### EQUALITY OF OPPORTUNITY COMMITTEE

Date:	15 February 2006
Time:	09:30
Venue:	Committee Room, National Assembly Building, Cardiff Bay
Title:	Policy Review of Service Provision for Disabled Young People – Draft
	Interim Report

#### Purpose

1. This paper invites the Committee to discuss key issues and recommendations for its interim report, and agree next steps for the review.

#### Recommendation

2. Members are invited to consider key issues and recommendations for an interim report on the Policy Review of Service Provision for Disabled Young People. A draft structure for the report, and part 3 of the report (Next Steps) is attached at Annex A.

#### Background

3. In November 2004 the Committee agreed that it would produce interim reports at each stage of the review, which was planned to last up to two years. The draft structure at Annex A is for the first such interim report.

4. The plenary debate slot for the Committee's interim report has been deferred from 7 March 2006 until the summer term, to allow more time for a report to be finalised and laid before the Assembly.

5. A reference group of disabled young people began working with the Committee in January 2005, and in November 2005 the Committee nominated Lorraine Barrett AM and Helen Mary Jones AM to undertake, with the Committee Clerk, a review of how the Committee and the reference group had worked together. The recommendations arising from that review exercise were considered in Committee on 18 January, and a decision on whether to endorse the recommendations was deferred to today's meeting.

#### Action

6. To consider key issues and recommendations for a draft interim report, and whether to adopt the recommendations attached at Annex A on future work with the Committee's reference group.

# Members' Research and Committee Services

# DRAFT

# Equality of Opportunity Committee – Policy Review

Service Provision for Disabled Young People – An Interim Report

"Why is it that disabled young people are always left until last?"

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# CHAIR'S INTRODUCTION

The Equality of Opportunity Committee first decided to undertake a policy review of service provision for disabled young people in October 2003, after being presented with the manifesto of disabled young people involved in organising the first ever 'Rights into Action' International Congress of Disabled Young People, held in Swansea. The manifesto identified a number of important issues that were affecting the young people's ability to have control over their lives and achieve their full potential. The motto adopted by the Congress, which was an initiative emerging from the European Year of Disabled People 2003, was 'nothing about us without us'. It reflects the fact that historically services have been provided to disabled young people by non-disabled people, without young people themselves having a real say in what they want and need. The Committee has adopted the motto 'nothing about us without us' for its review.

The Committee's review is rights-based, and to ensure that it is driven by issues important to disabled young people, and no other agenda, the Committee decided to set up a reference group of disabled young people to advise it throughout the course of the review. The Committee believes this is a unique approach and many lessons have been learnt from it. These lessons are included in the report, so that others may benefit from the experience.

The reference group has met separately from the Committee on six occasions, and its members have directly participated in Committee evidence sessions – asking questions alongside Committee Members. The Committee is very grateful to the reference group members, their support workers and families, and the organisations with which they are associated, for the hard work, time, energy and enthusiasm they have put into working with the Committee.

None of this would have been possible without the professional facilitation provided by Barnardo's Cymru, who have shared their rich experience of participation and consultation with young people. The Committee is also grateful to the Disability Rights Commission in Wales, whose Director is a standing invitee to the Committee and which has provided ongoing advice and support to the review. It also thanks all those who have given both written and oral evidence to date.

Members hope that the experience has been a positive one for all concerned, particularly the young people involved, and that it will encourage other policy and decision-makers in the future to see the benefit of working directly and appropriately in partnership with young people when developing policies and delivering services.

The reference group has produced its own interim report and recommendations, with help from Barnardo's Cymru, and this is included as an integral part of the

Committee's report. The Committee fully endorses all the group's recommendations, and has added to them with some of its own.

The title of this report is a question. It is a question that was asked by one of the young people in the Committee's reference group at an evidence session. It was chosen for the title because it sums up the frustration that is felt by many disabled young people, and those who work with them, about the barriers they face and their exclusion from the decision-making processes that affect the way they can live their lives. The Committee hopes that this report will help to focus on these issues and identify some practical solutions.

