

Health and Social Services Committee

HSS(2)-03-07(p4)

Meeting date: Wednesday 7 February 2007

Venue: Committee Room 3, Senedd, National Assembly for Wales

Title: Update on the Implementation of Recommendations of the Committee's Previous Policy Reviews

Purpose

The Health and Social Services Committee has undertaken several policy reviews since 1999 and has requested an update on the implementation of the recommendations on the following:

- The implications for Wales of the Phillips (BSE) Inquiry Report;
- Services for Children with Special Health Needs;
- The Interface between Health and Social Care; and
- The National Service Framework for Adult Mental Health - Standard 2 - User and Carer Participation.

Summary / Recommendations

The Implications for Wales of the Phillips Inquiry Report into BSE

- The Phillips Inquiry report was published on 26 October 2000, and included findings and recommendations for the conduct of business relevant to all UK Health and Agriculture Departments. The terms of reference of the inquiry were:

"To establish and review the history of the emergence and identification of BSE and new variant CJD in the United Kingdom, and of the action taken in response to it up to 20 March 1996; to reach conclusions on the adequacy of that response, taking into account the state of knowledge at that time; and to report on these matters to the Minister of Agriculture, Fisheries and Food, the Secretary of State for Health and the Secretaries of State for Scotland, Wales and Northern Ireland."

The report set out 166 detailed findings from the examination of events relating to the BSE epidemic. It includes findings and recommendations for the conduct of business relevant to all UK Health Departments. Many of these were addressed on a pan-UK basis and National Assembly officials worked closely with Whitehall to prepare the Government's response.

Formally, the report was not made to the National Assembly for Wales, but many of the issues on which the report comments have been devolved and consequently fell to the National Assembly to

deal with. The Health and Social Service Committee took the lead in looking at protection of the human food chain and at the provision of care and support to victims and their families, whilst the Agriculture and Rural Affairs Committee focussed on the agricultural and animal health issues raised by the inquiry report.

After reviewing the issues, the joint report ‘The Implications for Wales of the Phillips (BSE) Inquiry’ was produced by the Health and Social Service Committee in conjunction with the Agriculture and Rural Affairs Committee, and made a number of conclusions and recommendations for implementation in Wales.

For the purposes of this Committee paper, an update on the progress of implementing the recommendations of the National Assembly for Wales report is provided in the Annex 1.

Services for Children with Special Health Needs

The Welsh Assembly Government has made significant progress in delivering the recommendations made by the Health and Social Services Committee in 2002, following its Review of Services for Children with Special Health Needs and in some areas, action has gone significantly further than the recommendation.

In Wales we do not just concentrate on one aspect of a child’s development, we are mindful of the close inter relation between their health, education and the environment in which they grow.

One of the driving forces in achieving optimum health and well being for all our children and young people is setting standards which will achieve this. That is why the National Service Framework (NSF) for Children, Young People and Maternity Services in Wales, launched by the First Minister in September 2005, was developed as a cross cutting strategy.

The NSF is a 10-year strategy that sets national standards to improve and reduce variation in service delivery for children and young people. The development of the NSF was an inclusive process involving professionals from all areas of children’s services as well as children, young people and their families. It contains 21 cross cutting standards and 203 specific and measurable key actions, which put children, young people and their families at the core of the services.

The Assembly Government believes that Wales can deliver on these standards through partnership and collaboration across organisations, enabling service planners, and providers to work effectively together.

A web based Self-Assessment Audit Tool (SAAT) has been developed to enable Children and Young People’s Partnership Frameworks to monitor progress in implementing the NSF standards. Organisations can use the SAAT as a benchmarking tool, and it also has the facility for organisations to use best practice.

One of the messages we took on board from children, young people and their families was that they often had to deal with many professionals and provide the same information time after time. As a

result of direct feedback from children and parents and carers during the consultation process undertaken for the Children's NSF we produced an All Wales Hand Held Record – "My Orange Book" for disabled children and young people with complex health needs.

We hope that 'My Orange Book' will help alleviate some of the anxiety and stress that families and carers of disabled children with complex needs feel at having to repeat the same story to the many professionals they are in contact with. The book is a family held record written as though the child had filled it in. It is written in a way that professionals and carers can have an understanding of the world through the eyes of the child. To date seven thousand copies of 'My Orange Book' have been distributed to Local Health Boards and a review will be carried out this year to measure the effectiveness of the initiative.

We launched the Autistic Spectrum Disorder (ASD) Strategic Action Plan Consultation Document on 30 January 2007, which covers both children's and adult services. It identifies the responsibilities at national and local level to deliver on specific actions that require a co-ordinated approach to planning, commissioning and the delivery of services for people with ASD across health, education and social services and with partners in other agencies and areas of non devolved responsibility. Children's health and well being must continue to be at the forefront of policy development.

An update of work carried out to date is at Annex 2.

The Interface between Health and Social Care

I set out my response to the Committee's report in Cabinet Written Statements on 4 and 10 May 2005. The Committee considered my response at its meeting on 13 July 2005. The update on each recommendation should be read in conjunction with my Written Statements and particularly that of 4 May also which responded recommendation by recommendation.

The publication of the Assembly Government's document "Making the Connections: Delivering Beyond Boundaries" (November 2006) broadens considerably the context for work at the interface of health and social care. The document sets out the Assembly Government's overall framework for public services in response to the Review of Local Service Delivery, chaired by Sir Jeremy Beecham, which reported in July 2006. It describes how we will transform the way that public services in Wales are delivered and experienced by citizens and how, working with our partners, we will:

- put citizens first;
- foster effective collaboration across the boundaries of organisations;
- promote new skills and redefined roles for the public services workforce;
- get better value for money for the investment in services; and
- lead and support change through new forms of partnership and local agreements.

This envisages a sharp shift to a public services ethos based on a new commitment to high quality, accountable, ethical and collaborative services focussed on the well being of the citizen. It means public services working well together, not letting the boundaries of between sectors, organisations or professions stand in the way of meeting people's needs.

It announces new models to work together to deliver locally. Local service boards, based on each local authority area will bring together the key contributors to local service delivery. Their role will be to improve delivery and undertake joint action in services including health and social care where good outcomes for citizens depend upon joined up action. Local service agreements will be developed between the boards and the Assembly Government to implement shared programmes of action.

‘Making the Connections: Delivering Beyond Boundaries’ foreshadows a number of specific policy statements which will help to deliver this framework, including ‘Fulfilled Lives, Supportive Communities’ which is due to issue in its final form in the next few weeks. ‘Fulfilled Lives...’ describes how modernised social services will contribute to a better Wales and to improving the lives of its citizens in the context of the vision of modernised services set out in ‘...Delivering Beyond Boundaries’.

Annex 3 provides more information on work carried out to date.

National Service Framework for Adult Mental Health – Standard 2

The Assembly Government has accepted 10 of the recommendations in full and two in principle. Many of the findings from the Committee's short policy review will be incorporated into the Assembly Government's revised mental health service user involvement guidance, an updated version of ‘Stronger in Partnership’ which is currently being developed.

A draft version is near completion. This will be subject to consultation with key stakeholders. It aims to give commissioners and providers better and more up to date advice on why involving service users is not an option but a requirement. It provides practical advice and information on how to effectively involve people who use or have used mental health services and their carers in the design, planning, delivery and evaluation of those services.

The mental health sector has led the way in developing systems and initiatives to involve people who use services in planning and delivering them. Some Welsh Trusts have introduced initiatives whereby service users sit on selection and recruitment panels for all clinical and managerial posts and have equal responsibility in appointing new staff.

Initiatives have also been developed to ensure that service users are involved in training, and of raising awareness for both new and established staff. Evidence shows that involving people in planning and developing health services contributes to changes in the provision of services across a range of different settings.

The Assembly Government requires commissioners and providers to ensure that service users and

their carers are genuinely, meaningfully and constructively involved in all aspects of mental health services. This is a fundamental principal of our adult mental health strategy published in 2001, and is one of the standards set out in 'Raising the Standard', the revised adult mental health National Service Framework published in 2005.

In Wales there is a network of 'Mental Health Development Workers' and 'Service User Involvement Development Workers' whose role is to help build capacity and ensure that service users views influence the development and delivery of services, and are empowered to take a lead in the running of projects.

The Committee's report and recommendations has proved an extremely useful tool, and health officials in the Assembly Government have copied its findings widely across the mental health sector in Wales. Many of the findings from the Committee's review are quoted extensively in new guidance on service user involvement currently being developed by the Assembly Government.

More information is available at Annex 4.

Background and Consideration

Progress on the reports' recommendations is set out in more detail in the following annexes:

Annex 1 – The implications for Wales of the Phillips (BSE) Enquiry Report:

Annex 2 – Services for Children with Special Health Needs;

Annex 3 – The Interface between Health and Social Care; and

Annex 4 – The National Service Framework for Adult Mental Health - Standard 2 - User and Carer Participation.

Compliance

There are no compliance issues. This paper is for information only.

Financial Implications

None.

Cross Cutting Themes

Where appropriate, these will be covered in the main body of the reports.

Action for Subject Committee

The Committee is invited to note progress on the three policy reviews.

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Annex 1a

HSSC Review of the implications for Wales of the Phillips Inquiry report into BSE.

Arrangements for Caring for Sufferers

1. Diagnosis of the disease

Conclusions and recommendations

(i) The development of an effective diagnostic test in the early stages of the disease is a priority.

Tonsil biopsy remains the main pre-morbid test for diagnosis of the disease. Samples continue to be collected following an announcement in September 2002 by the CMO England to establish a national archive of tonsils for use in research to establish the prevalence of variant CJD in the UK population. Following the OJEU tendering exercise, suitable tests for rapid screening on the stored tonsils have recently been identified and work on the prevalence of infection can proceed. It is anticipated that the first blood screening tests will become available shortly on the international market. Expert committees have advised the use of UK vs. US donor pools for assessment.

(ii) GPs should be made more aware of the early symptoms and signs of vCJD and have access to guidance on diagnosis and care planning.

Guidance was issued to GPs in Creutzfeldt-Jakob Disease: Guidance for Healthcare Workers – Issued 26 October 2000. The guidance contained advice on:

- Care requirements & Co-ordination
- Information needs & Communication
- Precautions, Risks & Infection control

The purpose of the guidance was to aid healthcare professionals caring for patients with Creutzfeldt-Jakob disease and their families. It also addressed patients' and families' care and information needs.

