

Health & Social Services Committee HSS-16-01(p.3)

Date: Wednesday 21 November 2001
Venue: Committee Room 3, National Assembly for Wales
Title: Report of the Learning Disability Advisory Group

Purpose

The report of the Learning Disability Advisory Group "Fulfilling the Promises" was issued for consultation on 20 September.

The Committee is invited to comment on the proposals and recommendations in the Advisory Group's report, and in particular those areas highlighted in the consultation letter:

- recommended priorities, targets and performance indicators;
- proposed implementation approach;
- assessment of the workforce implications and their proposals to address these; and
- proposed service principles and service responses.

Committee Secretariat



Cynulliad Cenedlaethol Cymru

The National Assembly for Wales

To : Chief Executives and Directors of Social Services of all local authorities; Chief Executives of Health Authorities and Trusts; all Local Health Groups and other interested organisations

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Eich cyf / Your ref

Ein cyf / Our ref

Dyddiad / Date 20th September 2001

Dear Colleague,

LEARNING DISABILITY ADVISORY GROUP REPORT: CONSULTATION

1. At the end of 1999, the National Assembly established an external Learning Disability Advisory Group to prepare proposals for a framework for services for people with a learning disability. The intention was to give people with learning disabilities, their families and carers a clear picture of the services and support they are entitled to.
2. The Advisory Group's final report entitled "Fulfilling the Promises" was submitted to the National Assembly earlier this summer. The Report covers people from childhood to old age and puts forward proposals for services that include education; training; employment and housing as well as social services and the NHS. A copy of the report is attached.
3. The National Assembly is now seeking comments on the Advisory Group's proposals. The National Assembly has not yet decided whether to adopt any of the proposals contained in the report. The National Assembly has, however, noted that the Advisory Group has acknowledged in their report that there are significant additional resource implications should the Assembly adopt and implement the Advisory Group's proposals. In reaching decisions about whether to adopt the Advisory Group's proposals, the National Assembly will consider any additional financial requirements alongside other demands for Assembly funding as part of the Assembly's budget planning process.
4. The National Assembly invites comments on the Advisory Group's report but in particular on the Group's:
 - recommended priorities, targets and performance indicators;
 - proposed implementation approach;

 - assessment of the workforce implications and their proposals to address these; and
 - proposed service principles and service responses.
5. In addition, the Advisory Group, in submitting their report to the National Assembly, have recommended that any guidance to Social Services, issued by the National Assembly in response to the proposals in their report, should be issued under Section 7 of the Local Authority Social Services Act 1970 with equivalent 'status' being given to any Assembly guidance issued to other services e.g. housing, education and health. The National Assembly invites comments on this suggested approach.
6. Accessible versions of the Advisory Group's report in text, CD and audio formats are available and enquiries should be addressed to Alyson Collins. The Advisory Group's report is also available on the National Assembly's website www.wales.gov.uk
7. The deadline for receiving responses is Friday, 18th January 2002 – responses received after this date will not be considered. Responses, and any queries, should be addressed to Alyson Collins, Social Care Policy Division, National Assembly for Wales, Cathays Park, Cardiff CF10 3NQ (tel. 02920 825441 or E mail Alyson.Collins@Wales.gsi.gov.uk). In line with the National Assembly's policy on open government, your responses may be made publicly available. Please state clearly if you would wish us to anonymise your contribution.

Yours sincerely,

M J Shanahan

Head of Social Care

Policy Division

Learning Disability Advisory Group

Report to the National Assembly for Wales

"Fulfilling the Promises"

Proposals for a framework for services for people with learning disabilities

June 2001

Preface

The Learning Disability Advisory Group was established by the National Assembly for Wales to prepare a draft service framework for people with learning disabilities. The Advisory Group first met in December 1999 and concluded that the service framework should cover services for children, adults and older people and should encompass all aspects of a person's life including: education, training and development including lifeskills and lifelong learning, accommodation, leisure and work as well as the more usual services from social services departments and the National Health Service.

In undertaking its work, the Advisory Group has sought to ensure that the views and hopes of people with learning disabilities and their families and carers have been taken fully into account. This has been done through three main strands:

- by including representatives from People First Wales, the All Wales Forum of Parents and Carers, SCOVO and Mencap Cymru as members of the Advisory Group;
- by taking fully into account the findings and outcomes from the stakeholders conference report "Moving Forward to a Better Future: Conference Report and Agenda for Action"; and
- by establishing focus groups across Wales comprising people with learning disabilities and their families and carers initially to seek their ideas about what should be included in the service framework and then to consider whether our draft proposals reflected their needs.

The Advisory Group's report to the National Assembly has five main sections:

- the first section contains the Advisory Group's guiding principles; our vision for services for 2010; our recommended priorities, targets and performance indicators; our proposed Action Plan approach to implementation and our initial assessment of the financial implications;
- the second section sets the context of our work including the National Assembly's and Advisory Group's vision for people and services in Wales and the policy context in which we have developed our proposals;
- the third section is an assessment of the progress in the development of services since the Welsh Mental Handicap Strategy was launched in 1983;
- the fourth section looks at the population changes that will influence services and service development over the coming years; and
- the fifth section are our detailed proposals for the framework for services;

A summary of this report is attached as Annex B.

The Advisory Group wishes to thank the many other individuals who contributed to the work of its sub groups, other organisations that wrote to convey their views/ideas and the National Assembly for providing the secretariat support.

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Section One

1.1 Principles

"Disabled people, whatever their origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible."

United Nations (1975) The Declaration on the Rights of Disabled Persons

First published in 1983, the All Wales Mental Handicap Strategy sought to enable people with learning disabilities to enjoy the full range of life opportunities and choices, to have positive identities and roles in their families and communities, to exercise choice and to develop independence, self respect and self fulfilment. It established the rights of people with learning disabilities to normal patterns of life within the community, to be treated as individuals, and to receive additional help and support from the communities in which they live and from professional services in developing their maximum potential.

The Learning Disability Advisory Group endorses the continued relevance of the Strategy's aims and guiding principles particularly as these can now be seen as a specific expression of the vision recently set out by the National Assembly in Better Wales. The National Assembly want Wales to be a place where its citizens:

- are united, confident and creative
- are committed to fostering its unique and diverse identity, and the benefits of bilingualism, while looking confidently outwards and welcoming new cultural influences,
- are prosperous, well-educated, skilled, healthy, environmentally and culturally rich,
- are active in local communities, where the voice of local people is heard
- are treated fairly, while everyone is valued and given an opportunity to play a full part
- want to live, work and enjoy a high quality of life, and
- are served by modern, effective, efficient and accessible public services.

The Advisory Group welcomes, and shares, the National Assembly's core values set out in Better Wales for social inclusion, equality of opportunity and the promotion of a tolerant society, within which diversity is valued.

The Advisory Group believes that it is a sign of the progress made in the last twenty years that the vision for people with learning disabilities can now be understood in terms of their right to be included in the general hopes of society as a whole. In this respect, we now have a clearer view as to what inclusion and equality of opportunity means to people who may be excluded. In the inclusive society envisaged in Better Wales, the aspiration for a decent quality of life, and all that follows for progression through life and experience of its full richness, is recognised for each and every citizen. The Advisory Group equally believes that people with learning disabilities need to be empowered and (where appropriate) supported to face the challenges and the disappointments of day to day living.

In putting forward our proposals, the Advisory Group has sought to achieve positive outcomes across a range of human concerns. Achieving the best quality of life across all these human concerns should be the aim of us all.

In seeking to support and add to the AWS principles in line with the vision set out in Better Wales, and in recognition of the current concern with quality of life issues, the Learning Disability Advisory Group commend the following principles that people with learning disabilities:

- are full citizens equal in status and value to other citizens of the same age
- have an equal right to expect a high quality of life - in practice this means having exactly the same expectations of decent health, education, housing, safety and financial security, protection from harm, positive social relations and roles within family and community, employment opportunities, personal development, emotional well-being and civic rights
- have a right to decide for themselves and to join in all decision-making which affects their lives, with support if necessary
- have access to the support of their families and the communities, of which they are a part, and to general and specialist public services to improve their chosen quality of life.

1.2 The Advisory Group's Vision for services in 2010

The 1983 All Wales Strategy and the updated 1994 Guidance, set out proposals for the development of services consistent with the principles which underpinned the Strategy and the aim to improve the quality of lives for people with learning disabilities, their carers and families. The process of service development is far from finished. The Advisory Group wants to see the continuation and hopefully the acceleration of that development until all people with learning disabilities receive services which are modern, flexible, appropriate to their needs and circumstances and accessible.

All services must aim to secure the inclusion of people with learning disabilities. Everyone should have appropriate support to allow them to take their place in their communities.

There is a need for clear direction from the National Assembly to bring service support throughout Wales up to similarly high standards. The National Assembly's Better Wales document sets a deadline of 2010 for the achievement of its vision and objectives. The Advisory Group's vision for 2010 is that by that time services for people with learning disabilities in Wales will:

- provide comprehensive and integrated services that will effectively support and enable people to achieve social inclusion in all aspects of life and society in Wales
- be person centred (i.e. respond to individual needs, including language, race, gender and religious requirements and circumstances)
- improve empowerment and independence, with the individual having the maximum possible control of their lives
- ensure effortless and effective movements between services and organisations at different times of life (individuals and services should be properly prepared in advance for these movements)
- be holistic in approach and delivery taking fully into account an individual's preferences, hopes and lifestyle.
- ensure that a range of appropriate advocacy services is available for people who wish to use them
- be accessible - in terms of both service users and their carers and families having full information about availability and service users receive services as close to their home as possible.
- have fully developed collaborative partnerships to deliver flexible services, which are able to respond appropriately and quickly to the changing needs of users.
- be developed on evidence of their effectiveness and transparency about their costs
- be delivered by a competent, well-informed, well-trained and effectively supported and supervised workforce.

Underlying this 2010 vision for services is the necessity for people living inappropriately in long stay learning disability hospitals to have been resettled into the community. The Advisory Group believes that without the early completion of the National Assembly's resettlement programmes to enable all people to return to live in the community, Wales cannot claim to be a country where every person is valued and given an opportunity to play a full part.

1.3 The Advisory Group's recommended priorities, targets and performance indicators

After careful consideration the Advisory Group has agreed 17 priorities for action by the National Assembly and others. These are not ranked priorities as all must be progressed in parallel. Without the full and effective implementation of these priorities, the Advisory Group does not believe that its vision for services in 2010 will be achieved. The priorities, targets and performance indicators are set out in the following paragraphs. The targets are those that will apply to all authorities and provide a measure of progress made in the implementation of the priorities across Wales. The performance indicators provide the National Assembly and authorities and other stakeholders with a structured, systematic and comparative framework for the measurement of local progress on the implementation of more specific aspects of service change and development.

A. Policy Direction

The principles of the 1983 All Wales Strategy have commanded broad support. The aims of the AWS remain entirely

consistent with policy developed since that time, as confirmed in Better Wales and other key documents. The Advisory Group do not consider that there is a need to change policy direction but rather to reinforce it.

The National Assembly should reaffirm its commitment to develop the means to extend to all people with learning disabilities in Wales the opportunity to lead a life consistent with the AWS and this Report.

Local authority elected members, members of Health Boards and Local Health Groups and senior managers in authorities should promote and introduce policies to achieve the aims and targets of this Report.

Target

By Spring 2002, all Authorities will have reviewed their services against the 'Service Principles' and 'Service Responses' set out in Section 5 of this report.

B. Funding

The Advisory Group is keen to emphasise the link between policy aims, their implementation and financial realities. The previous AWS set out a potential 40-year investment programme aimed at both reform and growth of services. Further considerable additional investment will be required to meet demographic changes and the proposals in this Report.

The National Assembly should consider introducing a structured investment programme to increase and develop service availability in line with this Report.

Target:

By July 2002, all Authorities will have prepared Health and Social Care Plans, which include costed 5-year projections of needs, targets, and service developments for people with learning disabilities.

Performance Indicator:

The amount spent by Authorities on services for people with learning disabilities as expressed as a rate per head of the (16-64) population.

C. Completion of Existing Programmes of Reform

The Advisory Group agrees with the priority placed by the National Assembly on the long stay hospital closure programme and the re-provisioning of services to achieve this. We also commend the central planning and funding role of the Assembly in resettling people into the community and securing the closures.

The National Assembly should review its commitment to achieve the closure of long stay hospitals and set a new target date for completion of 2006 or preferably earlier. It should also extend the scope of this initiative to include other inappropriate accommodation settings.

Target:

By 2006 all resettlement programmes should be completed and all long-term hospitals should be closed. By 2010, other inappropriate accommodation should be phased out.

D. Individual Planning (Person Centred Planning)

People with learning disabilities tend to be lifelong consumers of health, social care education, housing and other support services. Person centred planning should be confirmed as the key mechanism to plan people's care and support for their whole lifetime.

The National Assembly should confirm that person centred planning is fundamental to addressing individual needs and aspirations. The cornerstone should be multi-disciplinary and multi-agency Community Learning Disability Teams and the National Assembly should promote this approach. The National Assembly should consider how to meet any additional resource requirements within its larger investment programme.

The National Assembly should review the requirements placed on local authorities in relation to social care and educational planning for individuals and consider whether a more coherent approach could be adopted.

Target:

By 2003/2004, all people with a learning disability will have an individual person centred plan, normally reviewed annually.

Performance Indicator:

The number of people whose plan has been reviewed expressed as a percentage of the number of people with learning disabilities known to the Authority.

Performance Indicator

The number of people with learning disabilities receiving a written statement of their needs and how they will be met (NAWPI 3.9)

E. Independent Assessment of the Needs of Carers

The Advisory Group recommends that these parallel but separate assessments should adopt best practice standards similar to those proposed for Individual Planning.

The National Assembly should invite the Carers Strategy Review Panel to consider best practice standards, training requirements and resource implications of separately assessing carers needs and to respond appropriately within its National Carers Strategy.

Target:

By 2001/2002 independent carers assessments will be available as of right.

Performance Indicator:

The number of carers assessments expressed as a percentage of the number of people with learning disabilities helped to live at home.

F. Information

The Advisory Group believes that service users and carers should have good quality and accessible information on the help and support that is available and on their rights to participation in service planning. Consideration will need to be given to information that should be made available on a national level and that expected to be provided locally.

The National Assembly should commission research to identify best practice in respect of the collection, provision, sharing and dissemination of information. The National Assembly should consider what information could appropriately be provided on a national level across Wales.

Target:

By 2002/2003 all Health and Social Care Plans and Annual Statements/Reviews for services for all people with learning disabilities will include the programme of public information about services and service developments

Target:

By 2002/2003 arrangements will have been made to ensure local and national information is widely available to all people with learning disabilities, their parents and carers using all appropriate formats.

G. Advocacy

There are no precise estimates of supply and demand for advocacy. Consultation exercises indicate that advocacy services are inadequate to meet demand.

The National Assembly should evaluate how a centrally funded advocacy service can be developed and regulated on a national basis. These services should include citizen advocacy, self-advocacy and paid advocacy. Any evaluation should take full account of the UK Government's response to the advocacy section of the Disability Rights Task Force report.

Target:

By 2002/2003, the National Assembly will have completed its evaluation and be consulting on proposals to introduce a national centrally funded advocacy service.

H. Partnership in Planning

It is recognised that effective joint agency planning is important but such arrangements must also include service users, parents, carers and other interested organisations including service providers. This will be of particular significance when addressing low incidence needs.

The Advisory Group believes that the local authority via its Social Services function should continue to be the lead authority and should recognise the importance of effective strategic planning for learning disabilities services.

The National Assembly should reaffirm the lead role of the local authority Social Services function and make available further resources to facilitate implementation of the increased flexibilities under the Health Act 1999.

The National Assembly should ensure that national guidance requires authorities to constructively include users and others in the planning and development of services. Agencies should agree protocols for joint working and the National Assembly should facilitate the pooling of resources between agencies to remove the financial incentive accompanying the redefinition of responsibility from one agency to another.

The National Assembly should introduce a financial and management information framework with standard definitions, for authorities to collect, collate and distribute data on capacity, usage and expenditure on all learning

disability services.

Target:

By 2003/2004, authorities will have published plans to improve the joint working of health, social services and other agencies including the use of pooled budgets, integrated provision and lead commissioning of services and facilities.

I. Children and Families

The Advisory Group believes that children with learning disabilities have a right to normal childhood experiences. This includes both equality of access to pre-school and later provision with the opportunity for additional support when required.

The National Assembly should invite services and education bodies to review the availability of:

- **effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour**
- **effective ways of supporting and encouraging integration in general pre-school and later provision**

Services and education bodies should then develop an action plan to make effective services and supports generally available.

