

Equality of Opportunity Committee

Service Provision for Disabled Young People

**“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 twelve occasions, and its members have directly participated in nine 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, which has shared its 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 the review.

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) | Labour | Neath |
| Lorraine Barrett | Labour | Cardiff South and Penarth |
| David Davies (until May 2004) | Conservative | Monmouth |
| Lisa Francis (until January 2004) | Conservative | Mid and West Wales |
| 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 |

Introduction

Rights into Action 2003 – the first International Congress of Young Disabled People

The first International Congress of Disabled Young People was held in Swansea in July 2003. It was organised by a coalition of groups working to secure the rights of young disabled people. The event brought together young disabled people between the ages of 14 and 25 from 35 nations across the world to explore issues and concerns affecting their lives. At the end of a week dedicated to discussion and plenary sessions, the Congress agreed a manifesto¹ of issues it wanted to see tackled on a local, national and international level.

In October 2003 the Committee received a presentation from disabled young people and discussed some of the issues included in the Congress' manifesto². It was largely as a result of this session that the Committee decided to undertake a review into service provision for young disabled people.

The Committee acknowledged it would be unable to tackle all issues covered by the Congress' manifesto. Instead it agreed to focus on issues that were most relevant to disabled young people in Wales, in particular those over which it would have the greatest influence. To assist in identifying issues for inclusion in its work, the Committee carried out a scoping exercise³, with support and advice from the Disability Rights Commission in Wales and Children in Wales. The results of the scoping exercise were used by the Committee to draw up the terms of reference for its review.

¹ <http://www.rightsintoaction.org.uk/Manifesto/Manifesto.asp>

² Equality of Opportunity Committee 2 October 2003 EOC(2) 03-03(p1)

³ Equality of Opportunity Committee 1 April 2004 EOC(2) 03-04(p8)

Terms of reference

In June 2004 the Committee agreed the terms of reference⁴ for its review of service provision for disabled young people.

The Committee identified three over-arching themes on which it would focus its work:

- promoting and supporting independence and autonomy of young people;
- responsive, customer-focused and joined-up service provision; and
- age appropriate support and services

Within these 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

In order to inform its work the Committee carried out a written consultation, the aim of which was to establish whether the Assembly's existing policies around service provision adequately met the needs of disabled young people. It also sought to identify good practice and, where it existed, the extent to which it was being shared with service providers across Wales.

The Committee received a total of 67 responses from a wide range of sources⁵. During the course of the review, it took oral evidence from 28 witnesses⁶ in connection with issues raised by the Reference Group.

⁴ Equality of Opportunity Committee 17 June 2004 EOC(2) 05-04(p3)

⁵ See Annex D for a list of respondents

⁶ See Annex E for a list of witnesses

Reference Group of disabled young people

In recognising 'participation' as a key theme in the Congress' manifesto, the Committee gave a firm commitment to involve young disabled people at all stages of its review. In view of this, a reference group made up of young disabled people from across Wales was set up, the purpose of which was to offer advice to the Committee based on first-hand experience.

The Committee recognised the need for the Group, in so far as possible, to represent young people with a range of disabilities, including physical and learning disabilities, as well as sensory impairments. In addition, the Committee felt it was important for the group to be gender balanced, include at least one Welsh speaker and represent the black minority ethnic community.

In January 2005 a facilitator⁷ was appointed by the Committee to help establish the group and organise its work. The facilitator made initial contact with an extensive list of existing organisations and groups working with disabled young people in an attempt to raise awareness of the Committee's work and stimulate interest in the reference group.

The group was established in March 2005 and its members included 15 disabled young people who represented peers from the following organisations: Mencap Cymru, Viva, Young Voices for Choices in Pembrokeshire, People first Cardiff, Barnardos Cymru and Dynamic Wrexham⁸. Despite a concerted effort the Committee and group facilitator were unsuccessful in securing input from young people from black and minority communities.

Throughout the review the reference group provided advice to the Committee on the areas it felt were most important to them, namely, education, training and employment, transport, transition to adulthood and independent living. The group met before each formal Committee meeting to examine issues to be discussed. At formal meetings group members shared their views and experiences with the Committee and assisted Members in questioning witnesses who attended to give evidence to the review.

⁷ Tim Ruscoe, Barnardo's Cymru

⁸ See Annex E for a list of Reference Group Members

Using a reference group to assist the Committee with its work was both original and innovative. During the course of the review the Committee agreed to assess the way it worked with the group with the aim of ensuring that the young people were happy with the level of participation and engagement. In November 2005, Members⁹ undertook an initial assessment and produced a report¹⁰, which contained a series of recommendations, was agreed by the Committee.

We are indebted to the reference group for their honesty, openness, confidence and professionalism throughout the review. It could not have taken place without them.

Definitions

Throughout this report we use the terms disabled and access and accessibility.

- Disabled – a disabled person is one who has a physical or mental impairment or a long-term health condition that has an impact on their day to day lives.
- Access and accessibility – these do not just cover physical access for wheelchairs. It includes access to information, employment and services in ways which are appropriate for disabled young people.

General Recommendations

As we listened to the evidence presented to us throughout the review, we recognised the need for some general recommendations which should underpin the other recommendations in the report.

Recommendation 1: The Welsh Assembly Government should develop a strategic policy that includes all services that young people need to help them develop the skills they need to live a fulfilling life. Young people should be involved in working out the best way of making this happen.

⁹ Lorraine Barrett AM and Helen Mary Jones AM

¹⁰ Equality of Opportunity Committee 18 January 2006 EOC(2) 01-06(p.5)

Recommendation 2: The Welsh Assembly Government to produce guidance for all policy divisions, local authorities and other public bodies in Wales on involving disabled young people, their families and carers in policy making. The guidance should identify good practice (e.g. the work of the Disabled Young People's Reference Group) and emphasise the need to listen to the views of disabled young people as articulated by them rather than focussing on the views of their families and carers.

Recommendation 3: The Welsh Assembly Government should issue guidance to all public, private and voluntary sector bodies who provide services, one to one, groups, projects and initiatives for young people to ensure that they are as accessible as possible for all young people.

The guidance should include:

Making information on projects accessible;

Creating an environment that the young people feel comfortable in;

Ensuring that young people's needs are fully understood;

Making progress towards projects as enjoyable and challenging as desired by all young people, whilst assessing and minimising any risks involved.

Recommendation 4: The Welsh Assembly Government should set up a review of disability equality training for professionals working with disabled young people and employers.

The outcomes of the review should feed into the development of professional training which covers the provision of advice, information and support on relationships, sexuality and sexual health, as well as educational and careers advice.

Recommendation 5: The Welsh Assembly Government should issue guidelines to local authorities on how to ensure that disability equality training in local authorities is being delivered by people with sufficient and appropriate experience and training of the issues facing disabled people.

CHAPTER 1

LEGISLATIVE AND POLICY FRAMEWORK FOR SERVICES FOR DISABLED YOUNG PEOPLE

The United Nations Convention on the Rights of the Child

1.1 The United Nations Convention of the Rights of the Child was adopted by the UN General Assembly in November 1989, opened for signature in January 1990 and ratified by the UK Government in December 1991. The Convention provides a set of minimum standards relating to children's rights which should underpin the development of law, policy and practice. It contains 54 articles broken down into three main categories, namely, provision, protection and participation. The core articles are as follows:

- **Article 2** states that all rights shall apply to all children without discrimination on any ground and specifically mentions disability.
- **Article 3** states that in all actions the child's best interests 'shall be a primary consideration.'
- **Article 6** states that every child has the inherent right to life, and each country should ensure the child's survival and development to the maximum extent possible.
- **Article 12** states the right of the child to express an opinion and to have that opinion taken into account, in any matter or procedure affecting the child.
- **Article 23** states the right of disabled children to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community. It also states the right of the disabled child to special care, education, health care, training, rehabilitation, employment preparation and recreation opportunities; all these shall be designed in a manner conducive to the child achieving 'the fullest possible social integration and individual development, including his or her cultural and spiritual development.'

- **Article 28** states the child's right to education, and says it shall be on the basis of equal opportunity.
- **Article 29** states that a child's education should be directed at developing the child's personality and talents, and mental and physical abilities to their 'fullest potential'. It also states that education shall prepare the child for an active and responsible life as an adult, fostering respect for basic human rights and developing respect for the child's own cultural and national values and those of others.

Legislation

The Human Rights Act 1998 and the European Convention on Human Rights

1.2 The Human Rights Act 1998 came into effect in October 2000. The Act gives legal effect in the UK to certain fundamental rights and freedoms contained in the European Convention on Human Rights (ECHR). There are 16 basic rights taken from the European Convention on Human Rights, which not only affect matters of life and death like freedom from torture and killing but also affect rights in everyday life such as the right to education and the prohibition of discrimination.

The Disability Discrimination Act 1995

1.3 The Disability Discrimination Act (DDA) 1995 was the first anti-discriminatory legislation specifically about disabled people. Its aim is to end the discrimination that many disabled people face by giving them rights in the areas of:

- employment
- education
- access to goods, facilities and services
- buying or renting land or property

1.4 The Act also allows the government to set minimum standards so that disabled people can use public transport easily.

1.5 As a result of the legislation:

- it is unlawful to treat disabled people less favourably than other people for a reason related to their disability;
- service providers are required to make 'reasonable adjustments' for disabled people, for example, providing extra help or changing the way in which they provide their services;
- service providers are required to make 'reasonable adjustments' to the physical features that act as a barrier to disabled people who want to access their services.

Special Educational Needs and Disability Act 2001

1.6 In September 2002 new duties for education providers came into effect under Part 4 of the DDA amended by the Special Educational Needs and Disability Act 2001.

The Disability Discrimination Act 2005

1.7 The Disability Discrimination Act 2005 amends or extends existing provisions in the DDA 1995, including:

- making it unlawful for operators of transport vehicles to discriminate against disabled people;
- making it easier for disabled people to rent property and for tenants to make disability-related adaptations;
- making sure that private clubs with 25 or more members cannot keep disabled people out, just because they have an impairment;
- extending protection to cover people who have HIV, cancer and multiple sclerosis from the moment they are diagnosed;
- ensuring that discrimination law covers all the activities of the public sector; and
- requiring public bodies to promote equality of opportunity for disabled people.

1.8 Some of the new laws, including the increased protection for people who have HIV, cancer and multiple sclerosis, came into force in December 2005. Others, including the new duty on the public sector 'to promote disability equality' will come into force in December 2006.

Equality Act 2006

1.9 The Act provides for the establishment of the Commission for Equality and Human Rights which will promote equality across seven strands in Wales. This will include both disability and age.