No specific new management guidance has been issued to GPs, but the information on vCJD blood associated cases and advice on individual management has been forwarded to specific GPs and other

parts of the service, including GPs, have been informed so as to continue to maintain a high profile of the disease.

(iii) The underlying causes of psychiatric symptoms should be investigated fully, whether or not vCJD is suspected.

It is part of good professional practice to investigate any underlying causes of organic illness that is causing a psychiatric disorder. Services for younger people with dementia were addressed within the 'Older Persons National Service Framework' (published March 2006) standard entitled 'Mental health in older people: including Dementia in Younger Adults' (page 132).

2. Further Guidance for Professionals on Care

Recommendation

- The National Assembly, working with the CJD Surveillance Unit, should ensure that comprehensive, multi-disciplinary guidance is disseminated and regularly updated.

Guidance on Transmissible Spongiform Encephalopathy (TSE) agents, safe working practices and the prevention of infection, was issued in March 1988, was subsequently revised in June 2003 after a review by the Advisory Committee on Dangerous Pathogens & the Spongiform Encephalopathy Advisory Committee. Further revisions of this guidance have continued to be placed in the public domain, the most recent in summer 2006. The guidance is aimed at staff working with human or animal TSEs in the laboratory, and provides advice also to those involved in the management and care of patients; on the handling of deceased patients; and on the minimisation of risks to other patients and staff.

The CJD Incident Panel's Framework guidance for the management of CJD Incidents has been accepted in the main by the UK CMO's. The panel agreed at their last meeting of 2006 that the framework is now due for a full review and revision where appropriate. This will be taken forward in 2007.

3. Mechanisms to Facilitate a Speedy Joint Response to Care Needs

Recommendation

- (i) Plans for meeting the needs of sufferers and their families should be an integral part of the joint working arrangements between the health service and social services.

The National CJD Care Team is based within the National CJD Surveillance Unit and was formed in response to concerns regarding the care of CJD patients. The Care team provides a co-ordinator who will work alongside the patient, their carer, professionals and other organisations involved in the patient's care, to provide advice, information and support. In addition, there is a team now working within Health Protection Agency that support the practical aspects of many of the management issues

around CJD.

The Unified Assessment Process (UAP) in Wales provides an assessment and care management approach to link victims with key professionals to provide a sound foundation for joint working with all service-user groups.

- (ii) Victims and their families should be able to fast track access to the aids and adaptations they need to help them to live as independently as possible.

A Care Fund is available through the National CJD Surveillance Unit. This is aimed to supplement local care provision for all strains of CJD, rather than replace it, as health and social services are required to provide necessary elements of the care package. Assessment of need is the basis by which access to and the provision of aids is determined.

4. The Role of a Key Worker

Recommendation

- (i) A key worker should be assigned to every vCJD case in consultation with the patient and his / her family or carers. The key worker should be responsible for drawing up and implementing the individual care plan with the patient and family or carers.

Staff from the National CJD Unit make an initial assessment of the patient's needs, and arrange ongoing care via the relevant Local Authority Social Services Departments. The Unified Assessment Process in Wales makes provision for the allocation of a care co-ordinator. This person may either be a social care or health professional, depending on which professional is best placed to meet the individual's needs. The Care Co-ordinator will hold responsibility, often on behalf of all agencies, to draft, monitor or review a person-centred care plan with family and carers.

5. Access to Care Budgets

Recommendation

- (i) The key worker should have a budget on which they are authorised to draw to meet patients' needs for care, aids and adaptations.

The key worker is able to apply to the National CJD Surveillance Unit's Care Fund. The Welsh Assembly Government holds a budget to reimburse these costs. It is recognised that access to the care funds should be as easy and non-bureaucratic as possible and that both critical and lower level needs are met.

6. Support for Families / Carers

Recommendations

- (i) The National Assembly for Wales should monitor the incidence of vCJD in Wales and keep under continual review the capacity of the CJD Care Co-ordinator(s) to meet the needs of sufferers in Wales, their families and carers. If necessary it should consider whether a separate care co-ordinator is needed for Wales.

There have been 158 cases of vCJD in the UK to date, 5 of which have occurred in Wales. The Wales figure has remained static for a number of years which is probably a reflection of the current decline in numbers, suggesting the first peak of cases is over. However, there is a need to continue to be conscious of the risks of person to person spread via blood and via contaminated surgical instruments. Wales was the first country to achieve EU accreditation of all its hospital sterilisation units. The incidence of vCJD, and indeed, all strains of CJD, are kept under review by the CJD surveillance unit in Edinburgh. There is no apparent evidence of an increase in numbers. The numbers of vCJD in Wales do not justify a need for a separate care co-ordinator in Wales at the present time.

- (ii) It should be part of the key worker's role to make sure that victims and their families and carers have early advice on any financial benefits to which they might be entitled and are given any help they may need in making and pursuing claims for benefit.

Part of the key worker's role is to provide financial advice to victims and their families. The Unified Assessment Process provides a vehicle which enables an assessment of families alongside the service-user, as part of an holistic approach, and provides for a separate, individual assessment of the carer as an individual within their own right. Some Local Authorities have separate staff/personnel who seek to help service-users maximise their income.

The CJD care-coordinator should integrate with Local Authority social workers, occupational therapists and health care professionals to ensure that duplication of roles and responsibilities were kept to a minimum. By law local authorities must charge for residential care and have discretion over whether to charge for non-residential care. To assist sufferers of CJD in accessing social services, the charging guidance that the Assembly Government issues to Local Authorities includes advice to cover CJD. In the "Charging for Residential Accommodation Guide", authorities are required to disregard any compensation payments made to CJD sufferers and their families during the charge assessment. In the "Fairer Charging Policies for Home Care and other Non-residential Social Services" good practice guidance, authorities are asked that users of non-residential social services suffering any form of CJD should not undergo a charge assessment, but should be treated as automatically exempt.

The Welsh Assembly Government's refocused carers' strategy for Wales, which was published for consultation on 21 December 2006, re-affirms carers' needs for information on services and benefits as a priority area. The consultation paper proposes working in partnership with carers and the statutory and voluntary sectors to develop a carers' information strategy. This will build on the existing range of sources of information and advice to ensure that carers have timely access to the information they need. The consultation runs until 26 February 2007.

7. Palliative and Hospice Care

Recommendation

- (i) The National Assembly should consider how palliative care for vCJD patients can be made available.

Palliative care services are an important part of the total care for people with vCJD. The responsibility for commissioning these services to assess and meet patient need rests with Local Health Boards working with their partners. The Assembly Government's overarching policy aim is to develop a more integrated approach to meeting patient need for palliative care between the NHS and the voluntary sector and is set out within 'A Strategic Direction for Palliative Care Services in Wales'.

The Assembly Government made ?10 million available non recurrently over four years to support and develop palliative care services within the voluntary sector. This funding has had a positive effect and has highlighted the need for continued support to ensure that the voluntary and statutory sectors work in partnership to provide palliative care services, based on patient need. The Assembly Government has therefore announced that as part of its budget for 2007-08 there will be ?2 million for hospices to provide them with recurrent core revenue funding, from central funds, for the first time. How this funding will be allocated is yet to be determined, but it will need to be informed by the recommendations of the baseline service review for palliative care, currently underway. This review once completed will help inform future commissioning.

8. Support for Families following the Death of a vCJD Patient

Recommendations

- (i) Bereaved families should be offered counselling, with special arrangements for children where required.

Affected families are able to obtain counselling through their GPs or through the Alzheimer's Society or a number of other bereavement counselling groups.

- (ii) The services of the key worker should continue to be made available to the family to help them through the transitional period following the death of the patient. This should extend to helping them make any adjustments to their lifestyle resulting from reduced income, or securing help for carers to return to employment.

Key workers continue to provide support for victim's families for a period after death.

9. Improving Public Information and Understanding

Recommendation

- (i) The National Assembly should consider what more can be done to target information on

the nature of vCJD.

The Spongiform Encephalopathy Advisory Committee (SEAC) was established in 1990. It provides scientifically-based advice to DEFRA, the Food Standards Agency, Department of Health and the devolved administrations on matters relating to spongiform encephalopathies, taking account of the remits of other bodies with related responsibilities. SEAC now has meetings open to the public and the minutes of the Committee are published in the professional and public domain. Any closed sessions have generally reviewed pre-publication information only and once a paper is published, the information is released to the web site. Transmissible Spongiform Encephalopathy advice is updated regularly in the light of new findings.

In July 2003, the Assembly issued a CMO letter containing information and advice for all those involved with the preparation and transport of bodies (which may pose a risk of infection) to Funeral Directors / Mortuaries.

The Measures in Place to Protect the Human Food Chain from the Effects Of BSE

10. The Food Standards Agency

Conclusion

- (i) The Committee applauds the FSA's aim to put the consumer first and to be transparent in its operations. It is early days to make firm conclusions on the FSA's effectiveness, but the Committee will continue to monitor its work.

The Food Standards Agency (FSA) is a non-Ministerial Government department that has the power to publish its advice to Ministers. The FSA is led by a Board appointed to act in the public interest and not to represent particular sectors. It is a UK department, accountable for its activities to the Westminster Parliament, and to the devolved administrations in Scotland, Wales and Northern Ireland through Health Ministers.

In October 2004 the FSA Board commissioned Baroness Brenda Dean to carry out an independent review of the Agency's performance since it was set up in April 2000. The Review was intended to consider how far the Agency has delivered on its promises, and the extent to which it has lived up to its core values:

- to put consumers first;
- to be open and accessible; and
- to act as an independent voice.

In the course of the Review, and in order to reach conclusions about the Agency's effectiveness, over 100 interviews with a broad range of stakeholders from across the UK were undertaken and over 60

written submissions were considered. The general consensus was that the Agency had worked hard to deliver objectives in accordance with its core values. Only a small minority of respondents did not believe the Agency had lived up to its guiding principles.

The report, presented to the Agency Board in February 2005, made 22 recommendations that would, in the view of Baroness Dean, help the Agency "to build on this positive position, to learn lessons of its short history, and to continue to move on innovatively". The Board accepted all of the recommendations.

A copy of the full report can be accessed at: www.food.gov.uk/multimedia/pdfs/deanreviewfinalreport.pdf

11. The Role and Effectiveness of Local Authority Public Protection Departments

Recommendation

- (i) Consideration should be given through the Partnership Council to ensuring that comprehensive information on local authorities' expenditure and performance on food standards work is published

The Food Standards Agency monitors local authority enforcement of food law and requires annual returns from each local authority which set out their inspection plans for the year ahead, and quarterly returns providing details of the work undertaken. The local authority monitoring returns are collected annually, analysed and presented to an open FSA Board meeting. The returns for 2005-06 will be considered at the meeting scheduled for 15th Feb 07 and papers will be posted on the Agency's website.