Target:

By 2003/2004, Childrens Services Plans should promote equal opportunities and inclusion and indicate how local agencies and partner agencies propose to develop community based support strategies to enable younger people with learning disabilities to be included in mainstream activities as much as possible.

Performance indicator:

The percentage of cases of children with learning disabilities with an allocated social worker who are providing a service appropriate to the child's needs expressed as a percentage of all children with learning disabilities (P/A).

J. Education and Life Long Learning.

The Advisory Group believes that every person should benefit from an education that enables them to develop their maximum potential alongside non-disabled children and provide life long learning opportunities.

The National Assembly should :

- **Develop educational and life long learning policies which encourage arrangements consistent with inclusion**
- **Provide the resources to provide appropriate additional educational support to those with special needs**
- **Ensure that all teachers and teaching assistants receive appropriate training to effectively support learning and the development of people with learning disabilities**

Target:

In 2004 to have significantly improved the quality of education for children with special needs by completing the three-year action plan and the introduction of a new Special Educational Needs Code of Practice.

Performance Indicator:

The number of children educated in special schools as a rate per 1000 of the school population for the local area.

K. Community Living - Help in the Family home.

Significant increases in the number of families receiving help in the home and an increase in short term breaks have been real achievements of the AWS. The Advisory Group does, however, consider that service availability is still likely to be below that required to meet need.

The National Assembly should through its Carers Special Grant and other policies encourage authorities to make available a range and sufficient quantity of flexible support services and positive options for short term breaks.

Target:

By 2005, there should be a significant increase in the range and quantity of flexible support services and positive options for short term breaks.

Performance Indicator:

The number of people with learning disabilities whom the local authority helps to live at home expressed as a percentage of those with learning disability known to the local authority. (P/A)

Performance Indicator:

The number of nights of short-term care received by people with learning disability expressed as a percentage of the number of people with learning disabilities the authority helps to live at home.

L. Community Living – Support to Live Independently.

The Advisory Group considers that there has been no significant expansion of residential supports to promote and develop independence. We believe that a considerable expansion of service availability will be required. Effective planning and significant financial investment will be needed.

The National Assembly should make available additional resources to significantly increase the number of people who are able to access appropriate accommodation away from the family home.

Target:

By 2010, to have significantly increased the number of people who can realistically be expected to live independently with appropriate support irrespective of age or impairment - by 2010 this will require at least an additional 1,500 people with learning disabilities to be supported outside of the family home.

Performance Indicator

The unit cost of residential and nursing care for adults with learning disabilities (NAWPI 3.6)

Performance Indicator:

The number of people with learning disability living independently in the community as a percentage of all those with learning disabilities known to the local authority.

L(i). Direct Payments.

The Advisory Group acknowledges the importance of the Direct Payments Scheme in promoting independence and helping people to take control of their lives.

The National Assembly should consider changing the existing arrangements to enable local authority services to be encompassed in the Direct Payments Scheme.

Local authorities should design schemes to be accessible to people with learning disabilities and provide the right support to help them to manage a direct payment and remain in control

Target

By 2003, all local authorities are operating an appropriate direct payments scheme for people with learning disabilities.

Performance Indicator:

The number of people with learning disabilities receiving direct payments as a percentage of those receiving community based services.

M. Community Living- People with Complex and Challenging Needs

People with complex or challenging needs can be supported to live in ordinary accommodation in the community as long as extra facilities, support and professional inputs are planned and made available.

The National Assembly should ensure that authorities use their strategic planning processes to:

- **Provide up-to-date estimates of the accommodation and support needs of people with complex or challenging needs.**
- **Ensure carers are assisted to develop appropriate skills and have access to staff with specialist expertise who can assess complex needs and provide advice and support**
- **Develop plans to increase the availability of intensive rehabilitation services so that people in need of 'low security' can be placed within Wales.**

Target

By 2008, the number of people with learning disabilities accommodated in specialist facilities outside of Wales should be reduced by 50%.

By 2003, community facilities and intensive rehabilitation services to support people with complex or challenging needs must be an integral part of re-provisioning plans following the closure of existing long stay hospitals.

Performance indicator

The number of people with learning disabilities accommodated outside of Wales in specialist facilities.

N. Community Living - Day Activities.

The Advisory Group believes that priority in this area must be given to helping more adults with learning disabilities gain paid employment or to participate in meaningful day time activities including opportunities provided by local community consortia for education and training.

Currently, social security benefit regulations constrain the extent to which people with learning disabilities take up paid employment.

The National Assembly should set targets for the expansion of supported employment and supports for other socially integrative and educational and training opportunities.

The National Assembly should discuss with the UK Government how social security impediments to paid employment can be removed.

Target:

By 2004/2005 to have opened up opportunities for all people with learning disabilities by encouraging lifelong learning opportunities, more flexible ways of formal and informal learning, increasing the access to quality careers advice and supported employment.

Performance Indicator:

The gross expenditure on day services for people with learning disabilities as a percentage of all expenditure on non-residential services for people with learning disabilities.

Performance Indicator:

The number of adults with learning disabilities receiving college/educational opportunities as a proportion of all people with learning disabilities known to the authority.

Performance Indicator:

The number of adults with learning disabilities in supported employment schemes as a proportion of all people with learning disabilities known to the authority.

Performance Indicator:

The number of people with learning disabilities in work as a proportion of those with learning disabilities known to the authority.

O. Health

There is strong evidence to show that people with learning disabilities have poorer general health and more specific health needs than the general population. The Advisory Group believes that the overall health of people with learning disabilities can be improved with better access to ordinary services.

The National Assembly should make resources available to enable every GP to adopt the proactive identification and health checking recommendations contained in this Report.

Target:

By 2010, to have improved the health of people with learning disability and reduced any differences between the rates of illness and mortality experienced by them and overall national rates.

P. The Workforce

People with a learning disability when using any service should be able to rely on a workforce that is appropriately qualified, well trained, effectively supported and managed and properly regulated.

The National Assembly should extend the qualification regime and targets to include all the social care workforce and set complementary targets for the training of the NHS workforce as part of its Human Resources Strategy.

Target:

By 2005, to have all social care managers and 50 percent of the social care workforce providing services to people with learning disabilities with a listed qualification.

Target:

By 2005, the training of doctors, dentists, opticians other NHS staff, housing and benefit agency staff, teachers and the police to include an element that helps them to have a better understanding of learning disability issues.

Performance Indicator:

The number of social care managers with a listed qualification as a percentage of social care managers responsible for services to people with learning disabilities.

Performance Indicator:

The number of social care staff (excluding managers) with a listed qualification as a percentage of all social care staff working with people with learning disabilities.

1.4 Implementing the Advisory Group's proposals - an Action Plan approach

The Advisory Group considers that the most effective way of implementing our priorities and other proposals in this Report and to enable the National Assembly to make informed investment decisions and monitor progress would be to use an Action Plan approach. This would require the National Assembly to provide any additional resources to local authorities as a central direct grant rather than through the Revenue Support Grant mechanism. For health and education bodies an appropriate ring fenced funding arrangement would also have to be used.

The Action Plan would have to cover a long time period and therefore has to be organic and dynamic. A possible timetable for the first five years of the Action Plan is set out below:

Spring 2002

All authorities to have prepared, consulted upon and completed an audit of their services to people with a learning disability. It will include:

- A projection of the number of people with learning disability living in the area up to 2010
- An appraisal of their services against the 'Service Principles' and 'Service Responses' set out in Section 5 of this Report
- Broadly costed 5 year projections of needs, targets, and service developments
- Costed priorities for investment within the 5-year projection.

This Audit will form the basis of any request for investment in learning disability services to be made to the National Assembly.

The National Assembly to have established monitoring arrangements to advise on the implementation of the service principles, targets and performance indicators set out in the Advisory Group's Report.

Summer 2002

All Authorities will submit to the National Assembly their Health and Social Care Plans including statements about the development of services to people with learning disability which will form the request for National Assembly grant resources for investments in learning disability services.

Authorities will have produced their Second Round Education Strategic plans and their Childrens Services Plans will be published stating how they will promote equal opportunities and inclusion for children.

2002/2003

Authorities will have reviewed their three-year education action plans and the implementation of the revised Special Education Needs Code of Practice.

Authorities will have developed, consulted upon and published their joint health and social services arrangements for the provision of services to people with learning disability.

The National Assembly will have completed its evaluation and be consulting on proposals to introduce a national centrally funded advocacy service across Wales.

All SSIW Inspections and Joint Reviews will use the 'Service Principles' and 'Service Responses' as a basis for evaluating services for people with learning disabilities,

2003/2004

The programme of learning disability performance indicators will have been considered by all the agencies involved and implementation, collection and publication arrangements agreed.

The National Assembly commences the rollout of the centrally funded advocacy services across Wales.

The final re-provisioning plans for the closure of existing long stay hospitals are completed and authorities submit to the National Assembly and publish their first implementation progress report on changes to community based services for people with learning disabilities

2004/2005

Authorities submit to the National Assembly and publish their second implementation progress report on changes to community based services for people with learning disabilities

2005/2006

Authorities submit to the National Assembly and publish their third implementation progress report on changes to community based services for people with learning disabilities

2006

All hospital resettlement programmes completed and the long-stay learning disability hospitals are closed.

The National Assembly undertakes a full review of progress achieved across Wales and identifies any specific actions/ approaches necessary to secure the 2010 vision of services set out in this Report.

1.5 Workforce Training

People who use health and social care services in Wales should be able to rely on a workforce that is appropriately qualified, well trained and properly regulated. It is also essential that those who work in health and social care settings are effectively supported and receive recognition for the important work they do.

Key challenges facing the Learning Disability workforce.

Learning disability services at present face the following challenges:

- The achievement of the objectives of this Report when associated with changing demographic factors have brought about the need for changed patterns of service delivery and for a workforce with a diversity of skills and competencies.
- Staff in health and social care settings need, between them, to have a full range of skills which can be brought together to provide a seamless and comprehensive treatment, care and support service. Staff need to :
 - know both their own roles and the roles of others; and
- be confident in working in multi – professional teams and across agency boundaries.

Good joint working is essential at all levels of health and social care organisations to meet the needs of people with learning disabilities. The option of making use of the increased flexibilities, introduced by the Health Act 1999, makes it all the more important that the whole workforce has common values and standards. Training and qualifications enable staff to transfer from employment in one sector to the other where this promotes good and efficient practice.

Recruitment and retention of good quality staff is a fundamental issue for this sector. The social care workforce in Wales is predominantly made up of people over 35 and on the whole is not attracting younger people. The work, though rewarding, can be stressful and challenging and some of the hours anti-social. It is therefore essential that good working conditions, effective training and supervision and adequate reward are available to staff so that they feel supported and valued. Authorities should take into account in their contracting arrangements the resource implications of ensuring a properly trained workforce.

The difficulty of recruitment and retention of a range of clinical professionals including speech and language therapists, physiotherapists and clinical psychologists is a particular issue for community based teams across Wales.

To work effectively with people with learning disabilities staff in education or social care settings will require knowledge and training in dealing with some clinical procedures e.g. administration of medication. The initial and ongoing training and monitoring aspects of this need to be integral to the work programmes of relevant staff. Protocols should be developed between the authorities to govern local practice, and implications for staff such as insurance and accountability, should be properly addressed to safeguard both trainers and trainees.

As well as delivering services directly, the training of staff with specialist skills, knowledge and experience of working with people with learning disabilities should help to develop a better understanding of people with learning disabilities and their needs among other professionals such as doctors, dentists, opticians and other NHS staff, housing and benefit agencies, teachers and the police.

Developing the workforce

The Human Resource Strategy for NHS Wales, *Delivering for Patients*, aims to promote and support the delivery of high quality services in Wales. A comprehensive workforce planning process, supported by a new computer based system will be introduced for the NHS in Wales. Shortages and trends will be monitored, targets set to reduce turnover and improve retention rates and NHS Wales together with higher education institutions will enable people to access the professional education they need.

The Welsh NHS plan makes a commitment to extend the workforce and to increase the number of people in training in health-related fields. By 2004 there will be 1,360 more students on such courses than there are in 2001.

Over 60,000 people are employed in social care in Wales, many work in the private or voluntary sectors. Of these over 80% do not have the qualifications they need for the job they do. Estimates indicate that if annual expansion in this sector continues at its current rate approximately 2,000 new staff will be needed every year until 2006.

The Care Standards Act 2000 provides for the establishment of The Care Council for Wales on 1 October 2001. The main functions of this new body will be:

- to regulate the social care workforce in Wales through the registration of the individuals who make up the workforce.
- to drive up levels of training and qualifications
- to improve standards in social care through codes of conduct and practice for employees and employers.

The new Council will take over the task of regulating social work training, currently undertaken by the UK-wide Central Council for Training and Education in Social Work (CCETSW), and it will take over the functions in Wales of the National Training Organisation for Social Care (TOPSS). It is expected that TOPSS will produce a draft National Training Strategy in the summer of 2002.

The Training Support Programme (TSP) for the personal social services in Wales has the objective of increasing the proportion of staff with the specific qualifications, skills and knowledge they need for the work they do. The following targets are already in place for learning disability services and further targets will be set in the future.

Service	Staff	Proportion with a listed qualification	By 30 Sept
Residential care	Officer in charge	80%	2003
Residential care	Care officer /assistant	40%	2003

The Advisory Group endorses the target setting approach set out in the Assembly's TSP circular but believes that the targets should be more challenging than those proposed. The Advisory Group also believes that the Assembly should set further robust targets to ensure that our recommendations set out in this report are effectively implemented. The Group's proposals are that;

- the qualification regime and targets should be extended to include all the social care workforce;
- all social care managers should have a recognised qualification by 2005;
- by 2005 a minimum of 50% of the social care workforce should attain NVQ level 2; and
- the Human Resource Strategy for the NHS in Wales should set complementary targets for the training of its workforce

Involving service users and carers in training.

The direct involvement of service users and carers in training is currently too patchy. Such personal involvement helps front line staff and managers to understand the needs, aspirations and expectations of service users and their families/carers and how best to meet these. The Advisory Group believes that the National Assembly should positively encourage authorities to enable service users to play an effective role in the design and delivery of training.

1.6 Financial Implications

Firm and detailed costs for implementing the priorities and other proposals in this Report will not be known until the Summer of 2002 when all authorities have undertaken their audit of existing services and submitted to the National Assembly their costed priorities for the development of their services. That there will be significant additional resource implications cannot be denied, but the Advisory Group does not accept that this provides any substantive reason for the National Assembly and other authorities to shy away from addressing the issues raised in this Report. Authorities can absorb some of these costs by investing existing resources differently. But this re-investment of resources will not be sufficient to achieve the full vision of services set out in this Report.

The Advisory Group considers that the capital and revenue resource requirements to provide and sustain independent living for an additional 1,500 people by 2010 and to implement our other services development proposals for the NHS and local authorities will require an incremental new investment approach. The Advisory Group estimates that the National Assembly will need to provide at least an additional £20 million to be invested in 2003-04 rising cumulatively to £40 million in 2004-05 and £60 million in 2004-05. These investment figures will continue to rise in each year from 2005-06 to 2010. Only with such levels of new investment will the Group's vision for services in 2010 be attained.

Section Two

2. The National Assembly for Wales' and Advisory Group's Vision

2.1 The National Assembly for Wales : Better Wales

The Advisory Group has worked within the context of the National Assembly's vision set out in its Better Wales document which was issued in March 2000 and in the light of other related policy strategies including the Social Services White Paper 'Building for the Future' and 'Putting Patients First'. These Assembly strategies seek to ensure that Wales is served by modern, accountable, effective, efficient, appropriate, responsive, flexible, user centred, safe and accessible public services. That the voice of local people is heard and everyone is valued and given an opportunity to play a full part. The Assembly also emphasises that to achieve its policy objectives in the health and social care fields, agencies must work together in an effective partnership to provide wherever possible joined-up services.

The National Assembly's Better Wales sets out several themes that will influence the way in which the Assembly intends to develop its policies, budgets and programmes over coming years. These are :

- **Tackling social disadvantage** - the development of an inclusive society where everyone has the chance to fulfil their potential;
- **Equal opportunities** - the promotion of a culture in which diversity is valued and equality of opportunity a reality; and
- **Sustainable development** – meeting the needs of the present without compromising the ability of future generations to meet their own.

In October 2000, the National Assembly published Putting Wales First : A Partnership for the People of Wales. This first partnership agreement of the National Assembly committed the Partnership Government to the three guiding themes of Better Wales

2.2 The Advisory Group

In taking forward our work and in putting our proposals, the Advisory Group are seeking to ensure that people with a learning disability should enjoy as full a range of life opportunities and choices as their families, friends and other people living in the community. They should be empowered and enabled to play their full part in the community and should not be devalued because of their intellectual disabilities. Help in making opportunities and providing the kind of choices that make for a full life is not only the concern and responsibility of professionals but of everyone. The role of professionals should be to guide, to counsel and to encourage as well as to provide appropriate direct services.

