Health & Social Services Committee

Minutes (HSS(2)-01-05)

Meeting date: Wednesday 12 January 2005

Meeting time: 9.00am to 1.05pm

Meeting venue: Committee Room 3, National Assembly for Wales

Assembly Members in Attendance

| Assembly Member | Constituency |
|--------------------------|-----------------------------|
| David Melding (Chair) | South Wales Central |
| Jocelyn Davies | South Wales East |
| Brian Gibbons (Minister) | Aberavon |
| John Griffiths | Newport East |
| Val Lloyd | Swansea East |
| Sandy Mewies | Delyn |
| Jonathan Morgan | South Wales Central |
| Gwenda Thomas | Neath |
| Rhodri Glyn Thomas | Carmarthen East and Dinefwr |
| Kirsty Williams | Brecon and Radnorshire |

Officials in Attendance

| Name | Job title |
|------------------|---|
| Ann Lloyd | Head of Health and Social Care in Wales |
| Dr Sarah Watkins | Senior Medical Officer |
| Graham Williams | Chief Inspector of Social Services |

Others in Attendance

| Name | Representing (if applicable) | Agenda item(s) |
|-----------------|---------------------------------|----------------|
| Dr Roger Banks | Mind Cymru | Item 5 |
| Lorraine Best | | Item 5 |
| Dawn Gullis | Mind Cymru | Item 5 |
| Kath Jones | Rhondda Cynon Taff User Network | Item 5 |
| Polly Kitzinger | Rhondda Cynon Taff User Network | Item 5 |
| Liz Neal | Mind Cymru | Item 5 |
| Sara Nichols | Rhondda Cynon Taff User Network | Item 5 |
| Robin Williams | | Item 5 |

Committee Service

| Name | Job title |
|---------------|------------------------|
| Jane Westlake | Committee Clerk |
| Claire Morris | Deputy Committee Clerk |

Item 1: Apologies and Substitutions and Declarations of Interest

- 1.1 An apology had been received from Ann Jones. Sandy Mewies substituted.
- 1.2 There were no declarations of interest.

Item 2: Ministerial Report (9.05 to 10.35)

Paper: HSS(2)-01-05(p.1)

2.1 The Chair welcomed Dr Brian Gibbons to his first meeting as Minister for Health and Social Services. He also recorded his thanks to Jane Hutt for her contribution and participation over the last six

years and undertook to write to her on behalf of the Committee.

2.2 The Minister recorded his gratitude to Jane Hutt for her work and commitment to patients and the NHS in Wales. He said that having delivered the health reform package now was the natural juncture to move to delivering the potential and opportunities offered by reform. He believed there was broad agreement from all parties on the way forward and it was his intention to engage constructively with them.

The Minister provided the following additional information on the Second Offer Scheme:

- Over 50% of people approached had accepted a second offer, with over 2,500 people having received treatment;
- 1,500 people had been uncontactable as part of the exercise; and
- 1,000 had been ineligible.

2.3 In response to comments and questions from Members, the Minister made the following points:

Section 1: Modernising Medical Careers

• Evaluation would be undertaken when the first students had completed year 2 of the foundation programme.

Section 2: General Practitioners (GPs) Specialist Services

- One of the concerns in primary care was that a lot of unresourced work was undertaken and this scheme would address that.
- If Local Health Boards (LHBs) were not in a position to provide a full range of integrated services they would need to review their programmes.
- It may be that some LHBs were awaiting the outcome of pilots, but the Minister would be interested to hear of any who were not progressing services on financial grounds. The Wanless report was clear that GP services were crucial in sustaining acute care.
- LHBs would be expected to develop a commissioning policy based on a rigorous needs assessment of the local community.
- The Innovations in Care Team were undertaking an audit of how LHBs were taking this forward.
- GPs with a special interest who were able to refer a patient to an in-patient list for surgery would have received appropriate training. It was a fundamental principle that they should not exceed their competence.

Dr Watkins advised the Committee that doctors in the Barry musculoskeletal scheme had specific arrangements with consultants for referring patients for surgery.

