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

Consultation Document
Full Version
Further copies of this document can be obtained from:

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FOREWORD

The potential for the future prosperity and success of Wales resides with the children and young people of today. These standards are testament to the Assembly Government’s commitment to the children of Wales. This National Service Framework (NSF) sets out the quality of services that children, young people and their families have a right to receive. It also embodies our belief that, in Wales, we can deliver on these standards by service planners and providers working in partnership and collaboration across organisations to achieve this vision. The development of the Children’s NSF has been an inclusive process involving professionals from all areas of children’s services as well as children, young people and families. A Young Person’s Consultation Document has also been produced to enable young people to help shape the services they would like to receive.

We urge you now to participate in this consultation and to help us develop the standards further to make sure they have maximum impact on the health and well-being of children and young people. Ensuring that quality services are provided for our children and young people is the best investment we can make for the future of Wales.

Sue Essex
Minister for Finance, Local Government and Public Services

Jane Hutt
Minister for Health and Social Services

Rhodri Morgan
First Minister

Andrew Davies
Minister for Economic Development and Transport

Jane Davidson
Minister for Education and Lifelong Learning

Carwyn Jones
Minister for Environment, Planning and Countryside

Edwina Hart
Minister for Social Justice and Regeneration

Alun Pugh
Minister for Culture, Welsh Language and Sport

Karen Sinclair
Business Minister

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Alun Pugh
Minister for Culture, Welsh Language and Sport

Karen Sinclair
Business Minister
The Welsh Assembly Government’s Commitment to the Children and Young People of Wales

Wales – A Better Country1 set out the Assembly Government’s vision for creating a fairer, more prosperous, healthier and better-educated country. We committed to achieving this by putting health and wealth creation that is sustainable at the heart of policy making and by ensuring that:

“children and future generations enjoy better prospects in life, and are not landed with a legacy of problems bequeathed by us.”

The Assembly Government’s strategy for delivering this commitment is laid out in Frameworks for Partnership2. This gives guidance on setting up local Partnerships to ensure that policy formulation and service provision are appropriate to need, receive due priority and are delivered in a co-ordinated and focused way. Progress made is described in Children and Young People: Rights to Action3.

The National Service Framework (NSF) for Children, Young People and Maternity Services should not be viewed in isolation, as it is just one part of the delivery of the Assembly Government’s strategy for children and young people. The synergy that results from bringing together all policy development for children and young people will become a powerful force for helping all children and young people in Wales achieve their full potential and live healthy and satisfying lives.

All the work which the Assembly Government does with children and young people is guided by the UN Convention on the Rights of the Child4 and has been translated into seven core aims to ensure that all children and young people:

1. Have a flying start in life;
2. Have a comprehensive range of education and learning opportunities;
3. Enjoy the best possible health and freedom from abuse, victimisation and exploitation;
4. Have access to play, leisure, sporting and cultural activities;
5. Are listened to, treated with respect, and have their race and cultural identity recognised;
6. Have a safe home and a community which supports physical and emotional well-being;
7. Are not disadvantaged by poverty.
These seven core aims have formed the guiding principles for the development of these standards. The standards and key actions set out in this NSF aim to provide a yardstick against which the quality and equity of services can be measured over time. Delivery will ensure that the vision set out in Wales – A Better Country ¹ is achieved by improving the quality and equity of service delivery to children and young people in all the settings in which they spend time.
NOTE: Any section within these standards should be read in conjunction with Chapter 2, which contains key actions that are relevant to all children, young people and their families.

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Terms or words in blue in this document are defined in the Glossary of Terms
CONSULTATION QUESTIONS

Responses are invited to this consultation document by Friday 21st January 2005. Responses can be sent to the address at the end of the list of questions or sent electronically to: jean.christensen@wales.gsi.gov.uk. Responses to the consultation will be made public. Normally, the name and address (or part of the address) of the author are published along with the response. If you do not wish to be identified please state this expressly in your response.

1. Please state your name, title and place of work (please also state if you want your name withheld from the publication of the results of this consultation).

2. Some of the key actions within this document have been flagged for delivery by the end of March 2006. Implementation of these key actions has been estimated to be low or no-cost because they are organisational issues or are already being planned for, or worked towards, in many areas.

Do you agree that the flagged key actions are the right ones to prioritise for early delivery? Please state which of the flagged key actions you do not believe can be delivered by this deadline and why. Please also state if there are any unflagged key actions which you believe could be delivered by the end of March 2006.

3. Each key action has the organisations which are responsible for their delivery clearly identified.

Are there any key actions which you feel that the organisation you work for is not responsible for delivering? Are there any key actions which you feel your organisation could contribute to delivering but has not been listed next to a key action? (Voluntary organisations should read “Organisation of the chapters in this document” on page 14)

4. When you read this document you will notice that this NSF does not address specific conditions but instead addresses the overall needs of children, young people and their families.

Are there any important NEEDS of children, young people and their families which you feel have not been addressed by the key actions in this NSF?

5. When writing the key actions, every attempt has been made to make each one clear, specific and measurable to allow for easier audit.

Are there any key actions which you feel do not meet the above criteria? If so, can you suggest a form of wording that would improve the key action?
6. A self-assessment audit tool (SAAT) is being designed to measure the extent to which key actions are being delivered (a further explanation of this can be found on page 11 under Measuring Success). In many instances, local areas will already be gathering data for their own purposes that will assist organisations in assessing their progress against a key action using the SAAT.

**Are there any key actions in which you feel that it would be very difficult to assess your progress because of a lack of local information?**

7. Every attempt has been made to avoid the use of professional jargon within this document. Where use of professional terms has been unavoidable, these have been defined within a glossary of terms. Other terms included in the glossary are those for which there is already common understanding but they need definition with regard to these standards e.g. disabled child.

**Are there any terms or phrases used within this document that have not been included in the glossary, but which you feel require definition?**

8. Can you foresee any barriers to the implementation of these standards? If so, are there any actions which the Welsh Assembly Government should take to help overcome these barriers?

9. From those key actions which are NOT FLAGGED (i.e. developmental key actions) please select the three that you feel will have the greatest impact on the health and well-being of children and rank them in order of priority.

10. Do you have any other comments that you would like to make about this document?

Please send your consultation responses to:

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CHAPTER 1

Setting the Scene

The National Service Framework for Children, Young People and Maternity Services will contribute to the achievement of the Assembly Government’s seven core aims for children and young people by improving quality and reducing variations in service delivery through the setting of national standards. These standards have been set not just for health and social care but also for other local government services which have a strong influence on the health and well-being of children, such as education, housing, leisure and transport. Its value lies in the extent to which the standards and key actions can be incorporated into policy development and service planning and used to define measures of service quality that will be the basis for monitoring and evaluation.

The scope of the NSF includes all children and young people from pre-conception to their 18th birthday. As the health of the mother and her maternity care can affect the health of the baby, these standards also cover maternity services. Special consideration is also given for transition management into adult services beyond the 18th birthday, for those requiring ongoing services.

The NSF was developed by the following seven External Working Groups (EWGs), which comprised key stakeholders from all relevant children’s services:

- Improving Health and Well Being for all Children and Young People;
- Maternity;
- Mental Health and Psychological Well Being of Children and Young People;
- Disabled Children and Young People;
- Children and Young People in Special Circumstances;
- Children and Young People Suffering from Acute and Chronic Illness or Injury;
- Medicines.

Setting standards for an NSF with such a wide scope, and covering a range of NHS and Local Government services, has been particularly challenging but was made possible by the enthusiasm and commitment of EWG members who shared the same vision of improving the quality of services received by children and young people in Wales. The Welsh Assembly Government wishes to extend its sincere thanks to EWG members who gave their time and
Poverty and Social Inclusion

Poverty and social inclusion are very important factors, which influence the health and well being of children and young people, and this is recognised throughout the Children’s NSF. There is growing evidence that social disadvantage shapes the health of children and that this has a continuing legacy, influencing adult disease risk factors. Health inequalities do not simply emerge in mid-life, they accumulate over decades. Despite some evidence of redistribution of income in the UK, child poverty rates are still among the highest in wealthy nations. In 2001-02, 31% of children in Wales lived in households with incomes below 60% of the median income compared with 30% in Great Britain, and 17.1% of dependent children lived in workless households compared with 15.9% in the UK as a whole. Children and young people who grow up in poverty often feel alienated, have reduced expectations from life and have lower career aspirations. The fact that approximately one third of the children in Wales live in poverty has been described by the Children’s Commissioner for Wales as a national disgrace. The Welsh Assembly Government is addressing these issues and has set up a Task Group that has provided recommendations to the Assembly Government in relation to providing a long-term strategy for combating child poverty in Wales.

There has been recognition of strong links between ethnicity and low socio-economic status, and some recent research has shown that families of Pakistani and Bangladeshi origin are the most disadvantaged minority ethnic groups. Similar problems are also faced by the homeless and by mobile populations such as Gypsies, Travellers and some refugees and asylum seekers. These groups share socio-economic disadvantage evidenced by weak links with the labour market, poor housing conditions or no housing at all, uncertainty and lack of predictability in their lives, as well as discrimination and prejudice. The form that these disadvantages take varies from group to group and it defines the context in which children grow up, shaping parents’ ability to provide good enough parenting.

Patterns of health vary, not only by socio-economic status and ethnicity, but also by gender. Because women bear and generally care for children, they act as the guardians of the health of their families. Yet women are more vulnerable to poverty, in particular young lone mothers and those from minority ethnic groups.

There are key actions throughout this document which have been designed to address some of these issues, but in particular, chapter 4 on disabled children and chapter 5 on children in special circumstances place a strong emphasis on the need for social inclusion.
Evidence Base to Support the Standards

The rationale within this document contains some of the evidence base that supports these standards. Owing to limitations of space it has not been possible to include the entire evidence base within this document but further evidence will be available on the Children’s NSF web site: http://www.wales.nhs.uk/nsf when the final standards are launched in summer 2005.

The National Public Health Service (NPHS) was commissioned by the Welsh Assembly Government to produce *A Profile of the Health of Children and Young People in Wales* 15. Some of those data have been included in the rationale for the standards, but the full report can be viewed on the NPHS web site (http://www.nphs.wales.nhs.uk). This report will be updated on a regular basis and will provide useful information to inform Children and Young People’s Framework Partnership Plans.

Consultation with Children, Young People, Parents and Carers

When developing standards for the Children’s NSF it was important to listen to the views of service users. The Welsh Assembly Government commissioned an extensive series of consultation events with children, young people, parents and carers at a variety of venues around Wales, as well as through a questionnaire sent out to schools 108, 109, 110, 53, 248, 249, 250. The final reports of these consultation exercises are available to view or download from the Children’s NSF web site: http://www.wales.nhs.uk/nsf. The development of key actions within this document have been driven by the results of these consultation exercises to ensure that children and their families are placed at the heart of all service planning.

The 10-Year Vision

The key actions within the Children’s NSF set strategic priorities linked to the Community Strategies over a 10-year period. Key actions will need to be phased in over this period of time and prioritisation will be locally determined and informed by local Health Needs Assessments, carried out to inform the Health, Social Care and Well Being Strategies.

Leadership at All Levels

The Assembly Government’s commitment to delivering high quality services for all children and young people is going to require visionary leaders who are passionate about children’s services at all levels of service delivery.

Wales has a Minister for Children and a Cabinet Sub-Committee for Children and Young People which ensures that children’s issues are given a high priority on the government’s political agenda. The Assembly Government also has a Children and Young People’s Policy Co-ordination Group whose function is to ensure that there is
an integrated approach to policy development across all areas that can have an impact on the health and well being of children and young people.

In September 2003, the first Director of Healthcare Services for Children and Young People in Wales was appointed to act as a champion for children’s health interests in the development and implementation of the Health, Social Care and Well Being Strategies. The Director will lead the drive for innovation and continuous improvement of service standards for children’s healthcare services across Wales.

The Assembly Government recognises that this strong leadership is needed at all levels. Proposals in the Children Bill will require that each local authority identifies a lead director and a lead member for children and young people to oversee planning under the Framework Partnerships. Likewise, LHBs will be required to appoint lead officers and lead members for children and young people, and NHS trusts will be required to appoint lead executive directors and lead non-executive directors for children and young people. These arrangements are intended to ensure that effective joint planning takes place in the three Framework Partnerships and to promote the profile of children and young people in partner organisations.

Children’s Commissioner for Wales

The first statutory independent Children’s Commissioner for Wales was appointed on 1st March 2001. Peter Clarke was the first Children’s Commissioner to be appointed in the UK and has the powers to review the effects of policies, and the delivery of services, to children and young people in Wales, and act as a champion for their rights and welfare. His remit includes ensuring that children and young people are safe from harm and abuse, are respected and valued and receive the life chances that they deserve. Representatives from the Office of the Children’s Commissioner have acted as independent observers during the development of the Children’s NSF standards.

Coherent Policy Development and Delivery

The Children’s NSF is a joint policy initiative across the NHS and Local Government which supports the Assembly Government’s seven core aims for children and young people and is intended to support the delivery of other policies, reviews and government responses carried out or commissioned by the Welsh Assembly Government. The key actions of the NSF seek to facilitate partnership working and priority setting for children’s services in line with Policy Agreements between...

