

Disability Equality Scheme:

Setting the Priorities

Summary of Engagement Events

April – June 2006

Meetings facilitated, and summary prepared by

Marcus Longley

Professor of Applied Health Policy; Associate Director, Welsh Institute for Health and Social Care



Welsh Institute for Health and Social Care, University of Glamorgan,
Pontypridd, CF37 1DL
Tel.: 01443 483070 Fax.: 01443 483079
mlongley@glam.ac.uk <http://www.glam.ac.uk/wihsc>



THIS SUMMARY

This is an account of four 'engagement meetings' held in Mold (26th April, 2006), Aberystwyth (28th April 2006), Cardiff (2nd May 2006) and Cardiff (26th June 2006). The meetings were organised jointly by Welsh Assembly Government (WAG) and the Assembly Parliamentary Service (APS), with help from Disability Wales. Their purpose was to start involving disabled people and their representatives to help identify priorities for the WAG and APS Disability Equality Scheme Action Plans. Each meeting lasted for about three hours, and explored general issues relating to the responsibilities of WAG and APS, and also several specific policy areas, including Training and Education, Health and Social Care, Housing, Transport and Travel, Planning and Sustainable Communities, Economic Development and the future processes for engagement. The emphasis was on finding out the priorities of the participants, rather than any pre-determined agenda of Welsh Assembly Government (WAG) and the Assembly Parliamentary Service (APS).

The report is in two parts:

- the first is the key general issues that relate to WAG and APS; and
- the second is a list of specific issues relating to the various policy areas discussed.

Wherever possible, the words are those of the participants themselves, as captured during the events.

COMMON THEMES

A relatively small number of issues were raised time and again by the participants as having fundamental importance:

Need for Action

Disabled people have been involved in many engagement events organised by the public sector in Wales, over many years, and there is little progress to show for much of it. There is still so much to achieve in terms of disability equality, so it is vital that whatever results from these meetings does not 'gather dust on a shelf' – it should ensure that action on disability issues becomes mainstream for WAG and APS.

Respect

There are many examples throughout public services in Wales where the wishes and needs of disabled people are not adequately considered, and where they are not accorded the same consideration as the rest of the population. For example, assessments of need are still being made without the full involvement of the disabled person concerned. There is still a major effort required to ensure that all public servants are aware of their legal and professional obligations to accord disabled people the respect to which they are entitled.

Understand and Implement the Social Model of Disability

Much could be done to address the respect deficit if all public servants were aware of, and understood, the Social Model of Disability. It would appear currently that most do not, with the result that they and their organisations are still not doing all they can to avoid disabling people. There is a major staff information and development agenda here, and all key staff groups should be required to receive a standard level of disability equality awareness training.

The Assembly should look critically at how language is used in its policies and communication and should look to ensure that it is always consistent with best practice.

All published information and forms should be in accessible format (e.g. Arial 14pt) and should be readily available in alternate formats (e.g. Braille). There should be a commitment to make “easy read” documents available as a matter of course.

Income inequality

At the heart of many of the issues facing disabled people is income inequality. Many disabled people live on low incomes, and their exclusion from economic activity further exacerbates this problem. Though this is not a devolved matter WAG and the APS should ensure that they take full account of this when developing policy which affects disabled people.

Assembly Leadership

The Assembly and WAG have great potential to improve the quality of life of disabled people in Wales. *First*, they should ensure that disability issues are addressed within their work environment and ensure that disabled employees receive training and support in order to enable them to fulfil their potential and take advantage of developmental opportunities. *Second*, they need to ensure that other agencies in public life in Wales do the same. This latter is particularly important in the context of local government, where there are many examples of local authorities failing to accord sufficient priority to disability issues, and in health, where service provision varies significantly between areas. The Assembly should use a combination of information, cajoling and the setting of national standards to ensure that local government and all parts of the NHS bear their proper share of responsibility in this area.

Equality between Disabled Groups

WAG and the APS should consider equally the needs of *all disabled individuals* rather than looking at disabled people as ‘groups’.

Links between the Assembly and North Wales

Disabled people in North Wales feel detached from the Assembly and would particularly welcome more time and resources devoted to identifying and addressing their needs.

Involvement

The four events reported here are the beginning of a process, with the aim of substantially widening participation as the process continues (including those groups which are traditionally the hardest to reach). It is vital to ensure that disabled people are fully involved in the development and review of all policy areas within WAG and APS, since all have relevance to disabled people. In doing this, better use could be made of existing involvement structures. Further details are set out below in the section on Engagement; in addition, Disability Wales' project 'Disability Equality in Action' will provide a Best Practice Database.

Data Collection and Impact Assessments

APS and WAG need to look at their current evidence base and start (i) filling in any information gaps that exist (ii) disaggregating existing data that is already being collected.