It is not enough to provide services and to promote the integration of people with learning disabilities in their communities unless these efforts help to develop independence and self-fulfilment. There is not one answer or single model of service that can be prescribed for all the needs of people with learning disabilities. Each individual has different needs, capabilities and hopes which need to be identified and which must guide the efforts of service providers. Care must be primarily a way of encouraging development and widening opportunities for a fuller life, which must also involve a degree of adventure. Service providers will need the active guidance and support of their employing authorities to establish an approach to the needs of people with learning disabilities which emphasises their development and quality of life and which enables them to encounter and overcome the ordinary hazards of day to day life without being overly-protected.

The Advisory Group believes that there must be equity in provision of and access to services for people with learning disabilities wherever they live in Wales. The Advisory Group also believes that services should be designed to meet the identified needs of individuals. Access to services should not be restricted because of other existing health problems or because of an individual's age, ethnic origin, gender, culture, religion or sexuality.

This will require services for people with learning disabilities to be appropriate, flexible and responsive. Planners and commissioners of services should encourage and accept the involvement of users, their families and carers in the planning, development, delivery and monitoring of services.

The Policy Context

2.3 The All Wales Mental Handicap Strategy

Services for people with learning disabilities have been developing for nearly twenty years following the 1983 All Wales Strategy for the Development of Services for Mentally Handicapped People and updated 1994 Welsh Mental Handicap Strategy Guidance. This Strategy and Guidance are still in force to this day. The Advisory Group firmly believes that the three main principles that underpin this strategic approach remain valid today and for the future. These principles are that

people with learning disabilities have:

- the right to an ordinary pattern of life within the community
- the right to be treated as an individual
- the right to additional help and support in developing their maximum potential.

The 1994 Strategy Guidance has at its heart the need for each person with a learning disability to have an individual and dynamic plan co-ordinating care throughout their life which properly reflects their needs and choices. The Strategy Guidance also says:

"The dignity and self respect of individuals often depends on their ability to make everyday decisions and to feel that they are not only consulted but that they are listened to before decisions are made for them. Good quality care must not only meet the needs of the people it supports, but must also reflect their wishes and preferences."

These statements remain equally true today and we have sought to breathe life into this approach in drawing up our proposals.

2.4 Social Services White Paper : "Building for the Future"

This White Paper was issued in March 1999 and sets out the National Assembly's vision for modernised and revitalised social services. It is based on five key principles:

- to promote an inclusive society
- to support and promote effective social services providing Best Value on a fair and consistent basis for those who need them
- to provide support for those who need it in a safe environment which preserves dignity
- to encourage and support those who can do so to build their independence
- to promote the continued development of a high quality workforce

The Advisory Group fully endorses these principles and we have sought to apply them in preparing our proposals.

2.5 'Putting Patients First'

This document sets out how the NHS Wales is to be rebuilt with all parts focused on and expected to contribute to the achievement of seven core values. These are :

Fairness – patients should have access to treatment and services according to their clinical needs

Effectiveness – treatments should reflect the most up-to-date scientific evidence and clinical practice

Efficiency – NHS Wales should achieve best value in its use of resources

Responsiveness – services should be designed with the individual patient's needs in mind

Integration – NHS Wales and other organisations should work together to deliver integrated packages of care for patients

Accountability – NHS Wales should be more accountable to people

Flexibility – services should be flexible enough to meet local needs, while also delivering wider improvements in health.

The Advisory Group's proposals will support the achievement of these core values.

2.6 Education

The National Assembly through its Action Programme for Special Educational Needs is seeking to strengthen and improve the support and advice made available for children with special educational needs and their parents and carers; give them a greater involvement in the decision making surrounding that support; and strengthen the arrangements for planning the transition of young people with special educational needs to further or higher education and adult life.

Our proposals are consistent with and complement these Assembly policy developments.

2.7 Partnership

Delivering co-ordinated packages of care to individuals is central to the National Assembly's Better Wales and the more specific proposals being put in place as part of the Social Services White Paper and Putting Patients First. To achieve this requires an effective partnership approach.

Local Authorities have a crucial and important role in driving forward in a corporate way the social services, education, housing, leisure and social inclusion agendas that are cornerstones of learning disability policies. More needs to be made of these new agendas and the opportunities that increased flexibilities will bring to enable traditional and new partners to create innovative models and approaches to the development of learning disability services and the systems that support them. It is also about good government, using resources wisely and efficiently, and by listening to users, their families and carers to provide services that meet peoples needs, wishes and hopes. Local authorities will also play an important part in the achievement of quality and equity in the delivery of learning disability services through their community care and social care responsibilities. Through the planning process of social care they must take account of the health and other needs and aspirations of people with learning disabilities and their carers. This approach needs to be supported and developed in order that meaningful participation and involvement in the planning and running of services leads to a fuller empowerment of service users, their carers and families

The NHS, the voluntary and independent sectors will all have critical roles to play in this partnership. All parties involved must be sure that there is a seamless approach to meeting the needs and hopes of people with learning disabilities. There must be a high level of commitment from the organisations and individuals to ensure the partnership works effectively for the benefit of people with learning disabilities. The role of all those involved in the partnership must be valued and their contributions must be properly and fully taken into account.

2.8 The National Assembly's Programme of Reform

The National Assembly is presently taking forward a substantial programme of reform that puts people and their improved health and well being at the forefront of their activities. This includes :-

- introducing new "flexibilities" for funding and commissioning to create the right climate to maximise the benefit of collaboration between health and social care agencies for the benefit of the user
- the implementation of "Improving Health in Wales"
- the development of a NHS user and public empowerment strategy
- developing a new Health and Social Care Charter which will set out key national standards which reflect best practice across health and social care services
- reviewing the NHS complaints procedure to see if it can be made more open, more objective and more responsive to patients
- the development of a Carers Strategy to improve the long term health and well being of carers and those for whom they care, including a right to assessment for respite needs

- the proposed amendments to the Mental Health Act legislation and the proposals for updating the Welsh Adult Mental Health Strategy and introducing a new Children and Adolescent Mental Health Strategy
- the proposed changes included in the Supporting People programme
- the implementation in Wales of the Government's response to the Royal Commission on Long Term Care
- the establishment of the Care Council for Wales and the Care Standards Inspectorate for Wales who will be responsible for raising professional standards for the social care workforce; protecting vulnerable people from abuse and neglect and promoting the highest standards of quality of care that people receive, whoever is providing it to them.
- the implementation of the 'Children First' programme.

2.9 Contribution to achieving Better Wales objectives

We consider that our proposals will help achieve many of the key National Assembly's objectives as set out in Better Wales, in particular, to:

- ensure that the needs of disadvantaged groups are better met by involving patients, users, carers and voluntary organisations in the planning and review of health and social services programmes
- raise standards of social care
- help the elderly and those with disabilities to live independently, and support their carers
- achieve an equitable distribution of health resources in line with the best evidence on needs and to ensure that all health authorities have Health Improvement Plans in place which allocate resources in line with health and service needs
- deliver joined up and more effective services for users and carers by making full use of the flexibilities available under the Health Act 1999 to improve joint working between health and social services, including the use of pooled budgets, integrated provision and lead commissioning of services
- assist at least 90% of those assessed as needing community care to receive support to allow them to live at home
- reduce unemployment and inactivity amongst groups which have traditionally experienced high unemployment such as young people, lone parents, ethnic minorities, disabled people and the over 50's
- encourage young people and people from excluded backgrounds to participate more and have their voices heard
- achieve a significant improvement in the quality of education for children with special needs
- open up opportunities for everyone, whatever their age and wherever they live, by encouraging lifelong learning and more flexible ways of formal and informal learning

The Advisory Group is also satisfied that our proposals are fully consistent with the Assembly's Voluntary Sector Scheme and the Human Rights Act 1998.

Section Three

3. Progress in the Development of Learning Disability Services to date

3.1 Intentions set out in 1983

The All Wales Strategy for the Development of Services for Mentally Handicapped People (AWS) was launched in 1983 to "correct the historic anomaly ... which has left the bulk of public service provision in large and, for many, remote hospitals whilst the great majority of mentally handicapped people and their families receive little or no support in their homes where it is most needed". It set out three guiding principles and emphasised that these applied to all people with learning disabilities, however severe their disability. People were to have rights to normal patterns of life within the community, to be treated as individuals, and to receive additional help from the communities in which they lived and from generic and specialist professional services in order to develop their maximum potential as individuals. The AWS set a direction for the development of a range of local services and gave explicit guidance on the form of some of the needed services. It was

given an initial life of ten years, during which additional recurring revenue investment would grow to approximately £26 million per annum at 1983 prices. However, neither the initial term nor the additional funding on offer was sufficient to make the pattern of services envisaged by the Working Party, which preceded the AWS comprehensively available throughout Wales. The intended financial investment in the first ten years was about a quarter of that estimated to be eventually required.

The AWS reflected the idea of a comprehensive local service of its time; it was clearer in some areas than in others. However, it stated that "the concept of new patterns of comprehensive services lies at the heart of the Strategy".

Fundamental change in the nature of residential provision was central to its implementation and symbolic of the move from institutional to community services. The AWS was very clear: "support staff should be available to help run a range of accommodation ... which caters for individual preference and ability ... in ordinary houses ... made available from local ... housing stock". The Working Party Report estimated that provision for between 7,300 and 11,200 adults was ultimately required, based on a then total population of 2.8m. This compared to the current level at the time of 3,200 places, mostly in the long-stay hospitals (2,300 places) and hostel accommodation (the majority of the remainder). The provision target converts to a rate of 260-400 places per 100,000 total population.

Development of other community services stemmed from "the pre-eminent importance of the family ... and the heavy burden on the family that is caused by stress and lack of help". In response, "short-term relief should be readily available ... (and) locally based, flexible and capable of responding to emergencies", and help to families was also to include "a range of domiciliary support ... (such as) family aid (sic) services". The Working Party Report gave target provision figures for families with children only, in view of the comprehensive targets set for alternative supported accommodation for adults. Both respite and domiciliary support services were to be sufficient to provide for a total of 2,700 children and families, rates that convert to 96 per 100,000 total population.

The AWS was less specific on education and day services. It endorsed section two of the 1981 Education Act and sought "the maximum possible access and integration with ordinary education facilities" but without giving any guidance on minimum targets or reasonable achievement. In keeping with the times, it did not set a clear vision for day services for adults. Existing segregated and centralised day services (adult training centres, social education centres and the like) were seen as the primary source of day provision, a situation that would continue into the future for many service users. The AWS recognised some of the inherent problems in the model: such centres "provide an all-purpose service which is not conducive to the promotion of independence or responsive to individual needs". It therefore sought a broadening of the range of options available: "more appropriate forms of constructive activity need to be developed, (and) there needs to be imaginative developments ... to create employment opportunities and ... better career guidance and work preparation courses". The AWS, therefore, called for innovation and the development of diversity; it did not provide a clear direction towards a new pattern of local day services. The Working Party Report set a target for the combined extent of day service options of 6,500 places for working aged adults (232 per 100,000 total population) and 800 places for adults over 65 years (28 per 100,000 total population).

For each person and family, the AWS sought "full access without question to the same services, including health services that are available to the rest of the community". It wanted to help general service providers to be more open to serving people who had traditionally been marginalised, a task it saw primarily as educational. It also sought to promote professional input and a greater network of community support: the availability of "advice, support and teaching from social workers, community nurses, care assistants, other parents and voluntary organisations ... as and when required".

Ultimately, the AWS sought to influence the place which people with learning disabilities had within society, substituting a life apart or on the margins for one of full involvement. "Provision for recreational and social opportunities" was urged "in parallel with dwellings" and success was seen as dependent "on the involvement of the general public ... (which) service providers should place special emphasis on sensitive and imaginative efforts to develop". Establishing neighbourhood networks of voluntary help was also seen as desirable.

Finally, consistent with its individual focus and with the emerging idea that effective support required the pulling together of services and resources, the AWS advocated the widespread introduction of individual planning. "Staff should work together with mentally handicapped people and their families in the preparation, implementation and regular review of individual programme plans for the development of the mentally handicapped person". Co-ordination of the individual planning system was to be done by multidisciplinary professional teams established locally. Each person with a learning disability was to have a nominated keyworker. In addition to providing specialist professional input, the multidisciplinary team was to act as a single point of contact for individuals, families and generic services alike, and be a focus for local planning and the collation of information on individual need which could be fed into the county planning system. Involvement of the consumer - the individual with a learning disability and the family - in the decisions surrounding the provision and review of services was an avowed commitment. Such involvement was mirrored by a similar commitment to representation in local and county planning forums. Both commitments were an attempt to make needs led and individually focused service provision a reality.

The AWS, therefore, set a framework for the administrative arrangements to be followed. It put forward a model planning system in which representatives of consumers and all relevant agencies met at county level to produce a single joint plan. It was made plain that the Welsh Office would expect people with learning disabilities, their families and voluntary sector representatives to be widely consulted about the content of plans and have a permanent place in the planning and monitoring of services. Local authority social services were given 'lead agency' status in recognition of the shift from the medical model to a social care definition of the prime task to be achieved. This clearly signalled the eventual patterns of resource investment in the area. The AWS envisaged that the expenditure tied up in traditional services would be liberated as new and better services were developed and that this would be available for reinvestment. Increased revenue could also come from local authorities. However, the allocation of additional funding as part of the AWS recognised that the redevelopment and growth in the scope of services was of such a scale that it would need to be largely funded by central government.

3.2 Progress against AWS objectives

(a) Financial investment

The level of investment promised by the AWS was slightly more than delivered. Social services expenditure in 1994-95 was £93.3m (£55.04m at 1983-84 prices) and the AWS (then) Welsh Office grant allocation for that year was £49.2m. Since then, the central funding of strategic development of services has continued in a more limited way. A second phase of central funding to achieve the broad targets of the AWS was not pursued. Rather, central investment was increased to progress the hospital resettlement programmes only (see Table). The total budgeted social services expenditure for 2000-01 is £142.2 m (£71.25 m at 1983-84 prices). However, despite increase in the resettlement grant allocation, the proportion of personal social services expenditure on people with learning disabilities has remained almost constant since 1994 (21.7% in 1994/5, 22.1% in 1999/00). Thus, learning disabilities has not received a proportionate share of other growth in PSS expenditure, a sign of the lower priority accorded learning disability service development since the ending of the first phase of the AWS. In addition, the increase of the mainstream AWS grant at a rate less than actual cost inflation has placed pressure on local authority finances.

Table: Personal Social Services Expenditure on Learning Disabilities (£m)

Year	PSS* spend on Learning Disabilities (£m)	Proportion of Total PSS* Expenditure	AWS Mainstream Grant (£m)	AWS Resettlement Grant (£m)
1994/5	93.3	21.7	49.2	
1995/6	101.3	20.9	57.1	
1996/7	117.1	22.2	57.4	1.8
1997/8	125.4	22.4	27.7**	11.1

1998/9	132.9	22.3	28.0	12.0
1999/00	136.8	22.1	28.2	17.2
2000/01	142.2		28.4	19.1

* Personal Social Services

**£28.4m of mainstream grant transferred to LAs

Estimated expenditure by health authorities on learning disability services in 1999/2000 was £56.5m. Combined health and local authority expenditure in that year is estimated at £193.3m, which converts to a sum of approximately £66 per head of population. This is in line with Scottish Executive estimates. They report that the spend per head of population on supporting people with learning disabilities is

1. £63 in Wales
2. £59 in England
3. £54 in Scotland.

(b) Residential service provision

Providing supported accommodation in the community is the main way to enable adults with learning disabilities to leave the family home and live typical mature lives, consistent with AWS principles. Welsh Health Circular (85) 46 requested health authorities to prepare proposals for the future of the long-stay hospitals and indicated that the progressive reduction of long-term hospital populations should be an integral part of such proposals. The development of accommodation in ordinary community housing was one of the core priorities stated following the 1988 review of progress, and the need to accelerate resettlement was explicitly recognised. As a consequence, Wales has made great progress in reforming the nature of residential services so that in contrast to what existed in 1983, available services are smaller in scale, within ordinary housing stock, and local to the communities which they serve. At 31 March 2000, there were 366 people still resident in long stay hospitals and the National Assembly has set a target to close all remaining long stay hospitals by no later than 2010. Otherwise, settings provided by local authorities and the independent sector in Wales in 1995 had average residential groups of approximately three people. By way of comparison, the character of English services was very different. English local authority accommodation in 1995 had resident groups of just under 13 on average. They provided no 'small' homes with fewer than four places. In addition, independent sector homes had average residential groups of six. Such differences may be related to differences in assessed quality. Compared to a random sample of services in England conducted at about the same time as research on housing services in South Wales, the houses in South Wales were smaller and more individually-oriented, allowed more choice and promoted greater community integration.