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a Health and Social Services Committee Review of Children with Special Health Needs (National Assembly for Wales, November 2002)
b Child and Adolescent Mental Health Strategy Everybody’s Business (National Assembly for Wales, September 2001)
c Review of Tertiary Services for the Children of Wales (Specialised Health Services Commission for Wales, May 2002)
d Lost in care – report of the tribunal of inquiry into the abuse of children in care in the former county council areas of Gwynedd and Clwyd since 1974 (Waterhouse et al, 2000)
Local Government and the Assembly Government and the Wales Programme for Improvement. The delivery of specialised services (tertiary services) for children and young people are being developed as a separate project but with very close links to the Children’s NSF. There are also close links with other NSFs published in Wales which are relevant to children and young people, including the Coronary Heart Disease NSF, the Diabetes NSF, the Adult Mental Health NSF, as well as the Renal NSF which is currently being developed.

The Review of Health and Social Care in Wales [advised by Derek Wanless] made recommendations for reform to the way health and social care services are delivered in Wales. This includes a greater emphasis on prevention and individual responsibility for health with a shift towards greater service delivery in primary care, better access to secondary care when needed, improved public and patient participation in service delivery and an improved performance management framework. The key actions of the Children’s NSF have been designed to facilitate the changing pattern of service delivery recommended in this report.

**Joint Working Across Organisations**

It is crucial that planning is co-ordinated across the various organisations that deliver services to children and young people. However, consultation exercises carried out with children, young people and their families to inform the development of these standards tell a story of inflexible and disjointed services that are unable to adapt to the specific needs of children and their families. This is reinforced by the findings of Professor Kennedy’s Report *Learning from Bristol*. As an example, poor communication between different organisations is often a reason for failure of the child protection system to protect children from harm.

The Children’s NSF is founded on a philosophy of placing children and their families at the centre of service delivery, with services designed to meet their particular needs. This will only be achieved by a commitment to joint working between all organisations which deliver services to children and young people. Most of the key actions within this NSF are the responsibility of multiple organisations that will be required to work in partnership. Partnership working means equality of responsibility and respect for each organisation concerned. The achievement of true partnership working will achieve more in terms of improvement in services and outcomes for the benefit of children and families than anything else contained within these standards.

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e Too Serious a Thing: the review of safeguards for children and young people treated and cared for by the NHS in Wales. The Carlile Review. (National Assembly for Wales, March 2002)
f Learning from Bristol: The Report of the Public Inquiry into children’s heart surgery at the Bristol Royal Infirmary 1984-1995. (Kennedy et al, 2001)
f The Royal Liverpool Children's Inquiry (Redfern, January 2001)
g The Victoria Climbié Inquiry (Laming, 2003)
Commissioning

Where organisations commission services to meet these standards, the process of commissioning should be transparent and accountable and has to be undertaken by staff who are trained and competent to undertake this vital role. Most importantly, they must have an understanding of the special requirements of children’s services and the joint responsibilities held by services in meeting many of their needs. Good commissioning is a skill that has to be learnt and if carried out effectively will resolve some of the issues around implementation by maximising use of resources. This will be carried out in the NHS at the local level by Local Health Boards and nationally by Health Commission Wales. Both sets of commissioners are bound by the priorities set by the Minister, who has clearly stated that children’s issues are a key priority area. Commissioners will therefore be expected to incorporate the NSF standards in their agreements with providers. Where these are not achievable within the commissioning timescale, a development plan will need to be agreed to meet the standards over a longer period. Regional Offices will need to be alert to the possibility of differential service standards and advise commissioners if this appeared to be developing.

Many of the key actions of the Children’s NSF involve joint working and some will require joint commissioning. Local Children and Young People’s Framework Partnerships are ideally placed to facilitate this process. The Welsh Assembly will strengthen their role by a requirement to ensure senior officer and elected member representation on the Partnerships and to empower local organisations to pool budgets. The Partnerships will be setting out the agreed priorities to inform joint commissioning through local Health, Social Care and Well Being Strategies and the planning of direct service provision. Commissioners from different organisations are challenged to overcome the historical creation of barriers to effective joint working.

How will the standards be delivered?

The standards are wide-ranging and deliberately drawn to encompass a broad range of service areas. The success of the Children’s NSF is wholly dependent upon an implementation plan which involves rigorous performance management across the NHS and local authority services. Developing a performance management framework that is compliant with the different accountability and funding mechanisms of NHS services and local authority services has been a challenging task.

Standards have been incorporated into the design of statutory performance measures for local government that is currently being drawn up by the Local Government Data Unit and will form a basis for the monitoring of service standards that constitute the next stage of the Wales Programme for Improvement 20.

Monitoring of service standards in the NHS is achieved through organisational balanced scorecards. Local health organisations should assess their progress against
the NSF standards and carry out a gap analysis. The self-assessment audit tool described in this chapter under Measuring Success will facilitate this process. The gap analysis will direct prioritisation of key actions to generate an action plan, which will in turn become measures for the Children’s NSF balanced scorecard. The iterative use of the self-assessment audit tool will assess whether key actions are being delivered and form an evaluation of the action plan. If improvement is not being achieved there should be a check back to the balanced scorecard and a realignment of action plans.

The co-ordination of planning and prioritisation of services for children and young people in Wales is the responsibility of Children and Young People’s Framework Partnerships in each local authority area in Wales. Partnerships are made up of local authorities, health services, other statutory bodies such as the police, and voluntary organisations. Each Partnership is asked to involve children, young people and families in preparing their Framework Plan. Each Framework sets out agreed strategic priorities for services for children and young people aged up to 25, based on the Assembly’s seven core aims.

More detailed planning is undertaken by two sub-groups, the Children’s Partnership (set out in Early Entitlement Guidance 21) covering the 0-10’s and the Young People’s Partnership (set out in Extending Entitlement Guidance 22) for 11-25’s. Under the Children Bill, the Framework and Children’s Partnerships will be made statutory, as are the Young People’s Partnerships. The results of the Framework Partnerships’ planning for children and young people are incorporated into local Health, Social Care and Well Being Strategies, which in turn contribute to the Community Strategies. As the determinants of health and well-being include a mix of social, economic and environmental factors, the Community Strategy aims to address these factors and contribute to sustainable development 23. As well as setting out the overall priorities, Framework Partnerships are responsible for making sure that there is continuity of service provision across key areas of transition, particularly at age 11 and as young people begin to receive adult services after they reach 18 years. This is particularly relevant for children and young people in need, for whom services often change at these ages.

In November 2003, the Cabinet Sub-Committee on Local Government and Public Services agreed to establish a plan rationalisation programme to reduce the planning burden on local authorities and to develop a more streamlined and coherent approach. The revised planning programme will be based on the use of a common structure, based on community strategies, policy agreements and the Wales Programme for Improvement 20, supported by a new performance measurement framework for local government and the audit and inspection regime.

Frameworks, Children and Young People’s Plans and the Partnerships on which they are based provide a practical context for the incorporation of the standards and key actions of the Children’s NSF into local policy development and service planning.
Children Bill Guidance, which will be issued by the Welsh Assembly Government in the autumn of 2004, will clarify the children's planning processes in the light of the Plan Rationalisation Programme and the interface between the Framework Partnerships, the Health, Social care and Well Being Strategies and the Community Strategies.

**Workforce Development**

Some key actions within the NSF are going to have significant workforce implications and will require additional trained staff. Workforce development requires co-ordinated joint planning at both national and local level if it is to achieve sustainable solutions to the extra demands of delivering the NSF. This will be made all the more challenging by the requirements of the European Working Time Directive and the recruitment and retention problems that are currently being encountered.

Furthermore, many of the weaknesses identified in the provision of children’s services from the Chief Nursing Officer (CNO) focus visits across Wales in 2003 have been addressed within the Children’s NSF, including the need for improvements to transition services, child protection arrangements and communication systems during transfers of care. This report also highlights that staff shortages in some areas have already been addressed through innovative reconfiguration of services. Adequate staffing levels and training issues identified in the CNO report will be considered alongside workforce implications resulting from implementation of the Children's NSF.

Training new staff to sufficient levels of competency takes many years. The Children’s NSF is a 10-year programme, and it is accepted that some of the key actions within the NSF will not be achieved until the latter part of that programme because of the additional workforce requirements.

**Information Management and Technology (IM&T)**

The advent of electronic recording systems has the potential to have a dramatic impact on the efficiency and effectiveness of the delivery of services to children and their families. *Informing Healthcare* sets a 10-year plan to move the NHS into the Information Age. The introduction of a single electronic health record will improve communication between primary, secondary and tertiary services. The addition of decision support systems and staff access to knowledge and information to support practice will transform the way that we deliver services. Recently reported failures in communication and effective information systems, such as those highlighted in the Bristol Royal Infirmary, Alder Hey, the Shipman case, the Waterhouse Inquiry, the Birchard Inquiry, the Victoria Climbié Inquiry and the Clwyd Report demonstrate that the need for effective information management systems is well overdue. As well as improving communication, electronic systems will
facilitate easier audit and measurement of the effectiveness and efficiency of services provided resulting in better quality services for children and their families as well as cost savings for the NHS.

*Informing Social Care*[^31] is a sister document to *Informing Healthcare*[^25] which sets out the strategic vision that information systems will make in the delivery of social services. The pillars around which the work programmes for social services authorities have been built are collaborative working, introducing and operating relevant information systems, the effective use of information and the introduction of a strong information governance framework to ensure that information is shared appropriately. The aim is to create IM&T systems which support front line practice effectively with access to round the clock electronic records and decision support systems. The ability to collect, aggregate and analyse up-to-date and accurate information will enable service planners and managers to plan and deliver services which meet current and future needs of children and their families. Alignment and integration with other systems in health, education, youth justice and housing will facilitate and create better information flows so that care delivery can be well co-ordinated around the needs of children and their families. A common approach, across disciplines and agencies, to the core process of assessment, care planning, intervention and reviewing of children's cases would help agencies to pool their knowledge of the circumstances of individual children, understand their needs and identify interventions that are most likely to be effective. The *Integrated Children’s System* (ICS)[^32] has been developed to support multi-disciplinary and inter-agency working with children in need and their families. It provides the basis for developing a common language across disciplines and is designed to capture the information practitioners need to support their work with children and families as well as the information local authorities need to manage and plan children's social services.

**Measuring Success**

The key actions within this NSF will only be as good as our ability to implement them. We cannot know if we are being successful in our implementation unless we measure the extent to which they are being delivered. The challenge is to develop a methodology for measuring success that is compatible with the performance management framework already developed for the NHS and Local Government services, and which assists local areas with service planning without being too burdensome.

To meet this requirement a self-assessment audit tool is being developed which will enable local measurement of progress in achieving key actions within the NSF that can be used to inform local service planning. As the Children’s NSF is a 10-year programme it is important to measure progress iteratively, so that at any point in time local areas are able to easily assess their achievements against a key action and what is still left to be done. The self-assessment audit tool will be a web-based tool.
that will use a maturity matrix to provide a numerical score for each key action as well as qualitative information that will assist local areas in identifying actions they need to take to overcome any barriers to success. In the NHS, this information will also feed into organisational balanced scorecards. The self-assessment audit tool will be published at the same time as the final standards in the summer of 2005.

**Inspection**

As with all NSFs these standards will be subject to inspection processes. Healthcare Inspectorate Wales (HIW) was established in April 2004, and it is likely that HIW, or the Healthcare Commission (formerly known as CHAI), will take the lead for inspection of the Children’s NSF standards in Wales. As many of the key actions of the Children’s NSF involve joint working, we anticipate that joint inspections will be carried out between HIW, Social Services Inspectorate for Wales (SSIW), Care Standards Inspectorate for Wales (CSIW) and Estyn, the Inspectorate for Education and Training in Wales.

**Making it Happen**

The Welsh Assembly Government acknowledges the difficulties encountered by service providers when asked to implement new policies in a climate of financial restraint. In the Children’s NSF this is made all the more challenging by the fact that funding mechanisms are different in the NHS from Local Government services. In the NHS, funding is centrally controlled by the Welsh Assembly Government, but in Local Government services such as social care, education, housing, transport and leisure, funding decisions are made by local authorities. The Children’s NSF sets the direction for a 10-year journey of travel to meet nationally agreed priorities to be achieved at the end point of the journey. Decisions about which key actions within the NSF should be prioritised for delivery after March 2006 should be made locally, dependent on local assessment of need and priorities for investment set by local Partnerships.

One mechanism that is used for aligning national and local priorities in NHS organisations is via the Service and Financial Framework (SaFF). Targets set in the SaFF direct how discretionary money is used at local level to meet national priorities. An example of where this has already happened in the Children’s NSF can be seen in key action 5.4 where a hand held record for disabled children with complex needs has become a SaFF Target for 2004/05, ahead of publication of the standards.