# Gwenda Thomas AM Chair – Equality of Opportunity Committee

# **COMMITTEE MEMBERSHIP**

Gwenda Thomas (Chair)	Neath	
Lorraine Barrett	Labour	Cardiff South and Penarth
John Griffiths	Labour	Newport East
Mark Isherwood	Conservative	North Wales
Helen Mary Jones	Plaid Cymru	Mid and West Wales
Laura Anne Jones	Conservative	South Wales East
Huw Lewis	Labour	Merthyr Tydfil and Rhymney
Jenny Randerson	Liberal Democrats	Cardiff Central
Catherine Thomas	Labour	Llanelli
Leanne Wood	Plaid Cymru	South Wales Central

# **EXECUTIVE SUMMARY**

[to insert here]

# BACKGROUND

# The Social Model of Disability

The National Assembly for Wales adopted the social model of disability by a resolution in early 2002. Unlike the medical model of disability, which defines disability in terms of the 'label' of a person's medical condition or impairment, the social model defines disability in terms of the barriers which stand in the way of disabled people, for example environmental, psychological or attitudinal barriers.

The social model focuses on bringing down the barriers that disable people from participating in everyday activities and living life to its full potential. This policy review focuses on what the Assembly can do to remove the barriers that still prevent disabled young people in particular from achieving the independence and autonomy they seek.

# Implementing the Social Model

During the course of this review the Committee it became clear to the Committee that although policy makers and service providers may consider the social model a good thing, there is not consistent understanding of how to do things differently in order to implement it. The social model is still something being aspired to, not a reality for disabled people. The Committee welcomes the Welsh Assembly Government funding for a Disability Wales project to assist the Assembly with implementing the social model of disability in policy development and service delivery, by:

- increasing understanding of Assembly equality champions and other officials;
- producing best practice guidance for consultation with, and participation of disabled people as part of the decision-making process;
- looking at the Assembly's grant-making criteria to address barriers in the funding regime that might perpetuate models of dependence in projects where the beneficiaries are disabled people, and to enable more disability groups to access Assembly funding;
- developing a tool from the social model perspective to ensure it is considered first and not last in the policy-making process.

The Disability Discrimination Act 2005 legislates for a duty on public bodies to have a disability equality scheme, and the Committee also sees this as a driver to move closer to the social model of disability. The Committee will continue to keep a watching brief on developments in this area.

Suggested Recommendation: The Welsh Assembly Government takes steps to ensure that the social model of disability is integrated into its business functions, policy development and service delivery, including prompt and effective implementation of a Disability Equality Scheme.

Suggested Recommendation: The Assembly Parliamentary Service takes steps to ensure that the social model of disability is integrated into its functions and the conduct of its business, including prompt and effective implementation of a Disability Equality Scheme.

#### The Approach

This review was inspired by evidence the Committee received from a group of disabled young people about their issues and concerns. It is about finding out what disabled young people think they need, not what their support workers, parents, siblings, friends or social workers think they need. Therefore the Committee's approach has been to be advised by young people themselves.

#### Themes and Issues

The International Congress of Disabled Young People was organised by disabled young people and held in Swansea, South Wales, in July 2003. The Congress produced a manifesto of issues to be tackled and it was on the basis of those issues that the Committee decided to base its review. The Manifesto is at Annex A. It contained a great number of diverse issues, some of which were less relevant to young people in Wales, so the Committee conducted a scoping exercise, with support and advice from the Disability Rights Commission in Wales and Children in Wales, to help identify the key issues to focus on. It also decided to appoint a reference group of young people to provide further advice as the review developed.

# **Terms of Reference**

The Committee agreed a terms of reference for its review in June 2004. The full terms of reference and summary of the scoping exercise are at Annex B. The three key themes to inform the review are:

- Promoting and supporting independence and autonomy of young people
- Responsive, customer-focused and joined-up service provision
- Age appropriate support and services

Within these over-arching themes, the Committee agreed to give particular regard to the following eight areas:

- Education, training and employment
- Leisure
- Housing
- Transport
- Equipment
- Transition to adulthood
- Access to information
- Poverty

The Committee then undertook a consultation to identify whether the Assembly's existing policies on services for disabled young people adequately met their needs in those areas, what best practice existed in service provision and whether this was being shared adequately throughout Wales. The 67 responses came from a diverse range of sources.