Section 3: Overseas Nurses: Recruitment, Retention and Career Development

- While recruiting nurses from overseas could prevent them making a contribution to their own country, they could benefit from the training opportunities available in Wales before returning home. The majority were employed on fixed term contracts, but it was a matter of personal choice if they decided to stay in Wales at the end of their contract.
- Information was not collected centrally on where the 40% of overseas nurses that did not renew their contract at the end of their first contract period went but this would be obtained from Trusts and collated for the Committee.

Section 4: Agenda for Change: Implementation

- Any individual issues relating to Agenda for Change should be passed to the Minister to be taken forward.
- Agenda for Change needed to pick up other healthcare professions such as Occupational and Speech Therapists who work for non-NHS organisations.
- Job matching should be completed by the end of March so people would be assimilated by September. A report on job matching would be provided in the March Ministerial report.

The Director advised that the role and career structure of the school nurse were being examined.

Section 5: Commissioner for Older People

- The Deputy Minister accepted that there should be no duplication between the Older People's Commissioner and the Commission for Equality and Human Rights (CEHR). The CEHR would primarily be concerned with employment issues and would not therefore replicate the work of the Older People's Commissioner.
- Ministers and officials were in discussions with their UK counterparts in taking forward the proposed legislation.
- It was envisaged that the Health & Social Services Committee would work with the Welsh Affairs Committee during the pre-legislative scrutiny process.

• The Assembly Government was constrained by resources in implementing free personal care as recommended by the Royal Commission on the elderly. Wales had a relatively high proportion of elderly people, who were home owners but on a low income. Steps needed to be taken to ensure their homes were not put at risk.

Section 6: European Working Time Directive

- There was an uneven pattern of compliance across Wales. A large number of Trusts were now compliant and had worked hard over the last year to achieve it.
- Trusts having difficulties with compliance were mainly those with a large number of staff

- affected by the Directive.
- Regular updates on the progress of the 'Hospital at Night' projects would be provided.
- Further details of compliance would be provided to the Committee as a paper to note.

Section 7: Changes to the Relationship with the National Institute of Clinical Excellence (NICE)

• Arrangements were being made to enable health professionals in Wales to access NICE guidance after restructuring.

Section 8: Informing Healthcare

• People involved in pre-clinical training received IT training in advance of taking up their post to ensure a smooth transition.

Section 9: Infertility Services

- 2.4 Jocelyn Davies raised the following concerns on the proposed social criteria for IVF treatment funded by the NHS:
 - Same sex couples must demonstrate that they had been in the same relationship for at least two years, but there was no such requirement for heterosexual couples.
 - Couples with an adopted child would be excluded, but there were many different reasons why people adopted, for example some people adopted a sibling on the death of their parents.
 - Neither partner must have undergone a sterilisation procedure, but in some cases sterilisation was carried out for medical reasons.
 - Neither of the couple must smoke, but other substances, such as alcohol or drugs, were not prohibited.
- 2.5 It was agreed that the Committee would consider whether it should look at this in more detail in the future.

Section 10: NHS and Local Government Joint Working Special Grant 2003-04

• Consideration would be given to targeting project money to address problems where GP practices straddle local authority / LHB boundaries.

Section 11: Opening of the A&E and Intensive Therapy Facilities at Morriston Hospital

 The Cardiac ITU/CCU at Morriston Hospital was commended on its award of "practice development unit" status by Leeds University. The Minister said he was keen to recognise and disseminate good practice.

Section 12: Suspension of Day Care Providers and Child Minders (Wales) Regulations 2004 - Role of the Criminal Record Bureau

• It was agreed that the concerns raised by Gwenda Thomas would be taken forward at the next meeting of the Safeguarding Children Working Group.

Section 13.1 NHS Direct Wales

• All LHBs would be expected to have undertaken a rigorous evaluation of out of hours provision by 31 March. A detailed report would be provided to the Committee once all the information had been collated.

Section 13.3 Second Offer Scheme

- The cost of extending the scheme to patients waiting 12 months would be around £25m.
- A standard tariff had been agreed with NHS providers in England and the private sector from the outset.
- The second offer scheme was a short-term initiative to address waiting times not a long-term policy.