To give a longer-term context and ensure that a clear and co-ordinated approach to service delivery is adopted the Minister for Health and Social Services has directed the development of a 3-year strategy for health and social care for the period 2005/06 – 2008/09. The strategy will be completed by autumn 2004 and sets out national priorities and clear objectives for the 3-year period.
The 21 standards and associated 203 key actions in this NSF present a challenging number of implications for the service providers affected. Some actions will already be planned and underway, and others will have little additional burden in terms of cost or staff time. However, others will have extensive resource implications that need to be identified.

EWG members, in each of the seven modules, have quality assured the key actions that they developed using a tool designed for the purpose. Part of the quality assurance process involved making an assessment about how long it would take to deliver each key action. Those key actions, which EWG members assessed as being low or no cost (because they should already be happening or were organisational issues), have been flagged for early delivery. Flagged key actions are thus the ‘core key actions’ of the NSF and all should be implemented by the end of March 2006. One of the functions of this consultation is to determine whether these are the right key actions to prioritise for early delivery.

The remaining key actions may be termed ‘developmental key actions’ because they will require additional resources to deliver them and will be worked towards over a number of years. Developmental key actions which have significant extra resource requirements, especially those that will require extra staff to be trained, may take 10 years to be fully delivered. Whilst core key actions are nationally prescribed, the delivery of developmental key actions will be prioritised locally to meet the needs identified in the local Health, Social Care and Well Being Strategies. Regional Offices will oversee the prioritisation of developmental key actions to guard against different service standards occurring in the three regions.

The final NSF document, which is due for publication in summer 2005, will therefore include a phased programme for the introduction of the standards and key actions into local practice. The programme will be reviewed on a three-yearly basis to ensure it remains relevant and up to date and make recommendations for revision to key actions in consultation with stakeholders. In this way we will constantly strive to deliver better services for children, young people and their families.

**Service Models of Best Practice**

Development of these standards has involved wide consultation with organisations that deliver children’s services across Wales. What has become evident from this process is that there are already many areas of Wales in which there is excellence in the delivery of services to children, young people and their families. The Children's NSF web site will be used to collate and share service models that illustrate best practice and innovative examples of service delivery to achieve the key actions of this NSF.
Organisations are invited to submit service models for inclusion by following the instructions on the website: http://www.wales.nhs.uk/nsf (click on Children’s NSF).

Organisation of the Chapters in this Document

The standards and key actions which populate the Children’s NSF were developed in seven modules. To avoid repetition, key actions which apply to all children and young people, no matter what their circumstances, have been grouped together under Chapter 2 as universal key actions. This chapter therefore forms the core part of the NSF and should be read in conjunction with any other chapter. The remaining chapters relate to more specific sections of the NSF.

Each of the remaining chapters contains a number of standards within them which contain a standard statement that sets out the quality to be achieved, and is supported by a rationale which describes some of the supporting evidence base. Underneath each standard are listed specific and measurable key actions with the organisations that are responsible for their delivery clearly identified. A number of voluntary sector organisations may be responsible for the delivery of some of these services. They have not been specifically listed against key actions as they would be commissioned by NHS or local authorities to deliver services on their behalf for different key actions in different areas. It is the responsibility of the commissioning body to ensure that any voluntary sector organisations that have been commissioned, deliver services to the standards required.

As the scope of the Children’s NSF is so broad, this is by necessity a long document. A shortened version of the NSF has also been produced which contains an introductory chapter, a short introduction to each chapter, the key actions and a glossary only. The full version of the NSF (which also contains the rationale and references), which you are currently reading, will only be available on the web site when the final NSF is published in summer 2005.

The Transitions Standard has been placed within Chapter 5 (Disabled Children and Young People) but readers should note that this standard applies to all young people who require on-going services or support after their 18th birthday. This standard therefore also applies to young people who are chronically ill, have mental health problems or disorders or are young people in special circumstances. For the sake of parsimony this standard has not been repeated in each chapter, but this does not make it any less relevant to the young people referred to in Chapters 4, 6 and 7.

Terminology Used in these Standards

All key actions within this NSF are written as present tense “is” statements rather than future tense “should”, “will” or “must” statements. Present tense statements are the strongest way of wording key actions to ensure compliance and will make it
possible to monitor against them using the self-assessment audit tool developed for the purpose.

Whenever “children” are referred to in this document it should be accepted that this also includes young people. Reference to “parents” includes mothers, fathers, carers, and other adults with responsibility for caring for children, including those responsible for Looked After Children, those in young offender institutions or juvenile units. Throughout this document “Children’s NSF” is used as an abbreviation for “National Service Framework for Children, Young People and Maternity Services”.

CHAPTER 2

Key Actions Universal To All Children

Introduction:

This chapter defines standards for the universal services which all children and young people in Wales should receive in order to achieve optimum health and well-being. This is a core chapter and should be read in conjunction with any of the other chapters in this document.

This chapter contains 5 standards:

1. Child and Family Centred Services

2. Access to Services

3. Quality of Services

4. Promoting Health and Well-Being

5. Parenting

6. Safeguarding

STANDARD – CHILD AND FAMILY CENTRED SERVICES

STANDARD:

Children, young people and their families receive services that meet their particular needs. They are treated with respect by service providers and are provided with information and support appropriate to their needs and ability that assists them in making decisions about the care that they receive.

RATIONALE:

“The child who is capable of forming his or her own views has the right to express those views in all matters affecting the child, the views of the child being given full weight in accordance with the age and maturity of the child.”

(Article 12, Convention on the Right of the Child 4)
The Kennedy Report highlighted the need to involve children in making decisions and give them choice about their own care by giving them information that is sensitive to their level of understanding and culturally appropriate. The Welsh Assembly Government supports the participation of children and young people in decision-making at all levels of service delivery. At the service delivery level this may involve giving choice, listening to children and young people and respecting their views. But children and young people can also participate in the design and evaluation of services at higher levels.

In support of this principle the Assembly Government has helped to set up Funky Dragon, the Children and Young People’s Assembly. This gives children and young people the opportunity to be heard and influence decision making at a national level. At local level, the Assembly Government has asked each local authority to set up a Children and Young People’s Forum, and has consulted on proposals to set up school councils in all LEA maintained primary, secondary and special schools by July 2005.

The rights of parents and carers also need to be respected and their views should be sought with regard to the treatment and care that their child should receive, but it must be recognised that as children grow older their wishes might conflict with those of their parents/carers. These conflicts need to be resolved in a sensitive and appropriate manner.

Upholding the rights of children and young people and empowering them to have a voice in matters and decisions that affect their lives are at the heart of the Assembly Government’s agenda. This is especially important for our most vulnerable children, such as those looked after by local authorities or placed away from home in hospital or education settings. Access to independent advocacy is central to safeguarding children and protecting them from harm and poor practice. It is the Assembly Government’s long term aim of making advocacy available to all children and young people in social care, education and health settings, building on national standards issued to local authorities social services in February 2003, and adopted by the NHS under services provided by the Community Health Councils Independent Complaints Advocates in June 2003. Extending advocacy also supports the Assembly Government’s commitment to recommendations in the Waterhouse Report, the Carlile Report, the Children Commissioner’s for Wales report Telling Concerns and Lord Laming’s Report on the death of Victoria Climbié.

“Children need an independent advocate, as parents may be too close to the child to be aware of their needs. There should be an automatic right to advocacy, an independent advocate who is specifically trained in the child’s needs.”

(Parent quote from Contact a Family, Sept. 2003)
The right to participate in decisions about services that affect them belongs to every child, including those for whom English or Welsh is not their first language and those who have difficulty communicating. Access to information is crucial for disabled children as well as their parents and this needs to come from a number of sources and in a variety of formats. Innovative communication methods need to be used to reach those children with communication difficulties.

Likewise children and young people from minority ethnic groups need to receive information in appropriate languages and formats, and which is sensitive to their cultural background. These children’s needs are often overlooked in the design and planning of services and as a result they are more likely to report difficulties in accessing services as a result.

Services that are truly child centred are dependent upon comprehensive holistic assessment processes, which should consider all aspects of the child’s life in the context of the family. Assessment should build and concentrate upon the positive attributes of children and young people, parents and families to provide services which maximise their social, emotional, physical, intellectual and behavioural development within, where possible, stable family settings. The Data Protection Act (1998) requires that personal or sensitive data cannot be disclosed from one agency to another. Information can however be shared with the consent of the patient, and organisations must be fully aware that they have a duty to share information where the protection of children is an issue.

Children and young people from poorer families, those living in areas of high unemployment or in areas with fragile social networks, are more likely to experience poor health and social outcomes than those from richer backgrounds. In some cases, and for a variety of reasons, these children and young people miss out on the surveillance and preventive interventions that are available. However, even in cases where needs are identified, the presence of multiple risk factors is often not considered in an integrated way across agencies and opportunities for preventive interventions, which would reduce the burden on services providing crisis interventions, are consistently missed.

Care planning that is child-centred should be well co-ordinated and involve multi-agency protocols to ensure close co-operation between social services, health, education and the voluntary sector. Where there are complex health needs the child and their family may need assistance from a key worker to help them access these services and information, as they are needed.

Integrated care pathways should be developed for specific conditions that affect children and should demonstrate a smooth, timely and equitable access to multi-agency services. The care pathway should link services together to form a coherent whole around the child’s journey through the system, and identify what standards of services should be received at each point of the pathway.
Care planning becomes particularly important at the point of transition into adult services. Bridging this gap needs careful and co-ordinated management. Problems may occur due to a lack of liaison between paediatric and adult services or because of significant differences between the thresholds for delivery of services.

The development of these standards has been founded on extensive consultation exercises commissioned by the Welsh Assembly Government with over 100 disabled children and young people, over 200 children in special circumstances as well as questionnaires sent to schools. Feedback has been given to the children and young people who participated in the exercises about what the main themes were. A young person friendly version of the Children’s NSF consultation document has been produced, so that young people also get the opportunity to comment on how their views have been used to influence the development of these standards. As the child cannot be considered outside the context of the family in which they live, consultation exercises were also carried out with parents and carers across the whole spectrum of the standards considered within this NSF.

One of the main themes that emerged from the consultation exercises with children and young people was the need for better environments. All of the consultations said they wished that waiting rooms and hospitals were more cheerful and less clinical, and that there was more for them to do. Many waiting rooms will have toys for children, but young people also get very bored when waiting and need activities to keep them amused. Schools also attracted some criticism from children and young people, especially with regard to the condition of toilets. This view was reinforced by the Children’s Commissioner for Wales Report on school toilets in Wales.

The following key actions have been designed to ensure that children, young people and their families are placed at the centre of service planning with services designed to meet their needs.
KEY ACTIONS:

Participation of Children, Young People and Families

2.1. Agencies implement a policy for the participation of children, young people and their families as partners in planning and evaluation of the services that affect them.

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2.2. Children and young people, receiving services from any agency, are fully involved in regular reviews that allow them to express a view about how their needs are met, including the professionals and organisations that will provide the services.

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2.3. Accurate and timely information on services is provided to meet the needs of all children and young people, but particularly those from marginalized communities. The information is written with the participation of children, young people and their families using a variety of formats, media and languages.

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Culture, ethnicity, language, religious and spiritual concerns

2.4. When required, there are independent, appropriate translation services and sign language interpreters readily available wherever professionals have contact with children, young people and their families. Children and young people are never used as sole interpreters.

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2.5. Children in hospital and care settings are offered choice in the services they receive that enables them to fulfil their developmental potential and meets their social needs, including their right to follow cultural and religious beliefs.

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## Advocacy and Complaints

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<th>2.6.</th>
<th><strong>Independent advocacy</strong> is freely available to all children and young people where and when needed and requested, in line with Welsh Assembly Government Standards 47.</th>
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<th>2.7.</th>
<th>Organisations who deliver services to children have a complaints system that is child friendly and accessible, and acknowledges complimentary letters. Organisational plans take account of key messages received and feedback to children, young people and their families about how this information has been used to improve service planning.</th>
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## Assessment

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<th>2.8.</th>
<th>Children and young people receive an <strong>holistic assessment</strong> of their needs that:</th>
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<td>Includes an evaluation of the child’s social, physical, emotional, educational, cultural and spiritual needs in the context of the family and community in which they live;</td>
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<td>•</td>
<td>Offers choice to the child whenever possible about how, where and by whom the assessment is carried out;</td>
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<td>•</td>
<td>Is carried out by staff with relevant skills and competencies developed through regular training;</td>
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<td>•</td>
<td>Results in appropriate referrals to other agencies where required.</td>
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<th>2.9.</th>
<th>A common electronic health record is used so that organisations have access to assessment information, with the agreement of the child or young person and their parents/carers, where appropriate, so that children and their carers do not need to give the same information many times.</th>
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2.10. All health professionals are responsible for recording relevant information, including medicines, in the **Personal Child Health Record (PCHR)** whenever a child is seen. Information is recorded in a way that is easily understood by the parent/carer or young person.

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2.11. Service providers ensure that families receive information, explanation and support concerning benefits they are entitled to, particularly when there are children with complex needs in the family.