The first programme of audits is complete and reports of all 22 audits are available on the Agency's website. The Agency is currently conducting an audit of all Welsh local authorities with regard to the investigation of outbreaks of food related infectious disease. The programme is being considered and all local authorities will be given the opportunity to input their views on the process at an independently facilitated meeting in March.

The Agency is currently undertaking a major policy review called Changes to Local Authority Enforcement (CLAE). This includes a review of enforcement policy, the framework agreement, the audit process and the monitoring arrangements. FSA Wales' officials and Welsh Local Authorities are fully engaged in this process.

The Agency is rolling out its Food Surveillance system throughout the UK, permitting key stakeholders to compare local data within a regional and national perspective.

12. The Control of Imported Meat and Meat Products

Conclusions

- (i) Both the Health and Social Services Committee and the Agriculture and Rural

Development Committee are satisfied that the animal health controls now in place in the UK are adequate to deal with the known risks.

- (ii) Both Committees welcome the introduction of similar controls across the European Union and hope that they will be applied with sufficient vigour.
- (iii) The FSA should provide information on how intelligence is gathered on the safety of meat and meat products sourced from outside the European Union.
- (iv) The Agriculture and Rural Development Committee is concerned that imported meat should meet the same high standards applied to beef produced in the UK, and that controls must be seen to be applied and enforced to ensure continued customer confidence.

The FSA is responsible for the public health aspects of food imported into the UK. Following a Cabinet Office study on the organisation of import controls, the FSA has been tasked with securing a 'step-change' in the co-ordination and delivery of local authority inspection of imported food stuffs and products of animal origin at ports by April 2004. Actions include:

- Establishing an electronic database for port health authorities;
- Providing enforcement officers with training and support for imported food control functions; and
- Providing funding for sampling and monitoring to encourage proactive sampling to identify potential new problems.

The Step Change programme is continuing and has been successful to date. The "GRAIL" database is operational and allows Port Health Officers direct access to port health and food legislation and guidance from their laptop computers.

The Cabinet Office study noted that there was no shared intelligence base for local authorities at ports and that their access to data that would enable better targeting of anti-smuggling searches is sometimes limited. It acknowledged, however, that this was improving through measures set out in the cross-government action plan on illegal imports of meat and other products led by Defra. The action plan aims to co-ordinate action across central and local government and complements the FSA 10-point action plan.

All imports of products of animal origin, such as meat and dairy products, to the UK from outside the EU are subject to harmonised EU import controls. Such products must have been produced to standards at least equivalent to those that apply inside the EU. Administrative procedures and individual plants in exporting countries outside the EU are subject to inspection and audit by the European Commission's Food and Veterinary Office. Countries wishing to export to the EU must also submit information that will allow the Commission's Scientific Steering Committee (SSC) to determine their BSE risk status, and from this the BSE controls that must be applied in that country. Details of these risk classifications are available on the Commission website at: <http://europa.eu.int/>

All such imports must enter the UK through designated Border Inspection Posts (BIPs) operated by local port health authorities and local food authorities, where they undergo documentary and identity checks and a proportion are subject to physical checks. There are currently no BIPs in Wales. Any seizure or voluntary surrender of third country products of animal origin is notified to Defra who hold the information on a central database of Illegal Animal Product Seizures (ILAPS). Details from ILAPS are available to approved users in relevant enforcement bodies and are used to target enforcement activity. There are no BIPs in Wales currently. All guidance that is sent to BIPs in England is routinely circulated to Port Health Authorities in Wales for information.

Training on imported food procedures at basic and intermediate level has been provided for enforcement officers from both port and inland local authorities. Further training is ongoing and all Welsh local authorities have participated. The Agency also invites bids from local authorities on a UK basis for grants to carry out additional targeted food sampling activity.

The Meat Hygiene Service (MHS) continues to check every notified consignment of imported carcass beef for the presence of specified risk material (SRM) when it arrives at a licensed cutting plant in Great Britain. In the period 1 April 2002 - 31 March 2003, the MHS discovered SRM in beef carcasses on 44 occasions. All the meat was detained for disposal under MHS supervision and none of it entered the food chain. The FSA has taken action to prevent recurrences of such breaches of the BSE controls, including formal complaints to the veterinary authorities in the countries concerned, discussions at the EU Beef Management Committee (which resulted in a change of legislation requiring more stringent checks by Member States) and representations to the European Commission to take appropriate action against the Member States concerned. Further details are at www.food.gov.uk/bse/bsearchive

The action taken by the FSA to prevent occurrences of such breaches has resulted in a steep decline in the number of incidents -12 breaches were found in 2004, 5 in 2005 and 1 in 2006. In view of the current very low level of breaches and the fact that 100% checks exceeds EU requirements, the FSA is considering changing the system to one of random checks.

13. The Effectiveness and Enforcement of the 30 Month Rule

(Paragraph 4.4 The Implications for Wales of the Phillips (BSE) Inquiry Report – A Report for the National Assembly for Wales by the Health & Social Services Committee in conjunction with the Agriculture and Rural Affairs Committee)

The rule does not prohibit the import of beef from cattle over that age, only its use for human consumption. Thus it can be used for pet food. The Meat Hygiene Service advised the Committee that the rule was difficult to enforce as it was impossible to assess the age of meat off the bone, and with meat on the bone it was only possible to gauge whether it was from very young or very old animals. The importer was responsible for checking the documentation. The Service carried out checks at the eventual destination and the indications from their checks, and those of local authorities, were that there was a high level of compliance.

Conclusion and recommendation

- (i) This is a potential weakness in the measures for public protection. Any instances of non-compliance should be pursued rigorously to prevent recurrence, and the effectiveness of the rule kept under constant surveillance.

The Over Thirty Month (OTM) rule was a national measure introduced in the UK in March 1996 which kept most older cattle (both UK and imported) out of the food supply.

On 15 September 2005, the Government announced that it was to replace the OTM rule with a BSE testing regime for OTM cattle born after 1 August 1996 (meat from animals born before that date are permanently excluded from the food chain). This decision followed advice from the FSA that this UK control measure was no longer proportionate to the risk. An Independent Advisory Group (IAG) was set up to ensure robustness ahead of any change to the OTM rule.

On 7 November 2005 a new BSE testing regime was introduced following government acceptance of advice from the FSA in September 2005 that a robust testing regime for testing for BSE has been developed. The FSA's advice was forthcoming only after assurances from an Independent Advisory Group that the system would be robust. This means that cattle aged over thirty months and born after 1 August 1996 are now able to enter the food chain but only if they have tested negative for BSE.

The primary BSE control measure, the removal of specified risk material from carcasses, remains in place. This control removes 99% of any infectivity that may be present in the carcasse.

OTM cattle born before 1 August 1996 can be disposed of under the Older Cattle Disposal Scheme, a compensation scheme for farmers operated by Defra on a GB basis, which replaced the Over Thirty Month Scheme from January 2006.

Further information about the FSA review of the OTM rule is available at:

<http://www.food.gov.uk/foodindustry/meat/otmreview/>

The Progress of the Variant CJD Epidemic and the way in which Scientific advice is made Available

14. Tracking the Trends of the Disease in Humans and Cattle

Conclusion

- (i) The Committee agrees with Dr Salmon that it is too early to relax vigilance, and that planning should be based on a realistic assumption of the likely size range of the epidemic. The Committees support the programme of continuing research into BSE and other Transmissible Spongiform Encephalopathies, including the work underway to develop a reliable diagnostic test for BSE in live cattle.

Defra/Devolved Administrations continue to fund research into BSE aimed to contribute to scientific knowledge and to the eradication of BSE in cattle, to safeguard public health, to support changes to statutory controls and to understand the potential persistence of prions in the environment.

The Food Standard Agency continues its programme of TSEs research. The main focus is an FSA strategic objective, which is to aid the development of a TSE test for use in live animals. Research is also being undertaken on the identification of the TSE infectious agent and emerging strains of TSE diseases e.g. atypical scrapie. Research also continues on risk assessment, public health issues and susceptibility of other food species (deer) to infection from encephalopathies. Further details are available at www.food.gov.uk/science/research/meat_hygiene_research/m03programme

Further details of research into TSEs since 2003 are available at:

http://defraweb.defra.gsi.gov.uk/animalh/bse/pdf/tse-gb_progressreport12-05.pdf

<http://defraweb.defra.gsi.gov.uk/animalh/bse/publications/progress/dec04/order.pdf>

15. The Value of Autopsies

Conclusion and recommendation

- (i) The Committee notes that some doctors may be reluctant to seek a post mortem in order to save relatives from further distress. However, doctors should be encouraged to discuss the importance of establishing the cause of death with the bereaved relatives if they suspect that vCJD may be the cause.

This area of responsibility has not been devolved to the Welsh Assembly Government. However, this remains an area of great difficulty, as has been demonstrated during discussions held by SEAC.

The National CJD Surveillance Unit has a very close working relationship with family support organisations, who remain keen to encourage this practice.

16. The Relationship between the National Assembly Professionals, National Assembly Ministers, Whitehall, SEAC, the FSA and Other Sources of Scientific Advice.

Conclusions and Recommendations

- (i) The National Assembly should work to develop a multi-disciplinary public health protocol for the assessment and management of risks to food safety and the response to outbreaks of human disease derived from food. This should embrace the Assembly's relationship with Whitehall and the other devolved administrations as well as its partners within Wales.

The Health Protection Agency is resourced to develop multi-disciplinary training for professionals in

a range of settings. Wales is fully engaged and staff have access to training provided.

A range of measures have been implemented to encourage multidisciplinary responses to disease outbreaks. Paramount amongst them is the adoption by health and local authorities of the "Lead Officer Concept". The aim of this initiative is to train a cadre of professionals from health and local authorities sufficient to provide a critical mass able to respond quickly to actual and threatened outbreaks.

- (ii) The current arrangements for receiving scientific advice appear to be working, but should be kept under review and evaluated.

This is monitored and reviewed. See points below.

- (iii) The National Assembly should consider pressing for further formalisation of the arrangements for sending observers to SEAC meetings. Similar arrangements might be appropriate for other scientific advisory committees.

There is continued good working across government departments and with SEAC. The position of Wales' observer status is well recognised.