However, while the quality of residential provision has improved, no progress has been made in extending service availability towards the comprehensive levels envisaged by the AWS. Wales began the AWS with a low rate of residential service provision (approximately 105-110 places/100,000 total population). By 1995, the rate of provision was assessed as 98-places/100,000 total population. The AWS years may have seen an increase in supporting people to live more independently in accommodation outside of that notified in official returns but it is likely that overall service provision was certainly no more extensive in 1995 than in 1983. (It is conceivable that the level of service provision may have fallen, as provision was not made for revenue to be redirected into community services when individuals died in hospital.) In 1991, Wales had a lower rate of provision than all but one English Regional Health Authority and a lower rate than the average in England and Scotland. Although provision estimates are now somewhat dated, it should be remembered that the priority throughout the 1990s was on hospital resettlement. It is unlikely that the 1995 figures seriously underestimate the total service availability currently. Therefore, one can conclude that the current rate of provision in Wales is lower than (a) the level of provision in England (by about 20 places/100,000 total population), (b) the norms set in the 1971 White Paper (by about 32 places/100,000 total population), (c) its 1980 update (by about 55 places/100,000 total population) and (d) the eventual comprehensive provision estimate discussed by the AWS Working Party Report (by at least 160 places/100,000 total population). It should be remembered that the 1971, 1980 and 1983 estimates took no account of the need to increase

provision in line with better survival of people with learning disabilities.

(c) Family-support services: respite and family aides

The development of respite and family aide services was a high priority of the AWS. The number of individuals and families in Wales in 1995 using respite services was 2,278 and receiving domiciliary support worker input was 1,914. It is not known whether comparable growth in family aide provision has occurred in England but it is perhaps less likely given the strong deinstitutionalisation emphasis to English policy. However, developing respite services has been a priority throughout Britain. According to the second national survey of family-based respite care, Wales had more family-based respite care services in ratio to population (9.0 per million) than the United Kingdom as a whole (5.8 per million), although they were biased more towards children (25 services to 1) than in the UK generally (257 children's services to 74 for adults). The same source estimated that 9,821 children and 2,960 adults received some family-based respite care in the UK in 1992 (a combined rate of 22.4 per 100,000 total population). The number of Welsh users in 1995 was 739 (a rate of 25.5 per 100,000 total population). It is important to emphasise that none of the figures reflect whether the extent of offered support or respite per family is adequate or even differentially related to assessment of need. It is also possible that service availability has continued to expand since 1995 despite the emphasis on resettlement and the absence of central funding for purposes beyond this.

Calculation of need for family support and respite is clearly relative to the level of other services. If, for example, adults were supported to live in homes of their own, then the remit for family support services would be reduced to supporting children, as originally envisaged by the AWS Working Party. At the end of March 1999, the 12,363 people recorded on learning disability registers were reported as living in the following circumstances: 9,776 in their communities, and 2,010 in statutory or independent sector residential accommodation. Were residential support for adults to increase to the comprehensive level envisaged by the AWS Working Party, the numbers living in their own rather than parental homes would need to increase by some 4,800. The 1995 availability of domiciliary support and respite services exclusively focused on this smaller target population would meet a high proportion of potential need. However, until such service expansion has occurred, family support services are likely to be insufficiently extensive and, therefore, effectively rationed.

(d) Day Services for Adults

The AWS recommended greater variety in day provision and less reliance on large, multi-function day centres, although it was not specific on the form of service support to be developed to take their place. In 1983, there were about 3,000 day centre places together with just under 200 day service places in the large hospitals, giving a combined rate of provision of about 110 places/100,000 total population. By 1988, day centre places had increased to just under 3,200 places. Since that time, there has been an increasing diversity of day service options and an increase in sessional attendance at both the new and more traditional service forms. Twenty-three percent fewer people attended day centres in 1995 than did in 1988 although it was still the dominant form of provision. There was increased attendance at satellite units, colleges of further education, work experience, paid employment and a range of other service and community placement options. A few Adult Training Centres or Social Education Centres have been completely reprovided and the old centres closed.

As a consequence of more recent trends towards sessional attendance, it is difficult to convert figures on the number of attendees to the number of whole-time-equivalent places available. Nor is it possible to add the number of attendees across different service forms without double counting of individuals. About 3,500 people with learning disabilities were reported as being provided day care commissioned by local authorities during the week ending 1st March, 1998, although the balance between full and part-time provision is not clear, a rate of just under 120/100,000 total population. The available evidence therefore suggests that total service availability has not altered greatly since the start of the AWS. It would certainly be safer to assume that there has been no overall increase as a sample survey of the services received by people with learning disabilities in four local government districts in Wales between 1986 and 1990, the middle four years of the first 10-year phase of the AWS, found that the proportion receiving a full-time day service had declined and the proportion receiving either no day service or only a part-time one had increased.

Development of day services for adults under the AWS has been, therefore, somewhat similar to the development of residential accommodation in that reform of large centralised provision has taken precedence over expansion of service availability in line with demographic change and progress towards more comprehensive provision. However, reform of the nature of day services achieved to date, although significant, is not as complete as that brought about in relation to residential services. Further reform is anticipated. The 1971 White Paper reported that there were, on average, 113-day service places in hospitals or the community in England and Wales per 100,000 total population in 1969. It set a target for this to increase to 195 places/100,000 total population, which would imply 5,750 places in Wales overall. The AWS Working Party estimated a need for 6,500 places for adults of working age (about 220-places/100,000 total population). The 1994 Guidance reported that 3,665 individuals received "new patterns of daytime care" in 1993, which represented 53% of potential need. This suggests that support would need to extend to 6,915 individuals for it to be regarded as comprehensive (about 235-places/100,000 total population).

There is now considerably more emphasis being given to supporting people in productive employment rather than programmes of diversional activity than at the beginning of the AWS. Supported employment in Wales has grown more rapidly in ratio to population than elsewhere in the UK. However, available evidence suggests that the costs of supported employment outweigh savings. Current welfare benefit arrangements lead to a high level of part-time working in line with the therapeutic earnings disregard. This often means that savings in welfare benefits payments or from reduced use of alternative services are minimal. Reform of welfare benefit regulations could alter this greatly. Analysis suggests that supported employment could become cost effective with a higher level of full-time working. The impact of supported employment on day service provision may remain marginal if reforms, which would facilitate this, do not occur.

Greater survival is also seeing the beginnings of a significant population of people with learning disabilities of retirement age (possibly up to about 850 people over 65 years). This is creating the need for a new form of service support. The AWS Working Party Report anticipated this trend by estimating a need for about 800-day places to support people in retirement. This is equivalent to a further 28 places/ 100,000 total population.

In summary, reform of the nature of day services has occurred in line with the direction set by the AWS in bringing a greater variety of options. However, the large day centre is still the core of provision and much redevelopment is still required. Supported employment has grown and is seen as having great potential to meet the fundamental AWS principle of individuals living as normal and productive a life as possible. Wales has led in the development of supported employment in Britain. Co-ordinated policy developments are required across government departments to allow its potential to be reached. Across all forms of day provision, service availability is substantially lower than estimates of what is required. Greater survival of people with learning disabilities means that (a) it will become increasingly difficult to meet the needs of school leavers, and (b) policy and service development are required for day support of people of retirement age.

(e) Multi-disciplinary community teams and individual (person-centred) planning

The development of multi-disciplinary community teams in Wales was rapid in the first years after the inception of the AWS; only one of the 37 teams in existence in 1987 pre-dated the AWS. Such development followed similar development in England and could therefore be construed as catching up, at least initially. It is not known whether the professional infrastructure is now better established or organised in Wales than elsewhere. Moreover, since the research conducted in Wales on community teams predated the introduction of the purchaser-provider split, care management and local authority reorganisation, what was known about their working is unlikely still to apply.

People with severe learning disabilities tend to be lifelong consumers of health and social care services. They also make a heavy demand on education services during their developmental years. The AWS proposed that strategic and operational planning should be underpinned by a comprehensive system of Individual Planning (IP), detailed reviews of people's objectives in life and the service supports required to realise them. Such IPs were to be regularly conducted at least annually if not more frequently and differ from more traditional case conferences in that they would be held to consider the effectiveness of service supports even though changes in service placement were not pressing. At an individual level, such

planning was to inform the service elements and processes required to meet the person's needs. At an authority level, an overview of such plans and identified service deficiencies was to inform strategic development.

Individual Planning (IP) as a means of service co-ordination and review grew in Wales but was only ever available to a minority of service users. Service authorities launched IP systems without thorough assessment of the resource implications of comprehensive implementation. IP systems were often established but not sustained. When first established, community teams experienced early difficulties in progressing towards the idea of IPs for all. By 1987, 68% of teams had done either no IPs or had done them for less than 10% of users. Only five of the thirty-seven teams claimed a 25% or greater coverage. Three years later a family survey found little advance with only 11% of carers identifying an IP meeting in the previous twelve months, though other forms of meeting were recorded, e.g. case review, service review, case conference. This figure, however, concealed considerable variation in the prevalence of IPs between counties (from 3% to 30%), reflecting both the priority accorded IPs by senior managers and the available staffing levels in community teams. A survey of four local government districts at about the same time, which included people living in different types of residence as well as the family home, reported higher coverage of IPs but there had still only been a marginal increase in coverage from 29% to 33% between 1986 and 1990. Whether IP was more or less available in Wales than in England is not known.

Now, the emphasis on IP within statutory sector planning has been replaced by care assessment introduced by the NHS and Community Care Act and formulation of school transition plans introduced in 1994 but now subsumed by the 1996 Education Act. Care assessment has been viewed as a return to a resource rather than needs-led approach to planning. Proponents of a more person-centred approach now refer to Person-centred Planning rather than IP. The 1994 AWS Guidance maintains reference to IP as a process of co-ordinating care in a way, which properly reflects individual's needs and preferences. It recommends that IP should begin in early childhood and persist throughout life, and be available to everyone who wants one. Current policy, therefore, endorses a cradle-to-grave, comprehensive, system of multi-agency, multi-disciplinary co-ordination and review.

While policy reference to some form of IP has been long-standing, realistic assessment of the resources required to instigate and sustain such a system of planning has never been undertaken. Even care assessment has been achieved for only a minority of people at any one time. Expressed as percentages of the number of persons with learning disabilities on local authority registers, the number of assessments undertaken was 22.6% in 1994, 12.5% in 1995, 8.2% in 1997, 13.3% in 1997 and 11.8% in 1998* (*returns from two authorities are missing from the 1998 numerator).

(f) Joint planning and family and user consultation

In establishing the social services department as lead agency, Wales has achieved a more wholehearted transition from health to local authority commissioning of social care services than elsewhere in Britain. Allied to this, the then Welsh Office insistence on the creation of a single joint agency plan at county level, although creating a challenge to all concerned, eventually produced a distinctive level of joint agency collaboration. However, reforms of recent years have not helped to further this. The separation of purchasers from providers divided the interests of newly established collaborators both between the statutory agencies and between statutory agencies and voluntary bodies. Health and local authority reorganisations removed the high level of territorial coterminosity which previously existed. The creation of a large number of small unitary authorities, coinciding with the evident weakening of policy priority, broke up pre-existing specialist learning disability planning teams which had thrived under the AWS.

Alongside the development of joint agency planning under the AWS was the injunction to develop consumer representation in planning at local and county levels. Family representation was the easier to establish and came first but the number of self-advocacy or service user groups which had representation on local or county planning groups grew between 1986 and 1994, reflecting the growth of such groups (from 2 in 1985 to 58 in 1994). There was a strong association between whether such groups were funded, usually through AWS monies, and (a) the numbers of representatives at local and county planning levels and (b) whether such representatives were likely to have paid supporters with them at meetings. Little is known about the impact of consumer representation on the plans formulated but reflection by those involved suggested that families did exert an influence, particularly in the emphasis given to developing family support services, but that

representatives with learning disabilities largely did not.

A small, number of citizen advocacy projects developed in Wales at the end of the 1980s and beginning of the 1990s. The projects were geographically scattered and covered only a small proportion of Wales. It proved difficult to recruit advocates. In 1992, a particularly high point in terms of advocate numbers, the four longest established projects had a total of 50 advocates. Their total funding was £124,500, around £2,500 per advocate per annum. Compared to the 8,886 adults with learning disabilities over 16 years of age recorded on health and social services registers in Wales in 1992, this number was insignificant. Even within the catchment areas they served, the availability of advocates was low. For example, the project with the most citizen advocates (27) and the smallest catchment area of all projects in Wales served an area which had over 300 registered adults with a learning disability, together with a hospital population that was still over 100.

(g) Comprehensive provision

The concept of comprehensive services was said to lie at the heart of the AWS. Comprehensiveness implies service availability commensurate to need. It also implies equality of provision and access to services across the localities and communities which constitute Wales. Yet, there is clear evidence that change in service provision has neither been uniform across Wales nor evenly distributed. For example, rates of residential provision across the former counties in 1994/5 varied between 60 and 214 places per 100,000 total population, an inequality which has given the recently created 22 unitary authorities very different service inheritances. Those of the old counties, which had concentrations of traditional hospital provision, became authorities with higher provision rates of alternative community residential accommodation. Provisional personal social services expenditures on learning disabilities for 1989/99 show considerable variation across unitary authorities, with higher spending per head of population being associated with proximity to traditional hospital provision (Newport, Gwynedd, Cardiff, Bridgend and Powys being the five highest). Redevelopment of other major services, such as day provision for adults, is equally patchy.

With the benefits of hindsight, despite its strategic intent, the AWS was characterised by pragmatic rather than strategic planning, shifting priorities and a sense among families and people in need in the community of opening and closing windows of opportunity. Difficulties of co-ordinating large, multi-agency joint planning groups were identified as contributing to poor strategic planning and the absence of a comprehensive view. Failure to estimate need at the population level or to aggregate assessed individual need (impeded by the low level of IPs) meant that AWS proposals were developed expediently. The absence of quantified, developmental stages for the unfolding of the comprehensive intent of the AWS produced an inability to determine how the incremental year-by-year progression contributed to a final coherent pattern of local services. This sense of incomplete and patchy development has an obvious corollary that some individuals and families benefited from the AWS and others did not. It would be safe to assume that precisely who benefited and in what ways they benefited varied from county to county. However, the status of information on the demand and supply of services at local level is too uncertain as to be able to elaborate on this further.

Clearly the central goal of the AWS remains to be achieved both in terms of equality of access and adequacy of service availability. That the AWS has not resulted in a comprehensive pattern of services by this stage is not in itself surprising given that the original Working Party calculated that the investment provided in the first phase was only about a quarter of that required. Given no change to the aims of the AWS, the constraint on additional central resourcing after 1993 and its narrow focus on achieving hospital closure did not appear to stem from an evidence-based assessment of how much of the envisaged service reform had been achieved.

(h) Improving Service Quality

Significant areas of service reform, such as deinstitutionalisation and provision of supported community housing, day services and supported employment, and the provision of family support services, have been the subject of evaluation. A number of broad generalisations are possible:

(i) Compared to hostel or hospital accommodation, supported community housing provides (a) a better material environment, (b) a more resident-oriented social milieu, (c) more staff attention to residents, (d) greater access to community activities, (e) greater opportunity for the use of skills, (f) greater choice, (g) increased constructive activity, and (h) residents with greater satisfaction with life.

(ii) Day centres differ greatly in the activity programmes that they offer service users and in the number of hours per week that they offer organised activities. The 'working week' often lacks intensity. Little is known about the relative merits of many alternative day services. Managers of various community or employment focused alternative day services in Wales thought that those using the services increased in personal competence, had a sense of achievement and enjoyed greater community integration. Evaluation of supported employment has shown that supported employees gained income, spent more time constructively occupied than when attending day services and had greater contact with people without learning disabilities other than paid care staff.

(iii) The growth in domiciliary and respite care services have been deeply appreciated by family carers and led to improvements in their quality of life, particularly in relation to helping carers balance the time demands of their caring and other commitments. Extended caregiving has become less claustrophobic as a result. However, important questions remain concerning the extent to which carers are able to increase their social participation or participation in the labour market as a consequence of receiving support as currently conceived. Carers still feel excluded from these areas of life, an exclusion which contributes significantly to their distress. Support services are generally insufficiently extensive, scheduled at the right times or flexible to allow carers to achieve significant ambitions in these areas.

(i) Service costs and quality

Economic evaluations have attempted to identify the costs associated with particular approaches to providing supports for people with learning disabilities. Much of this work has examined the costs of residential supports. The research indicates that:

1. Costs vary dramatically within all forms of providing residential supports
2. A significant proportion of this variation is associated with varying levels of need or dependency
3. Supports provided in newer community-based services are generally more expensive than support provided in old 'learning disability' hospitals (although this is probably mostly due to avoidance of some of the worse inadequacies of traditional services being repeated in the new community services rather than through inherent economies of scale within the large hospitals)
4. Once levels of need or dependency are taken into account, there is little association between size of home and costs, although cost inflation may set in at very small scale
5. Village communities and other campus-style arrangements may be marginally less costly than community-based provision.