An impact assessment tool should be developed as part of the existing policy making machinery to ensure that disability issues are considered from the outset in the development of any new policy.

SUBJECT-SPECIFIC THEMES

Training and Education

1. Access to education and training premises and facilities for disabled people of all ages and abilities is still inadequate.
2. Disability equality training should be included as part of the curriculum in schools so as to raise awareness of disability issues before barriers are built.
3. BSL should be easily available in all schools and all pupils should be taught how to use it.
4. Teachers are not sufficiently aware of the needs and wishes of disabled people – disabled people should be engaged to raise their awareness, as part of the overall staff development strategy
5. The transition between the various stages in education (e.g. KS2 to KS3, child to adult) is often difficult.
6. More positive role models are needed in schools e.g. more disabled teachers, governors, visitors.
7. The post-16 assessment processes most commonly used are based on testing and do not properly measure the different abilities of disabled people.
8. Disabled children who do not attend their local school often miss out on out-of-school activities (e.g. breakfast clubs, after-school groups) because of the inflexible nature of free school transport.

Health and Social Care

1. Joint commissioning between health and social care is still underdeveloped, with disabled people experiencing dis-jointed services as a result. There should be more shared/pooled policies and budgets.
2. The distinction between health and 'social' needs for charging purposes should be abolished. Models of delivery and funding

should be investigated that are equitable and fair and that do not place unfair financial burdens on disabled people.

3. Ring-fencing of budgets in local authorities is an effective way of ensuring that the needs of disabled people are properly addressed – without them there is a danger that a combination of general financial pressures, and the perception that disabled people are a small minority, may result in inadequate attention to disability and funding issues.
4. Disabled people still do not enjoy equality of access to many NHS buildings and services, not just in terms of physical access to the buildings but the public transport to get there:
 - Many services - e.g. physiotherapy - are not available locally for disabled people;
 - Out-of-hours services do not always recognise the greater difficulties of disabled people in getting to medical centres;
 - Many buildings do not have adequate physical access for disabled people; and
 - The current service re-design in healthcare – *Designed for Life* – does not appear to take account of the much greater difficulty of disabled people in travelling to more remote hospitals, in terms of accessible transport, available routes and the cost this incurs e.g. the impact of the centralisation of services on Carmarthenshire for disabled people living in Ceredigion.
5. Services do not always in practice recognise the *rights* of disabled people – there is often a perceived feeling that disabled people should be *grateful* for what they get, and that sometimes it will be too difficult or expensive to meet their full needs. Similarly, services are not always responsive to the needs and wishes of disabled people - they sometimes appear to be set up and run for the convenience of their staff rather than the service users. There should be a general recognition that usually disabled people understand their own circumstances far better than do those providing services to them and that they have a right to receive appropriate services for their needs.

6. Many staff are not aware of the needs of disabled people, especially those with 'hidden' disabilities, or are reluctant to meet them. Primary care staff are especially important in this context, including both clinical staff and receptionists. Staff may need training in meeting the needs of particular disabled people e.g. administering injections to some people with learning disabilities.
7. More NHS staff should be competent in the use of British Sign Language.
8. It is difficult for disabled people to know what services they are entitled to – a statement of entitlements and clear rights for all are needed.
9. Services are not always honest about what they provide and the constraints under which they have to operate – greater honesty would improve the relationship with disabled people, and would allow them to make informed choices about what should be made available now, and in the future.
10. Wales' various inspectorate functions have an important role to play in ensuring that disabled issues are being addressed in reality. There should be effective mechanisms for ensuring that all parts of the service adhere to accepted good practice.
11. It is difficult for disabled people to exert real influence on the planning and provision of local services. Similarly, Social Services provision is often not user-led – staff still sometimes make decisions without allowing the service user to say what they need. Furthermore, risk assessments carried out by service providers may unnecessarily restrict the choice of service users.
12. The transition from children's to adult services is often not smooth, with many people left without adequate services when they are deemed to have become 'adults'.
13. Long waits for care (primary and secondary) are having an adverse effect on disabled people e.g. delays in accessing the psychology service.
14. Nurse-led clinics and nurse prescribing are welcomed, but it is still often necessary to make an appointment with the GP to get a straightforward prescription.

15. Clinical staff do not always read the notes of disabled patients before appointments, with the result that such patients often have to repeat their history to staff.
16. More effort should be devoted to promoting the uptake of independent living schemes.

