers and not have to remain on waiting lists*
- *Young disabled people should have equal opportunities to have things to do and places to go as their non-disabled peers*
- *Appropriate wheelchairs and mobility aids to be supplied to children and young people within timescales that recognise the speed of child development*

- Transition key workers to be provided for each young person approaching transition and a seamless agreed transfer from child to adult services with 'no detriment' in quality of support are essential.

2. Unified Assessment for Adults and Eligibility Criteria

Strengths;

W.A.G. has recognised the need to review the U.A. process.

Specific Barriers;

The Unified Assessment process was originally designed with older people in mind. It does not reflect the 'encouraging independence' ethos that directs WAG learning disability policy. The documentation required is very substantial and unwieldy.

Eligibility criteria are tightening up all the time and vary across local authorities. This creates the 'postcode lottery' that many users of service find unfair and inexplicable.

We are concerned that through tightening eligibility criteria social service departments are writing themselves out of being the guardian of all citizens who need social care or social service assistance. An increasing number of citizens are falling out of this safety net because they do not meet the outdated learning disability test of having an I.Q. of less than 70. Are the costs being saved by social service departments at this point merely being picked up elsewhere by other state and local govt. agencies?

Individuals requiring social care are frequently unaware or confused about their rights. It is not in the short term interest of social service departments to spell out these rights and entitlements. Leonard Cheshire and the Multiple Sclerosis Society are promoting the adoption of a Social Care Charter of Rights.

Action;

- We need a person centred planning led assessment process that reflects the ethos of increasing the individual's independence, is consistent across Wales and is not compromised by being a rationing tool.

- Consideration should be given to the introduction of a Social Care Charter of Rights for Welsh Citizens

3. Continuing Health Care

Strengths;

The complex needs of some individuals are being met, with funding secured through assessment for 'continuing health care'.

Barriers;

The categorisation of an increasing number of people with learning disabilities as needing 'continuing health care' undermines the long established and widely supported W.A.G. and Welsh Office policy that social services leads on the commissioning and funding of services for people with learning disabilities.

This policy has ensured clarity and that learning disability services are rooted in the social model of disability.

The CHC process creates perverse incentives to shunt costs from social services to health and often results in a medicalised and inflexible pattern of service being provided for the individual. The commissioning process is often uninformed, paying little attention to promoting independence.

The AWASH tool used to provide an assessment framework for transfer to continuing health care is crude and arguably could allow very many people to be inappropriately assessed as requiring continuing health care. People with learning disabilities are not ill and do not require healthcare per se.

Transfer to 'continuing health care' precludes the individual from seeking a direct payment to meet his/her needs since the NHS cannot sanction any direct payments. Apparently this position may be open to legal challenge.

Assessment for CHC and related negotiations are enormously wasteful of the time of skilled social service and health service staff. A recent study in Gwent calculates that 60% of the time of community nurse managers is taken up with work on assessments.

Action;

- *WAG to end CHC for all people with learning disabilities and place all responsibility for meeting intensive needs and funding with social services*
- *health interventions to continue to be delivered by health professionals through joint teams*

3. Demand for Accommodation and Support for Adults

Specific Barriers;

Substantial bottled up demand for these services is building up as adults with learning disability continue to be cared for at home by increasingly elder parents or family carers. This concern has been communicated to W.A.G from several quarters, but no additional funding has been offered.

Absence of capital funding and revenue funding at local authority level will prevent action being taken. There is a substantial and fundamental weakness in cross departmental planning between social services and housing departments, with only a small minority of local authorities identifying the needs of adults with learning disability in their Housing Strategies.

A proportion of this demand for accommodation is likely to be met through very high cost unplanned responses to a family emergency.

There has been an absence of innovation and smarter thinking about accommodation support and there have been few incentives to encourage this. Individuals may sometimes remain in group homes when they may be capable of living more independently and the Chief Inspector of Social Services, in his 2008/09 report, noted that there had been no expansion in the provision of assistive technology to support people.

There has been a similar absence of innovation in day services for adults. Many people with learning disabilities have been required to access traditional day centres for their whole adult life, with all the costs that this entails. Opportunities continue to be missed to encourage the independence of these individuals. Relatively small expenditure early on could considerably reduce demand upon social service budgets later.

Action;

- WAG to provide additional capital and revenue funding.
- WAG to require coherent joint planning by social service and housing depts. to identify capital and revenue cash needs
- WAG to invest funds for greater development of, and experimentation in, shared ownership models of tenancy
- WAG to introduce incentives to encourage the introduction of appropriate and ethical assistive technology
- WAG to place greater emphasis upon and incentives to achieve move-on from group homes to more independent models of service for adults with learning disabilities
- WAG and social services to 'invest to save' in more progressive models of vocational training and supported employment

4. Parents with Learning Disabilities

Strengths;

WAG has accepted that there needs to be policy and guidance in this area. They commissioned a research report from LDW that they are now considering.

Specific Barriers;

People with learning disabilities are frequently discriminated against. LDW has participated in a UK project to address the needs of people with a learning disability. There are too many stories of parents with learning

disabilities being subjectively judged about their parenting skills and of children being removed from their care. These actions may in the long term create more dysfunctional families and more young people in the long term care of local authorities, with all the additional costs that this entails.