An independent secretariat steering committee has been established to service SEAC. Wales, and the other devolved countries, are seen as equal partners within this group, which has ensured much closer working relationships. Wales hosted the first meeting in a Devolved Administration in Autumn 2004 and is due to host the next in Autumn 2007.

- (iv) The independent role of the Chief Medical Officer in providing objective advice on public health matters should be safeguarded.

The role of the CMO in providing objective advice remains.

- (v) The National Assembly should consider the benefits of re-instating the Health Professionals Group that existed prior to the implementation of the Hart report.

OCMO encompasses the range of health professionals expertise which existed in the previous Health Professionals Group, but also includes policy teams working on public health protection, strategy and promotion. Health professionals working in OCMO continue to report to the CMO on professional matters and work closely with colleagues in the NHS and Social Policy Group and across the Assembly in providing expert advice.

Work is taking place to strengthen the health professional collegiate group within the context of other management developments in the health department.

Annex 2

Services for Children with Special Health Needs

Recommendation

- 1. Where an early diagnosis cannot be made, access to appropriate services should be made far more flexible for parents and their children, pending diagnosis.

The Welsh Assembly Government recognises that early diagnosis of conditions and early appropriate intervention is desirable. However in some conditions a diagnosis cannot be made quickly and involves the need to observe the development of the child. During this period it is important that families have access to appropriate support and information. Allocating a key worker would be of great assistance to parents at this stage, and this is addressed in Key Actions 2.14 and 5.7 of the National Service Framework (NSF) for Children, Young People and Maternity Services in Wales, which was launched in September 2005 and can be viewed at - www.wales.nhs.uk/nsf.

Progress in implementing the Key Actions of the NSF will be monitored via the Self-Assessment Audit Tool (SAAT).

- 2. The recommendations of the Chief Medical Officer's working group on child health surveillance should be widely disseminated and taken into account in the development of the National Service Framework.

The Child Health Surveillance Programme is currently being reviewed in Wales, to take account of changes in the infant and early childhood screening and immunisation programmes and service developments such as the new GP contract. The Children's NSF, in key Action 2.19 states that all children have access to the All Wales Core Child Health Surveillance Programme.

- 3. Local Health Boards should develop strategies to ensure that low birth weight babies and the children of disadvantaged families, travellers and transient families, young lone parents and ethnic and other minority groups have access to diagnostic services.

One of the highest priorities of the Welsh Assembly Government is to promote the health and well being of all children in Wales. Low birth weight is a factor that can affect the future health of the individual and is the result of a number of social factors. It is not one that can be tackled by the NHS alone.

Equity of access is a consistent theme throughout the Children's NSF – All children should have equitable access to appropriate high quality health and social care irrespective of where they live, their ethnic group, culture, linguistic or other social circumstances.

In respect of delivering Maternity Services, Key Actions 3.1, 3.9, 3.11, 3.12 and 3.21 of the Children's NSF refer, Local Health Boards have been tasked with their delivery in partnership with NHS Trusts.

Core Key Actions 3.1 and 3.12 were flagged for delivery as part of the 2005/06 SaFF Target Process.

SAAT returns for 2005/06 in respect of Key Action 3.1 indicate that 100% of responsible organisations achieved implementation and for Key Action 3.12 SAAT returns indicate that 79% achieved implementation.

Infants born pre-term or low birth weight have special nutritional needs. The Welsh Assembly Government's Breastfeeding Strategy "Investing in a Better Start" promotes breastfeeding in Wales. Health professionals give particular encouragement to mothers to breastfeed or use their own expressed breast milk, while infants are in neonatal units and when they go home.

The Healthy Start Scheme – which provides pregnant women and children under four in families receiving certain qualifying benefits and pregnant women under 18 with Healthy Start vouchers that can be exchanged for milk, fresh fruit and vegetables and infant formula rolled out across the UK in November 2006. Beneficiaries are also entitled to free vitamin supplements.

In addition to mainstream services the Assembly Government provides support to communities in areas of deprivation, and to non-geographical communities of need, through Cymorth – the children and youth support fund. One of the aims of this Fund is to promote the healthy development of children (including before birth) and young people by providing more intensive community health support or to break down barriers to mainstream health services. Under the Scheme help is given on a wide-ranging set of issues connected with good parenting from advice about bonding and playing with young children to guidance on nutrition and family health. In practical ways Cymorth, attempts to address some of the issues that are associated with low birth weight babies such as poverty and unemployment.

- 4. Where appropriate, pre-conceptual genetic counselling should be offered.

The "Choices" report on the options for antenatal screening covered the area of genetic counselling to families with an identified risk. Awaiting further advice from external organisation

- 5. An evidence based antenatal screening should be available unconditionally to all pregnant women.

This recommendation is reflected as Core Key Action 3.15 of the Children's NSF and was flagged for delivery as part of the 2005/06 SaFF Target Process. The SAAT returns for the 2005/06 indicate that 94% of responsible organisations achieved implementation

- 6. Information at the time of diagnosis should be planned in advance and be sensitive to the parents' needs. Parents should have the opportunity for further discussion with the specialist or other appropriate practitioner after they have had time to reflect upon the diagnosis.

This is recognised within the Children's NSF – Core Key Action 5.22 of the Children's NSF focuses on support for families following diagnosis. Core Key Action 5.22 was flagged for delivery by March 2006 as part of the 2005/06 SaFF Target Process. The Self-Assessment Audit Tool (SAAT) returns for 2005/06 indicate that 52% of responsible organisations achieved this action.

This is also addressed in the All Wales Universal Standards for Children and Young People's Specialised Healthcare Services, issued for consultation in 2005, and developed as part of the Children and Young People's Specialised Services Project (CYPSSP). Consultation responses are currently being considered, final standards are expected to issue at the end of the year.

- 7. Parents/ guardians should be given comprehensive advice from a designated and trained person at the time of diagnosis, including information on the support and advice available from the voluntary sector.

The allocation of a named key worker to support parents and families and to advise and co-ordinate services is recognised within the Children's NSF - Key Actions 2.14 and 5.22 of the Children's NSF refers. Progress in implementing Key Action 2.14 will be monitored via the SAAT during the course of the 10 year strategy. Core Key Action 5.22 was flagged for delivery by March 2006 as part of the 2005/06 SaFF Target Process. The Self-Assessment Audit Tool (SAAT) returns for 2005/06 indicate that 52% of responsible organisations achieved this action.

This is also addressed in the All Wales Universal Standards for Children and Young People's Specialised Healthcare Services, issued for consultation in 2005, and developed as part of the Children and Young People's Specialised Services Project. Consultation responses are currently being considered, final standards are expected to issue at the end of the year.

- 8. Good practice should be disseminated to help overcome some of the difficulties in co-ordinating resources and services.

The Welsh Assembly Government is always keen to ensure that best practice is disseminated across Wales. A Self-Assessment Audit Tool (SAAT) has been developed as part of the performance management system for the Children's NSF for use by all statutory agencies that deliver services for children and young people. Local Authority Children and Young People's Framework Partnerships (CYPFPs) are able to use the SAAT data to determine progress that is being made against implementing the NSF Key Actions. It also has the facility to share examples of best practice.

The Autistic Spectrum Disorder (ASD) Strategic Action Plan, launched for consultation on the 30 January was developed in conjunction with Autism Cymru and the National Autistic Society (Wales). The Strategic Action Plan will cover children's and adult services. It identifies responsibilities at national and local level to deliver on specific actions that require a co-ordinated approach to planning, commissioning and delivery of services for people with ASD – across Health, Education, Social Services and the Voluntary Sector and provides examples of good practice.

- 9. The early appointment of a key worker or care co-ordinator is recommended in all cases where the child needs services or care from one or more speciality or service.

This is addressed in the Children's NSF - Key Action 2.14 refers - Children and Young People, requiring two or more services, should have their services co-ordinated by a commissioned key worker - Progress in implementing this Key Action will be monitored via the SAAT during the course of the 10 year strategy.

This is consistent with Standards being developed as part of the CYPSSP.

- 10. The potential for extending the use of the existing parent held record and the introduction of electronic records as a means of sharing information between agencies should be explored.

The Informing Healthcare Programme is developing an implementation strategy and plan for creating an "Individual Health Record" which supports patients and clinicians in all care settings. The aim is to provide patients and their carers with access to their record via an on-line portal called "My Health On Line" for which a national prototype is currently under development. Clinicians and care providers will have access to the patient's record via a separate common portal, which is also under development.

Information sharing between agencies will require a national approach to information governance and patient consent. Informing Healthcare has successfully tested out some of the operating principles that will be required, beginning with an Out-of Hours care setting in Gwent. This has involved representatives from the BMA, CHC, local clinicians and patients. Based on the experience and knowledge gained, a position paper setting out how this could be approached across all care settings is being prepared for submission to the Minister and wider consultation.

- 11. Agencies should be encouraged to make better use of the funding flexibilities and to pool budgets.

The Welsh Assembly Government has continued to support joint working and has provided the legal and financial frameworks through which statutory service providers can work together to plan, commission and provide their services in ways most appropriate to the needs of users and carers.

This includes significant financial investment via the joint working special grant.

The reports submitted for the financial year 2005-06 show that the grant supported 213 projects involving 92 different partners.

- 12. The Welsh Assembly Government, together with the UK government, should review the speech and language therapy service and draw up strategies for meeting the shortfalls in the short term and in the long term.

In 2002, the Minister for Health and Social Services and the Minister for Education and Lifelong Learning jointly commissioned a multidisciplinary Action Group to advise on improving access to speech and language therapy for children and young people across Wales. The result of this was the joint consultation document 'Working Together', which issued in July 2003.

As a result of its recommendations – and agreement reached at a bi-lateral meeting between the Minister for Health and Social Services and the Minister for Education and Lifelong Learning in 2004 - The establishment of four pilot projects working across health and education to develop joint commissioning, under the auspices of the Health Act 1999 (Partnership Arrangements) began in

April 2005. Bridgend, Neath/Port Talbot, Gwent and Conwy/Denbighshire were also successful in their phase 2 bids and the pilot projects commenced in June 2006.

A Speech and Language Co-ordinator has been appointed to monitor the development of the projects and work with the Welsh Assembly Government on any subsequent advice that will issue.

A National External Reference Group has been established and 2 meetings have taken place – the group will monitor progress on the delivery of the recommendations and advise the Assembly on matters relating to speech, language and communication difficulties.

- 13. The feasibility of the position of speech therapy assistants should be explored to undertake, under supervision, basic therapy services.