Actions

- Information to be provided on what happens to the 40% of overseas nurses that do not renew their contract at the end of their first contract period.
- A report on job matching in respect of Agenda for Change to be provided in the March Ministerial report.
- Regular updates to be provided on the progress of the 'Hospital at Night' projects.
- A paper to note would be submitted on compliance with the European Working Time Directive.
- Committee to consider whether it will look at infertility services in more detail.
- A detailed evaluation of out of hours provisions to be provided.

Item 3: Schedule of Secondary Legislation

Papers: HSS(2)-01-05(p.2a) and HSS(2)-01-05(p.2b)

3.1 The Committee identified the following items for consideration:

| Reference No: | Title |
|---------------|--|
| HSS 64 (04) | Revised Directions to NHS Bodies on Counter Fraud Measures |
| HSS 67 (04) | Children Act 2004 (Commencement Order) (No. 1) (Wales) 2004 |
| HSS 68 (04) | The Arrangements for Placement of Children (General) Regulations 1991 (Amendment) (Wales) Regulations 2005 |
| HSS 70 (04) | Shipman Inquiry Regulations 2005 |
| HSS 71 (04) | Independent Prescribers Regulations 2005 |

3.2 It was also agreed that the Committee would have a wider discussion on the transfer of CAFCASS.

Item 4: Current European Issues

Paper: HSS(2)-01-05(p.3)

4.1 The paper was noted.

Item 5: Policy Review: The National Service Framework for Mental Health: Standard 2 - User and Carer Participation

Papers: HSS(2)-01-05(p.4); HSS(2)-01-05(p.5) and HSS(2)-01-05(p.6)

Mencap Cymru

- 5.1 The Chair welcomed Liz Neal and Dawn Gullis from Mencap Cymru and Dr Roger Banks, a Consultant Psychiatrist who specialised in learning difficulties. A copy of their introductory evidence is attached at Annex 1.
- 5.2 In response to questions from Members, the presenters made the following points:
 - There were a number of factors that contributed to people with learning disabilities being denied access to mainstream services, such as limited resources, or a lack of understanding of how to diagnose and treat someone with a learning disability.
 - Concern was expressed that people with a mild learning disability and mental health problems would be moved into specialist services rather than mental health services.
 - The Mencap report 'Treat Me Right' included a number of cases where carers felt very strongly that if they had been listened to there would have been a very different outcome.
 - Most healthcare practitioners had not received training in communicating with people with

learning disabilities and understanding their problems. Professionals tended to assume that any problem was related to their learning disability, often missing the signs of other treatable illnesses.

- The definition of 'mental disorder' in the easy read version of draft Mental Health Bill included learning disability. This would mean that anyone with a learning disability could be subject to the provisions of the Bill.
- People with learning disabilities experienced problems in the transition from children's to adult services. Many carers reported a drop-off in support on moving to adult services and felt they were left to cope alone.
- Some problems with provision of services in Welsh had been reported, especially with speech and language therapy but they were now being addressed.
- A lot of mental illnesses were treated in general practice. The primary care sector, and also secondary healthcare providers, needed to receive more information and support, not just about learning disabilities, but mental health and behavioural problems which could be a barrier to people with learning disabilities accessing services.
- The Welsh Assembly Government had made funding available to set up advocacy services for people with learning disabilities. 20 of the 22 local authorities had increased their advocacy provision but more was needed.
- Consideration also needed to be given to the implications of the Mental Capacity Bill.