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**Confidentiality**

2.12. Service providers have a nominated person who is responsible for implementing the recommendations of the Caldicott Committee Review on patient identifiable information and Data Protection Act 1998. The nominated person ensures professionals receive training about sharing information that is relevant to the well-being of children and young people, particularly at **key transition stages**, and following confidentiality guidelines.

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**Co-ordinated multi-agency services**

2.13. All health settings have appointment systems which:
- Include a booking system that is flexible and takes account of the needs of children and their families;
- For children who require multiple appointments, these are synchronised in one setting and on one day whenever possible;
- Have maximum waiting times of 30 minutes;
- Do not move children from one waiting area to another unless unavoidable.

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2.14. Children and young people, who require more than two on-going services in addition to the universal services, have their services co-ordinated by a **key worker**. The name of the **key worker** is made known to the child and is recorded in the child’s care plan.

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### Service Planning/ Environment

#### 2.15. LAs

LAs have a Lead Director and Lead Member, who is responsible for co-ordination and partnership working in the delivery of children’s services in the local authority area.

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#### 2.16. LHBs and NHS trusts

LHBs have a Lead Officer and a Lead member, and NHS trusts have a Lead Executive Director and a Lead Non-Executive Director. It is their responsibility to ensure that the interests of children and young people, including clinical governance and child protection issues, are considered at all levels of commissioning, planning and service delivery.

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#### 2.17. Staff

Staff who identify areas of risk for children and young people, or who have ideas about how services could be improved, have access to a mechanism for feeding this information to those who are responsible for service planning in the organisation.

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#### 2.18. Hospital or Residential Placement

When a child or young person requires admission to hospital or residential placement, either in or out of county:

- They are placed in settings which are most appropriate for their developmental as well as clinical needs;
- They are only admitted to adult settings in exceptional circumstances;
- When placed in adult settings, systems are in place to protect them from harm.

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STANDARD – ACCESS TO SERVICES

STANDARD:

All children, young people and their families receive equitable access to appropriate, high quality services irrespective of where they live, their ethnic group or their social circumstances. Services are available as close to home as possible, whilst ensuring that care remains of the highest quality.

RATIONALE:

There is clear evidence of inequity in the uptake of services and in health outcomes, particularly among children and young people. Babies born to poorer families are more likely to be born prematurely, are at greater risk of infant mortality and have a greater likelihood of poverty, impaired development and chronic disease in later life. This sets up an inter-generational cycle of health inequalities.

Children and young people from minority ethnic groups are particularly likely to report difficulties in accessing primary care and outpatient services and their needs are often not considered in the design and planning of services.

Young people identify a range of barriers which prevent them from accessing services, including concerns about confidentiality, lack of understanding about the services available to them, and concerns about whether health professionals will take them seriously. Young people in special circumstances who were consulted also said that inadequate or expensive public transport systems affected their access to services.

Child health surveillance, including specific population based screening programmes can result in the early detection of health problems and social needs in babies and children. Where this is followed by effective and timely intervention, such a programme can improve outcomes. The early years are particularly important for identification of the presence of multiple risk factors so that action can be taken to enable the child to start school ready to learn. For health problems where clinically curative treatment is not available, early detection can support adjustment and acceptance of the condition, and can contribute to improved quality of life for children and their families through, for example, the early provision of therapy, social support, financial support, special educational input and physical aids.
**KEY ACTIONS:**

*Universal services*

2.19 Uptake of universal services by children from **marginalized communities** is monitored and appropriate action taken to ensure they are reached. In particular, there are local mechanisms for joint working that ensure:

- They have access to a local GP;
- They have access to the all Wales core child health surveillance programme (guidance to be issued by Assembly Government towards the end of 2004);
- They have access to a local family dentist or salaried dental service providing a full range of preventative oral health advice, care and treatment;
- They receive appropriate universal and targeted health promotion information and advice;
- They have access to education appropriate to their needs.

2.20 Service providers publish and disseminate referral guidelines and pathways for access to their services.
STANDARD – QUALITY OF SERVICES

STANDARD:

Children, young people and their families receive timely, high quality, co-ordinated services delivered in an environment which is safe and well suited to their age, needs and stage of development. Service delivery is evidence based or innovative with a structured evaluation, and delivered by competent staff.

RATIONALE:

High quality services cannot be delivered without well-trained and competent staff. This standard sets out minimum core training requirements for all staff who work with in children’s services. Other chapters within this document also specify minimum core training requirements for staff who work in more specialised areas, such as for those who work with disabled children, children who are sick or have mental health disorders, and those who work in maternity services.

Clinical governance systems provide a framework in which “NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care, by creating an environment in which excellence in clinical care will flourish” 55. Present clinical governance systems however do not always recognise children as a separate and vulnerable client group. Clinical governance arrangements should have a multi-disciplinary, and when appropriate multi-agency, approach with children’s services clearly identified within the local Clinical Governance Development Plan.

Gaining consent for assessing, intervening with and/ or treating children and young people is more complicated than with respect to adults. Presently the law in England and Wales on consent by or for minors is guided by the (amended) Children Act 1989 56, other legislation (e.g. the Human Rights Act 1998 57 and the Family Law Reform Act of 1969 58), court judgements (e.g. the Gillick Case 59), the Mental Health Act 1983 60, and common law (e.g. the principle of necessity). The law places the onus on professionals to obtain consent appropriately. Therefore all practitioners who work with young people, and managers who are responsible for commissioning and delivering services, must have adequate levels of knowledge so that they proceed in appropriate and lawful ways 61. In particular, all services must identify who has parental responsibility for each child in their care and their staff must be aware of the significance of this concept. Any professional or manager who is in doubt about the process should have access to a children’s lawyer for advice.

“More training for staff in working with parents and children and understanding child development is essential.”

(Parent quote from Contact a Family, Sept. 2003)
Most children will require medications at some time in their lives and there is some evidence that medication safety needs to be improved. Medication errors occur in children at about the same rate they occur in adults, but because of the small size of children, and in particular babies, they are three times more likely to cause harm. Most new medicines are only licensed for use on adults, because there is little commercial incentive for manufacturers to carry out studies in children, or because, for ethical reasons, it is more difficult to recruit children into clinical trials. Medicines prescribed for a child that are not licensed for that age group or for their health problem are referred to as *off-label* and medicines that do not have a license at all as *unlicensed*. The informed use of unlicensed or off-label medications is unavoidable if children are to have access to the most effective medicines. Because a medication is unlicensed or off-label it does not mean that it is unsafe but it is important for parents to be given accurate information to enable them to give informed consent. European Regulations will be introduced some time after 2006 which will ensure that medicines are appropriately formulated and labelled for paediatric use. In the meantime there will be a UK-wide strategy to raise awareness in the pharmaceutical industry about these issues.

Medicines will only be effective if they are taken, and in accordance with the prescriber’s instructions. Time and effort invested in discussion between the prescriber and the child, young person and family, to ensure they understand the risks and benefits and the effects of the proposed treatment on daily living, will result in improved treatment outcomes. Central to these discussions is the provision of clear, up-to-date information that is available in a variety of languages, formats and media. Parents also, rightly, have an expectation that there will be effective communication mechanisms between hospital and primary care, particularly prior to a child’s discharge from hospital.

Some children regularly have to take medicines during the school day and this presents its own problems in relation to the storage and administration of medicines in schools. At present schools are guided by two documents: *Supporting Pupils with Medical Needs: A Good Practice Guide* and *The Education of Sick Children*. The Assembly Government recognises that local education authorities need clear guidance on this issue and therefore plan to issue guidance shortly which will provide an update for both of these documents.
KEY ACTIONS:

Training and support for staff

2.21. All organisations have in place agreed core joint education and training programmes for staff who deal with children and young people, including:

- Child protection training that includes recognition of signs of neglect, sexual, physical and emotional abuse, and procedures specified in *Working Together to Safeguard Children* and associated guidance in collaboration with ACPCs;
- Identification and management of domestic violence, following guidance issued by the Welsh Assembly Government;
- Child and family centred assessment and care;
- Use of the *Framework for the Assessment of Children in Need and their Families*;
- Identification of the early warning signs of mental health problems and disorders in children and how to make appropriate referrals;
- Cultural awareness training;
- Principles of gaining legally valid consent from children of all ages and/or persons with parental responsibility;
- Data Protection Act training, including awareness of situations in which disclosure of information is in the best interests of the child;
- Availability of local services to support families;
- Communicating effectively and with sensitivity;
- Advocacy rights of children and their families.

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2.22. All staff delivering services for children have:

- Protected time for professional development, audit and appraisal;
- Appraisal at least annually;
- Access to a desk, phone, e-mail and Internet.

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2.23. Service providers have protocols for resolution of differences in professional opinion and raising concerns about service provision both internally and between organisations. All staff are aware that they have a responsibility to critically challenge decisions which they feel may not be in the best interests of children and their families.

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### Clinical governance systems with a focus on children

#### 2.24. Patient Safety Incidents and prevented accidents

In near misses, including medicines errors, are thoroughly investigated and reported to the National Patient Safety Agency and other relevant agencies/bodies in line with the Welsh Assembly Government requirements.

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#### Commissioning

2.25. Commissioners of NHS services carry out all of the functions specified in NHS Planning and Commissioning Guidance.

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#### Consent

2.26 All health professionals follow the Guidance about Consent for Examination or Treatment for the NHS in Wales.

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#### Medicines

2.27. LHBs and NHS trusts have a medicines strategy that includes:
- A named pharmacist with expertise in paediatric prescribing who can provide advice when needed;
- Access to a standard and regularly updated information source on children’s medicines for all practitioners who prescribe, administer or dispense medicines for children, available both as hard copy and electronically;
- Implementation and monitoring of any National Institute for Clinical Excellence (NICE), National Patient Safety Agency (NPSA) and All Wales Medicines Strategy Group (AWMSG) guidance relating use of medicines by children;
- Efficient reporting systems for adverse drug reactions seen in children, including those seen with off-label or unlicensed medicines, through the Medicines and Healthcare products Regulatory Agency (MHRA) Yellow Card System;
- Mechanisms for the annual review of prescribed medicines to treat chronic conditions that include community pharmacist and GPs;

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- Provision of facilities for preparation of **parenteral** doses of medicines for children to take place centrally, under controlled conditions in a hospital pharmacy;
- Promotion of prescribing and dispensing of sugar free medicines for children whenever possible;
- Provision of information for young people, parents and carers, in a range of appropriate languages, formats and media to enable them to manage their medicines accurately, safely and effectively, including **unlicensed medicines** or those prescribed **off-label**.

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2.28. When it is necessary to import medicines from another country because there is no licensed children’s formulation available in the UK, the purchasing pharmacist ensures that technical information and clinical information is translated into English.

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2.29. **Children’s homes, foster care, hospices and secure units** implement guidance on the safe use of medicines that adheres to Care Standards Inspectorate Wales standards, and have a pre-agreed contact point for pharmaceutical advice.

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2.30 Service providers ensure safe and effective administration of medicines to children and young people in education settings by adherence to guidelines recommended in the new Welsh Health/ Education Circular to be issued in winter 2004.

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2.31. Service providers ensure that staff receive the appropriate training to develop relevant competencies in dosage calculation, prescribing, dispensing and administration of medicines for children.

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2.32. Undergraduate and postgraduate pharmacy curricula include training in the principles of prescribing and use of medicines for children.

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STANDARD – PROMOTING HEALTH & WELL BEING

STANDARD:

All children, young people and their parents and carers have access to a range of services that promote health and well-being and prevent ill-health.

RATIONALE:

The Review of Health and Social Care in Wales (Wanless Report) 16 emphasised the importance of health promotion in preventing ill health and therefore reducing the burden on scarce resources. To achieve maximum effectiveness, health promotion advice should be evidence-based, or innovative but with a structured evaluation programme, and consistent with current government guidelines. This standard is central to enabling families to improve their own health and that of their children.

Current guidelines recommend that young people undertake at least moderate activity for an hour or more each day. The recently published Health Behaviour in School-aged Children (HBSC) study from the 2001/2002 survey 69 showed that proportions of children and young people who meet these guidelines in Wales decline with age and are higher for boys than girls. Among 11 year-olds, 46% of boys and 37% of girls meet the current guidelines. The proportions fall by age 13 (46% and 29%) and again by age 15 (39% and 18%).

There has been much media coverage recently about the growing problem of obesity in children and young people, and this is likely to be no less a problem in Wales than it is in the rest of the UK. Children who are obese have increased risk of suffering from cardiovascular problems, Type 2 diabetes, respiratory and musculoskeletal problems 70. Obese children are also more likely to become obese adults with all the associated health risks 71. Changing lifestyles, with a decrease in physical activity and an increase in sedentary pursuits such as watching TV and playing computer games, associated with increased consumption of energy dense foods, may contribute to the problem 70. The HBSC study also showed that the proportion of young people in Wales who eat fruit and vegetables every day declines with age, particularly for girls. Despite the five-a-day message, as few as 23% of 11-year-old boys and 31% of 11-year-old girls reported eating fruit every day, the proportions are even lower in older age groups, with a similar picture seen for consumption of vegetables.