Variation in costs has also been found to be a feature of day services for adults, with ten percent of local authorities reporting average gross revenue costs of £13 a session or less and ten percent £39 or more. This is consistent with a three-fold difference in staff: user ratios between day centres at either end of the range in a recent sample in eight English local authorities and a five-fold difference in an earlier survey of Welsh centres. In the latter, smaller centres were more costly than larger ones.

Comparison of outcome in new community services with that found in traditional hospitals has shown that there is a quality gain to set against the increase in costs. However, there are no simple associations between the costs and quality of services.

The largest element of the revenue costs of services is attributable to staffing. The majority of economic evaluations of specific forms of support services for people with learning disabilities (e.g., residential supports) have reported a modest positive association between indicators of 'need' and the costs or staff: user ratios of provision.

To look at the association between costs and quality, therefore, it is also necessary to take into account differences between services in the needs of people served, especially as there is extensive evidence to suggest that people with greater or more complex needs often experience poorer outcomes. Studies that have done this suggest that the link between resources (costs or staff: user ratios) on the one hand and quality on the other is tenuous indeed. Some studies have reported that increased resources are linked to an extent with increased quality but others have failed to find a link at all.

Section Four

4. People with Learning Disabilities and Demographic Change

4.1 Defining learning disabilities

Stephen Dorrell, then Minister of Health, first officially used the term ‘learning disabilities’ in a speech to MENCAP in 1991. Learning disabilities replaced previous terms that now seem very pejorative, such as ‘mental handicap’, ‘mental retardation’, ‘mental subnormality’ and ‘mental deficiency’. The term ‘learning difficulties’ is used in the education system, though with a broader meaning, and some health and social care professionals and agencies, in common with some self-advocates, also prefer this term. The term ‘intellectual disabilities’ is increasingly used in international dialogue.

The formal definition of ‘learning disabilities’ or ‘intellectual disabilities’ includes the presence of:

- A significant intellectual impairment and
- Deficits in social functioning or adaptive behaviour (basic everyday skills)
- Which are present from childhood.

‘Significant impairment of intelligence’ is usually defined as an intellectual quotient (IQ) score more than two standard deviations below the general population mean, in other words an IQ below 70 on a recognised IQ test. Deficits in social functioning or adaptive behaviour refer to how well people cope with both the natural and social demands of the environment. This may be assessed by a normed behavioural checklist covering such areas as communication, daily living skills and socialisation like the Vineland Adaptive Behavior Scales and the AAMR Adaptive Behavior Scales - Residential and Community.

4.2 Causes of Learning Disabilities

It is well established that biological, environmental and social factors are all relevant in the causation of learning disabilities. Historically, it used to be asserted that severe learning disability was due to biological variables whereas mild learning disability was due to social and environmental factors. It is now known that the picture is not quite as clear cut as this.

It has been long established that there is a relationship between the occurrence of mild learning disabilities, parental social class and instability of family background (such as changes of carers, abuse, neglect) which is not as evident in relation to severe learning disabilities. However, advances in understanding have increased the proportion of children with mild learning disabilities where there is a known biological contribution to 20-40%. Contributory biological factors can be identified for around 80% of children with severe learning disabilities.

The majority of these factors operate pre-natally. Together they account for two-thirds to three-quarters of all cases of severe learning disabilities. The most common pre-natal factors are chromosomal and single gene errors, such as Down’s syndrome or Fragile-X syndrome. Disorders of development (such as neural tube defects) and intrauterine problems, such

as foetal alcohol syndrome, listeria infection, rubella embryopathy, account for the remaining pre-natal factors. The perinatal disorders include birth trauma and cerebral hypoxia, while the post-natal causes include accidents and infections.

4.3 How Many People Have a Learning Disability?

Most epidemiological studies of learning disability typically use IQ assessments to classify a person as having either a mild or severe learning disability, rather than using the combination of IQ and adaptive behaviour assessments recommended in current classification systems.

The birth prevalence of learning disabilities is difficult to estimate as it is not until later in life when IQ can be tested as a result of the characteristic delays in social functioning and adaptive skills becoming clear. Only a proportion of the conditions associated with even severe learning disabilities are identifiable at birth. Typically, the age-specific prevalence of severe learning disabilities grows through the pre-school and school years as children are identified. Estimates at the beginning of the 1990s suggested that there were about 5 people with severe learning disabilities per 1,000 total population aged 15-24 years. Allowing for mortality during childhood gave an estimated birth prevalence of at least 6 per 1,000.

The major factor underlying upward pressure on the prevalence of learning disability is increased life expectancy. For example, one would have expected, on average, about 3.5-4.0 people per 1,000 aged 25-44 years, 2.0-2.5 per 1,000 aged 45-64 years and 1.0-1.5 per 1,000 aged over 65 years. The overall prevalence rate for people with severe learning disability was estimated at between 3 and 4 per 1,000 total population, probably in the region of 360-380 per 100,000. Applied to the population of Wales such a rate would have suggested that there were about 10,830 people with severe learning disabilities living in Wales.

Population screening studies of mild learning disability yielded much higher prevalence rates (about 25-30 people with mild learning disability per 1,000 total population) than studies using administrative populations (i.e., those known to agencies that provide specialist services to people with learning disabilities) (less than 10 per 1,000). The former figure is approximately what would be expected given a normal IQ distribution. Including a measure of adaptive behaviour would be likely to reduce such a rate considerably, in line with the lower administrative prevalence.

4.4 Is the Number of People with Learning Disabilities Changing?

Learning disabilities is not a single condition. Therefore, it is likely to vary in occurrence as the factors, which influence its causes, vary. As an example, variation in prevalence between birth cohorts from under 2 to over 7 per 1,000 has been reported. One should only consider trends in broad terms, for example at a national level where one can expect variation across localities in a given time period to cancel out.

Upward pressures on the incidence of learning disabilities include:

- increases in maternal age (associated with higher risk factors for some conditions associated with learning disability, such as Down's syndrome)
- improved survival of 'at risk' infants, such as low birthweight infants, due to improved health care
- increases in more recently significant pre-natal threats such as HIV infection and substance abuse
- an increase in the proportion of children growing up in poverty.

Downward pressures on incidence of learning disabilities include:

- the impact of prenatal screening for Down's syndrome (estimated to reduce a 'natural rate' of 1.5 per 1,000 births to about 0.9-1.1 per 1,000)
- improved health care and support resulting in fewer 'at risk' infants developing learning disabilities.

The major factor underlying upward pressure on the prevalence of learning disabilities is their increasing life expectancy. Indeed, the fact that increased survival would lead to the need for increased service availability was predicted in the White Paper, 'Better Services for the Mentally Handicapped' as long ago as 1971, although the provision norms set at that time were not adjusted for such an increase. Although some changes since then have reduced the occurrence of learning disabilities, increased life expectancy has outweighed downward trends. It is now thought that most adults with learning disabilities in developed nations who live past their third decade are likely to survive into old age and experience the normal ageing process. There are more adults with severe learning disabilities aged over 45 years than there are such children aged under 15 years.

In addition, there also appears to have been a 'bulge' in the UK childhood prevalence of learning disability for births between the mid-1950s and mid-1960s, suggesting a higher prevalence for adults currently in their late 30s and 40s. Fryers estimates that the age-specific rates of severe learning disabilities in the UK (per 1,000 total population) have changed between 1990 and 1998 as follows:

Age	1990	1995	1998
25-29	4.5	4.5	4.3
30-34	4.0	4.0	4.5
35-39	3.5	3.8	4.0
40-44	3.0	3.3	3.5
40-44	3.0	3.3	3.5
45-54	2.5	2.8	3.0
55-64	2.0	2.3	2.5
65-74	1.0	1.3	2.0
75+	very few	1.0?	1.3?

In other words, there have been increases in the prevalence of people with severe learning disabilities between 1991 and 1998 in every 10-year age band between 35 years and 64 years of between 15 and 25 percent, together with a doubling of the prevalence of people aged between 65 and 74 years and the beginnings of a significant very old population. These estimates are consistent with the 22% reported increase in the number of people on local authority registers for people with learning disabilities in Wales between 1990 and 1999. Estimates from the Department of Health statistician suggest that the trend towards an increasing number of people with learning disabilities will be sustained over the first two decades of the Twenty-first Century.

The comparison between 1990 and 1998 above shows that the higher mortality of people with severe learning disabilities reflected in declining age-specific rates as people age is reducing. Early mortality was greatest among people with multiple disabilities and, therefore, greater survival implies not only the emergence of a significant elderly population but also increased numbers of people with complex needs requiring support throughout adulthood.

Change in prevalence among non-white ethnic groups is likely to be greater than among white groups. The absolute numbers of people from ethnic minority populations with learning disabilities and the proportion of people with learning disabilities from ethnic minority populations are likely to increase throughout the adult age range as a result of the very young age structure of that population currently. Research has also found tentative evidence to suggest higher prevalence rates of learning disabilities amongst some minority ethnic groups, for example, South Asian groups. Higher prevalence rates in South Asian communities are most notable for children and young adults with severe learning disabilities. (It is

unclear whether these higher rates are biologically or genetically linked with ethnicity, or are the result of other factors that have an impact upon minority ethnic groups, such as socio-economic status, poverty, access to health care or classification practices. For example, a study in Pakistan showed very high prevalence rates of learning disabilities in poor rural areas, compared with prevalence rates similar to North America and Northern Europe in wealthier middle class areas.

4.5 Autistic Spectrum Disorders

In the early 1940s, Kanner, working in Baltimore, and Asperger, working in Vienna, separately published accounts of children with autism. There were some differences in their two descriptions but the two disorders, Autism and Asperger's syndrome, are now considered by many people to be part of the same autistic spectrum or continuum. They are also referred to as 'pervasive developmental disorders' that have an onset before 3 years of age.

The crucial symptoms for autism are now considered to be:

- Absence or impairment of social relationships
- Delayed and abnormal language and imagination
- Narrow, rigid, repetitive activities and interests.

This is known as the 'triad' of impairments and must be present in all those diagnosed with autism, though levels of ability may vary, (about 20-25% of children with autism have a non-verbal IQ in the normal range). Asperger's syndrome is usually only diagnosed when a child (or adult) has a social impairment, very limited and rigid interests and rituals, an IQ in the normal range, and no significant delay in early language (though there may be severe impairments in the social aspects of language). Technically, then, people with Asperger's syndrome do not have learning disabilities. They may, however, sometimes receive learning disability services because their impairments are not well understood elsewhere.

Early studies reported a prevalence of four or five children in every 10,000 with classical autism. Later studies tended to find somewhat higher figures (for example, about 10 per 10,000). A recent review concluded that the median prevalence for autism was 5.2 per 10,000 and acknowledged that prevalence rates reported in later studies were somewhat raised (median 7.2 per 10,000 in studies after 1989).

Very few of these studies have attempted to cover the whole autistic spectrum. The prevalence of all spectrum disorders in children with learning disabilities has been reported to be about 20 children per 10,000.

All prevalence studies have shown a greater number of boys than girls with autistic spectrum disorders (the male: female ratio being about 3:1 or 4:1 on average, with an even greater number of boys (6:1) among individuals with an IQ in the normal range.

Section 5

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INDIVIDUAL PLANNING (PERSON-CENTRED PLANNING)

Good quality service support should reflect individual needs, goals and preferences. The failure to individualise service design tends to result in the provision of relatively similar forms of service provision, which may not be capable of adapting sufficiently to individual difference. By concentrating on the needs of individuals, individual planning should support greater service innovation and inform the strategic planning process.

Evidence shows that only a minority of people had the opportunity for their needs to be assessed and service supports to be developed through a process of Individual Planning. The 1998 Conference report suggested that plans were not always comprehensive in scope or sufficiently multi-disciplinary and multi-agency; and that individuals were not being fully and properly consulted about their needs, goals and preferences.

There are a number of factors that may have contributed to the above problems. Plans may not integrate social support, health, education and other perspectives if commitment to the process is not genuinely multi-agency and involving all stakeholder interests appropriate to the individual's age. Models of best practice were not disseminated across Wales. Given available resources, the intensive nature of individual planning was in competition with the goal of widespread implementation. These problems may reflect the absence of a strategic, national plan to meet the resource costs of comprehensive implementation and overcome the complexities of multi-agency co-ordination involved at different times of the service user's life cycle.

Unless real efforts are made to place the user at the centre of planning, there can easily be an unequal relationship between the care planner/manager and the individual. Understanding the views of people with limited language becomes more difficult with greater severity of learning disability. Sufficient resources (time and expertise) are not always given/available for intensive attempts to be made to understand individual wishes. In addition, resources are required to establish a range of advocacy services capable of representing the best interests of individuals who cannot represent themselves personally because of their disability.

Individuals with complex needs require agencies to work closely together to prepare a single individual plan. Concerns about the 'shunting' of costs between health and social care agencies has hindered agreeing individual plans and flexibly

responding to need. The development of eligibility criteria to operationalise separate health and social care responsibilities has not been helpful in the development of joint commissioning and delivery of services. Protocols for joint commissioning and joint working are required. Arrangements for pooling resources between agencies are required to remove the financial incentives accompanying the redefinition of responsibility from one agency to another

The extent to which the individual gives informed consent for the sharing of information contained in the individual plan is a difficult area. First, there is the question of deciding who is capable of giving informed consent. Second, the plan cannot meet its service co-ordinating objectives if it is not shared between the agency professionals whose action is required to implement the plan. Third, family and advocates who may in practice represent the individual's interests need to see the plan to check that it contains what was agreed.

SERVICE PRINCIPLE

Each person with a learning disability has a right to an individual plan to co-ordinate care from early childhood throughout life and properly reflect his or her needs, goals and preferences. There should be consistency across Wales in terms of the availability of individual planning.

Individual planning should provide a single, comprehensive review of need for each person to which all agencies are party.

There should be consistency across Wales in terms of the quality of individual planning.

SERVICE RESPONSE

The resource costs of comprehensive implementation need to be calculated and a strategic investment plan drawn up.

Agency responsibilities and commitments at different stages of a person's life need to be defined. Consideration should be given to relevant agencies pooling funding to provide a single multi-agency individual planning mechanism.

Best practice standards and criteria need to be agreed to provide the basis for a uniform approach. Standards to include:

1. access to named key worker and named care manager
2. use of specialist assessors as necessary
3. use of a person-centred approach
4. minimum review frequency
5. eligibility criteria which interface with other service sectors (NB some people outside of usual eligibility criteria for specialist learning disability services may need support in some areas of life e.g., employment, mental health needs)
6. coverage of quality of life concerns:

i) Health/appearance (my treatment)

ii) Accommodation (my home, my family/fellow householders)

iii) Support needs (my helpers)

iv) Pre-school provision, schooling, college, work or retirement provision (my career, my occupation)

v) Education (my skills, my independence)

vi) Domestic/Community lifestyle (my self-care, my household arrangements, my use of community)

amenities)

vii) Leisure (my interests, my hobbies, my social activities)

viii) Relationships (my family, my friends)

SERVICE RESPONSE

ix) Development (my skills, my independence, my autonomy)

x) Finance/security (my income/benefits, my legal status/rights)

xi) Emotional wellbeing (my happiness, my self-image)

Guidelines and training should be available to people with learning disabilities about individual planning to help them state preferences and formulate decisions. Attention should be given to the ways which people with limited communication skills can express preferences in a way, which will inform individual decision-making.

Individuals may be represented by their next-of-kin.

Access to a range of advocacy services should also be available (see the Advocacy section).

Individual plans should reflect realistic time perspectives (for example, over the next five-years). Special attention should be given to transition planning (see Transition Planning section).

Standards should be set for the frequency of review within best practice guidance (see above). Normally, such review must be undertaken annually, although there may be circumstances when it is necessary for them to be more frequent. Each individual plan should specify a review date and plans should be presented in such a way that outcomes can be evaluated.

Guidelines and protocols are required about the sharing of information within the standards and criteria for best practice recommended above.

SERVICE PRINCIPLE

Each service user must be enabled to play an integral part in the planning of their own lives and have the opportunity to state his or her wishes and preferences and have these fully taken into account.

Where the person's learning disability inhibits understanding of the issues involved in decision-making, individuals should be represented by people who can represent their best interests.

Individual planning should provide a future-planning perspective that anticipates future needs, forestalls crises and allows individuals, relatives and service agencies to plan well in advance, particularly at times of transition. This should set the occasion for continuity of service arrangements as individuals move from the care of one agency to another. Individual care plans should have an agreed and regular review process.