Substantial work needs to be undertaken with childcare teams in social services and with NHS professionals to ensure that a better approach is made to these difficult and emotive matters.

Action;

- *WAG to develop policy and guidance*
- *Better support and assistance to be provided to parent*

5. Advocacy

Strengths;

WAG has given priority to securing access to advocacy for all children in Wales. Work has taken place on standard setting and the creation of a comprehensive network of services.

There is a network of self advocacy, paid advocacy, citizen advocacy and crisis advocacy groups for adults with learning disability in Wales, albeit fragile. A WAG grant has assisted in strengthening the network.

The actions of advocates can be important in securing movement and change in the delivery of services and can bring cost savings for commissioners of social care services.

Specific Barriers;

The network is very fragile and the sustainability of many groups is constantly in question.

Action;

- *WAG Grant to be continued*
- *Advocacy groups to be assisted to improve their capability and capacity*

5. Budget Cuts

Strengths;

W.A.G. has recognised that the ambitions of 'Fulfilled Lives, Supportive Communities' cannot be achieved without a substantial change being effected in the way that services are commissioned and organised and has created the Independent Commission. The need for this review has been heightened by the international financial crisis and impending cuts in government expenditure.

Barriers;

Is the Commissions report going to arrive a year too late? To what extent will local authorities take the time honoured path of always looking first to 'salami slicing' efficiency savings and to cut funding to third sector organisations through re-tendering, ceasing non-statutory activities or cutting grants.

A different approach needs to be taken that starts from the position of outcomes to be achieved for individuals, looks to reduce competition and duplication amongst all relevant agencies, seeks to harness and enhance the capacity of community supports and helps people with learning disabilities who wish to move away from dependence on services to do so.

Very substantial amounts of cash are tied up in existing services and ways of doing things with little in the way of re-thinking the approach.

Action;

- *Strategic planning should take a far more holistic approach to meeting need based on the creation of joint budgets, joint teams and a fairer assessment of who does what best*
- *Budget review processes need to look in a much fairer way comparing true vol. sect unit costs against true local authority and n.h.s. unit costs*

6. Personalisation and Citizen Directed Support

Strengths;

W.A.G. has recognised that personalisation needs to take a route in Wales that complements Welsh social care principles, maintains social services responsibility and accountability, respects Welsh cultural norms, favours collaboration and co-direction over market led approaches and is not cost driven.

Barriers;

It is equally clear that action needs to be taken to encourage development of a Welsh model if frustrations on the part of service users and their carers with narrow, inflexible, standardized packages of care are not to boil over. Developments in England are being noticed and there is a risk that opposition to the 'In Control' approach being taken in England will merely be seen as reactionary.

Action;

- *WAG to set out a clear direction of travel on self- directed / co directed support, to establish leadership roles and support experimentation and sharing through networks of all stakeholders.*

7. Structural Change

Strengths;

WAG has established mechanisms to allow joint budgets between social services and health and has encouraged collaboration between social service departments through initiatives like the SSIA and ADSS collaboratives.

WAG is introducing new guidance on commissioning, and encouraged the development of occupational standards for commissioning staff.

WAG has created the County Social Care Workforce Development Partnerships that have enabled the third sector to access more staff training.

WAG and Care Council have created the regional social care partnerships to encourage a one sector/one workforce approach to recruitment, retention and training. These are unique fora, bringing together all stakeholders.

Barriers;

Joint budgets and joint teams between social services and health are an essential building block to the creation of seamless services for all client groups. The pace of their development has been very slow and contrasts markedly with England.

The key role of social services in combating poverty has not been grasped by social services. This has many personal consequences for a substantial section of the Welsh population and certainly for people with learning disabilities.

The skills and expertise are still not being appropriately utilised by local authorities.

Commissioning processes do not yet offer a level 'playing field' to the third sector. Costs are not fairly compared and the third sector is required to pay its support staff at rates substantially below statutory agencies.

The increase in the number of direct payments to people with learning disabilities has been very slow, particularly when compared to England.

Action;

- *WAG to drive up the number of joint budgets and joint teams*
- *WAG to further strengthen the role of SDWDP's and regional social care partnerships*
- *WAG to secure an equality of approach to utilising the Third Sector*
- *WAG to increase use of direct payments*
- *WAG to secure increased collaboration between social service departments*

8. Lip-service to Participation

Strengths;

All WAG policies emphasize that services must be planned with the central involvement of the individuals and their parents and carers.

Barriers;

While there is some evidence that pcp led approaches are developing at an individual level, there is every indication that there is less involvement of individuals and their parents and carers at a strategic level.

Current tendering processes are frequently conducted by social service departments with no steps being taken to apprise the service users or their carers of what is happening or to involve them in the selection of the provider.

Action;

- *WAG to review strategic county planning arrangements so that there is genuine participation by people with learning disabilities and their carers*

- *Commissioning processes are altered so that the rights of service users are properly acknowledged and so that they and their carers play an important role in selection and monitoring of providers*

Learning Disability Wales

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