1.10 Although the Commission is a GB-wide body, it will have a specific remit to cover Wales, offices in Wales, a Wales Commissioner, committee and designated Wales staff.

1.11 A working protocol will be established between the Commission and the Office of the Children's Commissioner in Wales. Disability issues have already featured prominently in the Children's Commissioner's annual report including issues around statements of special educational needs, disability related bullying, and services for young people experiencing mental health problems.

1.12 The CEHR will also have a disability committee to ensure the smooth transition of disability issues into the new Commission. A close working relationship will be needed between the Wales and Disabilities Committees.

The Welfare Reform Bill

1.13 In July 2006 the Welfare Reform Bill was introduced into Parliament. The Bill legislates for Government plans which aim to modernise the welfare state and break down barriers that prevent people from finding employment and staying in work.

1.14 The Bill contains powers to replace incapacity benefits with a new Employment Support Allowance that, alongside a new Personal Capability Assessment, aims to give individuals more relevant support and help them find appropriate work. It brings about changes in the Housing Benefit regime which includes the introduction of Local Housing Allowance to tenants in private rented accommodation.

Welsh Assembly Government Policies and Programmes

Children and Young People: A Framework for Partnership

1.15 In November 2000 the Welsh Assembly Government published *Children and Young People: A Framework for Partnership* which set out its vision for the future in the planning and delivery of all services for children and young people. It describes how those providing services can work together in partnership. It suggests an approach to ensuring the effective participation of children and young people at local level through which they can be involved in the planning and review of services across local authorities, health groups and in schools.

Children and Young People: Rights to Action

1.16 This policy document sets out the Welsh Assembly Government's core aims for children and young people, which are based on the UN Convention on the Rights of the Child. They are:

- A flying start in life
- A comprehensive range of education, training and learning opportunities
- The best possible health free from abuse, victimisation and exploitation
- Access to play, leisure and sporting and cultural activities
- Children and young people are treated with respect and have their race and cultural identity recognised
- A safe home and community that supports physical and emotional wellbeing
- Children and young people not disadvantaged by poverty

National Service Framework for Children, Young People and Maternity Services in Wales

1.17 In September 2005 the Welsh Assembly Government launched its National Service Framework for Children, Young People and Maternity Services in Wales (NSF). The NSF sets out the quality of services that children, young people and their families have a right to expect and receive. Its aim is to improve quality and reduce variations in service delivery through the setting of national standards. These standards are underpinned by

specific and measurable key actions to be carried out by organisations that are responsible for service delivery.

1.18 As well as the universal key actions, which apply to all children and young people, no matter what their circumstances, the NSF includes a chapter dedicated to disabled children and young people which sets out the following standards:

- *Disabled children, with their families from all communities, are fully supported to participate in valued childhood experiences and have access to the same range of opportunities, life experiences, and mainstream and community services and facilities as other children and their families.*
- *All disabled children and their families receive accessible information about, and equitable and prompt access to, high quality co-ordinated services appropriate to their assessed needs.*
- *Disabled children are provided with appropriate high quality, timely services in an environment that is suited to their needs, age and stage of development. Well co-ordinated multi-agency services are delivered to address all types of need.*
- *Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families, carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.*

Learning Pathways

1.19 Learning Pathways 14-19 is a commitment to the transformation of learning provision for all young people in Wales. It addresses the need for a more flexible and balanced approach to the education of 14-19 year olds, providing a wider range of experiences which will suit the diverse needs of Wales' young people.

1.20 Learning Pathways consist of a blend of six key elements which, in combination, will ensure that, over time, all learners receive the appropriate balance of learning experiences that best meet their needs. The key elements also enable learners to receive the support and guidance they need to realise their potential. The six key elements are:

- individual Learning Pathways to meet the needs of each learner;
- wider choice and flexibility of programmes and ways of learning;
- a Learning Core which runs from 14 through to 19 wherever young people are learning;
- Learning Coach support;
- access to personal support; and
- impartial careers advice and guidance.

1.21 Learning Pathways 14-19 is aimed at encouraging more young people to achieve their potential so they are increasingly better equipped for the world of work and to become better informed and more active citizens. It aims to do this by contributing to an improvement in qualifications, supporting an improvement in the proportion of 16 year olds progressing to further learning in education and training, widening choice, promoting equality of opportunity and supporting the achievement of *'Extending Entitlement'*.

The Social Model of Disability

1.22 In January 2002 the Assembly adopted the social model of disability following a resolution¹¹ in plenary. The model is based on the fact that disadvantage and social exclusion stem from the barriers disabled people face rather than from an individual's impairment. As explained by the Disability Rights Commission:

'...disabled people do not face disadvantage because of their impairments but experience discrimination in the way we organise society. This includes failing to make education, work, leisure and public services accessible...'

¹¹ Details of the resolution – 10 January 2002

1.23 The social model focuses on bringing down the barriers that disable people from participating in everyday activities and living life to its full potential.

CHAPTER 2

EDUCATION, TRAINING AND EMPLOYMENT

2.1 In looking at the theme of education, training and employment, the Committee inevitably touched on issues around the transition process for disabled children and young people and their access to information and advice. Both of these had been identified as separate themes in the review's terms of reference. The Committee has been keen to avoid duplicating the work of the Education, Lifelong Learning and Skills Committee, which has also identified transition as a key future theme for its review of Special Educational Needs. It therefore hopes that the issues it has identified and related recommendations will complement the work of the Education, Lifelong Learning and Skills Committee.

Education as an experience

2.2 Education for disabled young people is not just about gaining qualifications but about meeting new people and establishing friendships. Whilst the Committee's review has touched on the differences between mainstream and special education schooling, it has primarily focused on the issue of promoting independence and autonomy. The reference group has concentrated the Committee's attention on the importance of allowing young people to gain the life skills necessary to gain independence, rather than focusing on testing and qualifications. For example a 16-year old girl attending a special school was concerned that she had not been able to participate in a cookery lesson because the school had no home economics classrooms.¹²

Key Issues

2.3 The reference group identified the following priorities for 'education, training and employment'.¹³:

- No post 18 support in job training
- Having job related training in order to earn a wage which will allow life choice

¹² Glenys Griffiths (Barnardos Cymru) EOC Meeting 17 March 2005 para 9

¹³ Equality of Opportunity Committee meeting 17 March 2005 para 9

- Individuals being the main voice in life planning
- Meeting new people / friendships
- Food / school meals
- Informal education / project work / youth clubs
- Daily living / life skills
- Relationships – sexual – family / friends
- Limited choices – young people having to ‘fit in’
- Teacher training – awareness of individual needs
- Testing and qualifications
- Not same choices as mainstream
- Equal opportunities / fair chances
- Support to obtain paid work
- Curriculum – choices
- Transport
- Sincere / equal access to college

2.4 These priorities largely matched up with the issues raised by those who responded to the Committee’s initial consultation. The consultation identified that whilst educating disabled young people in mainstream schools has benefits for them and their peers, full inclusion has not always been achieved. Disabled young people need to be educated in a safe supported environment and there are limited fully inclusive opportunities. Young people need to be consulted and involved in all processes that affect them. Access and specialist equipment is not always available; there are insufficient therapy services and regional inconsistencies in provision, including provision in the medium of Welsh and languages other than English. There are not enough opportunities for informal learning.

2.5 The need for more joint working and less bureaucracy was highlighted, as was the delay in assessment before entering further or higher education, and in processing Disabled Students Allowance (DSA).

2.6 Of great concern is the fact that not only are there limited work-based training and employment opportunities for disabled young people, especially in rural areas, and a lack of information about opportunities in further and higher education, but that low expectations are often placed upon disabled young people in terms of what they can achieve.

Bullying

2.7 Both Children in Wales and the Disability Rights Commission recognised this as being a big issue for disabled young people in school and the reference group has also raised it. The Committee explored the impact of the Welsh Assembly Government's anti-bullying policies with the Minister for Education and Lifelong Learning at a Committee meeting in March 2006.¹⁴

A coherent framework policy for pre-16 and post-16 support

2.8 The Committee took evidence from the main provider of careers advice and support to disabled young people in Wales, Careers Wales¹⁵. It identified that the provision of education, training and employment services to help young people transition from school to college and work was a multi-agency collaboration, and that some good examples of protocols for pre-16 provision were in place, but that a coherent framework for that multi-agency working was lacking. This was identified as a potential weakness in ensuring a holistic, coordinated approach to supporting young people pre-16, and post-16 services provided by the Welsh Assembly Government (formally ELWa). In the case of disabled young people, many service providers, both statutory and voluntary, may be involved in their care and support at this critical time in their lives.

2.9 The Committee supports the view expressed by Estyn that for effective inter-agency working there must be a clear philosophy that crosses traditional boundaries and provides co-ordinated

¹⁴ Equality of Opportunity Committee meeting 22 March 2006 paras 14 – 108

¹⁵ Equality of Opportunity Committee meeting 17 March 2005

services. Estyn reported that transition planning was often just not good enough. Funding decisions were delayed, information transfer to new providers slow, assessments delayed and services not put in place quickly enough. The delays had a human cost for the young person who did not access the curriculum quickly enough and became discouraged. There was also not enough collaborative planning.

Recommendation 6: The Welsh Assembly Government should provide an holistic, co-ordinated framework policy for provision of pre-16 and post-16 (up to at least age 25) education, training and employment support and services.

The framework policy should cover early identification, assessment and service provision to clearly set out multi-agency roles and protocols for sharing information and providing services.

Funding criteria for post-16 support

2.10 Both Careers Wales¹⁶ and the Shaw Trust¹⁷ pointed out the dangers of the funding regime for post-16 training and employment services acting as a barrier to opportunity for disabled young people. Questions were raised over the extent to which current provision is leading to positive outcomes. In particular, assessment and funding criteria which reward educational qualifications and attainment, rather than life skills and ability to work and live independently, may act as a deterrent for service providers and learning disabled young people. Skill Build is an example of a service funded by the Welsh Assembly Government (formally ELWa) on the basis of qualifications rather than job outcomes.

2.11 The Shaw Trust stated that:

‘The funding levels are set so that no provider can afford to offer students with a learning disability the support required for them to achieve the necessary level. This approach completely fails to make the necessary adjustment for people with a learning disability to ensure equality of outcome, i.e. skills gained to enable the person to be employed.’

¹⁶ EOC Meeting 17 March 2005

¹⁷ EOC 22 September 2005 EOC(2) – 07-05(p7)

2.12 It was also questioned why funding for supported employment services for people with high support needs should come principally from Social Services budgets, rather than being mainstream funded through Jobcentre Plus. The example was quoted of Ireland, where supported employment is funded by the equivalent of Jobcentre Plus.