Housing

1. Many disabled people find interaction with the administration of housing particularly difficult:
 - There should be a strategic approach to funding disability groups to advocate for people in housing matters and to help them complete forms etc;
 - Many disabled people are not aware of what support is available to them – WAG, NHS Trusts, Local Health Boards, Social Services Departments and others should proactively promote benefits; and
 - Grants to support independent living are complicated to apply for and take a long time to be approved; the forms are impossible for many learning disabled people to complete and ask intrusive personal and unnecessary questions.
2. Different agencies providing adaptations should work co-operatively to the same standards. In particular, assessments for adaptations should be carried out when people first go into hospital so that the work can be carried out before they are discharged – this is not always happening.
3. Local registers of accessible housing are not always up-to-date – this should form the basis of a performance indicator.
4. It is unfair that private house holders are means-tested for DFGs whereas council tenants are not.

Transport and Travel

1. In many parts of Wales – rural as well as urban - public transport is still often inaccessible to disabled people because of an ageing bus and train stock, and routes are limited by geographical coverage and frequency of service. This point is particularly pertinent and referred to in more detail under Health and Social Care.
2. There should be a review of policies, codes of practice and guidelines to make roads and pavements more accessible. For example, local authorities should be given discretionary powers to adapt Welsh ‘national’ roads to meet the needs of disabled people e.g. provision of drop curbs.
3. There should be a review of the planning application process to ensure that any new development (bridges, roads, pavements etc) are accessible to disabled people.
4. Simplified public transport information e.g. 24-hour clock timetables can be difficult to understand.
5. More disability awareness training should be provided for taxi drivers.
6. Any funding provided to Local Authorities to improve pedestrian and transport links should only be allocated on the proviso that the work carried out will be accessible to disabled people. This requirement should be monitored and enforced and money clawed back where a local authority has failed to comply.

Planning and Sustainable Communities

1. WAG should examine current practice on the issue of ‘blue badges’ to encourage consistency and reasonable charging – there is considerable inconsistency at the moment between local areas, and some authorities impose very high charges.
2. WAG should aim to clarify policy on designating car parking spaces for disabled people and ensure that disabled people are aware of that policy – several examples of unclear regulations

were cited e.g. can parking spaces be designated for specific individuals or are they available for all disabled people?

3. There is often insufficient involvement of disabled people and access experts in the planning of public buildings – guidance should be strengthened to ensure greater involvement.

Economic Development

1. Self-employed disabled people need continuing support to meet the additional costs associated with overcoming their disability.
2. There should be greater support for social enterprise involving disabled people.

Engagement and Involvement

1. 'Consultation' is too limited a concept – the aim should be the full involvement of disabled people from the point where an issue is first being considered (and not just from the point where options have been short-listed).
2. All aspects of the public sector in Wales should cooperate to develop and support an on-going network of disability groups who would ensure full involvement of disabled people.
3. Disabled people should be paid to take part in engagement activities, and provided with training and support where appropriate. It is important before all meetings to be clear about support available for participants – e.g. payments, travelling expenses, communication aids and support arrangements.
4. There are several existing structures for engaging with the public – such as the regional meetings of the Assembly – they should be given more publicity and disabled people encouraged to use them. There is a lack of awareness of regional committees - more effective publicity strategies should be developed e.g. use of AMs' distribution lists, local radio, WAG/APS web pages (<http://www.wales.gov.uk/keypubassemcommittees/index.htm>). Involvement events need much greater publicity in the media e.g. radio.

5. It is important to ensure that papers are distributed before any consultation meetings so that people can prepare beforehand. WAG should ensure that web sites contain all the necessary information for attending the meeting e.g. parking arrangements on the Assembly web site.
6. There should be feedback for all participants from any engagement events.
7. Special attention should be given to new and dedicated ways of engaging young disabled people. The Young Disabled Persons network (run by Children in Wales) could have an important role to play in this context.
8. There should be more events in North Wales – there is a strong perception that the Assembly has less interest in north Wales than in the south.
9. In addition to holding meetings, WAG should explore more creative ways of communicating with disabled people e.g. the use of talking pictures, music etc.
10. WAG should come out to disability groups much more frequently – but this is not a substitute for ensuring that disabled people can and do attend WAG meetings.
11. Good practice in the public sector should be publicised on the internet, so that disabled people themselves, and those responsible for service provision, can see what should be achieved everywhere.
12. Consultation must lead to changes. The Disability in Action project and the Best Practice Database that is currently under construction will cover a significant number of the issues raised about effective engagement. The development of Effective Consultation Guidance should emphasise the outcomes of the consultation process.
13. AMs still do not always respond to constituency communications from disabled people within the recognised maximum periods.

The Way Forward

The findings from these four engagement events have been fed through to the relevant Policy Departments within the Assembly Government. The recommendations made and issues raised by the participants of the events will be used to help Departments set the priorities for their Disability Duty Action Plan for the first year, and will provide a robust basis for the Strategic Equality and Diversity Unit in drafting the first Welsh Assembly Government Disability Equality Scheme. The Statutory Consultation period for the first draft of the scheme will commence in July 2006. All those who participated in the initial engagement events will be invited to comment on the draft scheme.