Information protection must be consistent with statutory requirements and relevant guidance.

SERVICE PRINCIPLE

Individual planning and care management should take into account the costs of service provision in order to ensure best value is being provided.

SERVICE RESPONSE

The development of service unit costings is required to enable care managers to identify cost-effective packages to meet support arrangements generated by individual planning.

Carers are entitled to separate assessment of needs under the Carers (Recognition and Services) Act 1995. Implementation of the Carers and Disabled Children Act 2000 will entitle carers to services in their own right. The information obtained from individual planning should inform the strategic planning process.

Separate but parallel planning mechanisms are required for carers. Best practice standards and criteria are required for carer needs assessments (see similar item above in relation to individual planning for cared for individuals). Reliable and relevant information should be systematically abstracted from individual plans to inform strategic service development.

INFORMATION PROVISION

The provision of information empowers users and carers to make informed decisions, access services and exercise their rights. Currently, the provision of information lacks consistency and is not always available in a co-ordinated way or accessible format.

Individual agencies and organisations will be aware of the barriers to the free exchange of information and urgent attention will have to be given to this if partnership arrangements are to be productive and effective.

SERVICE PRINCIPLE

Service users and carers should have good quality and accessible information on the help and support available to them and their rights to participation in strategic and person centred planning.

SERVICE RESPONSE

Organisations should ensure that there is accessible information on the full range of services and facilities available. This information should be relevant, clear, timely and produced in a range of formats to ensure the most widespread and effective communication with potential audiences. Authorities should consider how the range of information can be made available in a co-ordinated way.

Authorities should publicise the rights of users and carers to participate in an informed way in the services planning systems/processes.

ADVOCACY

Better Wales.com emphasises the need to ensure that the voice of disadvantaged people and groups is heard and their views taken into account in policy decisions. The empowerment of individuals so that they play a full role in decisions surrounding and affecting their lives is an important aspect of the AWS. The 1994 AWS guidance specifies such need in relation to users, and parents or carers. The 1998 Conference report suggests that Local Authorities do not see advocacy as important with individuals being given very limited advocacy choice leading to their believing that they are not always being listened to or taken seriously.

It may be necessary for a person to make extensive use of advocacy services in order to assist their active participation in individual planning processes and to ensure that their views on their life are properly represented, understood and taken into account. In addition, clear and simple explanations of official decisions and policy are often best made by an independent advocate. This will be particularly the case where an individual has communication problems or perhaps belong to a minority ethnic group. These considerations apply equally to children with disabilities with or without supportive family. It should also be noted that parents and carers may often be in need of an advocacy service.

There are strong arguments in support of the independent funding of advocacy services.

SERVICE PRINCIPLE

SERVICE RESPONSE

A full range of independent advocacy services must be established to ensure that the views of vulnerable people can be listened to, understood and acted upon

Independent advocacy services should be made available whenever a need has been identified for a vulnerable person to have independent representation of their views.

Authorities should encourage the growth and use of a range of appropriately trained and regulated independent advocacy services.

PARTNERSHIP IN PLANNING

Experience in many parts of Wales after the launch of the 1983 All Wales Strategy showed clearly that joint working between local authority departments, health organisations, voluntary organisations, and parents, carers and service users had significantly improved. Equal partners in the planning, development and monitoring of services, led to decisions which had common ownership, were better informed and were more sustainable.

The thrust towards effective joint working has been promoted in subsequent National Assembly guidance to authorities and reinforces the need for the participation of parents, carers and service users in the planning process.

Since local government reorganisation, it would appear that there are significant variations in the planning process arrangements for learning disability services. Effective planning arrangements will require fully developed, collaborative partnerships which entitle service users, parents and carers to make meaningful contributions into service provision and development.

SERVICE PRINCIPLE

All authorities must work closely with stakeholders to maintain a planning function for learning disability services which regularly appraises policies and the performance of existing services and develops new objectives and service patterns

SERVICE RESPONSE

Authorities must consider the breadth of stakeholder interests and develop procedures in consultation with interested parties for their participation in the planning systems/processes.

Local partnership planning should :

- Include user and carer views and perspectives and summarise the results of local consultations about needs for local services.
- Establish the core aims and long term strategic, financial and performance objectives for services.
- Decide service priorities for competing resources and set out the basis on which they have been determined
- Report on achievement against the performance criteria and objectives that have been set, incorporating user evaluations of services.

These arrangements must be considered in the context of any national and local strategic objectives and local joint planning initiatives.

Authorities should ensure that the reasonable costs of small voluntary user and carer group participating in the planning process are met through suitable arrangements.

CHILDREN AND FAMILIES

Better Wales sets out a vision of Wales as a place which:

- values its children and where young people want to live, work and enjoy a high quality of life; and which is

- committed to fostering its unique and diverse identity, and the benefits of bilingualism, while looking confidently outwards and welcoming new cultural influences.

It includes among its core values the statement that:

children and young people should be treated as valued members of the community, whose voices are heard and needs considered across the range of policy-making.

The principle that a child with a learning disability is a child first is central to the Children Act 1989, the National Assembly's 'Children First' programme and our report, The early years are an important period and present real opportunities to promote the development of a child and the ability of the family to provide a secure and nurturing environment. Skilled and sympathetic disclosure of disability and subsequent counselling for the family and effective early intervention for the child can help these aims.

From the beginning, the child and their family need to be at the centre of all decisions about their needs. This should enable families to be well informed and to feel in control of their lives. It follows that parents should be treated as equal partners in any planning processes.

The All Wales Strategy brought about many positive changes in the lives of people who have a learning disability in Wales. Research into the effectiveness of the Strategy, showed that many carers and professionals believed that the needs of children had been largely overlooked. In particular, people felt that educational provision remained mostly unaffected. However, there have been significant moves towards inclusion within educational policy. The Welsh Office Green Paper 'BEST for Special Education' (October 1997) stated the desire for children with special educational needs to be educated in mainstream schools, wherever possible, and the UK Government promises in the forthcoming SEN and Disability Rights in Education Bill to introduce a new positive principle for inclusion.

The principle of inclusion must also extend to, and be embraced by those concerned with, the health care (which is addressed in the Health care section), local authority support and generic services provided for children, young people and their families.

Care and Support

SERVICE PRINCIPLE

Parents, carers and professionals must recognise that children and young people with special needs require care and support that promote health and well-being, protect from harm, minimise disadvantage and maximise potential.

Parents and carers should be informed of the child's disability in a sensitive and sympathetic manner and have access to appropriate and timely counselling and information about the help and support that is available.

Parents should be actively involved in the decision-making processes relating to their child.

SERVICE RESPONSE

The principle of inclusion must be applied by authorities in complying with regulations and statutory guidance when developing their guidance, policies, practices and procedures.

Authorities should ensure that all professionals involved in disclosure and counselling should have received training in line with best practice. Comprehensive information in an accessible form on help and support available should be provided when required. The aim must be for parents and carers to be kept fully and promptly informed of the child's diagnosis, prognosis and genetic implications.

The principles within the Individual Planning approach set out earlier should apply. Parents should be given the information and support that they need to participate effectively.

Children have a right to normal developmental experiences. This encompasses both equality of access to pre-school and later provision and opportunity for additional developmental input

Authorities should review the availability of (a) effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour, and (b) ways by which they can support and encourage integration in generic pre-school and later provision. The review should then be followed by the preparation and implementation of an action plan.

Education

SERVICE PRINCIPLE

The child should benefit from an education which enables him/her to develop their maximum potential, alongside their non-disabled peers.

The child should not be discriminated against by the school of his/her choice.

The child should ordinarily access their local school unless their Individual Plan indicates clear benefits from attending a school further away.

SERVICE RESPONSE

Sufficient support staff should be provided to ensure that children with learning disabilities are included and that other children in the classroom are not disadvantaged.

Funding arrangements for early years education should allow for a choice of providers and settings.

All teacher training should include content on working with children with a learning disability.

Existing teachers should receive in-service training on inclusion.

Core competencies and qualifications should be identified for all teaching assistants.

LEA's to publish information in their Education Strategic Plans about their policy on inclusion and the progress being made towards it.

LEA's to monitor admissions of children with SEN into mainstream schools.

Implementation of SEN and Disability Rights in Education Bill.

Funding should be provided for physical adaptation to school buildings to enable inclusion.

Additional costs incurred by local schools to be built into fair funding formulae for schools. Out of area placements to be kept to a minimum and reviewed regularly.

TRANSITION PLANNING

It is important to recognise that individuals will experience many important changes and phases during their life. One transitional period is that between the ages of 14 and 19 years old. Education legislation and guidance requires that a transition plan be drawn up. This plan may need to take into account that arrangements for education and training established during this period may extend until the person is 25 years old.

There are examples of good practice in respect of planning for individuals but this is not consistent across Wales and links between social services, education and health are often not effective. There needs to be recognition that time and resources have to be dedicated to transition planning if it is to be undertaken successfully. Consideration also needs to be given to how those involved in transition planning span the last years of schooling and the transfer to services for adults. The

consequence of poor planning and ineffective co-ordination between agencies is inadequate provision of support and services. (It is anticipated that person-centred Individual Planning will become the established process for considering individual need and the appropriate delivery of support throughout the life span. At this time, such planning processes are not fully developed and therefore additional mechanisms are required to ensure that Transition Planning is undertaken effectively.)

There should be named agency and individual responsibility for Transition Planning for all young people of appropriate age to ensure that all relevant aspects of the person's life are properly considered.

SERVICE PRINCIPLE

Transition planning should achieve a smooth, seamless change from child-centred needs to adult-focused needs, involving comprehensive review across all relevant agencies

SERVICE RESPONSE

Education, social services, health, ELWa and Careers Services should develop a joint protocol for undertaking transition planning. This should include: nominated individual and agency co-ordination arrangements, resource implications and mechanisms for joint funding, sharing of information about need and timetable for the planning process. The protocol should also state that transition plans should be consistent with best practice standards and criteria that apply to individual planning (see Individual Planning section). Full account should be taken of other plans, which are made for some young people e.g. Care Plans and Pathway Plans for children who are looked after.

COMMUNITY LIVING

Better Wales.com establishes the target that by March 2003 at least 90% of those assessed, as needing community care should receive support to allow them to live at home.

Community living extends to all ages and means living with family, friends or independently and playing a full part in the society in which we all live. It cannot be promoted without recognising that it requires the will and resources to make it rewarding. It is not just a matter of accommodation standards, although these are important, but of the active promotion of independence, citizenship, relationships and lifestyles.

Social services, health, education, housing and provider organisations should be working together, in both planning terms and day-to-day provision, to make life, lifestyle and well being of an individual compare with those ordinarily available.

The achievement of community living requires a range of community services and supports to be available to and sensitive towards the needs of people with learning disabilities. Accommodation, for example, should reflect a range of individual choices and preferences, and arrangements should help rather than hinder community life and offer tenants and owners the same rights as are available to others regardless of disability.

Recognition should also be given to the fact that some individuals may need additional help to maintain an acceptable lifestyle in the community. This should be available from people who have received the appropriate level of instruction for the tasks they face and at an acceptable cost. It should, moreover, be flexible and available at times when it is most needed rather than when provider organisations can deliver. The Direct Payment Schemes may provide opportunities for care responsive to individual requirements to be made available.

The needs of those who provide informal care, whether as family members or concerned others, should also be recognised and appropriate arrangements for a variety of support, including respite, should be readily available.

There are also concerns about specific aspects of learning disability services. These mostly relate to those people who may find it more difficult to use ordinarily available facilities because of aspects of their disability. Older people, for example, may require more individualised approaches than has been the case in the past. Certainly this will be the position for those

with complex and challenging needs but they too have the right to live in ordinary housing and enjoy local community life. In some situations special arrangements may be required to manage the possible risks that they pose to themselves and others.

There will be situations, particularly at times of crisis, where sudden, short or longer term interventions will be required and it is essential that the kind of resource to meet this need is readily available. Success will be seen as a return to community living.

Ultimately, community living is about personal lifestyles and the networks of friendships, support arrangements and opportunities that are available to individuals. It is important to remember that understanding about how to provide effective service supports continues to develop and, therefore, achievement of community living will require constant innovation to ensure that lifestyles keep up with changing individual and social circumstances, new ways of looking at individual needs and how they can be best met.

SERVICE PRINCIPLE

All adults with a learning disability, including people with complex and challenging needs, should have access to housing in the community, independent of the family home. Nobody should live in hospital. Accommodation should be available to meet a range of preferences and abilities of a size appropriate to the individual's choice, control, independence and privacy.

Housing arrangements should facilitate access to the local and wider community and offer tenants the chance to build a variety of personal relationships.

Adults with learning disabilities living in community accommodation should have the same tenancy rights as other people.

SERVICE RESPONSE

Social and health care authorities and housing providers should work together using their strategic planning processes to set out accommodation plans to achieve this principle in a way which reflects the demographics of the locality. This will include up-to-date estimates of the accommodation and support needs of those with complex and challenging needs. Individual planning should ensure that prospective tenants are consulted whenever possible about their housing arrangements, and that, over time, adaptations are made to reflect changing needs.

Consideration should be given to the neighbourhood and to access to community activities, shops and public transport when making accommodation arrangements.

Models of service should be developed which allow tenancies to be granted. This should provide equality of treatment with regard to the payment of Council tax, access to grants or any other issue.

Support Arrangements

SERVICE PRINCIPLE

People of all ages should receive support commensurate with their needs to enable them to live in their own homes or with their families. This will include people with complex or challenging needs.

The needs of individuals should be met by a skilled, well supervised, stable, motivated and well trained workforce. This will include enhanced competencies for working with people with complex and challenging needs.

SERVICE RESPONSE

An appropriate range of flexible support services should be available capable of responding to changing need. This will include positive respite care options such as respite at home, family placements and other age-appropriate provision.

The Workforce should be well managed, have the opportunity to progress. NVQ competencies should form the basis of staff development. Service contracts should be explicit in their expectations about support levels and quality of process and outcome. Best practice guidance should be available about exposure to risk.

Natural and informal support networks should be encouraged.

Support providers should explore every opportunity to develop personal and local networks to meet individual's support needs rather than relying exclusively on formal paid support

SERVICE PRINCIPLE

Supporting people to participate in leisure and community activities and to form personal relationships is as important as supporting other aspects of their lives and requires planning.

SERVICE RESPONSE

Service providers should assess individual preferences for leisure activities and plan how to teach and support people's effective participation in their chosen activities. Adoption of a 'natural supports' perspective and interventions such as 'Circles of Support' may broaden the range of personal relationships open to individuals. Friendships that people have formed with other people should be considered when planning transitions and included in individual plans. Existing ties can be positively nurtured and family involvement and the employment of local staff can assist with this. Statements to encourage this aspect of life should be written into service contracts.

Older People

SERVICE PRINCIPLE

The increasing longevity of people with greater and lesser disabilities must be recognised in the services provided.

SERVICE RESPONSE

Specific policies/strategies to meet the needs of older people with learning disability should be prepared both nationally and locally. They should reflect the chronological age differential between older people with learning disabilities and others and the non-normalising character of most generic services. They should include consideration of the resource implications of specialist services. Particular attention should be given to specific health risks, which may require specialist intervention.

Crisis Provision

SERVICE PRINCIPLE

Help must be available at times of crisis for people with ordinary, complex or challenging needs. Various events can precipitate these situations and a range of responses should be available to support the individual in either their own home or in an acceptable alternative location as need arises.

SERVICE RESPONSE

Such services should help the individual to remain in their own home and local community. Where this proves to be difficult or impossible to achieve, temporary residential provision and support may be appropriate and the individual should be helped to return to their home (or to a new long-term home) at the earliest opportunity.

EMPLOYMENT, FURTHER EDUCATION AND DAY ACTIVITIES

The chance to work or do other normal activities is a very reasonable expectation and should be available to all adults with a learning disability of working age. It is important to maximise individual potential and this can be helped by appropriate support which seeks to support the development of skills in every service user.

It is important to provide services and support processes that reflect need and respond to changing wishes. Opportunities for employment, further education and other meaningful activities must be considered within the person's Individual or Transition Plan (see earlier sections). This process will need to involve, as appropriate, the Community Consortia for

Education and Training.

It is now generally agreed that traditional large day centres cannot provide the range of occupation required. Recent years have seen the development of a range of alternative day activities, such as community enterprises, social firms, increased attendance at colleges of further education, supported employment and the provision of more localised supports to access community activities. Whilst some change has taken place, traditional services are still common and further change is required. Moreover change has not been consistent across Wales and the resulting inequality of opportunity needs to be addressed.