The Workforce Development and Contracting Unit within the National Leadership and Innovation Agency for Healthcare are working with SLT Managers in Wales to produce level 4 development units/modules for SLT support workers in Learning Disability, Dysphagia and those working with 0-19 year olds and in schools.

A level 3 BTEC in SLT Education Support is currently offered at 2 colleges in Wales, Bridgend and Llanidloes.

- 14. The recommendations of Professor Dame June Clark's report on school nursing services should be fully implemented.

As a consequence of The Future of Primary Care – July 2002, - An Action Plan for Primary Care in Wales, the office of the Chief Nursing Officer commissioned a wider review of roles and responsibilities of primary care and community nurses. The report of the review was received in December 2004. A mapping of school nursing across Wales was undertaken as part of this review and in addition, the recommendations of Dame June's Review of Health Visiting and School Nursing (2000) was revisited. In addition the Carlile Review (2002) also makes recommendations relating to the provision, employment and management of school nurses.

The Children's NSF also addresses school nursing services – Key Actions 2.35 and 5.23 refer. Progress in implementing these Key Actions will be monitored via the SAAT during the course of the 10 year strategy.

The Cabinet Sub Committee on Children and Young People has also requested that officials review school nursing services across Wales. An Assembly Government cross party group of officials, chaired by the Head of Public Health Improvement Division was set up, to develop a national consensus on the role of school nurses and to draw up an action plan to take forward a modern school nursing service in Wales. The group has taken evidence on different models, and a Public Health Trainee has recently drawn this evidence together to assist the group to develop a flexible model for the delivery of school nursing services for widespread consultation. Consideration is also being given to ensuring that Children and Young People are engaged in this piece of work.

- 15. Guidance on support for families of young children with special health needs, including examples of good practice, should be issued to all statutory and voluntary agencies in Wales. It is recommended that this be part of the Children's National Service Framework.

The Children's NSF sets out the quality of services that children, young people and their families have a right to expect and receive through the setting of national standards. Best practice will be shared between all statutory bodies and voluntary agencies in Wales through the sharing of information via the CYPPFs.

The Assembly established a Disability Network made up of managers of Children's Services across Wales who have strategic responsibility for work with disabled children. The Network has now been in operation for several years and as part of its work members have shared resources, experience and good practice in relation to services for disabled children in Wales.

- 16. The provision of effective and flexible respite services must be seen as a pre-requisite for sustainable caring responsibilities within families.

Respite care should be provided within the framework of the assessment process and should identify all the care and support needs using the Framework for the Assessment of Children in Need and their Families' issued by the Welsh Assembly Government in 2002. Disabled children remain a priority for use of Children First funding which has a specific objective to increase the number of children in receipt of family support services. Around ?200m has been allocated to the programme since its inception in 1999. The Assembly continues to fund a number of voluntary organisations which support disabled children and their families through the Children and Families Organisation (CFOG) including Shared Care Network which provides short breaks for disabled children and their families.

The Carers Strategy Review Panel is currently consulting on a refocused Strategy which will consider respite care.

The Assembly has continued to expand the groups of people eligible for a direct payment arrangement. Amongst others disabled children aged 16 or 17 and a person with parental responsibility for a disabled child are now potentially eligible for a direct payment.

This is acknowledged in Key Action 5.13 of the Children's NSF, that disabled children, young people and their families have access to services that meet their assessed needs, including short break (respite) and other services. Progress will be monitored via the SAAT during the course of the 10 year strategy.

- 17. The Welsh Assembly Government should encourage each local authority to support a "Special Needs Support and Advice Centre" to provide services for children and support for carers and families.

The Welsh Assembly Government will continue to integrate services for disabled children with mainstream services. It is recognised that it is important that parents, carers and children should be offered choice and the most effective mechanism is to signpost people where to go to access services

through the various general and specialist resource and information centres. Care needs to be given in developing any new specialist centres which could stigmatise and further marginalise disabled and special need groups. Our commitment is to ensure that appropriate support and information is accessible and available to special needs children, their families and carers through mainstream services and the allocation of a named key worker for each child or young person.

To date 39 Integrated Children Centres, satellite or networked facilities have opened across Wales. These centres are inclusive of all children and bring together services such as sure start, early education, childcare training, family support, health and open access play into an integrated network of services. There is also a Children's Information Service placed in each local authority providing assistance to anyone requiring signposts to appropriate children's services to meet individuals needs.

- 18. The Committee recommends that the supply of equipment should be formally co-ordinated between the statutory agencies with a designated lead agency in every area. The arrangements should include the pooling of equipment budgets, management of stores and monitoring of use.

The Welsh Assembly Government accepts the need to better co-ordinate the supply of equipment. It will continue to support the development of joint equipment stores through the use of the Health Act 1999. Increased Flexibilities mechanisms, lead commissioning, integrated provision and pooled budgets, which provide for the development of fully integrated equipment stores.

This recommendation has been incorporated within the Children's NSF - Key Actions 5.14 and 5.18 of the Children's NSF refers - Progress will be monitored via the SAAT during the course of the 10 year strategy.

As part of an overall package of support to older people and their carers, the Assembly Government is making ?12.5m (for 2006/07 and 2007/08) to local authorities and their partners to advance development in the provision of community equipment services in Wales. This will also improve the provision of equipment for disabled children.

- 19. The Committee's concerns about the terms of the legislation on disabled facilities grants and the process for applying should be brought to the attention of the UK Government with the request that it be reviewed.

The Assembly Government wants people with disabilities in Wales, including children, to have access to the help and support they need for their homes to be suitably adapted for their needs. This is an important principle of our National Housing Strategy "Better Homes for People in Wales". It has, and continues, to make substantial resources available to support Disabled Facilities Grants (DFGs) and other forms of assistance to adapt homes of people with disabilities. In addition we have not placed limits on the funding local authorities can use for DFGs. It is for authorities to decide how much of the resources they have available should be used to support these grants according to locally determined priorities. Demand for Disabled Facilities Grants (DFG) is high. It is therefore important that the available resources are used effectively and targeted at those in greatest need.

The Minister for Health and Social Justice and Re-generation commissioned a review of DFG's in Spring 2005. The review's report contained 37 recommendations which have almost all been implemented. One recommendation concerned the abolition of the means-test for DFGs for the parents of disabled children which was achieved through Regulations in September 2005.

In July 2002, the Rapid Response Adaptations Programme was introduced. The programme is aimed at vulnerable people, including those with disabilities. It provides immediate response to specific needs to provide small adaptations such as ramps, stair lifts and handrails, to people who require them either to sustain the occupancy of their existing homes or so that they can be released from hospital or temporary nursing home care. This has proved to be very successful and in its first three years has provided indicative savings of some ?41 million in terms of hospital stays and long term care. For 2007/08 budget the programme has increased to ?2 million.

- 20. Particular care should be taken to ensure that aids, equipment and adaptations are fit for purpose and child centred. This requires regular reappraisal of the suitability of materials as children grow older.

This recommendation has been incorporated into the Children's NSF - Key Actions 2.2, 5.14, 5.15, and 7.13 refer. Progress in implementing these Key Actions will be monitored via the SAAT during the course of the 10 year strategy.

Key Action 2.2 was flagged for delivery by March 2006 as part of the 2005/06 SaFF Target Process. The Self-Assessment Audit Tool (SAAT) returns for 2005/06 indicate that 68% of responsible organisations fully achieved implementation.

Health Commission Wales commission an agreed range of children's specialist services on an All Wales basis including the provision of Aids and Equipment ((WHC (2003) 63 refers)

- 21. There is much apparent good practice in special needs education around Wales that should be validated and disseminated.

The Minister for Education and Lifelong Learning has established an all Wales steering group for SEN. In support of this initiative officials have been asked to co-ordinate reviews of specific SEN services in order that the quality of service can be ensured on an all Wales level. A review of sensory impairment has been undertaken and quality standards have been drawn up and issued to the field. A review of Autism Services will also be undertaken following the launch of the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales on the 30 January 2006. Quality Standards will issue later this year.

Assembly Officials participate in termly meetings of the AEDW Inclusion Group and each year ANID stages an annual SEN Conference with appropriate and pertinent themes.

The Welsh Assembly Government has made ?5.1 million available to 22 Local Education Authorities (LEAs) in Wales to establish Special School Pilot Projects 'Unlocking the Potential of Special

Schools' over 3 years, from September 2006. This complimentary pilot aims to promote further inclusion and develop the role of special schools by identifying and disseminating good practice by special schools in developing practical links with mainstream schools and promoting special schools contribution to an increasingly inclusive education system.

Specific Wales only clauses have been included in the Education Act 2002, which allows the Assembly Government to bring forward proposals for regional provision and services if that is deemed appropriate.

To date over ?6.5m has been made available by the Assembly to help LEAs develop regional facilities - ?2.8 million of this has already been spent on the redevelopment of Ysgol Plas Brondyffryn as part of the development of regional provision for Autistic Spectrum Disorder (ASD) in North Wales. This provision will enable the special needs of children with extremely complex autistic spectrum disorder to be kept in North Wales.

A further ?2.8m has also been allocated to a number of authorities for 2006-07 which will see the development of three separate multi sensory impairment (MSI) units in North, South East and South West Wales.

The Assembly has recently agreed a 2 year secondment of a well experienced local authority officer to help us develop a comprehensive strategy for regional SEN provision in Wales and assist with its implementation.

We are in discussions with a number of authorities across Wales on further proposals to develop regional provision and in September 2006, all authorities were invited to bid for regional SEN SBIG funding for 2007-08. Allocations will be announced later this month (January 2006).

During 2005-06 a comprehensive audit of SEN provision and needs across all LEAs was undertaken by ANID.

An SEN Handbook of Good Practice has been issued to all schools in Wales and in 2006 a further section was added relating to the role of SEN Co-ordinator's (SENCO's). Further additions and updates are planned including one relating to transition following the ELLS Committee Policy Review of Special Educational Needs, the third one of which is transition.

- 22. The move to special needs provision within a mainstream setting should be welcomed, but greater emphasis should be placed on the monitoring of special needs services so that they do not become diluted.

The issue of quality is being addressed within the specific reviews of SEN. In addition ESTYN are undertaking "Best Value" reviews at LEA level. This is in addition to routine inspections of schools. A further ESTYN report is due shortly on the outcomes for learners with SEN.

The Wales Audit Office are also considering various aspects of funding relating to SEN – the Welsh Assembly Government anticipates that a report will follow in the Summer Term 2007.