The Welsh Assembly Government is addressing these problems through a number of initiatives, such as the Welsh Network for Healthy Schools 252 and the Food and Fitness Task Group described below. The key actions within this standard have been developed in conjunction with both of these initiatives.
The Welsh Network of Healthy School Schemes was launched in September 1999 to encourage development of local healthy school schemes within a national framework. These schemes support the development of health promoting schools in their areas. The work is based on recommendations from:

- The Independent Inquiry into Inequalities in Health Report which recommended “the further development of ‘health promoting schools,’ initially focussed on, but not limited to, disadvantaged communities” 39.

- A systematic review recommending continuing experimentation with the health promoting school initiative, taking into account the potential importance of the health and well-being of school staff. This involves among other things:
  - where schools are still providing school meals and commercial considerations permit, improving the content of school meals and promoting healthy options;
  - encouraging and supporting physical activity in schools, but not on a compulsory basis 72.

The Welsh Assembly Government has provided funding and guidance to help health and education services working in partnerships to set up and run local healthy school schemes in all areas of Wales.

The Minister for Health and Social Services has recently set up a Food and Fitness Task Group for Children and Young People. The aims of the group are:

- To respond to Health Challenge Wales, by taking forward the food & well-being and physical activity agendas for children and young people;
- To contribute to strategic planning and co-ordination of food and fitness initiatives for children and young people;
- To identify opportunities for links between existing strategies relating to nutrition and physical activity;
- To act as champions for the concept of initiatives on food and fitness operating in tandem;
- To advise on the development of additional interventions, evidence-based where possible or innovative with a structured evaluation, to address identified gaps in provision;

“The food in school is PANTS, all it is, is chips, chips, chips all the time. I hate them. I used to have a baked potato but it was very small and didn’t fill me up.”

(Child quote from NCH Cymru/Barnardo’s Cymru, Sept. 2003)
• To consider research and evaluation requirements;
• To consult with organisations engaging children and young people on food and fitness issues.

There is evidence to support the view that children who eat a healthy breakfast have better health, concentration and behaviour in school. In response to this, the Welsh Assembly Government is piloting the introduction of free school breakfasts for selected primary schools in Children First areas from September 2004, meeting a commitment laid out in Wales: A Better Country. It is anticipated that all primary schools will have the opportunity to participate by September 2006.

The HBSC study showed that 16% of boys and 27% of girls report smoking at least weekly. Since the 1997/98 survey the reported smoking rates have fallen for boys but increased for girls. Smoking is also linked to other behaviours which can result in negative health outcomes. Young smokers are three times more likely to use alcohol and eight times more likely to use cannabis than non-smokers. Cannabis use was introduced as a question for the first time in the 2001/02 survey and showed that a quarter of boys and girls (26% and 24%) in Wales report having used cannabis in the last 12 months. The number of 15-year-olds who reported regular alcohol drinking was fairly similar between boys (58%) and girls (54%), and having been drunk two or more times (58% and 60%). An overall decrease was demonstrated since the 1997/98 survey when the corresponding rates for drunkenness were 72% and 63%. The need to continue with initiatives to combat drunkenness among young people is reinforced by research which demonstrates the negative health outcomes among young people who get drunk more than once a week.

The HBSC survey for 2001/02 showed that mean age for first sexual intercourse among 15-year-olds in Wales was 14.3 years for boys and girls. Marked gender differences were seen in Wales though among 15-year-olds with 40% of girls and 29% of boys reporting ever having had sexual intercourse. Wales also has the highest teenage pregnancy rate in Europe, with a consistently higher rate than in England. The proportion of 15-year-olds in Wales reporting use of at least one method of contraception when they last had sexual intercourse was 82% for boys and 85% for girls. Diagnoses of chlamydia have doubled since 1995 and are now the most common form of female sexually transmitted infections (STIs) in Wales. In line with the rest of the UK, diagnoses of HIV infections in Wales are rising with 900 confirmed cases by the end of June 2004. In response to the high teenage pregnancy rates in Wales and the escalating numbers of STIs the Assembly Government published the Strategic Framework for Promoting Sexual Health in Wales: Post-Consultation Action Plan. Programmes, which have been shown to be effective in reducing STIs, include school-based sex education to reduce sexual risk behaviour and small group work. The most effective programmes are those which
are multi-factorial, addressing a range of personal and structural determinants of risk simultaneously 79.

Mental health promotion has been defined as actions to enhance the mental well being of individuals, families, organisations and communities 80. These actions commonly take place at three levels, by:

- Strengthening the emotional resilience of individuals by promoting self-esteem and coping skills;
- Strengthening communities (including schools) by improving social inclusion, safety, childcare and self-help networks;
- Reducing structural barriers to mental health by promoting access to education, employment, suitable housing and effective services to meet the needs of those who are vulnerable.

In the early years, effective mental health promotion programmes are those that focus on promotion of parent/ carer and child attachment and protection from abuse and neglect 81. In school years, effective programmes are those which develop whole school approaches to improving mental and social well being that include both staff as well as pupils 82, 83. Out of school approaches which appear to be most successful are those which focus on developing life skills and building social support networks. Research into outdoor pursuit programmes, such as Outward Bound, has demonstrated their effectiveness in improving self-esteem in young people 84. Evidence based health promotion in each of these areas has been listed in a Briefing Paper by mentality 80, though no doubt this list will evolve as research into what works best develops. There are also excellent examples within Wales of multi-faceted approaches to improving the emotional health and well-being of children and young people 275.

Injury is a major cause of death and disability in children 85. In Wales, fractures are the major cause of injury in the 5-14 year group, whilst in the 0-4 year group poisoning and accidental overdose is the major cause of injury 15. Road traffic accidents are another major cause of death and injury in children, with 192 children in Wales killed or seriously injured in 2003.

In early 2003, the Assembly Government announced its Road Safety Strategy for Wales 86, which outlines the key measures and polices to address the causes of road collisions and reduce casualties. The safety of children is an important element of the strategy, with the safe routes to school initiative as an integral part of this, along with the development of practical walking and cycling skills.

In 2004, the Welsh Assembly Government set new Health Gain Targets for Wales which included specific targets in relation to reducing death and injury rates in children from road traffic accidents:
• To reduce pedestrian injuries to children (0-14 years) from motor vehicle accidents by 35% by 2012;

• To reduce the incidence, severity and death rates of pedestrian injuries in the 0-14 year age group by 2012 (reduction in inequalities in incidence by quintiles of deprivation).

Reading et al 87 have explored the links between accidents, the degree of deprivation in an area and individual family factors. They found that accidental injuries among pre-school children were influenced by area deprivation and also by family characteristics, They recommended targeting accident prevention measures in deprived neighbourhoods and also improving child care for unsupported young families such as young mothers and single parents.

The prevention of communicable disease by improving immunisation uptake is another area which the Welsh Assembly Government has addressed, particularly in relation to MMR, through the following Health Gain Target:

• To eliminate person to person spread of Measles, Mumps and Rubella by 2015.

Coverage of 95% is required to achieve ‘herd’ immunity and maximum effectiveness of vaccines, but no area in Wales achieved 95% coverage in 2003 15. Travelling families in particular tend to have low uptake of vaccinations and to be at high risk for outbreaks of infectious disease 88.

Unfit housing is a major contributor to poor health in disadvantaged areas. A review of the literature on this topic 89 identified the following health outcomes associated with poor housing:

• The consequences of damp and mould include asthma and respiratory problems, eczema and depression;

• The consequences of cold include diminished resistance to respiratory infection and hypothermia;

• Poor quality housing overall can reduce people’s mental well being;

• Poor design and equipment can put people at greater risk of accidental injury, fires and carbon monoxide poisoning.

The homeless and families living in temporary bed and breakfast type accommodation are also at risk of respiratory diseases, gastrointestinal problems and skin disorders 90.

Several recent studies have shown the links between children’s health and the quality of a neighbourhood. In their analysis of data from the Canadian National Longitudinal Survey of Children and Youth, Curtis et al 91 found a strong association
between the quality of the neighbourhood and children’s mental health and behaviour.

*Health Challenge Wales* is a national initiative announced by the First Minister in February 2004 that builds on *Well Being in Wales*. It places responsibility on organisations in public, private and voluntary sectors, as well as on individuals themselves, to improve the health and well being of people in Wales. The standards within this NSF contribute to the implementation of that programme.

Poverty, unemployment, poor housing, poor quality of neighbourhoods, damaging gender relations and ethnic discrimination all impact on health. Several studies also point to the importance of developing the self-esteem of children and mothers and of providing early childhood education which helps to prepare young children for school and reduce pressures on young mothers. Above all, it is important to recognise that the biggest health gains will come from actions outside the health sector. The importance of social structure factors in explaining patterns of health and illness suggest that actions which focus solely on the individual ‘proximal’ causes of ill health such as smoking, nutrition and exercise, will be less effective than those which also target the social circumstances in which people live. The key actions within this standard have been designed to have maximum impact on the health and well being of children and young people in Wales.

**KEY ACTIONS:**

*Healthy schools*

2.33. All LEA maintained schools participate in the Welsh Network of Healthy School Schemes, and consider food and fitness actions during their involvement. | LAs
---|---

2.34. Service providers work together to ensure the successful reintegration of children and young people who have been absent from school due to hospital episodes or other long term illness, pregnancy, care or custodial placements away from their family and community, mental health problems, personal difficulties or a period of exclusion. | LHBs  
NHS trusts  
LAs

2.35. Every school has access to appropriately trained advisers, including named health advisers, so that supportive and confidential advice and counselling services are available to all young people. | LHBs  
NHS trusts  
LAs
### 2.36. Schools are supported to provide effective sex and relationships education, drawing on best practice as set out in *Sex and Relationships Education in Schools*.

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### 2.37. Schools, which are not LEA maintained, have policies that promote the health and well being of children that are consistent with the requirements of key actions 2.33 to 2.36.

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### Prevention of injuries and accidents

#### 2.38. Children and Young People’s Framework Partnership Plans (under Core Aim 6) include mechanisms for the prevention of accidental injuries in children that include:
- Monitoring of accidental injuries in children using effective data collection systems (see 7.21);
- Promotion of home safety, including safety equipment loan schemes in deprived areas and the safe storage and disposal of medicines;
- Safe play areas which are easily accessible for children;
- Traffic-calming measures in densely populated areas and near schools;
- School policies to encourage pupils to behave safely on their journeys to and from school.

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### Healthy and Safe Homes

#### 2.39. LAs use their housing strategies and related powers to facilitate the implementation of the *Housing Health and Safety Rating System* to ensure that children, young people and their families live in safe and healthy homes.

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### Food and Fitness

#### 2.40. Local organisations work together to develop and implement a policy to encourage health-promoting infant nutrition, including initiation and maintenance of breastfeeding in line with *Investing in a Better Start, Promoting Breastfeeding in Wales*.

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271. *Sex and Relationships Education in Schools*

96. *Investing in a Better Start, Promoting Breastfeeding in Wales*
| 2.41 | All settings where meals are provided for children and young people have policies in place to promote healthy food options (including in vending machines) as well as reducing the promotion and availability of snacks that are high in fat, salt and sugar and drinks that are high in sugar. | LHBs, NHS trusts, LAs, HCW |
| 2.42 | All settings that deliver services to children and young people have drinking water readily available in an appropriate place and at no charge. | LHBs, NHS trusts, LAs |
| 2.43 | Children and Young People’s Framework Partnership Plans include (under Core Aim 4) mechanisms to promote physical activity, particularly by providing services and an environment that supports active play and physical activity. | CYPFPs, LHBs, NHS trusts, LAs |

**Promoting positive mental health and psychological well being**

| 2.44 | Children and Young People’s Framework Partnership Plans (under Core Aim 4) include services and facilities to encourage the social interaction of children and young people with their peers, including playgroups, play facilities and youth services appropriate to the needs of the community. | CYPFPs, LHBs, NHS trusts, LAs |
| 2.45 | Children and Young People’s Framework Partnership Plans (under Core Aims 2 & 3) contain joint working arrangements to actively promote mental health and psychological well being in children and young people that include:  
  - Provision of a range of universal programmes to promote mental health and psychological well-being, in a variety of settings designed to maximise participation;  
  - Provision of easy and confidential access to advice for young people in the community setting on a range of issues that may affect their health and well-being;  
  - Implementation of effective anti-bullying policies in schools. | CYPFPs, LHBs, NHS trusts, LAs |
### Promotion of positive health-related behaviour

2.46. **Children and Young People’s Framework Partnership** Plans (under Core Aim 3) include:
- Tobacco control measures to reduce the numbers of children and young people who smoke or who are exposed to passive smoking;
- Delivery of a Local Substance Misuse Action Plan developed by the Community Safety Partnerships;
- Rapid access to confidential contraceptive and sexual health advice services, including emergency hormonal contraception as set out in *Best practice advice on the provision of effective contraception and sexual health advice services for young people*.