Recommendation 7: The Welsh Assembly Government to review the assessment and funding systems for support services to help disabled young people move from education and training into employment. The review should focus on work-based learning provision, and ensure that it emphasises equality of outcome in terms of jobs and progression, rather than on qualifications attained.

Access to information

2.13 The Committee received evidence that there is a lack of relevant information for young people during the transition process, in particular in the medium of Welsh, in ethnic minority languages, and in other accessible formats¹⁸. The internet is an important way for many disabled young people to communicate and access information, but the members of the Committee's reference group who had tried to use the Careers Wales Online service had found it unhelpful. There was no option to identify as having a physical or learning impairment and one wheelchair user with cerebral palsy had been offered career options as an air steward or a childminder.

'How does social services think people who can't read will be able to find out about their services if they only provide leaflets? Are your leaflets accessible or do you provide audio tapes? Does your website have a voice facility?'

Gareth Morgans, Reference Group member

2.14 Stephen Barry Lloyd is a web access auditor based at the Shaw Trust, who uses an electric wheelchair and assistive 'switch' technology. Steve has created his own web pages explaining his experiences of special needs and mainstream education and training. When asked what could be done to improve things for

¹⁸ Equality of Opportunity Committee Meeting 17 March 2005

disabled young people, Steve said:

'Getting a job for a start. I want to get a job in the media but it's difficult to get businesses to give me a placement and to get a personal assistant.' (to enable him to do the placement).

Recommendation 8: The Welsh Assembly Government to ensure that all advice and support on education, training and careers, whether spoken or written is in the medium of Welsh, ethnic minority languages and accessible formats. This should include ensuring that all Assembly-funded information services are available on-line.

Person-centred planning and service provision

2.15 A shared concern of several organisations giving evidence to the Committee was the need for those working with disabled young people to focus on what disabled young people can do, not what they can't, and to provide what young people want, not what service providers think they want.

'It was difficult for some of the group to get the choice to do the courses that they wanted at college, when they could not do them at school.'

Heather Graham, Reference Group member

2.16 The Conwy Children with Disabilities team reported how its assessment procedures for young people in transition had moved from a 'leaving care assessment tool' to 'essential lifestyle planning', which is person-centred, with the young person and their carers central to the planning process.¹⁹ It was consulting with young people about the transition process. The service providers that gave evidence to the Committee had either one person as the point of contact for the young person's transition planning, or were working towards that. However, Careers Wales said there was evidence that such one-to-one support was on the decline.

2.17 The Committee believes that one-to-one support is vital for disabled young people and should be provided by professionals who are adequately trained. It also supports transition protocols that focus on giving the young person control over the process,

¹⁹ Equality of Opportunity Committee meeting 26 May 2005

including full involvement in regular review meetings and control over which adults should and should not be involved. The transition planning process should also include mechanisms for responding to and addressing unmet needs where they are identified by young people.

‘We do not like it when we do not see our social workers enough, when there is no progress, and they decide to give you too much help without talking to you and letting you try for yourself. We do not like it when you ask us for help and you go round in circles without getting a result, and ending up back with the first person that you spoke to. However, we do like it when we get results, when they help you through bad times, and when they listen to us so that we can make our decision together.’
Robert Surrey, Reference Group member

2.18 The Disability Rights Commission pointed to the dangers of creating an underclass of disabled young people not being picked up either by the special educational needs statementing process in schools, or the social services register. This may be based on ‘decibel level management’, i.e. the carers who demand services the loudest receive the most²⁰. Both Flintshire and Conwy local authorities reported mechanisms in place to identify children who would not otherwise be included, for example those with low-level mental health issues, Attention Deficit Hyperactivity Disorder or high-functioning Aspergers syndrome, to ensure that they receive assistance through the transition process.²¹

Recommendation 9: The Welsh Assembly Government to ensure that all local authorities in Wales have systems in place to guarantee that all young people, irrespective of any impairment, receive appropriate assistance through the transition process.

2.19 The reference group identified provision of post-18 support in job-related training as a priority, to allow them to earn a wage and have independence and life choices. It also pointed out that many people will need support for many years or maybe at some level permanently and questioned what financial provision was

²⁰ Equality of Opportunity Committee meeting 26 May 2005

²¹ Equality of Opportunity Committee meeting 26 May 2005

available, what the limitations were and how young people could make best use of the opportunities.

'I did not get the support that I needed. It was hard for me to get support in the college and school; there was no support for the course that I wanted to do. I wanted to do a carpentry course. They said I could not do it because I had learning disabilities and it would be hard for me to get a job after it.'
Stephen Dyer, Reference Group member

Recommendation 10: The Welsh Assembly Government to ensure that one-to-one support is available to disabled young people as part of education, training and employment services.

Recommendation 11: The Welsh Assembly Government to assess the impact of education, training and employment service provision by measuring how accessible services are for disabled young people, whether the services are meeting individual needs and how many 16-25 year old disabled young people are in employment or the type of employment of their own choice.

Recommendation 12: The Welsh Assembly Government to act on the results of the assessment of education, training and employment services to increase their effectiveness.

Informal education

2.20 The value of informal education for disabled young people should be recognised, including materials and project work provided with support by out-of-school youth clubs. The Deaf Association Wales offers youth club activities for deaf young people that include advice and information on issues such as sexual health, drugs and alcohol, bereavement, careers, housing. Informal education services appropriate to the needs of disabled young people should be supported, whilst at the same time more effort should be made to address the exclusion of disabled young people from 'mainstream' youth activities both in and outside of school.

2.21 Disabled young people identified that they wanted better education on relationships including sexual health. They frequently

reported limited choice and having to fit in with current services that were not tailor-made to their needs. Disability awareness training for service professionals should take this into account. In providing evidence, the Family Planning Association stated that they provided the same information for disabled people as they do for non-disabled people. However, they probably do so in different ways. They start from the point where everyone, regardless of disability has the right to the same information and services, but that that information and the services may need to be delivered differently for people with or without disability.²²

Recommendation 13: The Welsh Assembly Government and service providers should review advice, information and support services for young people on relationships, sexuality and sexual health, both in-school and outside school, in full consultation with disabled young people themselves.

Any resultant good practice guide should be provided in ways that all children and young people with impairments can understand.

Disability equality training

2.22 Skill Wales and the reference group identified the need for better disability equality training to be provided to schools, careers advisers and employers.²³ Without adequate training there is a risk that young people were being given restricted options. The reference group particularly identified a problem with learning support assistants who had worked with them a long time not being adequately trained to help them with deciding on education options. There was also concern that learning support assistants might in some cases be excluded from participating in school INSET days. NUT Cymru noted that some learning support assistants are on short term contracts and may not be paid for attending training.²⁴ NUT and UNISON have drawn up an agreement stating that people who work in schools must be paid on the appropriate scale on an annual basis and should have holidays and training. The Committee also noted the planned review of teacher training in Wales and NUT Cymru's view that the

²² Equality of Opportunity Committee Meeting 22 March 2006 para 121 onwards

²³ Equality of Opportunity Committee meeting 17 March 2005

²⁴ Equality of Opportunity Committee meeting 17 March 2005

time taken to qualify for Postgraduate Certificate in Education courses was not long enough to meet disability training needs.

‘Food and school meals are an issue for younger members of the reference group. Not just in terms of consumption, but the whole process. An example used was that children who had autism did not understand the necessity to queue, and another was that older children were not allowed to carry their own money to pay for their food. Sometimes it was about respect.’

Glenys Griffiths, Reference Group facilitator from Barnardo’s Cymru

2.23 A disability access group member pointed to local authorities providing staff with ‘awareness’ training that was medical-model based, rather than equality training based on the social model. Consideration should also be given to the nature of training that public bodies are offering their staff, and whether it is being delivered by those who know best – people with direct experience of disability. Organisations like the Shaw Trust and Disability Wales are already offering training to the private and public sector and there is scope for training more disabled people as trainers. Local groups may also be able to build their capacity to deliver training if they can access the necessary funding.

Recommendation 14: The Welsh Assembly Government should ensure that the terms and conditions of all staff working with disabled young people in schools, including learning support assistants allow them to receive adequate training to enable them to fully support disabled young people.

EMPLOYMENT

Accessing meaningful employment

2.24 Several local authorities responding to consultation pointed to the need for meaningful employment opportunities, something that the reference group identified as a priority. NCH Action for Children noted that some good schemes existed in Wales but that meaningful employment was difficult to access and work placements did not always lead to jobs. It also said that education transition plans could be superficial and not followed up on an inter-agency basis.

‘Transition is not always clear. You don’t often have one person that you can talk to. Some people are not helped to make their own choices, and sometimes there are too many people trying to help. We think that special schools are a good idea but there should be lots of chances and support to go into mainstream schools or to mix with pupils at those schools.’

Heather Graham, Reference Group member

Work experience

‘Don’t stick me where I don’t want to go for the sake of it.’

Reference group member

2.25 Reference group members had a number of stories about meaningless work experience opportunities. Careers Wales identified incentives for employers as among the support measures to be considered when trying to help disabled young people move on from education and training into employment. TUC Wales supported making funding available to help employers make the necessary adjustments to enable young people to take up placements. Members recognised the pressures on employers to offer a range of work placements and training opportunities, particularly in rural areas, the issue of Criminal Records Bureau checks for those supervising young people, and practical barriers to be addressed for young people requiring additional support. However the Disability Discrimination Act 1995 covers work experience placements, so it should not be possible for employers to refuse opportunities to disabled young people. There are examples of good practice such as additional funding to allow learning support assistants to accompany young people on work experience, a Careers Wales database in Cardiff and the Vale of Glamorgan that identifies employers who offer work experience placements to disabled young people, and the youth gateway service to help people settle into work. Further financial investment was deemed necessary to ensure consistency of provision across Wales.

Recommendation 15: The Welsh Assembly Government should put in place additional measures, both practical and financial, such as incentives for employers and funding for

support workers to ensure meaningful work experience placements are offered to disabled young people.

Employment support services

‘Once a person has been on incapacity benefit for a year, they only have a one in five chance of returning to work within five years.’
Department for Work and Pensions, Pathways to work: Helping people into employment, 2002

‘There are currently 182,000 young people between the age of 16-18 that are not in education, employment or training (NEET)’
Department for Education and Skills First Release SFR 03/2005
January 2005

‘We have a chance to work in partnership to do things a bit differently and a bit better in Wales.’
Clive Stansfield, Director of Shaw Trust Wales

2.26 A range of services already exists to help disabled young people into sustained employment, for example promoting independence by training personal assistants (funded through the European Social Fund), employment programmes such as New Deal job broking and Workstep (funded centrally through Jobcentre Plus and the Department for Work and Pensions (DWP)), and the Direct Payments and Independent Living Scheme (local authority funded).