The Committee looked at an overview of the Welsh Assembly Government's strategies and policies for service provision for disabled young people. It then took evidence from key service providers, who were questioned by Members and disabled young people in Committee. The Committee held one of its meetings in North Wales to make it easier for organisations based there to give evidence, and included an open microphone session for questions from the floor. The Committee Chair also visited the Shaw Trust to learn about their work in providing supported employment and independent living services for disabled young people.

The Committee chose initially to focus on the theme of 'Education, training and employment', in the course of which it has explored some issues around 'Transition to adulthood' and 'Access to information', followed by 'Transport'. This is an interim report on those key areas. The Committee's reference group is advising on issues to explore in the second half of the review (see Part 3 of this report, Next Steps).

# PART 1: NOTHING ABOUT US WITHOUT US – A PARTICIPATORY MODEL

# The United Nations Convention on the Rights of the Child

The Convention, which the United Kingdom has ratified, sets out guiding principles and human rights of children, including their right to participation and an active voice. In particular Article 12 of the Convention (UNCRC) states that:

'When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account.'

In a Welsh competition administered by Funky Dragon and the Enabling Participation Consortium, aimed at finding the best young people's definition of participation, the winning entry was

"Participation means that it is my right to be involved in making decisions, planning and reviewing an action that might affect me. Having a voice, having a choice."

Barnardo's Cymru has stated that this definition is in line with the evolving thinking of rights workers: "It has several key components. Firstly that participation is a right and not a process. As a right, a state of entitlement can be achieved by promotion and protection. Secondly that participation goes beyond consultation into active and credible involvement in making decisions. And finally that participation relates to anything that might affect an individual."

Children in Wales, which drew upon the views of professionals working with young disabled people and participating in its Disability Forum, welcomed the proposal to focus on the provision of careers advice and advice on rights under the Disability Discrimination Act 1995. It also recommended that attention be given to providing advice to disabled young people on the rights enshrined in the UNCRC, as evidence would suggest that those in Wales are broadly unaware of it and therefore of their fundamental rights as children and young people. Raising awareness of those rights would underpin the Welsh Assembly Government's commitment to enshrine the UNCRC in all its policy developments.

# The Reference Group

The Committee decided to appoint a reference group of disabled young people to advise its review. To ensure that the young people's participation was safe and supported appropriately, a professional facilitator was appointed through an open procurement exercise – Barnardo's Cymru. The Committee wanted a reference group as representative as possible, given that members would be self-selecting, ie gender balanced, with ethnic minority representation, to include at least one Welsh speaker, and be representative of a range of physical disabilities, learning disabilities and sensory impairments. The group members are also linked to wider organisations and networks of disabled young people. The process has been less successful in securing ethnic minority representation and input from young people with sensory impairments.

# **Reference Group Activity**

Since appointing the facilitator in January 2005, the full reference group has met seven times for 1-2 day residentials: 24-25 February 2005 - Cardiff (first preparatory meeting) 7-8 March 2005 - Cardiff 11-12 May 2005 - Caernarfon 15-16 June 2005 - Cardiff 5-6 October 2005 - Cardiff 6-7 February 2006 – Cardiff

In accordance with the Committee's wishes, the reference group members are drawn from different geographical locations and at first attempted to meet at venues away from Cardiff. However they have had difficulty in finding venues with sufficient accessible accommodation and so have chosen to meet at a preferred venue.

"Increased pressure should be put on hotels and conference venues to become accessible so that young people can organise and meet. It is an outrage that there are no fully accessible venues in North Wales, and just a couple that are anything like being accessible. The Assembly, in its regional committees, is in a very strong position to exert that pressure for change." Vin West, Arfon Access Group

### Rec: The Welsh Assembly Government to audit the accessibility of all hotels and conference facilities throughout Wales with a view to producing a public list of accessible venues that will encourage all venues to attain higher standards of accessibility.

Members of the reference group attending Committee meetings have also met separately with Barnardo's Cymru and their support workers 6 times, to prepare for participation in evidence sessions on 10 February, 17 March, 26 May, 30 June, 22 September and 12 October 2005.

Written outputs have been provided from the young people after each meeting, including a newsletter which they have circulated to other disability groups and networks. This is in addition to the group's verbal reports and participation in meetings. In November 2005 the group provided an interim report to the Committee with recommendations and this is reproduced below.

# What the Committee learnt about participation

Members have learnt a lot from the disabled young people about how to work effectively together. After the first two meetings the reference group gave

Members some feedback, and the changes made as a result are outlined in Part 3 of this report.