Service models such as supported employment, which obtain jobs for people and then train them on site have been shown to be more effective for people with more severe learning disabilities and those with complex or challenging needs than traditional employment training. The progress made in helping people to obtain paid jobs through supported employment in the United States, and more recently in Wales, suggests that there is considerable potential to support a higher number of adults with learning disabilities in paid employment. However, the benefit system limits many people to part-time working and this reduces the benefit of the reform both in terms of lessening the need for alternative day services and the time taken to establish workplace skills. Supported employment requires well-trained job finders and job coaches and extra training may be required for effective support of people with complex and challenging needs.

There is still a small number of adults with learning disabilities in paid employment. While expansion of supported employment is an important goal, other routes to employment through, for example, social firms, and other meaningful day activities, such as community volunteering or individual occupation and training programmes, are still needed.

Vocational Training

SERVICE PRINCIPLE

People with learning disability have a right to equal access to government training schemes and other educational opportunities, when such training would help their personal development and careers.

SERVICE RESPONSE

ELWa need to fund and regulate post 16 education and training so that people with learning disabilities can access a full range of opportunities alongside non-disabled people.

Vocational training should reflect the available jobs market. Contracts with training providers should require training providers to develop their ability to provide individualised supports and amended courses to help people with learning disabilities progress on real work related courses. There should be appropriate records of achievement. Colleges should be encouraged to construct curricula and assessment so that individuals can build a portfolio of achievement (e.g., NPTC system).

Comprehensive information, advice and counselling should be provided to all young people.

Vocational training should normally result in individuals gaining a qualification recognised by employers. There need to be realistic entry criteria so that those accepted on courses have a reasonable expectation of reaching the required standards. Assessment of whether vocational training would be a productive route for people to follow should be part of their Individual or Transition Planning. People who do not reach entry criteria are probably better served by place and train approaches to gaining paid employment (i.e., supported employment).

Support to gain employment is required for people leaving vocational courses. Determining the nature of this support should be part of their Individual or

Adult Education and Lifelong Learning

SERVICE PRINCIPLE

People with learning disabilities have a right to adult education and lifelong learning which contributes to their own development.

SERVICE RESPONSE

Opportunities should be available throughout life, based on assessed need identified in the Individual Plan. Each person should have a learning portfolio, linked to their Individual Plan.

Education should be provided within integrated classes not just in integrated settings. College staff need to have an opportunity to upgrade their skills and knowledge for working with people with learning disability. Support to the individual should be identified and provided. ELWa should monitor all post 16 education and training provision to ensure that it promotes the inclusion of people with learning disabilities and require providers to take action.

Supported Employment

SERVICE PRINCIPLE

People with learning disabilities require systematic training and support to enable them to gain employment in real workplaces.

SERVICE RESPONSE

Social services, education and employment services should use their strategic planning processes to increase the number of supported employment services in Wales and the number of people supported in paid employment by them. There should be good links between employers, supported employment services and both social care day services and mainstream employment services so that supported employment can provide a bridge to the workplace for people moving out of traditional day services and those graduating from schools, colleges or other forms of vocational training.

Other Constructive Occupation

SERVICE PRINCIPLE

Outside of open employment and engagement in further education, people with learning disabilities have a right to day services, which provide them with meaningful and rewarding activities, which reflect their interests and develop their confidence and skills.

SERVICE RESPONSE

Authorities should use their strategic planning processes to ensure that a range of options are available in local communities which are collectively sufficient to meet need. Options to include: social firms, community enterprises, local community bases, programmes of individual community-based activity, involvement in civic works and voluntary activity, and retirement schemes. Consideration should be given to preventing unnecessary travel thereby promoting people's participation in their local communities.

Appropriate support may be provided as part of the service (e.g., within a social firm) or as an outreach programme from a local base (e.g., to a programme of community-based activity or voluntary placement).

Day activities should reflect people's interests and ambitions. They need to link in with other leisure, social and educational activities in people's lives. Co-ordination and forward planning should be achieved through Individual Planning.

Voluntary placements should be provided as something positive in their own right, not as a simpler alternative to supporting a person in paid work. People should be linked to a mainstream volunteering scheme wherever possible.

Services for People with Complex or Challenging Needs

SERVICE PRINCIPLE

People with complex or challenging needs should be included in the options available to other people with learning disabilities.

SERVICE RESPONSE

Authorities must systematically review the range of options available to people with complex or challenging needs. In so doing, authorities should ensure that there is a sufficiently skilled workforce, professional input and enhanced support that may include specialist equipment and environmental adaptations to meet peoples needs.

Authorities must work effectively together to end any dichotomy between 'health care' and 'social care' responsibilities (see the Severe Challenging Behaviour section).

GENERAL HEALTH NEEDS

There is strong evidence that people with learning disabilities have poorer general health and more specific health needs than the general population. The Health Evidence Bulletin-Wales indicates that there is increased illness in a number of areas, such as problems with hearing and eyesight, psychiatric and behavioural difficulties, epilepsy, thyroid disorders, heart disorders and dental problems. Specific health needs may also arise from some of the known causes of learning disability.

However, despite this increased need there is evidence that people with learning disabilities do not always receive the health provision required. There may be a lack of recognition of common and treatable medical conditions, particularly if the individual has difficulty in communicating symptoms, and carers lack training in the identification of health problems.

Problems in providing adequate health care may arise from:

- a. lack of accessible information about health promotion,
- b. varied attitudes of professionals in primary care,
- c. inadequate training related to the needs of people with learning disabilities and difficulties in communication, judging capacity and consent, and
- d. difficulties in accessing services that may be available.

Regular health checks have been shown to assist in identifying unmet need and requirements for action to address health problems.

SERVICE PRINCIPLE

People with learning disability of all ages have a right to similar good health as other people.

SERVICE RESPONSE

People with learning disability should have information in an accessible form to make choices about exercise, diet, alcohol and cigarette consumption, level of activity or exercise, oral health and dental care, substance misuse and sexuality. The individual plan should specify responsibilities and actions to meet agreed goals in these areas. Training of carers should include the promotion of healthy life styles, the recognition of symptoms of ill health or dental caries, and the recognition that medical or dental intervention may be required.

People with learning disability of all ages should have their general health needs met by primary health care services and equality of access to secondary and specialist health provision as appropriate.

Each GP practice should develop a Learning Disability database, to allow the practice to identify and target health interventions and health promotions accurately.

All practices should produce clear policies on how people with learning disabilities will be supported to access their services. These should recognise that longer consultation times may be appropriate.

Each individual should have regular health checks carried out by their Primary Healthcare Team. These checks should include regular reviews of prescribed medication. Various professionals may contribute to this care including GPs, practice nurses, community nurses and Health Visitors. They should be appropriately trained and working within the context of agreed, evidence based protocols e.g., the Cardiff Health Checks. There should be a system for ensuring follow-up action is undertaken after the health check.

All people with a learning disability should be registered with a GDP who should be able to access specialist support from the community dental services and specialist hospital provision (including emergency dental treatment where needed).

Health Authorities should require all Health Care Trusts to develop clear policies on how individuals with learning disabilities of all ages will be supported to access their services, including effective speech and other therapies and psychology services.

Individually held personal health records should improve communication between relevant health care providers. Pilots should be set up to assess their effectiveness.

SERVICE RESPONSE

SERVICE PRINCIPLE

People with learning disability have a right to expect treatment from health care workers who have received adequate training in the recognition and provision of appropriate health care to people with a learning disability.

Curricula/programmes for all health care professionals must include training in learning disability issues, including special health care problems, discrimination, communication, capacity and consent.

Aids to daily living and adaptations to premises and property, which contribute to the development and independence of individuals, must be available to them and their carers.

Health, housing and social services authorities should develop joint protocols for the assessment and where appropriate provision of aids to daily living and adaptations to ensure an accountable and effective response is made to requests.

Young people and adults should be able to access confidential advice and information about personal relationships and development.

Clear policies, curriculum coherence and co-ordination between agencies should ensure that appropriate advice is available to individuals about personal relationships and sexuality. Information and advice should be made available to carers about the policies that are in force.

Skilled specialist help should be available to diagnose and, if required, manage and provide appropriate support for particular conditions, such as autistic spectrum disorders, to promote inclusion.

The specialist nature of these disorders should not prevent individuals having access to those resources which will enable them to remain in their own homes and communities.

SERVICE PRINCIPLE

People with a learning disability who have acute mental health needs should be able to access their local acute mental health services.

SERVICE RESPONSE

Acute mental health services should provide the same level and quality of service for all, regardless of whether they have a learning disability.

Active efforts should be made to provide additional training for nursing and medical staff in acute mental health services concerning the needs of people with learning disabilities.

Local community learning disability teams should retain contact with their clients during periods when they are admitted to acute mental health units. Local community learning disability teams and their mental health colleagues should work collaboratively and learning disability teams should provide advice and support if and when admission to acute care is needed.

There should be no decommissioning of existing specialist services before adequate and appropriate mental health services are established.

COMPLEX HEALTH NEEDS

Some people with learning disabilities have complex health care needs due to the co-occurrence of physical disabilities, hearing/eyesight problems, epilepsy, chest problems, swallowing problems, and other chronic medical conditions. Advances in medical technology and care may mean that this group is growing in number.

Particular specialist arrangements may be required for people with complex health needs in order that their needs are met effectively and safely whilst still enabling the individuals to enjoy an ordinary life in their local communities.

The growing recognition by all organisations of the requirement to address this range of needs for increasing numbers of people is very important, Joint working in terms of service provision and personnel training will be essential. Well-trained and supported carers (both family and paid carers) can be taught to undertake specific clinical procedures safely. Individual clinical risk assessments should be done and regularly reviewed on a case-by-case basis.

SERVICE PRINCIPLE

SERVICE RESPONSE

People with learning disabilities of all ages who have complex health needs have a right to an ordinary life and to have their needs met at home in their local community.

Childcare teams and community learning disability teams for adults should provide a link between the home and primary care and specialist services. Teams should have a mix of staff skills, and include all relevant clinical disciplines.

Team members should develop the skills of carers by, as well as training them when specific procedures are required, providing them with regular consultancy and support.

Paediatric and learning disability services should review and strengthen their recruitment and retention strategies to ensure that specialist multi-disciplinary skills are available within the community.

Workforce planning should be sensitive to the need to train sufficient staff in the various clinical professions to meet the staffing needs of teams.

Standard protocols should be produced that clarify standards, responsibilities and accountability concerning the administration of clinical procedures by unqualified staff and family carers. These policies should include specific recommendations concerning administration of intrusive clinical procedures

SEVERE CHALLENGING BEHAVIOUR

Some 12% to 17% of people with learning disabilities show challenging behaviour and of those 40% to 60% will show more severe problems. This may include the committing of criminal offences. The critical issues concerning such people focus on how best to meet their needs effectively and safely whilst enabling the individuals to enjoy an ordinary life in their local communities and ensuring appropriate provision for those people who are detained under civil or criminal Sections of the Mental Health Act (1983).

In considering the needs of this group, the All Wales Advisory Panel report "Challenges and Responses" (1991) advised that provision should be developed to enable such individuals to live in ordinary housing, use local community facilities and wherever possible, participate in a stimulating and enjoyable day occupation preferably in an integrated setting, and thus have a genuine presence in their community. The Advisory group support this approach. This is reflected in the Community Living and Work and Day Services sections.

In addition to the regular social and health care services that people with learning disabilities require, those who have challenging needs also require specialist input:

- Early assessment, advice and support from professionals who have expertise in the analysis and design of intervention procedures for people with challenging behaviour. This can be provided from specialist challenging behaviour support teams or from community learning disability team professionals. The purpose of their work is to reduce the challenging behaviour, design management strategies, help carers to develop coping skills, and develop a plan to promote the quality of life and community participation of the people concerned. Much of their work involves providing consultancy, training and support to regular carers and service providers.
- At times of acute crisis, regular service provision needs to be improved with the aim that people remain in their homes and local communities. Where this proves to be impossible to achieve, temporary alternative accommodation

and residential support may be needed until they can return home or go to a new long term home (see item on Crisis Provision in Community Living section).

Currently, there is scarce provision for people detained under the Mental Health Act particularly if there is a need for long term treatment or management for mental impairment or severe mental impairment. Some people have been transferred to hospitals or services in England and this has created difficulties for family to maintain contact.

There is, however, a difference of opinion concerning whether the provision of accommodation, residential support, respite services and day services for people with such behaviour is considered to be "social care" (and be commissioned and funded by local authority social services departments) or "health care" (and be commissioned and funded by health authorities). The "health care" - "social care" split has proved to be a barrier to progress in recent years and continues to pose problems in assessing and categorising people. A system of genuine joint commissioning and "pooling" of resources for people with severe challenging behaviour could overcome these difficulties.

SERVICE PRINCIPLE

People with learning disabilities who present challenging behaviour should receive care and treatment appropriate to their needs as close as possible to their home, irrespective of the severity of the level of challenge.

People who are detained under civil or criminal sections of the Mental Health Act (1983), should be placed as close as possible to their home location

SERVICE RESPONSE

Authorities in each area of Wales should ensure that there is access to staff with specialist expertise in the analysis of challenging behaviour who have a remit to provide a pro-active assessment, advice and support service. This service can be provided from specialist resource teams or from individual professionals in local community learning disability teams. The aim is to enhance the capacity of regular carers and service providers to meet the needs of people with severe challenging behaviour through the training and support provided.

Out-of-area placements may still be the most viable means of providing for people with learning disabilities that require high or medium secure hospital accommodation because of their extremely low numbers.

Sub-regional intensive rehabilitation units should be provided in Wales for people requiring low security (also in relatively low numbers). In deciding the size and distribution of such units across Wales, issues that need to be considered include:

(a) average length of stay

(b) the need to build a 'critical mass' of clinical expertise

(c) the need to develop local follow up provision. Planning arrangements should recognise the possibility for people to step down from low security provision to enhanced community living schemes.

Clear co ordination links should be established in each area of Wales between the judicial, probation, health and social services in respect of individuals with a learning disability who have offended and are likely to be subject to the requirements of the courts and/or the Mental Health Act.

MEMBERSHIP OF THE LEARNING DISABILITY ADVISORY GROUP (WALES)

Dr Oliver Russell, Norah Fry Research Centre - Chairman

Howard Sinclair, Mencap in Wales

Jim Crowe, Standing Conference of Voluntary Organisations for People with a Learning Disability in Wales

Aneurin Williams, People First Wales

Norbert Flynn, All Wales Forum of Parents and Carers

Dr Sean O'Reilly, GP

Dr Peter Woods, Welsh Clinical Psychologists Advisory Group

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Dr Val Anness, Royal College of Psychiatry

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A SUMMARY

The number of people with severe learning disability increased significantly between 1991 and 1998. Official sources indicate that these trends will be sustained over the first two decades of the 21st Century. There is also the beginnings of a substantial group of older people with severe learning disability. Increases in numbers, increases in expectations and increases in aspirations require a new approach to the provision of effective and efficient services to people with learning disabilities.

The draft service framework prepared by the Learning Disability Advisory Group sets out the vision and guidelines, principles, the policy context, priorities, performance indicators and an action plan to ensure the highest standards of service to this growing number of people. It provides guidance to authorities and organisations who have responsibilities to secure the social inclusion of people with learning disabilities into all aspects of life and society in Wales and to provide the support to allow them to take their place in their communities.

THE VISION FOR SERVICES IN 2010

The Advisory Group believes that the principled service development initiated by the 1983 All Wales Strategy (AWS) should continue. By 2010 services for people with learning disabilities will be more accessible, comprehensive and person-centred than ever before. They will be more responsive to individual preferences, and reflect a greater commitment to partnership-in-provision, workforce training and best value.

POLICY CONTEXT

The vision for service and the standards of every day service provision mirror the policy context of modern day Wales.

The National Assembly's vision for Wales is set out in Better Wales. The present proposals are consistent with this report as well as the strategic planning arrangements the National Assembly for Wales is putting in place for Social Services, Health, the Special Educational Needs programme, the Carers Strategy and the Supporting People proposals. Moreover, it includes the necessity for people living in long stay learning disability hospitals and other inappropriate accommodation to have been resettled into the community.

PROGRESS AND CHALLENGES

When launched in 1983, the AWS was a far sighted policy which progressively gained popular support among people with learning disabilities, their families and carers, professionals and service authorities. Understanding about how to plan and implement effective service supports has developed since that time but the vision and strategic direction it set remain widely

endorsed. It provides a frame of reference against which the progress of the past and the challenges of the future can be measured.

Funding The level of investment promised by the AWS in its first 10 years was delivered. Since 1994, the central funding of strategic development of services has continued in a more limited way to progress hospital resettlement. Despite increases in the resettlement grant allocation, the proportion of personal social services expenditure on people with learning disabilities has remained almost constant since 1994.