2.27 There is a wide range of funding sources for voluntary sector organisations. However each would appear to bring its own difficulties. For example training personal assistants is not centrally funded but is the key to implementing the social model. There is also a ceiling on funding for New Deal for Disabled People, which would seem to have the potential for expansion if more money was made available. There is also potential for conflict and duplication between funding New Deal and funding the 'Want to Work' initiative supported by EU funds. Partnership working is vital as there is a place for different providers, voluntary, private and government, to offer employment services.

2.28 The Committee believes that there is a large group of disabled people who want to work, and while work to support this

is receiving low level funding, the cost of keeping those people on benefits is very high. The Pathways to Work programme addresses this issue and was initially piloted in Rhondda Cynon Taf and Bridgend local authorities. The Scheme has now been extended to Swansea Bay and West Wales, and the Gwent valleys. There is room for private and voluntary and community sector (VCS) providers to deliver Pathways to Work effectively in Wales. In 2004 a group of providers responded to the 2004 pre-budget report on increasing employment opportunities for disabled people and highlighted specific options for them to have greater involvement:

- **The VCS sector can provide a better connection with hard to help clients** - and have demonstrated their ability to meet the complex needs of hard to help clients. Job broking clients make no secret of the fact that they approach private and VCS providers because they are separate from Government.
- **Speed of roll-out of the Pathways pilot** - contracting out the Pathways service to the private and VCS sector in new areas may expedite the rollout.
- **Expansion of range of services within Pathways to Work** - services such as placing employment adviser support in GP surgeries and other ways to allow providers to reach clients are tailor-made for the VCS to help deliver.
- **Enabling Jobcentre Plus to deliver services with a more streamlined infrastructure and lower staffing numbers** - a closer connection between mandatory Work Focussed interviews and the action planning work undertaken by job brokers offers opportunities for greater efficiencies - as proposed by the Gershon review - without any detriment to disabled clients.

Laura uses a wheelchair and explained the problems she had at college:

'I didn't have any friends at Swansea college. I was just left in a corridor. Staff in the college didn't help and weren't friendly. I was at college for two years in special needs and then went onto a mainstream BTec entry course. I passed a keyboarding examination and now I work here. I'm on benefits so I can't work full-time but under the 'permitted work' scheme I work here two days a week. I've worked in different departments. I get a taxi here and my parents collect me.'

Laura from Morrision works in job-broking at the Shaw Trust

Recommendation 16: The Welsh Assembly Government should work with the Voluntary and Community Sector to identify ways by which voluntary organisations can be more involved in delivering initiatives aimed at helping disabled young people into sustained employment.

The Benefits system and barriers to work

'We looked at the sort of things that are generally a problem for young people in getting a job, and many of those centre on benefits. The benefits system is becoming more flexible, through things such as Careers Plus and supporting benefit into employment, as well as benefit out of employment, whereby, if someone has to leave employment because of inadequate support, there is financial support to do so. However, it is not available to everyone, and many people have to choose not to work because they cannot risk a period of no benefits, or no income, if they are unable to continue to work because of the lack of support, or appropriate support. That was quite a significant issue in terms of, 'I can't afford to take that risk.'

Tim Ruscoe, Reference Group facilitator from Barnardo's Cymru

2.29 Proposals designed to help people progress from benefits to work is an improvement on the current situation, but there are still blockages around housing benefit and income support and a need to review the rules around 'permitted work'. Work has been undertaken for the Sainsbury Centre by Patience Seebohm and Judy Scott on addressing disincentives to work, which proposed some radical improvements in relation to earnings disregard,

extension of permitted work and introduction of a tax credit starter.²⁵

2.30 Welsh partners in a Pan-Disability Partnership (including RNID, RNIB, SCOVO, Mencap, Scope, Shaw Trust) are keen to identify ways of utilising the different funding mechanisms and programmes of support in health and social care, employment and education sectors to develop best practice. There is a need for employment programme funding, direct payments, social and health care monies to be used in a more joined up way to enable people to achieve economic activity Welsh examples could then be fed into UK-wide policy development.

2.31 The bureaucracy around claiming benefits is a problem for many disabled people, and more flexibility, to allow people to work flexible hours dependent on their condition without losing benefits, would remove one disincentive to work. There are particular barriers to work for people in residential care because their benefits are tied into the provision of their residential care package.

2.32 Health and social care service providers need to be more proactive in assisting clients to move toward employment.

‘Many people seen as unemployable are actually seen by the Shaw Trust as highly employable and some are able to work a lot more hours than was thought possible. Social services need to move away from sending people to daycentres and into looking at employment options for them. The Shaw Trust wants to work with Social Services and Health professionals to move people into work and help them become more strong and confident. It is not about the disability but about changing the mindset.’
Clive Stansfield, Director of Shaw Trust Wales

2.33 The University of Wales Centre for Learning Disability is also conducting research into best practice in helping people in transition from learning to work.²⁶

²⁵ *Addressing disincentives to work associated with the welfare benefits system in the UK and abroad.* Patience Seebohm and Judy Scott. Sainsbury Centre for Mental Health - October 2004

²⁶ http://www.cardiff.ac.uk/medicine/psychological_medicine/research/welsh_centre_learning_disabilities/research/transition_from_school/index.htm

Recommendation 17: The Welsh Assembly Government should make representations to its colleagues in the Department of Work and Pensions on the following:

The need to overcome the disincentives to work within the current benefits system that are experienced by disabled people;

the need to build sufficient flexibility into the Personal Capacity Assessment (PCA) to take account of fluctuating medical conditions;

the need for PCA to be available through a medium appropriate to each individual.

Recommendation 18: The Welsh Assembly Government and the Department for Work and Pensions should work closely together to develop ways in which budgets and the benefits system can be used creatively to ensure that Welsh Assembly Government policies are supported by Whitehall Departments.

Limited opportunity for young people with hearing impairments

‘We have 60 members. Currently we have identified issues of isolation, confidence, self-esteem, and socialisation. Existing organisations do not have resources to provide services to our members. We have applied for funding but have been unsuccessful. How will your policy review change this situation to enable us to fill this huge gap which affects leisure, transition, training and employment?’

Les Rose, Cyswllt Deaf Children’s Society

‘Deaf young people are forced to be independent through their isolation.’

Deaf Association Wales

2.34 In responding to consultation the Deaf Association pointed out the fact that there are no schools for deaf children in Wales and partially hearing units for deaf children do not provide adequate communication support in British Sign Language (BSL).

Deaf young people are often isolated – they may not have any deaf peers, be bullied and unable to communicate with their class members. They do not have full access to higher and further education, training and employment partly due to over-emphasis on speech and language therapy rather than promoting use of BSL. The Deaf Association also reports deaf children being denied access to learn Welsh, even if they are from a Welsh-speaking family, due to professionals advising that it will be ‘confusing’.

2.35 The lack of attainment of deaf people in education and employment creates a vicious cycle as there are no deaf adults in professional roles to support deaf young people. The lack of BSL-trained service providers affects every area of a deaf young person’s life. It denies them deaf role models, prevents them communicating with peers, denies them access to information to allow them to travel or participate in leisure activities. Good quality careers advice in BSL is not available. Deaf students at the University of Wales in Cardiff have undertaken degree courses but their assessed work was presented in written format rather than their natural language of BSL. The scarcity and cost of BSL interpreters is a disincentive to colleges and training providers from catering for deaf students, who are then sometimes obliged to go to out-of-country residential colleges to pursue suitable courses.

‘I’m going to Wolverhampton University in September. The University has booked interpreters for the three years of my course and there is a deaf community there, but I would prefer to be able to study closer to home.

It is very important to have more qualified BSL interpreters in Wales. I went to a mainstream comprehensive, which was OK but I didn’t have a lot of friends because they weren’t able to understand me. I would have preferred to have been with lots of deaf people but the nearest school was very far and was more oral, whereas I like to sign.

For my exams it was mostly course work only. I was very stressed. There was a lot of pressure especially with English. I would have liked to be able to sign the answers to the questions in exams if possible.

I'm doing a BTec in Sports Science and I'd like to be involved with deaf athletics but the thing in Wales is, to be involved with deaf people the coaches need to be qualified in BSL to communicate with me.

There are lots of barriers for getting to the doctor and getting an interpreter to assist deaf people. Lots of GP surgeries don't even display the poster that shows the BSL signs for different medical conditions.'

Jodie, a young deaf women from Maesteg

Recommendation 19: The Welsh Assembly Government should ensure that its strategy to improve the provision of BSL services, including interpreters, in Wales is fulfilling its objectives by regular monitoring and review.

Role of Employers

'43 per cent of disabled people of working age are in employment in Wales, compared with 83 per cent of non-disabled people. 86 per cent of respondents thought that it was harder for them to find jobs than for non-disabled people. One in eight said that they had been turned down for a job and told that the reason related to their disability or impairment.'

Wales TUC

2.36 TUC Wales reported that it has worked with the CBI on raising awareness of disability and equality issues but that more could be done, including taking disability issues into account in the bargaining agenda and working with health and safety representatives to ensure that health and safety law is not being used as a barrier to employing disabled people²⁷. It is important that a lack of understanding about the nature of 'reasonable adjustments' required under the Disability Discrimination Act does not create a backlash against employees.

2.37 There would appear to be a lack of good quality advice and information about disability equality in the workplace. Research suggests that disabled people more likely to be in low-paid jobs and find it difficult to move up the career ladder. There is good and bad practice amongst employers in linking pay to appraisal

²⁷ Equality of Opportunity Committee meeting 30 June 2005

systems. Some systems still fail to take account of an individual's impairment, and are therefore discriminatory.

Recommendation 20: The Welsh Assembly Government should work with both public and private sector employers and Trade Unions to put in place structures to encourage the employment of disabled people.

Recommendation 21: The Welsh Assembly Government should work with the UK government to ensure that options for supported employment for disabled people are maintained.

Self-employment

2.38 The Committee found the main barriers to self employment to be:

- **Limited work experience** – 90 per cent of young disabled people have limited or no work experience, therefore no transferable skills for self-employment.
- **Benefits** – high dependency on benefits from an early age makes the move to becoming self-employed even more daunting.
- **Accessibility of information** – including information about how the benefits system releases individuals to test-trade their business – it is not readily available to disabled young people and is full of jargon
- **Accessible physical environment for business support services** – disabled clients must be referred to accessible venues to access business support services such as marketing and finance.
- **Confidence to communicate access needs** – some disabled people need help to be empowered to communicate their needs.
- **Discouragement from education professionals** – Disabled young people may be discouraged in school and college from considering self-employment in favour of more 'secure'

employment options. Encouraging entrepreneurship could help to reduce the number of highly qualified disabled college graduates failing to find employment.