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### Prevent communicable diseases

2.47. There is a communicable disease control programme for children and young people that includes:
- Offering all children and young people routine childhood immunisations in line with current UK policy;
- Follow up of children who have missed immunisation appointments before one year of age and again at school entry, with further appointments offered as appropriate;
- Monitoring of vaccine uptake by GP practice and managing support for those with the lowest uptake, particularly for MMR vaccine.

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STANDARD – PARENTING

STANDARD:

Parents and carers have access to a range of services to help them to nurture the physical, social and emotional growth of children and young people in their care.

RATIONALE:

“Bringing up children is perhaps the most challenging and important task that most of us perform. It is a lifelong commitment—sometimes described as the only job we have for life—and how well we do it is likely to have a continuing impact on future generations.”

(Pugh, De’Ath & Smith 97 1994 p.9)

Providing ‘good-enough’ parenting is a huge challenge to all parents, even when everything in their lives is going well. This task becomes more difficult when parents or children are ill, live in damp and overcrowded conditions, do not have enough money to buy everyday necessities or do not speak the same language as those around them. There are many factors which can confound parents’ attempts to bring up their children to live happy, healthy and fulfilling lives. Some parents require extra assistance at difficult times, but almost all parents require advice at some time or other. Parents should be enabled to seek and get the advice they require without feeling that they have failed in any way.

Parenting style has been shown to have a pervasive influence on health and well-being in adult life, especially mental health, and has been shown to have a protective influence against some of the factors linked to poverty. Parental style is also the most important influence on a person’s level of self-esteem.

Policies for maternal and paternal leave, and workplace policies that allow fathers especially to spend time with their children, have important roles in improving the quality of parenting that can be provided. Parental leave from work has been shown to result in closer bonding with children, better partner relationships and greater feelings of comfort and confidence for the whole family.

A National Mapping of Family Services in England and Wales has shown that the availability of one-to-one, group based, and home-based support for parents is extremely patchy, with some areas providing little or nothing. In particular, there is a lack of services for families with children over five years of age. Ethnic minority families and fathers are also relatively neglected in current services. Comprehensive planning of services is needed to ensure that the cultural and other preferences of these groups are taken into account, and to ensure more equitable distribution of services to include rural and suburban areas.
Sure Start was launched in Wales in April 1999. The scheme provided integrated, locally based services to support families with children aged 0-3 years. The programme aimed to improve the health, social and emotional development and the ability to learn of very young children so that they are ready to thrive when they get to school. It also linked to a wider social inclusion agenda, by providing support to parents and encouraging capacity building in the most disadvantaged communities.

Cymorth was introduced in April 2003. It aims to provide a network of targeted support for children and young people within a framework of universal provision, in order to improve the life chances of children and young people from disadvantaged families. Cymorth is administered through local Children and Young People’s Framework Partnerships within each Local Authority. Cymorth has replaced the former programmes Sure Start, Children and Youth Partnership Fund, National Childcare Strategy, Youth Access Initiative and Play Grant.

The positive benefits to families of home visiting services have been demonstrated in a number of areas, including injury prevention, encouraging and supporting breastfeeding, parenting skills, and detecting and managing post-natal depression. Professional emotional support for pregnant women who are already caring for existing young children can decrease the rate of postnatal depression. Helping new parents to develop child-rearing skills is effective and young, single parents can be helped to cope better. There is evidence for the effectiveness of, and need for, group-based parenting education and support programmes. Desired outcomes for both parents and professionals include a supportive network of friends, better relationships with children, greater knowledge of issues such as child health and development, and emotional benefits.

The need for high quality and consistent parenting information and advice was one of the key themes that emerged from the consultation exercises carried out with parents. "Parenting classes are offered but they are not always appropriate. There is only one class and it is aimed at couples, not taking into account single parents and is also held at an inappropriate time." (Parent quote from Contact a Family, Sept. 2003)

Birth to Five is published by the Welsh Assembly Government and is provided free to all first time mothers in Wales by health visitors. It includes information on coping with a new baby, growth and development, learning and playing, habits and behaviour, nutrition, accident prevention, managing minor illnesses, mothers’ health, services, rights and benefits. A new edition of the book will be produced in autumn 2004, and will also be available to download from the web site.
**KEY ACTIONS:**

**Parenting education and support**

2.48. Children and Young People’s Framework Partnership Plans (under Core Aims 1, 2, 3, 5 and 6) include joint working arrangements to promote and deliver parenting education that includes:
- Ready access for parents/carers to evidence-based information about parenting issues through a range of appropriate media;
- Programmes designed with the participation of parents;
- Service delivery in a variety of settings, including homes;
- Finding creative solutions for barriers to participation, which may include transport, timing and availability of childcare;
- Suggesting appropriate methods for managing children’s behaviour that support the Welsh Assembly Government’s views that physical punishment of children is unacceptable.

2.49. Parenting support programmes are available that include:
- A range of universal and targeted services to meet assessed need;
- Particular services for families who find themselves in difficult circumstances, such as support for parents of children with chronic illness, mental health or behaviour problems, services targeted at school-aged parents, and services for parents of disabled children or for those parents who are themselves disabled.
- Provision of advice which is consistent, achieved through multi-agency training programmes.

2.50. Service providers, in their role as employers, have family friendly and flexible staffing policies that recognises the valuable roles that their staff play as parents.
STANDARD – SAFEGUARDING

STANDARD:

In every area, there are multi-agency and multi-disciplinary systems and services in place, in line with local Area Child Protection Committee (ACPC) procedures, which safeguard and promote children’s welfare and development. These systems enable clear identification of risk, referral to the appropriate statutory agency with the duty to investigate and multi-agency participation in interventions to achieve the best possible outcome for children.

RATIONALE:

“Children have a right to be protected from harm and all adults have a responsibility to protect children from harm”.

(Article 19, Convention on the Right of the Child 4)

All children need to be safe but there are specific circumstances in which children are at greater risk. Particularly vulnerable children are those who are often marginalized within society and who traditionally have needs which have remained unmet. Many children in need are at greater risk because of their vulnerability and may include those looked after by local authorities, asylum seeking children (particularly those who are unaccompanied), disabled children, children in the youth justice system, children who participate in risk taking behaviour and children with troubled parents (such as those who misuse substances, have mental disorders or where there is domestic violence). This list is by no means exhaustive and children who are in need, as is defined within this NSF, should be identified through assessed need and professional judgement and not by a label attached to a particular group of children.

The Carlile Review 18 arose from evidence given to the North Wales Child Abuse Tribunal 28. The report contains 150 recommendations for improving standards and increasing safeguards for children and young people treated and cared for by the NHS in Wales. The recommendations are aimed at the Welsh Assembly, the NHS local authorities and the non-statutory sector. The Assembly published its response to the Carlile Review in July 2002 262. NHS bodies were asked to identify their level of compliance and to produce an action plan to take forward implementation.

In January 2003, the Welsh Assembly Government received Lord Laming’s report into the death of Victoria Climbié 19. Although Victoria did not live or die in Wales, the circumstances surrounding her death are of such concern that the Welsh Assembly Government decided to take appropriate action to prevent such a case from occurring in Wales. The Chief Inspector of the Social Services Inspectorate for Wales issued an audit framework and an electronic tool to all local authorities in Wales to assist them in auditing their position against the good practice recommendations.
contained in the report. In late 2003, as part of her response to Lord Laming’s report, the Minister for Health and Social Services asked NHS trusts and LHBs to complete a self-assessment audit, produced by Commission for Health Improvement (CHI), of Board Members’ awareness of progress made in meeting the recommendations of the Carlile Review and the Laming Report. The report of the results of this self-assessment audit, Protecting Children and Young People 112 highlights many areas of good practice in NHS trusts but also areas that need to be improved. As part of its response to Lord Laming’s report the Assembly Government has secured a number of Welsh clauses in the Children Bill, introduced in the House of Lords in March 2004. Also in March 2004, the Assembly Government published Safeguarding Children: Working Together for Positive Outcomes 257. Issued as supplementary guidance to Working Together to Safeguard Children 66, this new guidance sets out the procedures and steps to be taken where a child may be suffering or may be at risk of significant harm. It takes into account a number of Lord Laming’s recommendations, particularly on the need to record information and for agencies to work together.

The Bichard Inquiry Report 29 into the child protection procedures in Humberside Police and Cambridgeshire Constabulary following the murder of Jessica Chapman and Holly Wells highlight lessons to be learned by all organisations that deliver services to children. As with previous reports where children have died, organisations were criticised for inadequate understanding of the Data Protection Act 1998 38 and poor sharing of relevant information. The report also stated that there was an over-reliance on CRB checks when recruiting staff and recommended the need for increased awareness that not all abusers are known to the police.

The report by the Children’s Commissioner for Wales Clywch 30 into allegations of child sexual abuse in a school setting makes a number of recommendations for the safeguarding of children while they are under the care of school staff. A number of key actions within the Children’s NSF are already addressing some of the recommendations within this report. A response to the full contents of this report will be provided by the Welsh Assembly Government later in the year.

The Carlile Review 18 identified that children with complex health problems or multiple disabilities are at greater risk of abuse or neglect. It has also been shown that abuse is more likely to remain unrecognised in disabled children than in other children 54. Service delivery for these most vulnerable children in our society must therefore incorporate rigorous child protection procedures.

Area Child Protection Committees (ACPCs) bring together representatives from each of the main agencies and professionals responsible for helping to protect children from abuse and neglect. It is their role to ensure that professionals from all relevant agencies co-operate to ensure that children in their area are safeguarded. In line with the recommendation of Lord Laming, the Assembly Government intends to build on and enhance the work of ACPCs. The Children Bill, currently before
Parliament, will replace ACPCs with Local Children Safeguarding Boards. These will have the statutory responsibility for safeguarding and promoting the welfare of children in their area. Although the Boards will be established by local authorities, LHBs and NHS trusts, among others, will be partners in the Boards and will have a statutory duty to co-operate in making arrangements to protect children from harm and neglect.

The Child Protection Service/ National Public Health Service produced the Children’s Safeguards Framework for Use in NHS Services in Wales. The aim of the frameworks is to assist NHS organisations to identify safeguards in place and gaps in services. LHBs, NHS trusts and general practices in Wales have adopted and implemented the frameworks. The information collected as a result of completing these frameworks complements a number of the key actions in this standard and others throughout the document.

The Assembly Government is working through a number of programmes to minimise the danger of children and young people being drawn into sexual exploitation. In May 2000 guidance on Safeguarding Children Involved in Prostitution was issued that required ACPCs to explore the extent of the problem in their own areas and to provide resources for dealing with it.

Information sharing between professionals and agencies providing services to children was highlighted in both the Carlile Report and the Laming Report as an area of great concern, and one in which there are current failures in the system. Working Together to Safeguard Children states that safeguarding children’s welfare “requires professionals and others to share information about a child’s health and development and exposure to possible harm. Often, it is only when information from a number of sources has been shared and is then put together that it becomes clear that a child is at risk or is suffering harm.” Organisations must be clear about when sharing information is in the best interests of a child and find means of overcoming present barriers to this happening.

The key actions within this standard do not replace any existing guidance in relation to child protection, but serve to emphasise and enhance existing guidance and legislation.
### KEY ACTIONS:

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<tr>
<th>2.51. Executive and non-executive members of NHS Boards, and relevant local authority members and officers, school staff and governors receive child protection awareness training and understand their corporate responsibility for child protection issues.</th>
<th>HCW, LHBs, NHS trusts, LAs</th>
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<tr>
<td>2.52. There is a nominated person in every NHS trust, LHB and LA who is responsible for monitoring the implementation of the child protection procedures in line with <em>Working Together to Safeguard Children</em> and local ACPC procedures.</td>
<td>LHBs, NHS trusts, LAs</td>
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<tr>
<td>2.53. There is a named doctor, nurse and midwife in every NHS trust, and named child protection co-ordinators in social services and Local Education Authorities who take the lead in child protection matters. They are given protected time to fulfil this role.</td>
<td>LHBs, NHS trusts, LAs</td>
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<td>2.54. There is a preventative strategy to ensure the safeguarding of children in all areas that recognises the importance of creating communities which protect children from harm.</td>
<td>LHBs, NHS trusts, ACPCs, LAs</td>
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<td>2.55. School children are informed of the availability, purpose and access routes to services that are in place to protect them from harm, including ChildLine, the NSPCC Child Protection Helpline, social services, the Children’s Commissioner for Wales and advocacy services.</td>
<td>LAs</td>
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<tr>
<td>2.56. ACPCs adopt and follow protocols to seek to ensure that all children and young people are safeguarded from emotional, physical and sexual abuse and neglect. This includes monitoring the numbers of disabled children and young people who are subject to child protection processes.</td>
<td>ACPCs, LAs</td>
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2.57. **NHS trusts Chief Executives, Local Authority Chief Executives and Directors of Social Services** are aware of the outcome of the audit of their services following the publication of the Assembly Government’s response to the recommendations of the Laming Report 19, and Carlile Review 18, and ensure that they have implemented their action plan.

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2.58. **Primary care and contractor practices** implement written child protection procedures for dealing with child protection issues that are in line with local ACPC procedures, and there is a nominated lead practitioner in each practice who is responsible for child protection issues.