The funding allocated as part of 'Unlocking the Potential for Special Schools' is also relevant within the context of outreach provision for children with SEN in mainstream schools.

- 23. The National Service Framework for children should contain a detailed sub section on special education and health needs.

The Children's NSF is not just a strategy for health, but for education, housing, leisure and transport and other local services that strongly influence the health and well being of children. Key Action 5.29, states that a school health care plan is designed for every child with complex needs to identify the child's needs and how they will be met in a school setting. Progress on implementation will be monitored via the SAAT during the course of the 10 year strategy.

- 24. A member of the board of each local health board in Wales should be designated as responsible for children's services and children's rights.

Guidance issued under the Children Act 2004, Stronger Partnerships for Better Outcomes, places a statutory duty on LHB's to designate an Executive Director and designated non-officer Board Member with lead roles in respect of section 27(2) of the Act.

Their main responsibility is to make sure that partnership in planning for children and young people's services takes place effectively and that decision-making is properly shared. They must ensure that such planning is given a high profile within health services, that health services engage fully in arrangements for partnership governance and that they contribute effectively to completion of the local NSF SAAT.

They must make sure that due consideration is given to implementing the rights of children and young people, and that the views of children, young people and their families are listened and responded to in decision-making.

- 25. The situation of children aged under five years with severe health needs requires urgent attention so that they receive appropriate pre-school education.

For children with severe and complex needs the LEA has a duty to undertake a statutory assessment and make available suitable provision as set out in a statement of special educational need. Children are eligible for assessment from their second birthday. The Assembly Government has embarked on a major expansion programme to ensure that all children have an early education place available from the term following third birthday if they so wish. This includes children with special needs. The Welsh Assembly Government is also considering other relevant Early Years materials developed by Dfes for possible adaptation in Wales.

- 26. Good practice needs to be evaluated and benchmarked. The National Service Framework should provide for systems to be established at strategic and operational level to evaluate and benchmark services and to research and validate good practice. It should also provide the mechanisms for disseminating good practice and for statutory and voluntary organisations to

share experience.

A Self-Assessment Audit Tool (SAAT) has been developed as part of the performance management system for the Children's NSF for use by all statutory agencies that deliver services for children and young people. Local Authority Children and Young People's Framework Partnerships are able to use the SAAT data to determine progress that is being made against implementing the NSF Key Actions. It also has the facility for agencies to share examples of best practice.

Service and Financial Framework (SaFF) Targets have been set for 2005/06 and 2007/08 – to ensure that data for core key actions and developmental key actions is collected, via the SAAT, analysed and fed into local planning strategies.

An Implementation Working Group (IWG), chaired by Ann Lloyd, Head of Department for Health and Social Services and Steve Thomas, Chief Executive of the WLGA and including representatives of the NHS, Local Authorities and Voluntary Sector has been established. The IWG will ensure that a strategic overview and direction is maintained regarding the implementation of the NSF.

A NSF Implementation Support Manger has been appointed – the role is fundamental in supporting CYPFPs and taking forward the sharing of information necessary to promote best practice.

The Children's NSF will carry out a baseline assessment of services that will identify gaps in present service delivery and also act as a benchmark against which progress in achieving the set standards can be measured. Performance and outcome measures will be developed to assess the efficacy of interventions in achieving their goal. Such evaluation methods should be able to identify areas of best practice that can be disseminated to statutory and voluntary agencies.

Annex 3

The Interface between Health and Social Care

The Committee recommends that:

1. The two information and communication technology (ICT) strategies should be integrated as soon as possible to facilitate the provision of more effectively integrated health and social care and the development of the electronic patient record.

The two ICT strategies need to work well at the interface between health and social care. The issues of equipment, applications, security access arrangements, staff/user/patient identification and governance are being addressed and there is solid progress in all these areas. Some examples are:-

- The publication and provision of training on the 'Wales Accord on the Sharing of Personal Information – for organisations involved in the health and social well being of the people of Wales'. This is an essential pre-requisite of inter-agency information sharing; and
- NHS numbers being made available to local authorities in order to improve identification and

case finding.

The current work with Informing Healthcare and local authorities on the Individual Health Record will increase the level of collaboration and identify all of the complexities of information governance and patient consent surrounding the health social care interface which will need to be addressed.

The Performance Management Project in SSIW has encouraged the development of consortia to provide the social services information systems and particularly the Unified Assessment/Common Assessment Framework and the Integrated Children's System. We are currently considering with the consortia the development of an interconnectivity hub that will allow the exchange of information between health and social care systems. A Social Care Index based on summary information drawn from the social services systems and providing a single point of contact for authorised enquirers is planned for December 2008 and a more comprehensive approach providing wider access is planned for December 2010.

2. See Recommendation 17

3. The Welsh Assembly Government should review guidance to local health boards (LHBs), trusts and local authorities (LAs) to secure the engagement of the independent and private sectors in joint strategic and service planning and commissioning

LHBs and local authorities, when developing and reviewing their Health, Social Care and Well-being strategies, already have a statutory duty to co-operate with any private, business, voluntary or other organisation which is concerned with or has an interest in the provision of health and well-being services for the local population. The existing statutory provision also requires LHBs and councils to prepare a procedure of co-operation with the responsible bodies involved before developing their strategies for the first round (April 2005 – March 2008).

To assist and support LHBs and councils in preparing for the next strategies (which take effect from April 2008) revised draft Statutory Guidance for Health, Social Care and Well-being Strategies and revised Draft Regulations were published for consultation in November 2006 – the consultation period runs until the 16th February 2007. In the draft regulations we have suggested a number of changes to reduce administrative burdens, one of these is to remove the need for the parties to produce a written Plan of Co-operation. The rationale for this is the presumption that these partnerships are already in place. Consultation events have been held across Wales and this matter has been discussed. We will review the comments received on this issue at the end of the consultation period.

Current planning and commissioning guidance is already under review with a view to developing more robust guidance for both health and social care. New commissioning guidance for health should be published in February 2007. For social care it is a priority for the 2007-8 implementation programme for "Fulfilled Lives, Supportive Communities". Both sets of guidance will emphasise the opportunities for joint and lead commissioning in the context of the Health Social Care and Well Being Strategies and "Making the Connections: Delivering Beyond Boundaries". The importance of engaging the independent sector in strategic service planning and commissioning will be emphasised

in the new guidance. This will also address the current variability of engagement.

In our Social Services commissioning guidance and other work to improve the planning and commissioning of social services we will be working to secure the engagement of the private and voluntary sectors. Para 4.23 of the consultation version of "Fulfilled Lives..." emphasises the need for commissioners to work within developed partnerships with independent and voluntary sector providers

A consultation document on community health services will be issued shortly which sets out the future direction for these services and acknowledges the particular importance and opportunities from engaging all partners in developing these services.

4. Proposals for all short term funding schemes should include:

- a statement of the aims and objectives and a plan for evaluating the scheme's success in meeting them;
- an assessment of the impact of the scheme on core services; and
- proposals for mainstreaming the project where evaluation

demonstrates there would be benefit in so doing.

These principles are now reflected in new and revised short term funding schemes, and their supporting guidance and grant conditions, which impact on the interface between health and social care. Examples are the Joint Working Special Grant, the Community Equipment Services Capital Grant and the Telecare Capital Grant.

5. In giving guidance to the statutory agencies on strategic planning, the Welsh Assembly Government should emphasise the importance of effective research and intelligence gathering so that health and social services can meet the dynamic needs of the population they serve. This should include encouraging links with research and developments in higher education.

In our response to the Committee's recommendations, we acknowledged that research and intelligence is vital in underpinning improvements in health and social services planning and provision for the future. This is being emphasised in guidance and appropriate policy and framework documents.

For example, the Needs Assessments undertaken by the National Public Health Service as part of the planning for the next round of Health, Social Care and Well-being Strategies in April 2008 will have a key role to play in understanding the needs of the local population.

WORD has almost completed the commissioning of a new infrastructure for research and

development in health and social care. The infrastructure will increase the ability of the research community in Wales to engage in high quality and large-scale research studies that support the implementation of ‘‘Designed for Life’’ and ‘‘Fulfilled Lives, Supportive Communities’’. Particular care has been taken to ensure that social care is fully integrated, hence the inclusion of developing thematic networks such as children and young people, and older people and ageing. In building such an infrastructure, we have supported a collaborative approach to research by bringing together policy makers, practitioners and academics.

WORD has also commissioned a Co-ordinating Centre to provide services for the new research infrastructure as well as an All-Wales Alliance for Research and Development (AWARD) - a multi-centre disciplinary academic network whose remit includes undertaking research and evaluation studies each year for Welsh Assembly Government policy makers.

In addition WORD are currently strengthening the R&D strategy in Wales, again building on the theme of collaboration between policy makers, academia and service providers

The Accountability arrangements for joint planning and service provision

6. The following key indicators should be assessed within performance management arrangements for LHBs, NHS trusts and LAs to demonstrate progress towards effective joint working:

- early identification of care needs and early intervention;
- implementation of unified assessment;
- effective hospital discharge planning;
- integrated teams of health and social care providers;
- support for carers;
- involvement of voluntary and independent sectors.

Information is collected on all these activities through a range of mechanisms, for example the local government performance measurement framework, Service and Financial Framework, Balanced Scorecard and inspection regimes. Current guidance reinforces the importance of these, for example the National Service Framework for Older People launched in March 2006.

New Adult Performance indicators are beginning to measure timelines, e.g. from initial enquiry to completion of care plan and from completion of care plan to provision of aids and equipment. Indicators such as those suggested in the Committee’s recommendation above to support good partnership working will be considered as part of the ‘‘Fulfilled Lives, Supportive Communities’’ implementation plan in 2007-8.

7. The Welsh Assembly Government should make evidence of comprehensive joint working a clear and central performance indicator in the Service and Financial Framework and similarly it should be included as a performance indicator under the Wales Programme for Improvement. Although the Committee does not believe that sanctions to promote joint working are appropriate, rewards are a clear way to mainstream good practice

In our response to the Committee's Report, we pointed out that it would be difficult to include performance indicators for joint working in the Service and Financial Framework (SaFF) or the Wales Programme for Improvement (WPI) in the way suggested, as the SaFF does not cover non-NHS organisations, and the WPI does not cover non-local government ones. Moreover, the targets included in both focus more on service delivery outcomes and less on the mechanisms that support delivery.

However, the Balanced Scorecard introduced for NHS Wales specifically requires organisations to evidence joint working arrangements with all stakeholders and partner organisations. It also requires organisations to evidence that they work with, learn from and share knowledge with partners.