Recommendation 22: The Welsh Assembly Government to work with Disability Wales, the Confederation of British Industry and other employer's organisations to develop ways in which disabled young people can be encouraged to consider the option of self-employment as a future career path.

CHAPTER 3

TRANSPORT

3.1 Many disabled people in Wales are reliant on public transport, and lack of access is widely acknowledged as a problem, especially in rural areas. An inability to use public transport is depriving disabled young people in Wales of fundamental rights of access to leisure activities and employment. Some public transport is accessible to wheelchair users, but other disabilities may not be considered.

3.2 The Disability Rights Commission (DRC) told us that transport is essentially a 'gateway service' – stating that if individuals cannot access transport and do not have the confidence to get around their local environment then they are not going to be using services²⁸.

3.3 The Committee's reference group prioritised transport as an issue. The Committee took evidence from Arriva Trains Wales, BusUsers UK in Wales, the Welsh Assembly Government's Sustainable Travel Unit and the Disability Rights Commission, which sits on the Disabled Passengers Transport Advisory Committee²⁹.

3.4 The issue of access is not exclusive to those with mobility issues or wheelchair users. The wheelchair is considered as a universal symbol of disability, but many impairments are not visible – the DRC estimate that less than 6% of disabled people are wheelchair users. In their response to the consultation, the Deaf Association Wales noted that young deaf people have unequal access to public transport, citing the example that announcements at train stations are clearly inaccessible and that this can lead to decreased confidence in travelling alone and therefore decreased independence.

²⁸ Equality of Opportunity Committee meeting (12 October 2005)

²⁹ Equality of Opportunity Committee meeting (12 October 2005)

'Accessibility for wheelchair users is always an issue, but it is not only wheelchair users who face problems, but those who are visually impaired, hearing impaired and so on. It is not just about having accessible buses. It is about controlling parking at bus stops, having proper signs in bus stations and proper timetables for people who are unable to read a normal timetable – and most of us cannot – to present the information in ways that are easy to take on board.'

Leo Markham of BusUsers UK

Legislation

The Disability Discrimination Act 2005, Part 3

3.5 While the Disability Discrimination Act 1995 made it unlawful for the providers of services to discriminate against disabled people in the provision of goods, services and facilities, transport was not fully covered by the legislation. For example, although the Act required bus and railways stations and other public transport infrastructure to be accessible, the buses and trains did not need to be. However, the Disability Discrimination Act 2005 amended the original legislation to rectify this anomaly and further facilitate the accessibility of public transport.

3.6 From December 2006 it became unlawful for operators of public transport to:

- discriminate against disabled people;
- treat disabled people less favourably; or
- fail to make a reasonable adjustment to the way their services are provided.

3.7 In April 2006 the UK Government's Department of Transport launched a Code of Practice on the Provision and Use of Transport Vehicles. The Code, which was developed by the Disability Rights Commission in consultation with stakeholders, explains the purpose of the changes in the law and was issued on the basis of a request by the Secretary of State for Transport. It applies equally in England, Scotland and Wales.

3.8 The Committee welcomes the changes in legislation and the development of the Code, which is intended to improve accessibility for transport services for disabled people. However, it will be necessary to ensure that its application is carried out consistently across Wales.

Physical Access and Infrastructure

3.9 Whilst physical accessibility of bus fleets in Wales was reported at 80 to 90 per cent in some cities, overall it is only 30 per cent, which means that large areas are not served consistently with accessible bus services. Information about accessible buses is sometimes not communicated clearly enough. This can result in someone starting a journey on an accessible bus and finding that there is no accessible bus for the return journey.

3.10 Arriva Trains Wales serves Wales and English border counties. They have 235 stations, 48 of which are staffed. The issue of independence and the ability to be spontaneous in decision-making was raised by the reference group. Unmanned stations create specific problems for disabled passengers. The Committee noted that support services could be provided with advance notice of a journey.

3.11 BusUsers UK in Wales noted the specific problem of bus stops. They noted that in too many cases, it didn't matter whether a bus was accessible or not as car drivers all-too-often park in designated bays making it impossible for adapted buses to be utilised.

3.12 In terms of train and bus journeys, the DRC noted that consistency of service was a real problem, noting that when an individual requests assistance in one station, it does not necessarily follow that support will be available at the end or mid points of the journey.

Recommendation 23: The Welsh Assembly Government should monitor the implementation of the statutory code of practice on transport throughout Wales.

Access to information

3.13 The Committee felt that access to information was a key issue in improving the perception of transport services in Wales. Arriva noted that they publish a *guide for customers with disabilities*³⁰ which is available from staffed stations and the company website. The guide includes a listing of stations in Wales detailing the accessibility of stations in terms of staffing hours, the number of platforms, wheelchair access to platforms, accessible toilets and wheelchair access to trains. The guide also reports on the support available for customers with impaired hearing. However, Arriva shared the Committee's concern that the people who needed the information most were not routinely aware of it. Members of the reference group suggested that information like this should be made available at train and bus stations, information offices and so on and that users or potential users should be made better aware of it.

3.14 Although guides are published to assist customers with disabilities, it is suggested that very few of the target audience are aware of them. Disabled young people also did not see why they should have to ring up in advance of their journey to ensure that they could use services.

Recommendation 24: The Welsh Assembly Government should work with transport providers to ensure that information about the accessibility of transport services for disabled people is available in accessible formats.

³⁰ Arriva Trains: A Guide for Customers with Disabilities
<http://www.arrivatrainswales.co.uk/uploads/documents/1109.pdf>

Attitudinal barriers

‘One of the young people in the reference group carried out research in schools and colleges regarding transport. They discovered that many disabled young people seldom use buses or trains. The reason for this was that their parents were too afraid to let their children learn how to use public transport on their own, as they thought that there were too many dangers. Instead they rely on their parents or taxis to get around. How can you help to build the confidence of the young people and their families, allowing them to use your service in a safe way, and encourage independence?’

Heather Graham, Reference Group member, question to service providers.

3.15 The Committee was disappointed to hear evidence from the DRC and the Reference Group of poor attitudes amongst transport service staff. In terms of bus services, the DRC noted that there is a voluntary code of practice for bus drivers but it was also aware of examples of bad attitudes. For example, a wheelchair user had to wait three hours at a bus stop as three buses went past. Although each bus was wheelchair accessible the driver was unwilling to ask people with fold-up prams to move them from the space allocated for wheelchair users. The Reference Group noted that the problem of physical access was secondary to that of staff attitude, and it was the latter that made them feel unsafe and uneasy using public transport.

Recommendation 25: The Welsh Assembly Government to issue new guidelines for the tendering process that require local authorities to only offer tenders or contracts to operators who have undergone approved training disability awareness training.

3.16 BusUsers UK in Wales noted that training by larger operators generally was better delivered than that given by smaller companies. They suggested that one solution may be for the Assembly to provide local authorities with guidance to ensure that authorities only award contracts to operators who had undergone approved training. Smaller operators were less well-placed to

provide or support such training, so Government support may be needed.

Recommendation 26: The Welsh Assembly Government should work with public transport operators and the voluntary sector to produce guidance to ensure that training for drivers and guards on the needs and rights of disabled people using the transport system is appropriate and given regularly. It should be developed in conjunction with children and young people and its effects should be monitored.

3.17 The issue of transport support training for service users was also raised and the Welsh Assembly Government noted that in their funding of community transport, they would consider making training a requirement rather than an option. The Committee considered training for disabled service users a key issue.

3.18 While it is acknowledged that security is an issue for everyone using public transport, the perception about risk is often greater than the reality. It is also felt that service providers should do more both to publicise the information that is available about services and to build confidence about disabled young people using public transport. One reference group member had received public transport training and found it very beneficial, but it was apparent that the availability of travel training agencies across Wales is variable.

Recommendation 27: The Welsh Assembly Government should ensure that support training for disabled young people on using public transport is available across all parts of Wales.

Recommendation 28: The Welsh Assembly Government should work with transport providers and the voluntary sector to ensure that there is sufficient support and information for the parents and carers of disabled young people to have the confidence to allow their young people to use the transport system.

3.19 The DRC noted a problem with the existing law, in that they were finding difficulties with consistency of application. With accessible buses concentrated in the greatest areas of population,

this inevitably meant that there were large parts of rural Wales that were not served by accessible buses.

CHAPTER 4

INDEPENDENT LIVING

Independent living means:

To live on your own away from your family. Having the freedom to do what you want when you want to, with who ever you want. Taking control of you life. Paying your way and receiving the support you need when you want it.

Its our life.³¹

Statement by the Disabled Young People's Reference Group

4.1 The ability for disabled young people to live independently was a theme which ran through all the evidence given and issues raised by the reference group. Some of the issues raised have been covered in previous chapters. This chapter deals with other issues associated with independent living.

4.2 The Reference Group identified the following issues:

- Living on your own and having support when you need it
- Living with other young people
- Learning new skills
- Relationships – with other young people, with parents/family, with boyfriend/girlfriends, with carers and support workers
- Taking control of your life
- Being able to pay your own way
- Money – to pay for rent/bills/support/transport/gas/electricity/food/benefits
- Information-‘We need more information in more places because now we often find out by accident’

³¹ Equality of Opportunity Committee meeting 22 March 2006 para 214.

4.3 This final point was echoed by many of the individuals and organisations we received evidence from. In its written evidence, the Deaf Association for Wales said:

‘The current approach of promoting independence and autonomy of young deaf people occur by default in that lack of access to information, knowledge and facilities available to them, deaf young people are forced to be independent through their isolation.’

Chwarae Teg said:

‘Provision of clear accessible information is of the utmost importance to enable disabled young people to make informed choices’.

Housing and Accommodation

4.4 We heard examples of good practice in schools and colleges with residential facilities for young people such as Ysgol Hendre in Neath³². Their work includes not only academic education but also life, relationship and independent living skills. Residential colleges such as Beechwood College in Cardiff and Pengwern College of Higher Education in Denbighshire also offer a wide range of both vocational and life skill courses for young people with a range of disabilities.

4.5 Schools and colleges with residential facilities are not common place in Wales. Indeed, the evidence from Ysgol Hendre indicated that there are only three or four schools in Wales which have similar facilities to them.