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2.59. There are clear protocols on sharing of information to facilitate co-operative working between organisations. These protocols take account of and make reference to Government guidance and legislation.

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2.60. There is a mechanism for the early identification and referral of **vulnerable children** who are at risk of harm, and a well-defined early intervention programme.

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2.61. Agencies adopt and implement protocols which ensure that children and young people who are cared for by adults with mental health problems or disorders, or who misuse substances, are safeguarded. The **Framework for Assessment of Children in Need and their Families** 37 is used to make a multi-agency assessment of risk and need.

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2.62. **All staff who deliver services to children** and families, and those who have access to children’s records, receive child protection awareness training and appropriate **CRB checks**.

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2.63. Interview panels that appoint staff to work with children are aware that not all abusers are known to police and use robust selection and recruitment process as recommended in the Carlile Review 18.
### 2.64. Organisations develop and implement the following policies to ensure the safeguarding of children within their care:

- **Whistleblowing Policy** in relation to unsafe practices, including child protection issues;
- **Professional Abuse Policy** to detect and prevent professionals from abusing children and young people;

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### 2.65. Agencies responsible for children and young people placed outside the agency area ensure that the best interests of each child is safeguarded.

### 2.66. As soon as it is known that a child or young person on the Child Protection Register has moved, it is the responsibility of the named professional for child protection to:

- Inform the responsible LA;
- Secure all relevant records for the child;
- Inform the named professionals in the receiving area that the child has moved into their area within 2 working days;
- Ensure the named professionals in the new area receive the child’s records within 10 working days.

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### 2.67. When a named professional for child protection becomes aware that a child on the Child Protection Register has moved into their area, they are responsible for informing the local authority Child Protection Co-ordinator who informs other relevant partner agencies within 24 hours.

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### 2.68. Mechanisms are in place for prompt dissemination of lessons learned from other geographical areas as well as national reviews and guidance on child protection that are distributed by the Welsh Assembly Government.

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CHAPTER 3

MATERNITY SERVICES

INTRODUCTION

Pregnancy and childbirth are natural events but also have great social and emotional significance, particularly for those who are experiencing this for the first time. The prospect of transition into parenthood can bring great joy and excitement but also anxiety about the birth process and the responsibilities that parenthood brings. The challenge for health care providers is to minimise risks for mother and baby, ensure that the experience of pregnancy and childbirth is a satisfying one, and support the family in adapting to the changes needed to love and nurture a new member of the family.

Overall the birth rate in England and Wales has fallen between 1996 and 2001, with a lower conception rate in Wales (74.2 per 1000 women) than England (76.2 per 1000 women). Between 1990 and 2001, live births in Wales fell by 20%, with the greatest live birth rate reduction seen in Merthyr where it has fallen by 35% \(^{115}\). These changing birth rate patterns have significance for future service planning. There are just over 30,000 births per year in Wales currently \(^{116}\), with just 2% of births taking place at home or elsewhere and 98% taking place in a hospital setting.

There has been a statistically significant increase in the proportion of Welsh babies born with a low birth weight (below 2500 g) between 1993-95 and 1999-2001 \(^{15}\). Low birth weight babies have a reduced chance of survival in infancy and are at increased risk of suffering from chronic diseases in adulthood such as diabetes and heart disease \(^{117}\). The reasons for this increase in low birth weight are not fully understood and are likely to be multi-factorial but contributory factors are likely to include the increased numbers of multiple births (due to increased rates of assisted conceptions) and increased smoking rates in women. There is at present no routine national data collection on maternal smoking although this data may be available shortly from the new National Community Child Health Database. However, we know from the Health Behaviour in School-aged Children (HBSC) survey that the proportion of girls aged 15-16 who had ever smoked rose from 65% in 1986 to 74% in 2000, and that 25% of these girls in Wales reported smoking regularly, a higher rate than any of the other UK countries \(^{69}\).

There has been a statistically significant drop in the overall stillbirth rate in Wales from 5.7 per 1,000 in 1993-95 to 4.8 per 1,000 in 1999-2001 \(^{118}\). There has also been a drop in the perinatal mortality rate (number of deaths in babies born after 28 weeks and up to one week...
following birth) from 8.6 per 1,000 in 1993-95 to 7.7 per 1,000 in 1999-2001 \textsuperscript{118}. This is despite increasing levels of low birth weight and so is likely to be a reflection of improved antenatal, intra-partum and postnatal care of low birth weight babies, and babies with serious congenital abnormalities. Neonatal mortality rates (deaths in babies aged under 28 days) and infant mortality rates (deaths in infants under 1 year) have not changed significantly from 1993-95 and 1999-2001. There was also no statistically significant difference between different areas of Wales for stillbirth rates or perinatal mortality, neonatal mortality and infant mortality rates \textsuperscript{15}.

Birth is a normal physiological process in which medical intervention should only be offered if it can be demonstrated that there is proven benefit for the mother and/or her child. The caesarean section rate in Wales has increased steadily in recent years from 19\% in 1995-96 to 24\% in 2001-02, and is consistent with rising rates in many other developed countries \textsuperscript{116}. There has however been a slight decrease in instrumental deliveries from 10\% in 1995-96 to 9\% in 2001-02. One of the factors which may account for the increase in assisted delivery is that women generally are delaying the age at which they decide to start a family. In 2001-02, 65.8\% of deliveries in Wales were unassisted, with 73\% in the 16-24 years age group and 56\% for mothers aged 40-44 years. Maternal request only accounts for 7\% of the caesarean section rate in England and Wales \textsuperscript{119}.

One of the prime aims of the NSF is to reduce the inequalities in health that are currently evident. Disadvantaged women are more likely to die in childbirth, with the maternal death rate where neither the woman nor her partner have an occupation is close to 20 times higher than in social classes 1 and 2. For women in some ethnic groups, the risk of maternal death is twice as high as for white women. Women from travelling communities also appear to be at greater risk \textsuperscript{120}. Low birth weight levels in Wales demonstrated 40\% higher levels in the most deprived areas compared with the least deprived areas, as measured by the Townsend index \textsuperscript{15}.

In addition to developing standards, the EWG for the Maternity module also developed a Care Pathway for Normal Antenatal and Postnatal Care (see Annexe inserted in back cover of this document), which complements the \textit{All Wales Clinical Pathway for Normal Labour} \textsuperscript{121}.

The standards within this chapter have been developed to address these problems as well as issues highlighted by parents who were consulted to seek their views on present services and how they could be improved \textsuperscript{110}. The standards in this chapter should be read in conjunction with the standards in Chapter 2, which refer to all children and their families.

This chapter contains 3 standards:

1. Child and Family Centred Services 53
2. Access to Services 56
3. Quality of Services 61
STANDARD – CHILD AND FAMILY CENTRED SERVICES

STANDARD:

Women and their partners are empowered to make informed choices throughout their pre-pregnancy and maternity care. Services are co-ordinated seamlessly between hospital and community, and between agencies, to maximise the health and well-being of families.

RATIONALE:

To start planning to redress inequality in healthcare access and delivery it is particularly important to identify and listen to those women who at present have the poorest outcomes. Socially excluded and very young women often find it difficult to be heard, as was highlighted in the Confidential Enquiry into Maternal Deaths 120. Maternity services need to be flexible to reach and maintain the confidence of those women who are marginalized by society e.g. women who misuse substances, victims of domestic abuse or those who are at increased risk of mental disorders, and innovative ways should be used to address their needs 122.

In the consultation exercises with parents that were commissioned by the Welsh Assembly Government to inform the development of these standards, parents stated that they wanted greater control over the care they received and wanted to see midwives taking the lead role in the co-ordination of services. They felt that good quality information was essential for them to make informed decisions about the care that they received. A report by the National Childbirth Trust 121 on the experiences of women before and after giving birth highlighted that not only do women require good quality written information, but they also need professionals who are skilled at listening to and communicating with women.

Creating the right environment in which women can give birth is important, not only from the point of view of improving the whole birth experience, but has also been shown to result in less instrumental deliveries. A survey of 2,000 women in England, Scotland, Wales and Northern Ireland 124 demonstrated that:

- 90% of women felt that the physical surroundings can affect how easy or difficult it is to give birth;

“There needs to be better information about maternity services especially to first time mothers, as you only find things out as you go along.”

“Parents should have written information about scans and tests and someone talking you through.”

(Parent quotes from Contact a Family, Sept. 2003)
Many women had limited access to facilities that they felt were highly important during labour;

Most women said having a clean room with en suite facilities, being able to walk around and having comfortable furniture for themselves and their companions was highly important. Women wanted control over heating, lighting and who came into the birth room. They would prefer not to move to a different room for birth or a separate room to use birth pool;

Women who gave birth in hospital were less likely to have access to helpful facilities compared with women who gave birth at home or in a freestanding midwifery led unit;

Women who had good access to facilities were more likely to have a vaginal birth.

The role of fathers in families has changed in recent years with many fathers now playing an active role in child rearing, as opposed to the traditionally portrayed role of the ‘breadwinner’ but not the carer. For a variety of reasons, fathers have often been excluded from decision-making processes in pregnancy and childbirth. Assisting fathers to be involved from the earliest possible time and valuing their role can have a lasting positive impact on the family.

**KEY ACTIONS:**

*Pregnancy Care*

3.1. Pregnant women are offered an holistic assessment at their initial interview with a named midwife and care is planned to meet their needs and recorded in the jointly agreed individual care plan.  

Dads were not encouraged to attend appointments and were often sent home before labour to return - when they were needed.* (Parent quote from Contact a Family, Sept. 2003)

3.2. Women are given information about locally available services to allow them to choose the most appropriate options for pregnancy care, birth and postnatal care. Women who choose home delivery as their birth option are supported in that choice, appropriate to the level of clinical risk.
### Labour and Birth

#### 3.3. Care of women and babies is regularly reassessed and planned in partnership with women and their partners by a named midwife, or for high-risk pregnancy/birth by a named obstetrician and paediatrician.

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#### 3.4. Birth environments are regularly audited to ensure they optimise normality, privacy and dignity during labour and birth for the mother and birth partner(s) 258.

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### Postnatal

#### 3.5. Shortly after birth an identified lead professional, normally the named midwife, is responsible for reassessing individual needs and co-ordinating the postnatal care of all babies and women.

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#### 3.6. Wherever possible, separation of mothers and babies is avoided by nursing babies who require additional care with appropriately trained staff on the postnatal wards.

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#### 3.7. Parents of stillborn babies, or babies with identifiable medical or physical problems, receive timely and appropriate care and support.

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#### 3.8. Following the death of a baby, the lead paediatrician meets with parents within 6 weeks to discuss the results of a post-mortem examination.

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STANDARD – ACCESS TO SERVICES

STANDARD:

Maternity services are available to maximise the opportunity for all women to receive accessible care, focused upon maintaining and improving health and well-being. This requires that women are equal partners in planning the delivery of their care.

RATIONALE:

The Report of the Expert Maternity Group \(^{128}\) recommended that maternity services should be community based and women-centred with each woman getting to know one midwife to ensure continuity of care. This was supported by the Strategic Framework document Realising the Potential: “Delivering the Future in Wales” A Framework for Realising the Potential of Midwives in Wales \(^{122}\) which stated that women centred services require that midwives have a visible base within the community setting.

The achievement of equality of access to services is more challenging in rural Wales. The Review of Health and Social Care in Wales \(^{16}\) stressed that the current pressures on acute sector beds was unsustainable and that a reconfiguration of services was necessary with a move towards better use of community hospitals and primary care. The introduction of midwifery-led birth centres has helped to make services more accessible for rural communities while providing a family-centred, less technologically intrusive service that can be more appealing to those who traditionally have poor access to services e.g. teenage mothers, mothers from minority ethnic groups and mothers from travelling families \(^{129}\).

In 2001 Jane Hutt, the Minister for Health and Social Services, agreed that there should be a uniform service developed in Wales to inform the choices of all pregnant women with regard to antenatal screening and to maintain standards. As

\[ \text{“The midwives and health visitors were approachable – I was never made to feel a nuisance or stupid. I appreciate they have a large workload and must be in it for love of the job!”} \]

(Parent quote from Contact a Family, Sept. 2003)

\[ \text{“It takes one and a half hours to get to either hospital each way- by the time you’ve dropped off the children in the morning and got on a bus for an hour and a half you’ve got an hour and a half before you have to set off back for a deadline at 3 o’clock!”} \]

(Parent quote from Contact a Family, Sept. 2003)
the first step in developing an effective and appropriate antenatal screening programme for Wales, the Minister asked Velindre NHS Trust to carry out a baseline study and an option appraisal for the delivery of a uniform quality service that includes audit, monitoring, reporting and training.

In April 2003 the Minister for Health and Social Services agreed that a Managed Clinical Network for Antenatal Screening should be established in Wales, based on the principles described in the Antenatal Screening Project Report “Choices”. The network is known as Antenatal Screening Wales. The implementation of Antenatal Screening Wales will provide a sustainable, all Wales framework to improve the standard of antenatal screening offered to women. It will be the first step in developing an effective, appropriate, uniform, quality antenatal screening programme for Wales which includes all Wales policies and standards and service monitoring, audit and reporting.