The Committee received some criticism from disabled groups for the fact that its meetings are scheduled in the morning, which discriminates against disabled people who find it more difficult to attend meetings starting early in the day. Within the restrictions of its current timetable the Committee has tried to accommodate the needs of disabled guests by taking evidence towards the end of morning meetings, and by having a reference group that can choose the most convenient times to meet, but this is an example of the sort of disability equality issue that all organisations should be taking into account.

# Reference Group Interim Report to the Equality of Opportunity Committee.



# What is the reference group for?

The National Assembly for Wales Equality of Opportunity Committee want to make sure that disabled children and young people are involved in the committee's review of the services that disabled children and young people receive.

The committee asked organisations and groups how they thought that a reference group could work.

This would be a group of young people who have impairments (these used to be called disabilities) perhaps something physical like they have to use a wheelchair, a learning impairment when they might find it difficult to understand things and need extra help, a sensory impairment when they can not hear or see everything and sometimes people might have more than one type of impairment.

After the committee had looked at the ideas on how to run this type of group they asked Barnardo's Cymru to work with them to set the group up.

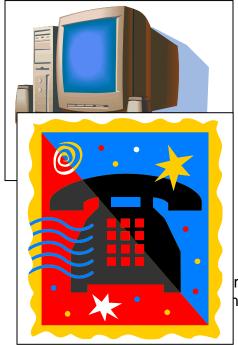
# What we have been doing so far.

The first thing we did was to try to contact as many groups of disabled children and young people as quickly as we could.

We did this by e-mail and phone.

An e-mail was sent to all of the groups on the Children in Wales list of addresses and contacts. The message also asked people to send the message on to anyone else they might know about. We also sent e-mails and made phone calls to other groups that we thought might be interested.

ready told the committee that they were interested so them by phone.



The interested groups were NSPCC Cymru, Mencap Cymru, Viva, Young Voices for Choices in Pembrokeshire, People first Cardiff, Barnardos Cymru and Dynamic Wrexham.

The NSPCC were not able to support young people being involved in the meetings but they keep sending the information around their contacts in the North West of Wales.

We then invited everyone who was interested to get together in Cardiff for a first meeting.



# The meetings

The group have now met 5 times at the Future Inn in Cardiff and once in the Celtic Royal Hotel in Caernarfon. The group felt that meeting mostly in Cardiff was a good idea as it has more accessible rooms and is easier to get to than some areas of Wales.

Julie has tried to find accessible places to stay in West Wales, there are not that many. There are other possible venues in both North and South Wales; we have not found anything suitable in Mid Wales yet.

Young people have also attended 5 Committee meetings, again 4 in Cardiff and one in North Wales in Conwy.

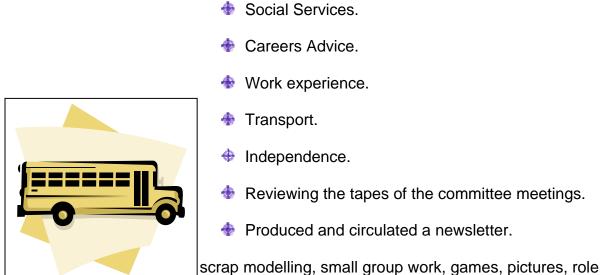
in February.

# The things that the group have been talking about.





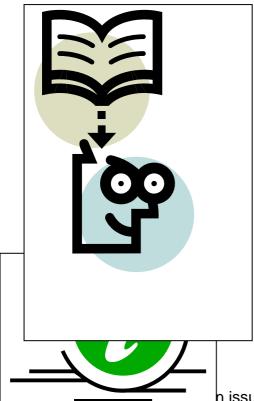
- Discrimination.
- Disability and impairment.
- The Social Model of Disability.
- The way the group and committee will work together.
- Education in schools and Colleges.
- Transition.



play, television, power point and flip charts.

The group have tried to produce information and questions aimed at the groups and people giving evidence to the committee.

Mostly the experiences of young people and their families have been mixed. Schools tended to be quite good but colleges seemed to be less supportive and in one case putting blocks in front of a student.