4.6 Scope Cymru’s evidence echoed the evidence produced by the Joseph Rowntree Foundation³³ about the lack of suitable housing to enable young people to leave home and live independently. The report cited especially a lack of suitable accommodation in the private rented sector which is often used by young non-disabled young people wishing to live independently for the first time. Young disabled people’s choices about where to live is often based on what vacancies exist within services and segregated schemes. Often these places are inappropriate to

³² Equality of Opportunity Committee meeting 22 March 2006 para 124 onwards.

³³ Morris, Jenny 2004 *Moving into Adulthood* Joseph Rowntree Foundation

young people in terms of their needs and the age and circumstance of other residence.

4.7 We also heard of differing approaches from local authorities, with many citing the lack of priority given by housing departments and a lack of 'joined up working between housing departments, planning and social services as the main reasons for the lack of suitable housing. Some local authorities are, however, introducing innovative ways of addressing the problem. The City and County of Swansea are developing an accommodation strategy for people with disabilities and they have a temporary post which supports people to find appropriate housing for their needs. In Pembrokeshire, the NCH is working with the local authority to deliver access to a range of housing options for disabled young people and an acceptance that they have a right to live independently from their parents.

Recommendation 29: The Welsh Assembly Government should require all local authorities in Wales to carry out regular housing needs assessments amongst young people with a range of impairments. These should be used to inform housing policy with a view to ensuring that the housing needs of disabled young people are met.

Recommendation 30: The Welsh Assembly Government to require all local authorities in Wales work with the public, private, independent and voluntary sectors to identify and increase the availability of rented accommodation suitable for disabled young people.

Recommendation 31: The Welsh Assembly Government should produce guidance for local authorities and Registered Social Landlords on the housing needs of disabled young people including their support needs, adaptations and funding available for any work required.

Direct Payments

4.8 We received evidence from the Shaw Trust³⁴ of the impact that Direct Payments are having on the lives of disabled young people. The payments are enabling them to live more

³⁴ Equality of Opportunity Committee 22 September 2005 EOC(2) – 07-05(p7)

independently by employing their own carers to provide personal and social care. We heard that employing a personal assistant can enable people to go out together as a family where there are disabled and non-disabled siblings, and can also allow a friend that the disabled person is comfortable with to help with personal care.

4.9 There are problems, however, with the Direct Payments Scheme. Scope's³⁵ evidence to us in September 2004 pointed to a number of problems with system. They highlighted:

- A lack of information about Direct Payment as an option;
- Insufficient support and information on how to apply for Direct Payments;
- Information that was available not being tailored to specific client needs;
- A lack of detailed knowledge and promotion of the Scheme by frontline social workers;
- Uncertainty by social services and disabled people as to what Direct Payments can be used for.

4.10 These issues do not appear to have been addressed quickly. The Shaw Trust's evidence twelve months later highlighted similar problems with the Scheme. They also highlighted the patchiness of take-up of the Scheme across the local authorities in Wales and the fact that it was not working well for people with learning disabilities when it came to them being assessed for their suitability to manage Direct Payments.

4.11 The Reference Group themselves in evidence to the Committee in March 2006³⁶, highlighted problem with the speed at which the payment system operated, often taking up to 12 months for assessments to be made and the fact that they were concerned about their role as 'employers' under the scheme. Its main concern, however, was the lack of information about, and help with applying for, the Scheme.

4.12 Whilst we recognise that the Direct Payments Scheme is a non devolved matter, we consider that more could be done by the Welsh Assembly Government and local authorities to ensure that the Scheme offers real choices for disabled young people in Wales.

³⁵ Equality of Opportunity Committee OC 13 January 2005 EOC(2) -01-05(p6)

³⁶ Equality of Opportunity Committee meeting 22 March 2006 para 222

Recommendation 32: The Welsh Assembly Government should work with local authorities in developing a more coordinated approach to the provision of direct payments. This would include the need for increases in the publicity of direct payments and the support provided to disabled people through the application process.

Recommendation 33: The Welsh Assembly Government should review the current mechanisms for assessing eligibility for direct payments with a view to ensuring that equal access is given to young people with learning disabilities.

Relationships

4.13 Throughout the review, the reference group cited the attitudes of family and carers as a barrier to them having independence. Although the group acknowledged that their families and carers had, for the most part, their best interests at heart, the two messages that were repeated in many sessions were:

‘They tell us what to do all the time’

and

‘They think they know what’s best for us – they don’t listen to what we want.’

4.14 This barrier to independence is encountered in many areas. The Committee heard evidence from the University of Birmingham about the experiences of disabled pupils and students and their families³⁷. Their research highlighted the difference in responses from parents of disabled young people and from the young people themselves.

4.15 As well as being an important issue in terms of independent living, we believe that this issue is fundamental to the problem of how we listen to the views of disabled young people when making and implementing policies which affect their lives. We believe that the way in which we have conducted this review – taking direct

³⁷ Equality of Opportunity Committee 14 June 2006 EOC(2) -05-06(p2)

evidence from the young people about the issues they feel are important – should be used as an example of good practice in this area.

4.16 Other important relationships for disabled young people are with their care and support workers. The group created two models, Cruella and Earl, to explain how they felt about the different types of people they have to work with.

Earl, their ideal, was described as:

- Supportive
- Lets me do the things I want to do
- Someone I can talk to
- Someone I can trust
- Has a good sense of humour
- Can communicate
- We respect each other
- Helps enough but not too much
- Talks to you not at you

‘Working together with people who have Earl’s skills, whoever they may be and whatever their position or place, as we said earlier, helps us to be more independent.’

Tim Rusco, Barnardo’s Cymru

Cruella, however was described as:

- Uncooperative
- Only doing it for the money
- Bullying, shouts, is rude
- Puts words in your mouth

- Has no respect for you
- Talks down to you
- Stops me from doing what I want to do
- Has a bad attitude

4.17 The group agreed that they met more Earls than Cruellas but the Committee was concerned that Cruellas do exist and most of the Group members had dealt with one at some time in their lives. The group endorsed the Committee's suggestion that it was important that reviews of performance and training are in place in social services departments to ensure that support workers and carers are of high quality.

4.18 Of even more concern was the view expressed by some of the Group members that they would not know how to complain about a support worker or carer and that if they did, their views might be dismissed³⁸.

4.19 We believe that every disabled young person should know how to complain about their treatment by carers and support workers if appropriate and should feel confident in doing so.

Recommendation 34: The Welsh Assembly Government should require all public and voluntary bodies that provide carers for disabled young people to demonstrate how disabled young people can be and are being involved in the process to decide on the person who will work with them.

Recommendation 35: The Welsh Assembly Government should require all local authorities to ensure that all providers of care and support services for disabled young people have mechanisms in place for the review of performance of their staff and that those reviews involve the views of the young people they work with.

Recommendation 36: The Welsh Assembly Government should require all social service departments and voluntary

³⁸ . Equality of Opportunity Committee meeting 14 June 2006 para 285

organisations working with disabled young people to have a clear, understandable complaints procedure which is widely advertised and made accessible to all service users.

Recommendation 37: The Welsh Assembly Government should establish a system of advocacy for all disabled young people, regardless of their impairment that is independent of service providers, accessible to all users and sustainable.

4.20 We received evidence from several organisations and from the young people themselves that many disabled young people are concerned about personal and sexual relationships. Many young people are concerned about personal and sexual relationships. The Reference Group felt that they should be able to have the same sort of relationships and the same access to help and advice.

4.21 The Group felt that it was often considered as 'not appropriate' for disabled young people to have relationships by their families and carers.

'It does not matter if you have a disability. If you want a relationship you should be able to have one. You have no right to stop us, but there is information that nurses, health centres and teachers treat other young people differently to us. Quite often, there are negative attitudes and I am worried that I will not be taken seriously. People expect us to have a relationship with another disabled young person. Other people make my choices. Disabled people are left until last, like toys at the bottom of the toy box.

Relationships are about trust, friendship, loyalty, openness, love, care, support, respect, understanding, and honesty. Relationships are a part of life and life is hard enough without barriers. We need education early on sex and relationships, and support and help from people such as parents, teachers, youth clubs, friends, carers and so on, and enough people to provide support and information that is understandable. We are the same as everyone else. We should have the right attitude from parents, teachers, friends and carers. It should not matter where you live.'

Jessica Roberts, Reference Group member.

4.22 We heard from the Family Planning Association (FPA) that it runs specific courses and projects for young disabled people to educate them about relationships and sexual experiences. It acknowledged the barriers that are often put up by families, especially those of young people with learning difficulties. The FPA tries to work with families to explain the young people's needs and to develop appropriate information and resources for them.

CHAPTER 5

OTHER ISSUES

The Social Model of Disability

5.1 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.

Recommendation 38: The Welsh Assembly Government and Assembly Parliamentary Service to ensure that the social model of disability is fully integrated into their functions, relevant and appropriate training for staff and conduct of business, including prompt and effective implementation of their Disability Equality Schemes.

Accessible accommodation

5.2 It has already been stated that the Reference Group found great difficulty in finding venues outside Cardiff where they could meet. This was accentuated by evidence given to the Committee by Vin West of the Arfon Action Group who said

‘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.’

‘We have schools, universities and public buildings that have had the period between 1995 and 2004 to become accessible, but that, at best, have just started the process. Some students in Caernarfon recently needed to access a museum as part of their course – I had to lend the museum one of my daughter’s ramps to get them in. We have people who are left with no means of communication, because the communication aids budget is too

small to meet either their needs or the development costs. I do not know if you can possibly imagine the levels of frustration and anger that that can engender.³⁹

5.3 In response to consultation, Bridgend Adult Community Learning and Youth Service pointed out that adult learning took place in a rented building so there was no control over disabled access and not all premises were accessible, with some schools ensuring that IT equipment was not on the ground floor.

5.4 Scope Cymru gave evidence about its 'Within Reach' campaign to increase accessibility for students with sensory and physical impairments and the amount of money being spent in England through the Schools Access Initiative.

Recommendation 39: 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.

Changing Places Toilets

5.5 The difficulties faced by young disabled people in accessing services have been illustrated throughout the body of this report. However, the inability of some disabled people to access the most basic facilities, namely public conveniences, is possibly the starkest example that the Committee came across in the course of its review.

5.6 While standard disabled toilets meet the needs of many disabled people, thousands of individuals with profound and multiple learning disabilities need 'Changing Places' toilets comprising a changing bench, a hoist, and enough space for two carers and a wheelchair. Currently, there are few public Changing Places toilets in the UK. The lack of appropriate, accessible toilets prevents individuals with profound and multiple learning disabilities from accessing services that most people take for granted.