Supported Accommodation Wales has made great progress in reforming the nature of residential services. In contrast to what existed in 1983, available services are smaller in scale, within ordinary housing stock, and more local to the communities which they serve. However, while the quality of provision has improved, no progress has been made in

extending service availability. Wales has a low rate of residential service provision in comparison to other countries of the UK, much below policy targets set in 1971 and 1983.

Family-support The growth of respite and family aide services was a high priority of the AWS and progress has been made. However, more needs to be done.

Day Services for Adults In line with AWS recommendations, there is now a greater variety in day provision and less reliance on large day centres. However, reform of the nature of existing services is not complete and there has been only limited expansion of service availability. Continuing reform and extending service availability now need to go hand in hand.

Expanding access to supported employment services is a particular priority. However, current welfare benefit arrangements lessen the cost effectiveness and potential impact of supported employment.

Greater survival is seeing the beginnings of a significant population of people with severe learning disabilities of retirement age and the need for appropriate support services.

Individual (person-centred) planning Individual Planning (IP) as a means of service co-ordination and review grew in Wales after 1983 but was only ever available to a minority of service users. Care assessment introduced by the NHS and Community Care Act has been viewed as a return to a resource rather than needs-led approach to planning. While policy reference to some form of IP has been long-standing, realistic assessment of the resources required to instigate and sustain such a system of planning has never been undertaken.

Joint planning and family and user consultation In establishing the social services department as lead agency, Wales has achieved a more wholehearted transition from health to local authority commissioning of social care services than elsewhere in Britain. The AWS saw the development of a distinctive level of joint agency collaboration and consumer representation in planning. However, reforms of recent years have not helped to further this and some good practice may have weakened. Advocacy has become established but is widely regarded as insufficient to meet need.

Pattern of provision It is clear that service development has not been evenly distributed across Wales. Current variation in local authority expenditure on learning disability services reflects prior institutional service concentrations.

Improving service quality It is now evident that resettlement from hospital or hostel accommodation to supported community housing leads to quality of life gains, moving from traditional day services to supported employment results in financial gains, more constructive activity and greater social integration, and also that the growth in domiciliary and respite care services has been deeply appreciated by family carers and led to improvements in their quality of life.

Service costs and quality It is also clear that quality of outcome and costs vary considerably across outwardly similar services, and that quality and costs are only weakly related to each other. Differences in what staff actually do seem to be the key to differences in quality.

SETTING SERVICE PRIORITIES AND TARGETS

The Advisory Group recommends that local authority elected members, members of Health Boards and Local Health Groups and senior managers in statutory and other organisations should promote and introduce policies to achieve the priorities and targets set out in this report as speedily and effectively as possible. The Report sets out 17 priorities for action by the National Assembly and others. These are not ranked priorities as all must be progressed in parallel. Each has an associated target and timescale. The National Assembly should:

1. *Policy Direction* - reaffirm its commitment to develop the means to extend to all people with learning disabilities in

Wales the opportunity to lead a life consistent with the AWS and this report

Target - By Spring 2002, all authorities will have reviewed their services against the 'Service Principles' and 'Service Responses' set out in the SERVICE FRAMEWORK Section of this summary and Section 5 of the main report

2. Funding - consider introducing a structured investment programme to increase and develop service availability in line with this report

Target - By July 2002, all authorities will have prepared Health and Social Care Plans which include costed 5 year projections of needs, targets and service developments for people with learning disabilities

3. Completion of Existing Programmes of Reform - review its commitment to achieve the closure of long stay hospitals and set a new target date for completion of 2006 or preferably earlier; and extend the scope of resettlement to include other inappropriate accommodation

Target - By 2006, all long term hospitals should be closed following completion of resettlement and by 2010 other inappropriate accommodation should be phased out

4. Individual Planning - confirm that person centred planning is fundamental to addressing individual needs and aspirations and that the cornerstone to their conduct should be multi-disciplinary and multi-agency Community Learning Disability Teams; any additional resource requirements should be considered within the National Assembly's larger investment programme

Target - By 2003/2004, all people with a learning disability will have an individual person-centred plan, normally reviewed annually

5. Independent Assessment of the Needs of Carers - invite the Carers Strategy Review Panel to consider best practice standards, training requirements and resource implications of separately assessing carers needs and to respond appropriately within its National Carers Strategy

Target - By 2001/2002 independent carers assessments will be available as of right

6. Information - commission research to identify best practice in respect of the collection, provision, sharing and dissemination of information; and consider what information could be appropriately provided on a national level across Wales

Targets - By 2002/2003, (i) all Health and Social Care Plans and Annual Statements/Reviews for services for all people with learning disabilities will include the programme of public information about services and service developments, (ii) arrangements will have been made to ensure local and national information is widely available to all people with learning disabilities, their parents and carers using all appropriate formats

7. Advocacy - evaluate how a centrally funded advocacy service can be developed and regulated on a national basis; these services should include citizen advocacy, self-advocacy and paid advocacy; any evaluation should take full account of the UK Government's response to the advocacy section of the Disability Rights Task Force report

Target - By 2002/2003, the National Assembly will have completed its evaluation and be consulting on proposals to introduce a national centrally funded advocacy service

8. Partnership in Planning - reaffirm the lead role of the local authority Social Services function; make available further resources to facilitate implementation of the increased flexibilities under the Health Act 1999; ensure that national guidance

requires authorities to constructively include users, carers and others in the planning and development of services; facilitate the pooling of resources between agencies to remove the financial incentive accompanying the redefinition of responsibility from one agency to another; introduce a financial and management information framework with standard definitions for authorities to collect, collate and distribute data on capacity, usage and expenditure on all learning disability services. In support of this, agencies should agree protocols for joint working

Target – By 2003/2004, authorities will have published plans to improve the joint working of health, social services and other agencies including the use of pooled budgets, integrated provision and lead commissioning of services and facilities

9. Children and Families - invite services and education bodies to review the availability of (i) effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour, and (ii) effective ways of supporting and encouraging integration in general pre-school and later provision; and subsequently to develop an action plan to make effective services and supports generally available

Target – By 2003/2004, Childrens' Services Plans should promote equal opportunities and inclusion and indicate how local authorities and partner agencies propose to develop community based support strategies to enable younger people with disabilities to be included in mainstream activities as much as possible

10. Education - develop education and lifelong learning policies which encourage arrangements consistent with inclusion; provide resources to provide additional educational support to those with special needs; and ensure that all teachers and teaching assistants receive appropriate training to effectively support the learning and development of people with learning disabilities

Target – By 2004, to have significantly improved the quality of education for children with special needs by completing the three year action plan and the introduction of a new Special Educational Needs Code of Practice

11. Help in the Family Home - through its Carers Special Grant and other policies encourage authorities to make available a range and sufficient quantity of flexible support services and positive options for short term breaks

Target – By 2005, there should be a significant increase in the range and quantity of flexible support services and positive options for short term breaks

12. Support to Live Independently in the Community - make available additional resources to significantly increase the number of people who are able to access appropriate accommodation away from the family home

Target – By 2010, to have significantly increased the number of people who can realistically be expected to live independently with appropriate support irrespective of age and impairment – this will require at least an additional 1500 people with learning disabilities to be supported outside of the family home

13. Direct Payments - consider changing the existing arrangements to enable local authority services to be encompassed in the Direct Payments scheme

Target – By 2003, all local authorities are operating an appropriate direct payments scheme for people with learning disabilities.

14. People with Complex and Challenging Needs - ensure that authorities use their strategic planning processes to provide up-to-date estimates of the accommodation and support needs of people with complex and challenging needs, ensure carers are assisted to develop appropriate skills and have access to staff with specialist expertise who can assess complex needs and provide advice and support, and develop plans to increase the availability of intensive rehabilitation services so that people in need of 'low security' can be placed within Wales

Targets – By 2003, community facilities and intensive rehabilitation services to support people with complex or challenging needs must be an integral part of the re-provisioning plans following the closure of existing long stay hospitals; By 2008, regional services should be available and the number of people placed outside of Wales reduced by 50%

15. Day Activities - set targets for the expansion of supported employment and supports for other socially integrative and educational opportunities; and discuss with the UK Government how social security impediments to paid employment can be removed

Target – By 2004/2005, to have opened up opportunities for all people with learning disabilities by encouraging lifelong learning opportunities and more flexible ways of formal and informal learning, and by increasing the access to quality careers advice and supported employment

16. Health - make resources available to enable every GP to adopt the proactive identification and health checking recommendations contained in this report

Target – By 2010, to have improved the health of people with learning disabilities and reduced any differences between rates of illness and mortality experienced by them and overall national rates

17. The Workforce – extend the qualification regime and targets to include all the social care workforce and set complementary targets for the training of the NHS workforce as part of its Human Resources Strategy

Targets – By 2005, (i) to have all social care managers and 50% of the social care workforce providing services to people with learning disabilities with a listed qualification, and (ii) the training of doctors, dentists, opticians, other NHS staff, housing and benefit agency staff, teachers and the police to include an element that helps them to have a better understanding of learning disability issues.

THE SERVICE FRAMEWORK

The service framework sets out the Service Principles and the recommended Service Responses as a guide to those who commission or provide services. Altogether there are nine areas covered: Individual Planning, Information Provision, Advocacy, Inclusion and Participation, Children and Families, Transitions, Community Living, Work and Day Services, and Health Care.

The main recommendations are summarised below:

Individual (Person-centred) Planning

Agency responsibilities and commitments at different stages of a person's life need to be defined.

Best practice standards and criteria need to be agreed to provide the basis for a uniform approach.

Guidelines and training should be available to people with learning disabilities to help them state preferences and formulate decisions.

Individuals may be represented by their next-of-kin. Access to a range of advocacy services should also be available.

Individual plans should reflect realistic time perspectives and standards should be set for the frequency of review within best practice guidance.

The development of service unit costings is required to enable care managers to identify cost effective packages to meet support arrangements.

Separate but parallel planning mechanisms are required for carers.

The resource costs of comprehensive implementation need to be calculated and a strategic investment plan drawn up.

Information Provision

Organisations should ensure that there is accessible information on the full range of services and facilities available.

Authorities should publicise the rights of users and carers to participate in planning.

Advocacy

Independent advocacy services should be made available whenever a need has been identified for a vulnerable person to have independent representation of their views.

Authorities should encourage the growth and use of a range of appropriately trained and regulated independent advocacy services.

Partnership in Planning

Authorities must consider the breadth of stakeholder interests and develop procedures in consultation with interested parties for their participation in planning.

Local partnership plans should include user and carer perspectives and summaries of consultations, establish core aims and strategic, financial and performance objectives, decide among competing priorities and report on achievements against objectives and on user evaluations of services.

Authorities should ensure that reasonable costs of user and carer group participation in planning are met.

Children and Families

The principle of inclusion must be applied by authorities in complying with regulations and statutory guidance when developing their guidance, policies, practices and procedures.

Authorities should ensure that all professionals involved in disclosure and counselling should have received training in line with best practice.

Parents should be given the information and support that they need to participate effectively in Individual Planning.

Authorities should review the availability of (i) effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour, and (ii) ways by which they can support and encourage integration in generic pre-school and later provision. The review should then be followed by the preparation and implementation of an action plan.

Sufficient support staff should be provided to ensure that children with learning disabilities are included in mainstream educational classes and that other children in the classroom are not disadvantaged.

Existing teachers and teachers in training should receive training on inclusion and how to work with children with a learning disability.

Education Strategic Plans should state policy on inclusion and provide monitoring information on the placement of children with SEN in schools.

Funding should be provided for physical adaptation to school buildings to enable inclusion.

Transition Planning

Education, social services, health and the Careers Service should develop a joint protocol for undertaking transition planning in line with best practice standards and criteria that apply to individual planning.

Community Living

Social and health care authorities and housing providers should work together using their strategic planning processes to set out plans for all adults with a learning disability, including people with complex and challenging needs, to have access to housing in the community, independent of the family home.

Consideration should be given to the nature of the neighbourhood and to access to community activities, shops and public transport when making accommodation arrangements.

Models of service should be developed which allow tenancies to be granted.

A range and sufficient quantity of flexible support services should be available capable of responding to changing need. This will include positive respite care options such as respite at home, family placements and other age-appropriate provision.

The workforce should be well-managed and competent and service contracts should be explicit in their expectations about support levels and quality of process and outcome.

Support providers should encourage natural and informal support networks.

Service providers should assess individual preferences for leisure activities and plan how to teach and support people's effective participation in their chosen activities.

Specific policies/strategies to meet the needs of older people with learning disability should be prepared both nationally and locally.

Help at times of crisis should be directed towards helping the individual to remain in their own home and local community.

Employment, Further Education and Day Activities

ELWa need to fund and regulate post 16 education and training so that people with learning disabilities can access a full range of vocational training opportunities alongside their non-disabled peers. Contracts with training providers should develop their ability to provide individualised supports and amended curricula to help people with learning disabilities progress on genuinely vocationally-related courses. There should be appropriate records of achievement and vocational training should be associated with an expectation of gaining a qualification recognised by employers.

Opportunities for adult education and lifelong learning should be available throughout life.

Social services, education and employment services should use their strategic planning processes to increase the number of supported employment services in Wales and the number of people supported in paid employment.

Authorities should use their strategic planning processes to ensure that a range of other day activity options are available in local communities which are collectively sufficient to meet need.

Authorities must systematically review the range of options available to people with complex or challenging needs.

General Health Needs

People with learning disability should have information in an accessible form to make choices about exercise, diet, alcohol and cigarette consumption, level of activity or exercise, oral health and dental care, substance misuse and sexuality.

Each GP practice should develop a Learning Disability database.

Each individual should have regular health checks and review of their medication.

All people with a learning disability should be registered with a GGP who should be able to access specialist support from the community dental services and specialist hospital provision

Trusts should develop clear policies on how individuals with learning disabilities of all ages will be supported to access their services

Curricula/programmes for all health care professionals must include training in learning disability issues.

Health, housing and social services authorities should develop joint protocols for the assessment and where appropriate provision of aids to daily living and adaptations to ensure an accountable and effective response is made to requests.

Clear policies, curriculum coherence and co-ordination between agencies should ensure that appropriate advice is available to individuals about personal relationships and sexuality. Information and advice should be made available to carers about the policies that are in force.

Complex Health Needs

Child care teams and community learning disability teams for adults should provide a link between the home and primary care and specialist services.

Team members should transmit their skills to carers.

Paediatric and learning disability services should review and strengthen their recruitment and retention strategies to ensure that specialist therapy skills are available within the community.

Workforce planning should be sensitive to the need to train sufficient staff.

Standard protocols should be produced that clarify standards, responsibilities and accountability concerning the administration of clinical procedures by unqualified staff and family carers.

Severe Challenging Behaviour

Authorities in each area of Wales should ensure that there is access to staff with specialist expertise in the analysis of challenging behaviour who have a remit to provide a pro-active assessment, advice and support service.

Out-of-area placements may still be the most viable means of providing for people with learning disabilities who require high or medium secure hospital accommodation.

Sub-regional intensive rehabilitation services should be provided in Wales for people requiring low security.

Clear co ordination links should be established in each area of Wales between the judicial, probation, health and social services in respect of individuals with a learning disability who have offended and are likely to be subject to the requirements of the courts and/or the Mental Health Act.

Additional Mental Health Care Needs

Acute mental health services should provide the same level and quality of service for all, regardless of whether a person has a learning disability.

Active efforts should be made to provide additional training for nursing and medical staff in acute mental health units concerning the needs of people with learning disabilities.

Local community learning disability teams should retain contact with their clients during periods when they are admitted to acute mental health units.

Workforce Training

Authorities should take the resource implications of ensuring a properly trained workforce into account in their contracting arrangements.

The Training Support Programme qualification regime and targets should be extended to include all the social care workforce.

All social care managers should have a recognised qualification by 2005.

A minimum of 50% of the social care workforce should attain NVQ level 2 by 2005.

The Human Resource Strategy for the NHS in Wales should set complementary targets for the training of its workforce.

Authorities should enable service users to play an effective role in the design and delivery of training.

FINANCIAL IMPLICATIONS

A number of the Service Principles and Service Responses will be implemented through the everyday development of service provision but to meet the full range of aims and targets the Advisory Group believe that the National Assembly will need to make available at least an additional £20 million from 2003-04 rising to £40 million in 2004-05 and £60 million in 2005-06. These requirements are likely to continue to rise each year up to 2009-10. Only with such levels of investment particularly in the accommodation sector will the vision for services in 2010 be attained.

THE ACTION PLAN APPROACH

The Advisory Group consider the most effective way of responding to the priorities and other proposals in this report would be to adopt the Action Plan Approach. As a first step, authorities will be required to carry out an Audit of their services and identify their priorities for action. Once this has been done (by July 2002) additional resources can be made available as a central direct grant and as a ring fenced funding arrangement to health and education authorities to meet the individual priority areas identified in the Audits. A possible timetable for the first five years of the Action Plan is set out in the Report.