Equally, the extent to which local authorities and others work in collaboration, and the effectiveness with which they do so, will continue to be assessed under the Wales Programme for Improvement. Any weakness in this area would be identified as a risk by a local authority's regulators, which would then need to be addressed

The Assembly voted unanimously on 8 March 2005 to support a new performance measurement framework for local government which focuses on outcomes (such as a reduction in delayed transfers of care) rather than processes (such as the extent of collaboration to that end). We have continued to develop the framework in line with that principle since then.

Under the wider public service collaboration agenda set out in "Making the Connections: Delivering Beyond Boundaries" there will be other action to encourage and support joint working across organisational boundaries.

Please see reference to new adult performance indicators in Response 6.

The Effects (both positive and negative) that decisions in one service can have on another

8. The Welsh Assembly Government should review the guidance on

- Health, Social Care and Well Being Strategies,
- Community Plans and
- Health Impact Assessments
to ensure that there is adequate consultation and recognition of the impact of local authority services on health and well being.

The existing legal requirements (The Health Social Care and Well-being Strategies (Wales) Regulations 2003) and current guidance on Health, Social Care and Well-being Strategies provide for adequate consultation and recognition of the impact of local authority services on health and well being.

Revised draft Statutory Guidance for Health, Social Care and Well-being Strategies and revised Draft Regulations (The Health, Social Care and Well-being Strategies (Wales) (Amendment) Regulations 2007) were published for consultation in November 2006 – the consultation period runs until the 16th February 2007.

The revised Draft Statutory Guidance will look to reinforce the continued inclusion of local authority services in the development of joint strategies. In addition, the Office of the Chief Medical Officer is working with Assembly Government colleagues and the WLGA to strengthen the links between HSCWBs and the development of our Public Health Strategy in relation to the contribution made by local government to public health.

Future guidance on community strategies will be informed by the evaluation of those prepared in the first round. These evaluations are contributing to the development of our policy towards community planning and the revision of existing guidance on the preparation and implementation of the strategies. We will consult on new proposals in the spring.

The 2004 Practical Guide to Health Impact Assessment reflects the experience of working with the NHS, the WLGA and Communities First partnerships. The guidance is highly relevant in helping to clarify the health contribution of local authorities and its application is assisted by a nationally funded support unit.

9. LAs and their partners should collaborate in identifying which social services are currently provided around the clock, seven days a week, and whether additional services should be available at all times.

Several initiatives are underway to improve emergency services including Developing Emergency Care Services (DECS) and the Welsh Emergency Care Collaborative. Social services have been engaged and this will develop further. Work now beginning will pick up the issues of extended access and more integrated working of emergency services and will address the priority areas that could make the greatest contribution to improvement. Following consultation, the final version of the DECS policy will be launched shortly and include an implementation plan with a work stream focused on social services to achieve a more integrated service.

Many social service users are, of course, supported around the clock. As part of the follow up to "Fulfilled Lives, Supportive Communities" we intend to consider emergency access more fully and to reinforce need for regular planning for contingencies.

Key areas that impact on the quality and provision of a seamless service

10. NHS trusts and LAs should take steps to ensure that:

- discharge staff of different disciplines co-operate and receive training to facilitate better understanding of the roles of the different professionals in the discharge team;
- discharge teams should have access to joint finances or joint resources to enable them to put services in place more quickly;
- the procedures for discharge planning should be established as soon as a patient is admitted to hospital;

Hospital Discharge Planning Guidance was issued as a WHC (2005)035 and NAFWC 17/2005 as planned in 2005. This set out requirements for training, accessing and sharing resources to deliver timely services and nurse led discharge. It emphasised the key principle that discharge planning must commence on (or, for planned admissions, prior to) admission to hospital. An updated version of the guidance will be issued this year to reflect additional requirements flowing from the Mental Capacity Act.

Further recommendations for action in these areas may flow from the review of delayed transfers of care which is to be undertaken this year.

11. The Welsh Assembly Government should explore the scope for innovative provision of intermediate care, including outside the hospital setting.

The NSF for Older People in Wales, issued in March 2006, acknowledged that some progress had been made with the development of Intermediate Care services across Wales, but that there should be a more strategic and co-ordinated approach to these services which should be mainstreamed. The NSF therefore requires the development of a local joint strategic plan for the development of Intermediate Care services by the end of March 2007, and the provision of services in accordance with the NSF standard by March 2008.

The National Leadership & Innovation Agency for Healthcare (NLIAH) has piloted an evaluation of Intermediate Care schemes with a view to rolling this out across Wales during 2007.

12. Health, Social Care and Well Being Strategies should address the issue of long term planning for social care needs for people with mental and / or physical care needs.

Existing Guidance on Health, Social Care and Well-being Strategies requires local bodies to plan services for all major client groups based on the local needs assessment. We will emphasise the need to address planning for long term social care needs of these groups in the final guidance for the next round of strategies which are due to start in 2008.

13. Commissioning agencies should have greater regard to the independent and private sector and involve them fully in the planning of services at all levels.

See update for Recommendation 3.

14. Service users should be informed about, and closely involved in, the planning of services.

As services develop, we are committed to an approach that more openly engages the public at all levels, in accordance with ‘Making the Connections: Delivering Beyond Boundaries’.

This is reflected in current guidance, for example Shaping Health Services Locally, which was issued in January 2005. This builds on Signposts – a practical guide to public and patient involvement in Wales, published in October 2001 to provide guidance to NHS organisations on how to undertake Public and Patient involvement (PPI) activities in a range of different circumstances. It also placed a duty on Welsh NHS organisations to carry out a baseline assessment of PPI activities and to develop and publish annual PPI plans which, for the first time, set out priorities for public and patient involvement.

Local authorities already have a duty to consult the public on the planning and development of their services. The review of the planning and commissioning guidance will reinforce the involvement of service users at each stage of the planning and commissioning cycle.

The NSF for Older People calls for evidence that older people are included in local arrangements for public and patient involvement. This builds on the establishment of Older People’s Forums in each locality, and is reflected at national level through the National Older People’s Forum.

The Healthcare Quality Improvement Plan (QUIP) which was published in November 2006, describes how we aim to create a world class health service in Wales drawing on the energy and enthusiasm of those who work in the service and informed by those who use it.

Although a lot of work is already happening at local level, we need more information about patients’ experiences of the NHS, which can be used both nationally and locally to pinpoint areas for improvement. One way of doing this at a national level is through annual public/patient satisfaction surveys and this will be taken forward over the next year. This is also linked to wider work being taken forward through the ‘Making the Connections...’.

Providing high levels of customer service, learning lessons from when things go wrong and making people feel involved is a complex and cross-organisational activity and needs the highest level support to make the changes that are necessary. We will be looking to Board Directors to demonstrate clear action and commitment to this and we will offer further support in developing this area.

15. See recommendation 3.

16. Care plans should take account of the level of care being provided by carers. Agencies should work together to ensure that they understand the role and needs of carers and that they support them as members of the care team.

Hospital Discharge Planning Guidance (issued as WHC (2005)035 and NAFWC 17/2005 in May 2005) reinforces the need to involve and support carers as part of the discharge planning process.

Annex 12 to "Creating a Unified and Fair System for Assessing and Managing Care" which deals with carers' assessments includes guidance on this issue.

We are currently consulting on updating the Carers' Strategy for Wales. The final document will emphasise that care plans should specifically take account of level of care being provided by carers and the need for good joint working to recognise and support carers as members of the care team.

In all these areas, progress will be monitored by the new Carers' Champion. See also paragraph 4.03 of the consultation version of "Fulfilled Lives, Supportive Communities".

17. The Welsh Assembly Government should consider the need for centralised accreditation and dissemination of good practice (from Wales and elsewhere) and investigate the scope for an award scheme for rewarding exceptional examples of innovation and good practice in joint working.

The National Leadership and Innovation Agency for Health care (NLIAH) exists to foster innovation and improvement within service delivery.

NLIAH promotes Health Services improvement and excellence by providing a range of services that

- build leadership and management capacity and capability
- increase organisational effectiveness
- promote and support the redesign of the workforce
- engender and embed innovation.

In support of this agenda, the organisation holds an annual conference at which awards are given for innovation and good practice which have led to real improvements. Importantly, all submitted work is published at the conference and is then available to the service via a searchable portal on the NLIAH Website. Work is in progress with a number of other organisations in Wales to ensure that work from other sources is accessible through this common pathway.

From April 2006, the Welsh Local Government Association has hosted the new Social Services Improvement Agency, funded by the Assembly Government, which will complement the work of NLIAH and includes both Assembly Government civil servants and the NLIAH Chief Executive on its Board. It was set up to increase the pace of improvement and promote excellence within social services. Its roles include enabling members and officers to understand better their performance, strengthen evidence-based practice and encourage collective working and the sharing of good practice. It uses results from the Wales Programme for Improvement to focus its approach.

We continue to support and fund the WLGA's "Excellence Wales" scheme, which identifies, commends and disseminates good practice in local government. In the current financial year, the scheme's focus includes integrated services for older people and local community leadership – both of which call for strong cross-sector working.

In response to calls to acknowledge and celebrate innovative practice in social care – especially in relation to the workforce – the Care Council for Wales has worked with partners to establish the Wales Social Care Accolades. The first Accolades ceremony was held in the Summer of 2005 and the 2007 Accolades were launched in the Autumn of 2006.

18. The Welsh Assembly Government should develop guidance for health and social care managers on providing training and development opportunities with the aim of breaking down barriers between different professionals / practitioners. These should include co-location of staff; reducing duplication of work, work shadowing and pre-and post-registration training.

Our commitment to breaking down barriers is a central element in "Making the Connections: Delivering Beyond Boundaries".

Working in partnership with the National Leadership and Innovations Agency in Healthcare (NLIAH), Public Service Management Wales (PSMW) has developed and agreed a Compact that sets out how the initiatives and programmes designed to support the development of leaders and managers in health and social care harmonise with the broader, cross-service programmes in realising the recommendations in Beyond Boundaries. This assists access to a wide range of activities and, in itself, encourages the removal of barriers. In particular, PSMW's People Exchange Wales programme helps individuals experience other organisations and learn together with them and PSMW's emerging work to support workforce planning across the public service helps provide a systemic approach.