In giving evidence to the Committee, Wayne Crocker of Mencap Cymru explained that:

³⁹ Equality of Opportunity Committee meeting 26 May 2005

‘Parents and carers are having to change children and adults with profound and multiple learning difficulties on toilet floors, which are unclean, however clean they look to the naked eye.’

He went on to suggest that the lack of Changing Places toilets:

‘...is an infringement of the human rights and the dignity of people with profound and multiple learning difficulties⁴⁰.’

The Committee welcomed the use of the disabled toilets in the National Assembly’s Senedd as an exemplar for other public bodies and organisations. It gave full support to the Changing Places Consortium national campaign for Changing Places toilets, which was launched in July 2006.

Recommendation 40: The Welsh Assembly Government should encourage, through the planning system, those seeking permission to build new public and commercial buildings, to include Changing Places toilets in their plans with a view to establishing, in the first instance, one facility in each local authority area.

⁴⁰ Equality of Opportunity Committee meeting 14 June 2006 para 241 onwards

Annex A

Summary of recommendations

Due to the nature of the review the Committee recognises that most of the recommendations cut across areas of Cabinet responsibility. The Committee therefore expects to receive an initial response from the Minister for Assembly Business, Equalities and Children, who has given an undertaking to raise equality issues with Cabinet colleagues on a regular basis. The Committee will regularly monitor progress with implementing any of its recommendations that are accepted by the Welsh Assembly Government.

Full list of all recommendations based on the evidence received and the views of the reference group:

General

Recommendation 1: The Welsh Assembly Government should develop a strategic policy that includes all services that young people need to help them develop the skills they need to live a fulfilling life. Young people should be involved in working out the best way of making this happen.

Recommendation 2: The Welsh Assembly Government to produce guidance for all policy divisions, local authorities and other public bodies in Wales on involving disabled young people, their families and carers in policy making. The guidance should identify good practice (e.g. the work of the Disabled Young People's Reference Group) and emphasise the need to listen to the views of disabled young people as articulated by them rather than focussing on the views of their families and carers.

Recommendation 3: The Welsh Assembly Government should issue guidance to all public, private and voluntary sector bodies who provide services, one to one, groups, projects and initiatives for young people to ensure that they are as accessible as possible for all young people.

The guidance should include:

Making information on projects accessible;

Creating an environment that the young people feel comfortable in;

Ensuring that young people's needs are fully understood;

Making progress towards projects as enjoyable and challenging as desired by all young people, whilst assessing and minimising any risks involved.

Recommendation 4: The Welsh Assembly Government should set up a review of disability equality training for professionals working with disabled young people and employers.

The outcomes of the review should feed into the development of professional training which covers the provision of advice, information and support on relationships, sexuality and sexual health, as well as educational and careers advice.

Recommendation 5: The Welsh Assembly Government should issue guidelines to local authorities on how to ensure that disability equality training in local authorities is being delivered by people with sufficient and appropriate experience and training of the issues facing disabled people.

Education, Training and Employment

Recommendation 6: The Welsh Assembly Government should provide an holistic, co-ordinated framework policy for provision of pre-16 and post-16 (up to at least age 25) education, training and employment support and services.

The framework policy should cover early identification, assessment and service provision to clearly set out multi-agency roles and protocols for sharing information and providing services.

Recommendation 7: The Welsh Assembly Government to review the assessment and funding systems for support services to help disabled young people move from education and training into employment. The review should focus on work-based learning provision, and ensure that it emphasises equality of outcome in terms of jobs and progression, rather than on qualifications attained.

Recommendation 8: The Welsh Assembly Government to ensure that all advice and support on education, training and careers, whether spoken or written is in the medium of Welsh, ethnic minority languages and accessible formats. This should include ensuring that all Assembly-funded information services are available on-line.

Recommendation 9: The Welsh Assembly Government to ensure that all local authorities in Wales have systems in place to guarantee that all young people, irrespective of any impairment, receive appropriate assistance through the transition process.

Recommendation 10: The Welsh Assembly Government to ensure that one-to-one support is available to disabled young people as part of education, training and employment services.

Recommendation 11: The Welsh Assembly Government to assess the impact of education, training and employment service provision by measuring how accessible services are for disabled young people, whether the services are meeting individual needs and how many 16-25 year old disabled young people are in employment or the type of employment of their own choice.

Recommendation 12: The Welsh Assembly Government to act on the results of the assessment of education, training and employment services to increase their effectiveness.

Recommendation 13: The Welsh Assembly Government and service providers should review advice, information and support services for young people on relationships, sexuality and sexual health, both in-school and outside school, in full consultation with disabled young people themselves.

Any resultant good practice guide should be provided in ways that all children and young people with impairments can understand.

Recommendation 14: The Welsh Assembly Government should ensure that the terms and conditions of all staff working with disabled young people in schools, including learning support assistants allow them to receive adequate training to enable them to fully support disabled young people.

Recommendation 15: The Welsh Assembly Government should put in place additional measures, both practical and financial, such as incentives for employers and funding for support workers to ensure meaningful work experience placements are offered to disabled young people.

Recommendation 16: The Welsh Assembly Government should work with the Voluntary and Community Sector to identify ways by which voluntary organisations can be more involved in delivering initiatives aimed at helping disabled young people into sustained employment.

Recommendation 17: The Welsh Assembly Government should make representations to its colleagues in the Department of Work and Pensions on the following:

The need to overcome the disincentives to work within the current benefits system that are experienced by disabled people;

the need to build sufficient flexibility into the Personal Capacity Assessment (PCA) to take account of fluctuating medical conditions;

the need for PCA to be available through a medium appropriate to each individual.

Recommendation 18: The Welsh Assembly Government and the Department for Work and Pensions should work closely together to develop ways in which budgets and the benefits system can be used creatively to ensure that Welsh Assembly Government policies are supported by Whitehall Departments.

Recommendation 19: The Welsh Assembly Government should ensure that its strategy to improve the provision of BSL services, including interpreters, in Wales is fulfilling its objectives by regular monitoring and review.

Recommendation 20: The Welsh Assembly Government should work with both public and private sector employers and Trade Unions to put in place structures to encourage the employment of disabled people.

Recommendation 21: The Welsh Assembly Government should work with the UK government to ensure that options for supported employment for disabled people are maintained.

Recommendation 22: The Welsh Assembly Government to work with Disability Wales, the Confederation of British Industry and other employer's organisations to develop ways in which disabled young people can be encouraged to consider the option of self-employment as a future career path.

Transport

Recommendation 23: The Welsh Assembly Government should monitor the implementation of the statutory code of practice on transport throughout Wales.

Recommendation 24: The Welsh Assembly Government should work with transport providers to ensure that information about the accessibility of transport services for disabled people is available in accessible formats.

Recommendation 25: The Welsh Assembly Government to issue new guidelines for the tendering process that require local authorities to only offer tenders or contracts to operators who have undergone approved training disability awareness training.

Recommendation 26: The Welsh Assembly Government should work with public transport operators and the voluntary sector to produce guidance to ensure that training for drivers and guards on the needs and rights of disabled people using the transport system is appropriate and given regularly. It should be developed in conjunction with children and young people and its effects should be monitored.

Recommendation 27: The Welsh Assembly Government should ensure that support training for disabled young people on using public transport is available across all parts of Wales.

Recommendation 28: The Welsh Assembly Government should work with transport providers and the voluntary sector to ensure that there is sufficient support and information for the parents and carers of disabled young people to have the confidence to allow their young people to use the transport system.

Independent Living

Recommendation 29: The Welsh Assembly Government should require all local authorities in Wales to carry out regular housing needs assessments amongst young people with a range of impairments. These should be used to inform housing policy with a view to ensuring that the housing needs of disabled young people are met.

Recommendation 30: The Welsh Assembly Government to require all local authorities in Wales work with the public, private, independent and voluntary sectors to identify and increase the availability of rented accommodation suitable for disabled young people.

Recommendation 31: The Welsh Assembly Government should produce guidance for local authorities and Registered Social Landlords on the housing needs of disabled young people including their support needs, adaptations and funding available for any work required.

Recommendation 32: The Welsh Assembly Government should work with local authorities in developing a more coordinated approach to the provision of direct payments. This would include the need for increases in the publicity of direct payments and the support provided to disabled people through the application process.

Recommendation 33: The Welsh Assembly Government should review the current mechanisms for assessing eligibility for direct payments with a view to ensuring that equal access is given to young people with learning disabilities.

Recommendation 34: The Welsh Assembly Government should require all public and voluntary bodies that provide carers for disabled young people to demonstrate how disabled young people can be and are being involved in the process to decide on the person who will work with them.

Recommendation 35: The Welsh Assembly Government should require all local authorities to ensure that all providers of care and support services for disabled young people have mechanisms in

place for the review of performance of their staff and that those reviews involve the views of the young people they work with.

Recommendation 36: The Welsh Assembly Government should require all social service departments and voluntary organisations working with disabled young people to have a clear, understandable complaints procedure which is widely advertised and made accessible to all service users.

Recommendation 37: The Welsh Assembly Government should establish a system of advocacy for all disabled young people, regardless of their impairment that is independent of service providers, accessible to all users and sustainable.

Recommendation 38: The Welsh Assembly Government and Assembly Parliamentary Service to ensure that the social model of disability is fully integrated into their functions, relevant and appropriate training for staff and conduct of business, including prompt and effective implementation of their Disability Equality Schemes.

Recommendation 39: 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.

Recommendation 40: The Welsh Assembly Government should encourage, through the planning system, those seeking permission to build new public and commercial buildings, to include Changing Places toilets in their plans with a view to establishing, in the first instance, one facility in each local authority area.

Annex B

Terms of reference

The purpose of the review is to enable the Committee to properly audit the Assembly's arrangements for promoting in the exercise of its functions the principle that there should be equality of opportunity for all people.

For those purposes, the Committee on Equality of Opportunity will review the provision of services for disabled young people in Wales. The review will include examination of the issues emerging from the first International Congress for Young Disabled People.

The potential scope of the review is vast, so to make it manageable the Committee will focus on the most significant or fundamental problems and those where the Welsh Assembly Government and the National Assembly for Wales can make a difference.

Three key themes will inform the review:

- 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 will give particular regard to the following eight areas:

- education, training and employment
- leisure
- housing
- transport
- equipment
- transition to adulthood
- access to information
- poverty

Issues which will require particular consideration

- The slogan of the 'Rights Into Action' International Congress for disabled young people was 'nothing about us without us'. The Committee will, therefore, ensure that young people are directly involved in the review by establishing a reference group of young disabled people
- To avoid duplicating the work of the Education and Lifelong Learning Committee's review of Special Education Needs provision, this review will focus on wider issues in relation to education, training and employment, ie: access to the whole school experience; preparation for employment - access to work experience, careers advice and advice on rights; the right to the same options available to other young people
- The review will consider whether the Welsh Assembly Government's existing policies on services for disabled young people adequately meet their needs in relation to education, training and employment; leisure; housing; transport; equipment; access to information; transition to adulthood and poverty.
- The review will consider whether the provision of services in the medium of Welsh, and provision in rural areas, is adequate
- The review will aim to identify best practice in service provision and whether this best practice is being shared adequately throughout Wales.