Rhondda Cynon Taff User Network

- 5.3 The Chair welcomed Sara Nichols, Kath Jones and Polly Kitzinger.
- 5.4 In response to questions from Members, the presenters made the following points:
 - There was sometimes conflict between the wishes of service users and their carers.
 - Carers invariably knew the service user better than the professionals and some service users found it very supportive for carers to be making requests on their behalf.
 - Carers felt they were valued in the community but once the service user was admitted to hospital some felt disempowered and distanced.
 - The principle behind the tidal model was that a person's experience was the reality of their illness. The tidal model meant that when someone was in crisis, nurses and professionals listened to their experiences and worked with them to plan what support they needed.
 - The tidal model was used in in-patient services at the Royal Glamorgan and St Tydfil's Hospitals, who chose to adopt it because it was more person centred in delivering services. Services users felt that time was being set aside for them and it linked into the care programme approach. Service users and professionals had welcomed the move.
 - Kath Jones said she was in hospital in 2004 and had seen a significant difference in the culture and how patients were being seen since her last admission in 2002. She commended the tidal model.
 - Users were involved in recruitment of staff at all levels. This gave a clear message to potential staff that service users were an integral part of service planning and delivery.

- Changing attitudes amongst staff was crucial to user involvement and one of the most successful ways of doing this had been joint training for staff and service users.
- Good practice took more time, which was a potential threat to the work being done in Rhondda Cynon Taff. Policies were being developed to try and safeguard it.
- Service users were experts on mental illness. Staff and users working together would achieve positive outcomes.
- Service users should not be passive recipients but actively involved in their treatment, and the care programme approach would ensure that happened.
- Kath Jones had been appointed to work with service user groups in Rhondda Cynon Taff to develop a tool that would equip them to become more involved in their treatment.
- A joint working group had been set up to look at running self management training so people could manage their own mental health conditions in the community and get the help they needed to do so. At the moment learning disabilities were not represented on the joint working groups.
- Merthyr Tydfil had a service user forum that brought users of all different services in the region together to share their views. The geography of the Rhondda valleys made this more difficult, so they ran a user network which relied more on telephone and written contact. They also had a worker dedicated to going out to different settings, such as day centres, and gathering views from people who might not otherwise have contributed.
- 5.5 The Chair welcomed Lorraine Best and Robin Williams.
- 5.6 Robin Williams said that his main concern was to see current legislation with regard to the involvement of users implemented. He believed that users' concerns were merely recorded and not taken into consideration as part of the decision making process.
- 5.7 In response to questions from Members, Lorraine and Robin made the following points:
 - Users of mental health services were often on debilitating drugs and many lost their confidence. They needed help and support to become involved as they had a lot to offer as a result of their experiences.
 - User groups existed but in many cases were not well publicised and poorly attended.
 - This could be because service user involvement was tokenistic. Many did not even receive a copy of the minutes of meetings they had attended.
 - Policies and frameworks existed on paper but were not being implemented.
 - Very often, it was the same users that became involved and they got burnt out.
 - When a person with a history of mental illness became unwell, doctors often prescribed drugs, rather than talking to them to try and find out what was at the root of the problem.
 - Greater access to counselling services was needed.
 - There was still stigma attached to mental illness and people with mental health problems were discriminated against in ways that would not be acceptable to any other group in society.
- 5.8 The Minister said that an evaluation of the facilitation of participation would be produced by Easter

and could inform the Committee's review.

Item 6: Forward Work Programme - January to March 2005

Paper: HSS(2)-01-05(p.7)

6.1 The forward work programme was agreed. Consideration would be given to adding to the agenda on 2 February.

6.2 The Chair asked that an item on access to dental services be included in the March Ministerial report.

Item 7: Minutes

Paper: HSS(2)-14-04(min)

7.1 The minutes of 24 November 2004 were agreed.

Annex 1

Service User Participation NSF - Mental health Services

Liz Neal

Dawn Gullis

Roger Banks

Mencap Cymru

Purpose: To enable people with a learning disability and their families to take control of their lives through:

- Campaigning
- Informing and supporting and
- providing good quality services

Treat Me Right

- Mencap Cymru report demonstrating that people with a learning disability are not receiving the health care they need.
- Reasons include: lack of training, discrimination, poor health promotion, don't know why people with a learning disability die from different causes.

Mental Health Issues for People with a learning disability

- 1 in 3 experience mental health problems (cf 1 in 4)
- 3% have schizophrenia (cf 1%)
- Some syndromes have mental health or behavioural disorders associated with them

Accessing mental health services

- Many people who have an unidentified learning disability are treated by mainstream services
- People with an identified learning disability often seen by specialist learning disability services

Accessing mental health services

• However, many people with an identified learning disability, albeit a mild learning disability are excluded from mainstream mental health services.