One young person presented their story to the committee. He now feels that he has an education that he is happy with, where he is supported in his choices, *"I believe that the reason I am now very happy with my education is that people now listen to my ideas on what is suitable and what meets my needs as a young disabled person".* 

Others have said that some changes had been good because of their involvement in planning, but sometimes these changes were not reviewed with the young people and they quickly became less enjoyable.

Information has been talked about at all of the meetings. Not many of the young people know what they are entitled to in all of the areas discussed. Information had not been provided in the right places for them, or in ways that they could all understand.

h issue for the support workers. Many were gaining

information from their colleagues in the group, information on things that were very relevant to their work.

Most of the young people would like to keep special education but felt that they could be more included in mainstream schools. They wanted more opportunity to do the things that they could do well.



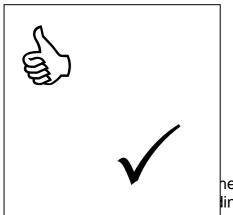
Their experiences of work experience were mostly negative.

After reviewing the tape of the March committee meeting the committee agreed to some changes.

The young people had not understood quite a lot of what was said or of what was happening. They felt that the questions from committee members were not clear enough and that they were not answered.

of their questions were being asked by committee

Since the May meeting in Conwy the young people have asked their questions first and members have asked their questions second and much more clearly for the young people.



The young people have felt this worked far better.

The young people who attended the Conwy meeting also felt the open session worked well.

The words used now are more understandable but the committee members and Tim still occasionally use complicated words.

he group are not making huge demands or asking for linary. What they want is to have the opportunity to do

normar mings to be seen as the same as others.

This is what the social model should provide. It means that the issues of access are fully considered both physical access and the access of attitude.

All of the group members want to work and live as independently as possible. However there are hurdles to face for example giving up benefits to start work with a company that might not give the disabled person the right sort of support and they have to leave voluntarily losing their benefits.

All of the young people would like to earn a living wage, pay their own bills and live the life of their choice.

There are still not enough people who know and understand about rights. The group understands that businesses have to make money but can not understand why businesses will not put money into pleasing them as possible customers.

Finally even if the young people do not feel more vulnerable than other people, very often their parents, carers and families do.

#### **Recommendations.**

From the young people's discussions.

1. Young people should be more involved in planning their education. Having an individual approach, deciding how much support they need, having choices and chances.

2. That mainstream and special schools have the same facilities. Where they are shared, priority is not given to the mainstream school.

3. Physical access is considered in all schools. The needs of Parents, carers and their families should be included.

4. There should be more work training available.

5. There should be more and quicker contact with Social Workers.

6. Social workers should have more time to listen to children and young people.

7. There should be a key worker who meets the young people often to help them with transitions.

8. Work experience needs to be linked to the young person's interests.

9. Benefits should be flexible enough to support people into work.

10. There needs to be work with employers so that they understand what they need to do to employ disabled young people and adults.

11. Disabled people should be more involved in designing buses and trains.

12. All buses need to be accessible.

13. All buses should have enough space for wheelchairs and push chairs.

14. Using public transport training should be available to all young people.

15. All bus, train and taxi staff should have training, disability awareness and customer service.

16. Information needs to be put in the right places and in the way that more people can understand. Information about rights, services and things like bus and train timetables and leisure information.

Barnardo's Cymru November 2005

# PART 3: NEXT STEPS

# The Committee and its Reference Group – A review

At its meeting on 24 November 2005, the Equality of Opportunity Committee decided to examine progress of the first year of its policy review of service provision for disabled young people. It asked two of its members, Helen Mary Jones AM and Lorraine Barrett AM to undertake this task on their behalf by meeting with members of the reference group.

Meetings were held with various members of the reference group and their support workers at Cardiff on 6 December 2005 and Colwyn Bay on 5 January 2006. Both meetings followed the same agenda. The young people were asked for their opinions on how the reference group was working by suggesting:

- What is good about being a member of the group?
- What is not so good?
- What could make it better? And
- Who should do it?