Gathering Evidence For The Review

Publicising the review and direct invitations for written submissions

- The Committee will publicise its review through the media and on its website. Written submissions will be invited from relevant organisations.
- The Committee will be provided with a list of potential consultees for review before starting a consultation at the end of the summer term 2004, with a view to consulting over the summer recess and considering a summary of responses in the autumn term.

- The evidence could then be analysed to coincide with the appointment of a professional facilitator and bringing together of a reference group.
- The submissions received will help identify the areas where the committee's time and effort would best be concentrated, and inform development of a detailed work programme.

Seminar Event

- At least one seminar event will be held for service providers. The Committee will consult with service providers when considering the most appropriate location, and ensure that service providers based outside Cardiff are not excluded from contributing fully to the review.

Evidence Sessions/Events and Visits

The Committee may hear evidence by:

- inviting organisations to formal committee meetings for focused evidence sessions on specific topics;
- holding informal committee meetings or visits in relevant locations around Wales which are more accessible to important witnesses - to discuss issues with disabled young people, their parents, relatives and support workers, and members of organisations working with disabled young people;
- using a system of rapporteurs to enable Members to visit disabled young people, and the people who provide services to them, across Wales. Each rapporteur visit will be reported back to the Committee
- inviting Regional Committees to take evidence on specific questions on behalf of the Committee on Equality of Opportunity.

Experience elsewhere

- The Committee will consider services provided for disabled young people in Wales at the UK Government level and may invite the Minister to pass on any recommendations to Whitehall departments as appropriate. The committee will liaise with the House of Commons Welsh Affairs Committee on issues relevant to its remit as appropriate.
- The international dimension of service provision for disabled young people will be taken into consideration, including through a desktop review and by seeking the views of the reference group.

Professional Facilitator and Reference Group

- The Committee has decided to bring together a reference group of young disabled people for the duration of the review.
- The group will draw its membership from across Wales, including rural areas, and include some young people who were involved in the Congress, but also other young people. All the equality strands will be given full consideration in conducting the review, and the aim will be for the reference group to be as representative as possible. This will include taking account of the Welsh language, British Sign Language and other forms of communication.
- It is acknowledged that, given its duration, the membership of the reference group may change over the course of the review.
- A professional facilitator will be appointed to assist the Committee in forming the reference group, arranging meetings and ensuring that communication and other needs of the reference group members are met. The facilitator will liaise closely with Members' Research and Committee Services, and Committee Members will also meet informally with the reference group members.
- The reference group will advise the Committee on:
 - The areas on which it should focus its attention
 - What disabled young people think about the service provision and policy issues the Committee is examining
 - Any recommendations emerging from the review
- The group will meet before every formal Committee meeting to discuss the issues that will be examined in the Committee meeting.
- At each formal Committee meeting where evidence is being taken for the review, one or two Members of the reference group will take part. They will provide the Committee with the perspective of the reference group on the issue and be invited to join in the questioning of presenters.

Scope of the Review

Education, training and employment

Reason for inclusion:

- Research suggests that disabled young people feel that they are discriminated against, discouraged and in some cases bullied at school.

- Lack of opportunities can prevent access to further and higher education and ultimately employment.
- Low expectations of teachers and others, affects the self-esteem of young people themselves and frequently reduces life chances.

Issues to note:

The Education and Lifelong Learning Committee is currently conducting a review of Special Education Needs (SEN) provision. The Committee will wish to ensure that the SEN review considers equality issues fully, but it is important not to duplicate this work. It may therefore be sensible for this review to focus on wider issues in schools and higher education, for example:

- Access to the whole school experience - statements only relate to the educational experience
- Disabled young people's experiences of accessing higher education and training
- Preparation for employment - access to a range of good quality work experience, careers advice and advice on rights under the Disability Discrimination Act
- The right to the same range of options as other young people

Leisure

Reason for inclusion:

- There are significant barriers to young disabled people's participation in leisure activities including gaps in suitable provision, lack of choice over activities available, difficulties in going on visits and holidays, lower participation in sports.
- Respite care is intended to provide a break for parents, but this means that the focus is not, necessarily, on how to make the break enjoyable for the child. (This is a particular problem where local authorities may only have a limited number of options available).

Housing

Reason for inclusion:

- The ability to move into your own home is one of the key steps to achieve independence
- Disabled young people have a wide range of housing requirements and it can be difficult to offer genuine choice of provision in many of the rural parts of Wales.
- For all groups there is a lack of suitable housing.

- It can be difficult for disabled young people to access local authority provision via the points system, and private provision is often not accessible.
- The limited range of suitable social housing provision available can lead to feelings of segregation.
- The cost of housing and care packages is seen as a barrier to access.

Transport

Reason for inclusion:

- Hugely significant issue because accessible transport provides independence.
- Problems in accessing public transport, or a lack of flexibility in provision, lead to difficulties in participation in education, employment and a social life.

Equipment

Reason for inclusion:

- Often delays in providing appropriate equipment (such as wheelchairs) for young disabled people.

Access to Information

Reason for inclusion:

- There are problems with access to information for young disabled people, their supporters and professionals that may affect their decision-making. Young disabled people from black and minority ethnic communities may be doubly disadvantaged in this area.
- Disabled young people are often given the information people think they need rather than the information they might want.
- Information may not be in an accessible format.

Transition into adulthood

Reason for inclusion:

- Often a lack of co-ordination and planning between education and social services.
- Replacing caring support provided free of charge by parents with local authority services for which there is a charge leads to a cut in income.

Poverty

Reason for inclusion:

- Parents of disabled children are likely to be poorer than those of non-disabled children, for example because caring responsibilities mean they are much less likely to be in full-time work.
- Poverty of young people themselves, not just child poverty and family poverty, will be examined, as this affects young people's ability to afford independent living.

Annex C

The Committee and its Reference Group – A review

Members of the Committee met with members of the Reference Group to review the process the whole process of the joint working initiative.

Members of the Group were asked:

- 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 from the young people. 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 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.

Members of the Committee believe that these points are worth recording as embodiments of good practice applicable to Committees both within and outside the Assembly.

Annex D

Written evidence

Anglesey County Council

ASBAH

Barnardo's

Blaenau Gwent CBC

Bridgend CBC/LHB/Bro Morgannwg NHS Trust

Cardiff and Vale NHS Trust

Carmarthen / Dinefwr Family Support Team

Carmarthenshire NHS Trust

Catholic Education Service

Ceredigion and Mid Wales NHS Trust

Ceredigion Carers Forum

Ceredigion Family Support Team

Chwarae Teg

City and County of Swansea

City of Cardiff

Community Health Council – Ceredigion

Community Learning, Youth Service, Adult Education Leisure and
Community Centres

Conwy and Denbighshire Trust

Conwy Federation of Community Health Councils

Council for Wales of Voluntary Youth Service

Countyside Council for Wales

Deaf Association Wales

Department for Child Health - Royal Gwent

ELWa

Estyn

Flintshire County Council

Gog Gwynedd Community Health Council

Gwent Healthcare NHS Trust

Gwynedd Council

Higher Education Funding Council for Wales

Merthyr Tydfil Local Health Board

Mid and West Wales ME Group

National Public Health Service

NCH Cymru

Neath Port Talbot County Borough Council

North West Wales NHS Trust

NUT Wales

Powys County Council

Powys Local Health Board

Rhondda Cynon Taff County Borough Council

RNIB Cymru

Royal Welsh College of Music and Drama

Scope Cymru

Skill: National Bureau for Students with Disabilities

Swansea Institute for Higher Education

The Sports Council for Wales

Torfaen County Borough Council

Torfaen Opportunity Group

Triangle

UWIC

Vale of Glamorgan Council

Wrexham County Borough Council

Ynys Mon / Anglesey County Council

Ysgol Gyfun Llanbed

Annex E

Oral evidence

Arfon Access Group

Arriva Trains

British Dyslexics

BusUsers UK in Wales

Careers Wales

Coleg Llandrillo

Conwy County Borough Council

Deputy Minister for Environment, Planning and Countryside

Disability Wales

ELWa

Estyn

Family Planning Association

Flintshire County Borough Council

Mencap Cymru

Minister for Assembly Business, Equalities and Children

Minister for Local Government and Public Services

NUT Cymru

Pembrokeshire County Council

Pontypridd & Rhondda NHS Trust

Remploy Interwork

Scope Cymru

Shaw Trust

Skill: National Bureau for Students with Disabilities

TUC Wales

Welsh Assembly Government official on behalf of the Minister for
Social Justice and Regeneration

Welsh Assembly Government official on behalf of the Minister for
Enterprise, Innovation and Networks

Welsh Local Government Association

Ysgol Hendre, Neath

Annex F

Members of the Disabled Young Peoples Reference Group and their support workers

Facilitators

Tim Ruscoe
Julie Mair Ward

Cyfle – Barnardo’s Cymru

Young Person – Heather Graham
Young person – Hannah Kubler
Young Person – Jessica Roberts

Staff - Gail Banks
Staff - Gareth Edwards
Staff - Glenys Griffiths
Staff - Victoria Parry
Staff – Yvonne Williams

Dynamic

Young Person - Robert Surrey

Staff – Mike Davies
Staff - Samantha Challis
Staff - Ray Clarke
Staff - Carol Gardner
Staff - Craig Harry
Staff - Philippa Horsefall
Staff - Edward Johns
Staff - Marie Shwartz

Viva! Project

Young Person- Keri Haines
Young Person- Richard Harris
Young Person - Gareth Morgans

Staff - Zoe Richards

Young Voices for Choices

Young Person -Amy Barrett
Young Person - Lynsey McCarthy

Staff - Nadine Farmer
Staff - Judith McNamara

Cardiff People First

Young Person -Stacie Edward
Young Person - Richard Horrigan
Young Person - Simon Richards

Staff – Joanna Bond
Staff - Davida Hewlett
Staff - Anna Suschitzky

Mencap

Young Person - Stephen Dyer
Young Person – Scott Randall

Staff - Wayne Crocker
Staff - Sue Edwards
Staff - Dawn Gullis

Interplay

Young Person - Daniel Beynon

Staff - John Thomas