A national regional and local partnership framework for workforce management and development in social care has been developed and promoted over a number of years. We expect the partnerships to include statutory partners such as health, housing and education as well as private and voluntary social care providers. Most partnerships also include training and education providers. The model expects that joint learning opportunities will be developed through the partnership allowing staff the opportunity to learn and train together. In addition to formal training, other options such as mentoring, shadowing and job exchanges are encouraged.

19. The initial unified assessment should be carried out early in the episode of health / social care, so that a care package can be developed quickly and where possible prevent the need for acute care. It should include housing needs.

The current guidance on unified assessment states the need for all levels of assessment and consequent care planning to be undertaken in a timely manner and to take account of a range of needs, including housing.

The forthcoming Chronic Conditions Model and Framework for Action sets out how we can work more effectively to deliver better chronic conditions management. It is based on integrated planning

and management of chronic conditions, including prevention, management and treatment and supporting independence across organisation boundaries consistent with the patient care pathway.

20. The Welsh Assembly Government should review the guidance on the unified assessment process to:

- address the concerns about its implementation;
- ensure that housing needs are taken into account;
- highlight the involvement of the voluntary sector in planning and delivering care where appropriate; and
- identify and disseminate good practice.

A stocktake of the operation of unified assessment has been undertaken. The 2007-8 implementation programme for ‘Fulfilled Lives, Supportive Communities’ will include a commitment to review thoroughly the working of the Unified Assessment Process, to refocus it as necessary, build upon the progress made to date and identify and share good practice.

The role of health and social services in promoting the independence of patients and the prevention of unnecessary admission or re-admission to hospital

21. Health and social care providers should be alert to the benefits of assessing care needs early in a care pathway in discussion with the patient or client and the carer(s), with a view to preventing deterioration and possible hospitalisation.

The response to recommendation 19 sets out the actions in hand.

22. Evaluation of the Blaenau Gwent Assist Project should be disseminated to the rest of Wales, and consideration given to how assisted technology can be used effectively to help vulnerable people live safely in their own home.

£9.8 million of funding has been made available to local authorities to promote the development of telecare services. All 22 local authorities in Wales have produced strategies for the development of local telecare services in partnership with LHBs and others. These strategies are in line with the guidance issued in October 2005.

An independent evaluation of the impact of the telecare grants on the social care, health and housing economies in Wales has been commissioned and will report in summer 2008.

An All-Wales Telecare Learning & Improvement Network (LIN) has been established with representation from all 22 local authorities and Wales plus Care & Repair Cymru. The LIN meets quarterly and operates as an e-mail community for the dissemination of learning and information. A

website for all matters relating to the development of telecare in Wales has been established.

A Joint Telecare/Telehealth Policy Board is being formed to a design agreed at a workshop held in November 2006 by the Welsh Assembly Government in Partnership with Informing HealthCare. The design allows for the Policy Board to be informed by two groups established to consider both technical design and service design issues and oversight of joint implementation programmes.

Annex 4

HSSC Review of the NSF for Mental Health – Standard 2: User and Carer Participation

The Committee recommends that:

1. Local Health Boards and Trusts should have a training strategy for identifying the training needs of all staff in relation to user and carer participation, including those in primary care, and delivering training.

This recommendation was highlighted to LHBs and NHS Trusts who are responsible for the training of their staff. This recommendation is being taken forward through the HR team within the Assembly's Department for Health and Social Services. The Assembly will be liaising with NLIAH to see whether this can become a part of NLIAH's Service Level Agreement with the Assembly. There have been examples of where service users have been involved in training General Practice staff, including GPs, reception staff, etc. and helping to raise awareness about mental health issues. The Towy Valley Mental Health Awareness Day saw Community Mental Health Teams (CMHT), the Older Age Psychiatry Team (OAPT), community nursing staff, health visitors, LHB, Carers services, counselling service and of course the users and carers representatives involved in raising issues relating to mental health service users.

2. User involvement development officers should be appointed. They should be independent of the statutory agencies. They should be appointed jointly by LHBs, Trusts and LAs. Their role should include training individual users and carers to participate in planning, commissioning, monitoring and evaluating services. It should also include cascading information and guidance and helping user and carer organisations to work with the statutory bodies

In Wales there is a network of 'Mental Health Development Workers' and 'Service User Involvement Development Workers' who are located in the voluntary sector and whose role is to help build capacity and ensure that service users views influence the development and delivery of services, and are empowered to take a lead in the running of projects. User Involvement Development Posts were first established in Wales in 2001 as a three-year pilot project covering the areas of Cardiff and the Vale, Merthyr Tydfil, and Rhondda Cynon Taff. Through this project, funded by the Assembly Government, a number of activities took place that improved the confidence of the people taking part. The mental health development service covers all areas of Wales, and in addition there are 10 'Service User Involvement Development workers' who provide a voice for service users.

One of the key actions of Standard 2 of the adult mental health NSF requires each LHB area to have service user and carer development workers or equivalent in place by March 2008 to ensure comprehensive approaches to user/carer involvement. The Assembly will be building on the current network to ensure there is a sustainable service in all parts of Wales.

3. 'Stronger in Partnership' should be reviewed with a view to giving more emphasis to the involvement of users, carers and the voluntary sector in the initial strategic planning of services.

The Assembly Government endorses what the Health and Social Services Committee have said about service user involvement, and accepts that more emphasis needs to be given to ensuring effective and meaningful involvement of 'users, carers and the voluntary sector in the initial strategic planning of services.'

An external Task & Finish group has been established, which includes representatives from the voluntary sector, service user groups, Local Authorities, Trusts and LHBs. In reviewing 'Stronger in Partnership' the Assembly Government has decided to develop a new, updated and improved version of this guidance, and to strongly emphasise and endorse what the Committee has said. A draft version is near completion which will then be subject to consultation with key stakeholders.

Examples of good practice will be included within the new guidance, for example ensuring that terms of reference for all mental health planning groups include the need for service user involvement and the need to detail the reasons and need for such a role, the advantages this will bring, and to clearly specify what the role involves.

4. All individual care plans should be 'signed off' formally by the service user and the appropriate health care professional and copies given to the user and or carer.

The Assembly Government has conducted a snapshot review of CPA across the whole of Wales. Details of our findings have been sent out to LHB and Trust Chief Executives in order that they can learn from good practice in other trusts, however, it is clear that the picture across Wales is mixed.

A copy of this report can be found at attached link:

<http://www.wales.nhs.uk/sites3/Documents/438/CPAReviewOneYearOn Epdf>

5. When a service user is not at a crisis point, he or she should be invited to agree that their carer should be involved in care planning at times of crisis.

All service users that multiple care needs should have contingency and crisis plans as part of their care plan, and these should include; early warning and relapse indicators, who it is the service user is most responsive to, and how to contact that person.

Our review found that only one Trust does not have arrangements in place governing the distribution of assessment outcomes, although this Trust does have a system in place to provide the service user

with a copy of the care plan.

In all of the Trust areas where systems are in place they all supply information on assessment outcomes and a copy of care plans to all of the following care providers:

- i. The Service user
- ii. Their Carer
- iii. The Nearest Relative if different from ii above
- iv. The GP
- v. The Local Authority
- vi. Other agencies

All of the trusts were clear, however, that in order to share information they would first seek the service users consent and that information would not be routinely shared with all care agencies unless they were actively engaged in delivering a component of the care. One Trust drew particular attention of the need for service user consent to share information with nearest relative.

6. The Welsh Assembly Government should take urgent steps to ensure that children and young people are treated in an appropriate environment.

The NSF for Children, Young People and Maternity Services in Wales has a key action that requires commissioners to ensure that children and young people are only admitted to adult settings in exceptional circumstances. The Assembly Government's longer term objective is that no child or young person should need to be treated in an adult facility; however it will take some time before sufficient facilities are in place to allow this to happen. In the meantime it may be necessary from time to time for children and adolescents to be treated on an adult ward and it is important for providers to ensure that appropriate safeguards are in place. Guidance has been issued regarding the safeguards that should be in place in such circumstances.

7. All staff involved in care planning should be trained to recognise the special cultural needs of some black and minority ethnic groups, and to know where to seek advice on how to respond to such needs.

A Race Equality Action Plan for mental health was issued by the Welsh Assembly Government in November 2006 endorsing this recommendation.

8. All staff involved in care planning for the elderly should be trained to recognise and respond to the special needs of vulnerable elderly people and their carers.

A National Service Framework for Older People was launched last year that includes a standard relating to mental health in older people. This states that older people who have a high risk of developing mental health problems and others with related diagnosis have access to primary prevention and integrated services to ensure timely and appropriate assessment, diagnosis, treatment and support for them and their carers. An 'All Wales Improvement Network for mental health of older people has been established in Wales which seeks to promote and implement good practice and evidence based developments. The principles set out in our guidance on the Care Programme Approach (CPA) apply equally to older people, and where needs of older people do not meet criteria for CPA they will be covered by the Unified Assessment process.

9. The six sectors listed in paragraph 2.4 should have regard to the points set out in that paragraph when improving service planning and commissioning and for improving individual care planning.

Standard 5 of the adult mental health National Service Framework sets out the standard for ensuring that services are jointly planned commissioned and delivered in an efficient and co-ordinated way.

This part of the Committee's review setting out what it saw as the key roles for each of the different sectors in planning and commissioning mental health services in Wales, has been reproduced in the new 'Stronger in Partnership' guidance being developed by the Assembly Government.

10. With appropriate training service users should be involved in the recruitment of staff at all levels.

This has been implemented fully in at least 2 Trusts in Wales. Our HR team within the Assembly's Department for Health and Social Services has discussed this with Trust HR Managers, and with HR specialists we are currently exploring options for ensuring this can be rolled out across the whole of Wales.

11. The Welsh Assembly Government should ensure that there is a mechanism for disseminating good practice in Wales and from other countries.

The National Leadership and Innovation Agency for Healthcare (NLIAH) developed and published in October 2006 an Improvement Guide setting out what service improvement tools are available, how to make best use of them, and detailing the benefits they can bring. NLIAH will be the main agency for helping disseminate good practice in Wales and is currently involved in developing Integrated Care Pathways for mental health conditions.

12. The Committee endorses the Welsh Assembly Government's proposal for an action plan for mental health awareness to address stigma. It recommends that Health Promotion Wales consider an award scheme that would celebrate and publicise cases where people have successfully overcome mental illness.

The Assembly Government has sought views from the mental health voluntary sector in Wales on this proposal. The view of the Mental Health Alliance is that this needs to be handled sensitively, and

although it could be of value, there is scope for it to backfire. We will continue to discuss with the voluntary sector ways of taking forward this recommendation.