# What did the Young People think?

There was general consensus within both groups. Their conclusions were:

What was good:

- Pleased to be involved
- Important for young people to be involved in a review of services that affected them
- •
- Working together and building new relationships
- Provides a forum for getting yourself heard
- Learn of the experiences of others
- Gives individuals confidence to speak out
- Mixing with AMs made them feel important
- Good to travel

What was not so good:

- People presenters and AMs use language the young people sometimes didn't understand – "hard words"
- People talk too quickly
- Some times, the points they wanted to raise didn't come out
- They needed more time to prepare
- Meetings of the reference group needed to be held nearer in time to the Committee meetings so topics are kept fresh in their minds
- The reference group members require more information before their meetings from presenters

- AMs engaged in the early meetings, but not so much now
- Sometimes young people cannot attend meetings because of school or college
- Preparation meetings are too long for some people
- Members of the reference group sit away from members of the Committee which means the presenters talk to the Committee Members, not to them
- Not sure how the agenda is determined
- Some disabled groups are not involved
- Not sure of what AMs do and how the system works

What needs to be done

- Presenters to be reminded to provide evidence in language all will understand. Questions to be answered in the same way
- Suggestions have been made for Committee Members to be twinned with individuals from the reference group. The pairings could sit together at meetings and the Member could be used by the young person to put his/her point across
- It may also help if there was a break between the evidence being given and the young people asking questions, to give the young people the opportunity to gather their thoughts
- Evidence from presenters should be provided well in advance. This will be further improved if presenters are asked to indicate three or four of the key points they are making.
- Preparation meetings should be held as near as possible to the time of the Committee meetings, possibly planning meetings so that only one visit to Cardiff is necessary
- AMs should take the opportunity to meet with the reference group members at their preparation meetings, which are held in Cardiff
- Suggest the Reference Group decides what questions they wish to raise at future meetings and inform the Clerk. The Clerk will then consult with the Chair and Members to discuss the organisations to be invited to best answer those questions and make the appropriate arrangements
- Members of the reference group could share what's going on with other disabled young people by relating their experiences in visits to other groups, colleges and schools, or perhaps producing a DVD on the work of the group. This may involve a financial input from the Assembly.

Who does what

- Arrangements for the preparation meetings are a matter for Barnardos as the facilitators and the reference group themselves. However the clerking team can assist the process by providing advance warning of meetings and the Forward Work Programme, and requesting from presenters an advance copy of their evidence, together with a brief summary of the three or four main points they wish to make.
- Members will note the comments about speaking slowly. The clerking team will emphasise this together with advice on appropriate language to be used, on the need to eliminate jargon and the need for short precise presentations to *supplement* their written evidence in contacting presenters

The following recommendations were made:

- Organisations invited to give evidence to the Committee on its policy review, are told to produce a written transcript of their evidence two weeks before the meeting. This is to be supplemented by a short summary paper which highlights three or four of the main points being made. Such papers to be written in language that the young people who participate in the reference group could be expected to understand.
- Organisations invited to give evidence are told that having provided the Committee with their evidence in writing, there will be no requirement to repeat that in an oral presentation. Such presentation should be restricted to introductory remarks. This will allow longer time for questions from Members of the Committee and the young people.
- Organisations invited to give evidence are reminded of the need to keep their language simple, avoiding acronyms and the like, in answering questions, both from Members and the young people. They should be further reminded that in answering questions from members of the reference group, they should address those members, not the Chair or other Members of the committee.
- Meetings of the reference group to be held nearer the time of the committee meeting preferably the day before. This arrangement will assist the members of the group in retaining focus of the issues and reduce the number of journeys the young people have to make to attend meetings.
- Meetings of the reference group are divided into two sessions, one to address the issues relating to specific questions to the presenters at the immediate meeting and the second to identify questions they will wish consider at the next meeting. Questions raised in the second session to be forwarded at the earliest opportunity to the Clerk of the Equality of Opportunity Committee.
- The Clerk to discuss with the Chair (and other Members of the Committee) the best organisations to invite in order to answer the questions raised by the young people and make the necessary arrangements.
- The Forward Work Programme to identify when members of the reference group will be required to attend Committee, allowing a programme of reference group meetings to be established
- Members to engage with the young people at or immediately following meetings of the reference group. The advance programme of meetings of the group may allow Committee members to include such meetings in their diaries.
- Individual Members to be twinned with individuals from the reference group. When appropriate members of the group attend Committee they should sit next to their "twinned AM"
- Members of the reference group to visit other groups of disabled young people to relate their experiences in working with Assembly Members and also to discuss with these groups what issues affecting disabled young people should be raised.

At its meeting on 15 February 2006 the Committee decided that..

-