Accessing mental health services

• "The culture is that people with a learning disability are actively excluded from services. In a number of policies it was stated that the services were not available to people with a learning disability. The understanding of the service being that intellectual ability like age is a legitimate discriminatory factor in services provision"

Accessing mental health services

- Dispute between teams.
- Should she be supported by learning disability or mental health service
- Eventually mental health service
- But delay in treatment and anxiety for Dawn

Accessing mental health services

o NSF mental health services says under the heading "equity":

"Mental Health services should be available to all and allocated according to individual need, irrespective of where someone lives, their ethnic origin, gender, culture, religion or sexuality or any physical disability."

o Remove the word "physical".

NSF mental health services in Wales

• Person A has a mild learning disability and a significant mental health needs. They are supported during the day by a mental health day service, but otherwise live independently. They do not receive any support from the learning disability team. However, if at some point the mental health team identify the mild learning disability they risk becoming ineligible for the day service.

NSF mental health services in Wales

- Specialist learning disability teams are important and necessary for some.
- However, they provide limited services. Greater range of therapies available from mainstream services. People with a learning disability are denied access to these.

NSF mental health services in Wales

- Inappropriate referrals to specialist services include people with Asperger's Syndrome, Autism, and borderline personality disorders
- People with a learning disability should get the right skilled staff to meet their needs wherever they are found.

NSF mental health services in Wales

- Peter has a mild learning disability and significant mental health problems
- Disagreements between learning disability and mental health teams as to who is responsible for support. Doesn't meet eligibility criteria. Therefore no support. Behaviour now attracting police interest.

NSF mental health services in Wales

• Service user and carer participation can only occur when there is integration between services or when there is a clear acknowledgement that people with learning disabilities should have access to the full range mental health services when required and in a co-ordinated, integrated and needsled (rather than "label-led") manner.

NSF mental health services in Wales

- Full and genuine participation means: service users and carers:
 - o understand what can be offered
 - o are able to make choices about their treatment
 - o have a record of the care plan that is easy to understand
 - are involved and consulted as stakeholders on the commissioning and monitoring of services.

NSF - full and genuine participation

Three barriers:

- Lack of understanding of community based services (social model).
- Lack of understanding of the needs of people with a learning disability
- Poor communication skills

NSF - full and genuine participation

- How lack of understanding is demonstrated by mainstream services
- Special schooling equated to learning disability specialist service required
- Asperger's Syndrome equates to learning disability specialist service required

NSF - Stigmatisation

- Sian's story
- Sian used to be seen by members of the mental health services. She had had a period of inpatient treatment on a ward with no additional support, but most of the time was treated in the community. She has a mild learning disability and some mental health needs. She moved to a neighbouring local authority. Here there was a period of arguing between learning disability services and mental health services about who should support her. Eventually the Learning Disability team agreed to provide support.

Children's Mental Health Services

- Issues same as adults
- No specialist learning disability service means there is a gap children fall through.
- At least three children admitted to adult wards in last 12 months.
- Out of county placements hundreds of miles from families.

Good practice examples

- Joint working in Conwy and Denbighshire
 - o clinical advisory group
 - o care pathways for planned and emergency admissions
 - o task and finish group working on virtual teams and joining up mental health, elderly and learning disability mental health services

Good practice Examples

- Gwent NHS trust service user group
- Health and Wellbeing Groups representation of people with a learning disability and carers
- Person centred planning
- Bangor university
 - o mental health in learning disability qualification. 9 out of 63 mental health professionals.

Recommendations

- No-one must be excluded from mainstream services on the basis of intellectual ability.
- Amend "equity" statement on NSF to the inclusive term "disability"

Recommendations

- Mainstream and specialist services must develop joint working protocols as a matter of urgency
- Commissioning strategies must take account of filling the current skills gap that creates inequality

Recommendations

• NSF for children must address CAMHS exclusion of children with a learning disability more robustly.

Mencap Cymru

Thank you for listening