Childbirth is an immense physical, emotional and psychological experience which may place some women at risk of developing a mental health problem or disorder. Depression during pregnancy may be as prevalent, if not more so, than postnatal depression 130, which affects around 13% of women 131. Maternal depression, which frequently remains undetected 132 can have negative consequences for marital relationships and lead to self-harm and suicide 130. It can also affect the cognitive development of infants 133; cause emotional and behavioural problems and cognitive delay in children 134, 135 and increase the risk of child abuse and neglect 136. Anxiety at this time can cause significant difficulties for many women and their families 137 and women with pre-existing mental disorder are especially vulnerable at this time. The treatment and management of mental disorder can be complicated by pregnancy, and some women may be at high risk of recurrence or relapse 138. Howard et al 139 found that women with psychotic disorders are at increased risk of suffering stillbirth or neonatal death, and there are a range of psychiatric disorders which can impact on the care and development of infants 138. Although suicide rates around this time remain relatively low, suicide has become a leading cause of maternal death and the importance of accurate detection and appropriate intervention for women with mental health needs has been highlighted 120.

As women have high levels of contact with health professionals at this time, it should be possible to detect many women at risk 138. Most can be helped within primary care and strategies already exist to improve detection and the management of postnatal depression by health visitors 140. Others will require the support of secondary psychiatric services, but this requires knowledge regarding the risks and skilful and effective screening and intervention within antenatal care. The importance of prevention at the earliest opportunity has been emphasised 120.

Prematurity is the major cause of neonatal death and neonatal intensive care is a high cost, low volume service not available at every maternity unit. If possible, premature babies should be born at units with appropriate facilities but since this
cannot always be predicted, it is essential that there should be efficient and safe systems for transferring mothers and babies 141.

Mothers who misuse substances are more likely to delay accessing maternity services because of concerns about how they will be treated because of their drug use 142. A study by Morrison & Siney 143 of 213 NHS maternity units in England and Wales, showed a substance misuse rate of between 1.5 to 50.1 per 10,000 deliveries. Maternity services need to be flexible and non-judgemental if they are to be acceptable to these women, and innovative ways need to be used to address their needs to minimise the impact on both mother and baby 142.

Women and their partners need to receive information on antenatal screening early in the pregnancy and have the opportunity to discuss any issues about this that concern them to enable informed consent 277. Prior to being asked to consent to screening tests women must be given information so that they understand why the tests are offered, what the tests are looking for and what the consequences of the results might be. The same is true for neonatal screening tests. Staff should take the time to explain the tests to women accurately and with sensitivity.

In general, teenage mothers are more likely to have poorer health, social and economic outcomes 144. Overall rates of teenage pregnancy are highest in the areas of greatest deprivation and amongst the most vulnerable young people including those in care and those who have been excluded from school 15, 253. Babies born to teenage girls have, on average, lower birth weights, increased risks of infant mortality, increased risks of congenital abnormalities, and are more likely to have the experience of being in a lone parent family, of living in poverty and in poor housing conditions 146. All these factors point to the need for targeted services for teenage mothers, particularly those who do not have the support of their extended family.

“There is a presumption that tests will be undertaken and not always offered as a choice – but there are implications if the tests show up any issues – should be informed and prepared- although you don’t want to scare people.”
(Parent quote from Contact a Family, Sept. 2003)

“There should be more parenting skills support for young mums, those who had gone found them very helpful.”
(Parent quote from Contact a Family, Sept. 2003)
The consultation exercises with parents commissioned by the Welsh Assembly Government highlighted the need for antenatal and parenting classes. They especially wanted classes that offered greater variety, flexible times that allowed fathers to attend also, and with some classes targeted at key groups. The issue of attending classes for those who lived in rural areas was also a concern of parents.

**KEY ACTIONS:**

**Pre-pregnancy Care**

| 3.9. | Women are able to access midwives in their community on a drop-in basis for pre-conceptual advice about developing healthy lifestyles, including taking folic acid supplements, and seeking maternity care as soon as pregnancy is confirmed. Early maternity care is promoted by the availability of midwives as the first point of contact for women. | LHBs NHS trusts |

**Pregnancy and postnatal care**

| 3.10. | Women have access to antenatal care, which is provided in a variety of local settings, and at times that take account of the demands of the woman’s family and working life. | LHBs NHS trusts |
| 3.11. | There are specialist services available for young, pregnant teenage girls, such as peer parent education and support groups. | LHBs NHS trusts |
| 3.12. | Pregnant women who smoke have access to information and support to assist them with smoking cessation. | LHBs NHS trusts |
| 3.13. | Women who have a termination of pregnancy are offered appropriate information and counselling, in line with guidelines from the Royal College of Obstetricians and Gynaecologists. | LHBs NHS trusts |

“Parents should be given the option of different classes and personal circumstances should be taken into account.”

(Parent quote from Contact a Family, Sept. 2003)
### 3.14. All pregnant women and their partners have access to parent education in their local areas, organised by an appropriately trained professional, and in a setting appropriate to their needs.

- LHBs
- NHS trusts

### 3.15. Pregnant women are offered antenatal screening as recommended by Antenatal Screening Wales.

- LHBs
- NHS trusts

### 3.16. Parents are offered newborn-screening for their babies, and appropriate follow-up care is commissioned if necessary.

- HCW
- LHBs
- NHS trusts

### 3.17. Mothers, babies and their families have access to services in the postnatal period from:
- A midwife for up to 28 days following birth;
- A health visitor from 10-14 days following birth;
- Other professionals according to assessed need.

- LHBs
- NHS trusts

### 3.18. Women are offered an assessment for depression in the antenatal and postnatal period by appropriately trained health professionals, and there is access to specialised follow-up support services if needed.

- LHBs
- NHS trusts

### 3.19. All women are given help line contact numbers for infant feeding advice before discharge from hospital or early in the postnatal period if their baby is delivered at home.

- NHS trusts

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**Labour**

### 3.20. When a potential risk or emergency occurs pregnant women have access to care and treatment as defined in **Welsh Risk Management Standard 15.**

- LHBs
- NHS trusts
STANDARD – QUALITY OF SERVICES

STANDARD:

Maternity services are delivered in partnership with women and their families and strive to ensure safe and positive outcomes for women and babies at all times.

RATIONALE:

High quality care from professionals who deliver maternity services is ensured through continuous professional development (CPD) that includes structured mentorship programmes, risk management and problem-solving skills, communication skills, child protection training and reflective practice. Delivering the Future in Wales \(^{122}\) recommended that high quality care during labour involved one to one care from a midwife as a minimum standard. Midwifery supervisors take the lead in developing effective systems for CPD of midwives as well as ensuring that they meet their statutory requirements for further development of supervision.

It has been shown that breastfeeding gives children the best start in life and yet the rate for breastfeeding initiation in Wales, at 46%, is one of the lowest in Europe \(^{96}\). Early skin-to-skin contact for mothers with their healthy newborn babies promotes maternal-infant attachment, initiation and maintenance of breastfeeding \(^{147}\) and so should be encouraged. In May 2003, the Welsh Assembly Government announced the appointment of the first breastfeeding co-ordinator for Wales to take forward the government’s strategy to promote breastfeeding in Wales.

The Pregnancy Book \(^{148}\) is a nationally developed handbook that offers evidence-based advice and information covering conception, pregnancy, antenatal care, labour and birth, everything needed to care for the new baby, mother and baby’s health, and rights and benefits entitlements. The book is regularly updated by the Welsh Assembly Government to reflect current recommended practice and is offered by midwives free to all women early in their first pregnancy.

Sudden Infant Death Syndrome (SIDS) affected approximately 2 per 1,000 live births from 1971 to 1988, but this rate has fallen by about 70% since the launch of the “Reduce the Risk” campaign in 1991 (http://www.sids.org.uk/fsid/index.shtml). This evidence of the effectiveness of the campaign demonstrates the need for information about cot death to be reinforced to parents by all the professionals who are in contact with them.

“Whilst there is general encouragement to breastfeed, in practice there’s not enough support or it’s not co-ordinated.” (Parent quote from Contact a Family, Sept. 2003)
Maternal death is a rare event but has a devastating effect on the remaining family. In response to this, the RCOG/RCM Joint Working Party Report Towards Safer Childbirth made a number of recommendations for the management of staffing, facilities and equipment and standards of care in labour wards to ensure a safe and pleasant childbirth experience.

**KEY ACTIONS:**

**Pre-pregnancy Care**

3.21. There is a multi-agency strategy to provide pre-pregnancy advice including nutrition and exercise, benefits of breastfeeding, sexual health and avoidance of substance misuse, starting with school-aged young people.

**Pregnancy, labour and birth**

3.22. Women in early labour have the opportunity to access a home visit from a community midwife.

3.23. There is an All Wales National Woman-Held Maternity Record (to be developed by the Welsh Assembly Government) that is used by both women and professionals.

3.24. Women receive one-to-one care (one woman receiving the dedicated time of a midwife) once labour is established.

3.25. All maternity units use the *All Wales Clinical Pathway for Normal Labour* and undertake regular audit of its implementation.

3.26. Maternity services follow any National Institute for Clinical Excellence (NICE) guidelines relating to maternity services.

3.27. Staff who deliver services to mothers and babies, in whatever location, are trained to carry out neonatal and adult life support.
### Postnatal Care

**3.28.** Women and their partners are offered the opportunity, by a named midwife in the postnatal period, to reflect on their experiences of pregnancy and childbirth. This information is sent to the Maternity Services Liaisons Committee to inform service planning and delivery.

**3.29.** Women who choose to breastfeed their babies are provided with appropriate support to initiate and sustain breastfeeding.

**3.30.** All babies receive a newborn examination within 24 hours by an appropriately trained professional.

**3.31.** NHS trusts which have consultant-led obstetric units have a named consultant paediatrician who has responsibility and a special interest in neonatology.

**3.32.** Babies requiring neonatal intensive care receive services in line with standards that are being developed by the Welsh Assembly Government and Health Commission Wales.

**3.33.** The lead midwife for child protection informs all appropriate staff of any agreed multi-agency arrangements for safeguarding of a baby e.g. babies subject to child protection plans and babies who are to be placed for adoption or surrogacy.
CHAPTER 4

CHILDREN AND YOUNG PEOPLE WITH MENTAL HEALTH PROBLEMS AND DISORDERS

INTRODUCTION:

This chapter sets standards for delivering services for children and young people who are experiencing mental health problems or disorders. Promoting psychological well-being, the right of every child, is addressed in Chapter 2.

In Wales, the meaning and scope of the phrase ‘child and adolescent mental health services’ (CAMHS) is inclusive. CAMHS means all of the services provided by all sectors that impinge on the psychological well-being, mental health, mental health problems and mental disorders of children and young people. In *Everybody’s Business* 156, this is termed ‘the CAMHS Concept’. Inclusion of CAMHS in two chapters in this NSF reinforces this holistic vision.

The term CAMHS is often taken more narrowly to imply those specialist services provided, mainly but by no means exclusively, by the NHS. Like *Everybody’s Business*, this NSF uses CAMHS to refer to all services that involve or affect the mental health of children and young people. Many of them do not specifically provide mental health services, nor are they all services aimed specifically at children and young people. The services described within these standards follow the 4-Tiered approach described in *Everybody’s Business*, which is a strategic and functional approach to ensuring that a comprehensive range of services is provided. In summary, the four Tiers are as follows:

- **Tier 1** – primary or direct contact services (usually provided by GPs, health visitors, school nurses, voluntary sector staff, social care and education staff). These services are available at every LHB/LA area.
- **Tier 2** – services provided by individual specialist CAMHS professionals and in support of Tier 1 services. These services should also be available at every LHB/LA area.
- **Tier 3** – services provided by teams of staff from specialist CAMHS. These are not always provided in every LHB/LA area but must be accessible to everyone in the area. They may be organised at a regional or sub-regional level.
• Tier 4 – very specialised in-patient and other residential services. These are currently only provided at a national or supra-regional basis to the population of Wales.

It should be emphasised that the Four-Tier strategic approach is a conceptual model for service delivery, and that particular services may deliver a mix of these tiered functions and actions.

Confusion in defining mental health problems and disorders can lead to tension and disputes about access to services, and which organisations are responsible for the provision of those services. For the purpose of these standards the definitions are drawn from the CAMHS Strategy for Wales Everyday’s Business 150:

“Mental Health Problems may be reflected in difficulties and/or disabilities in the realm of personal relationships, psychological development, the capacity for play and learning, development of concepts of right or wrong, and in distress and maladaptive behaviour...They are relatively common and may or may not be transient.”

“Mental Disorders are those problems that meet the requirements of ICD 10, an internationally recognised classification system for disorder. The distinction between a Problem and a Disorder is not exact but depends on the severity, persistence, effects and combination of features found.”

Current systems for routinely collecting data do not provide accurate figures for the scale of the problem in Wales. However, the ONS has conducted research in Wales and has shown that rates of occurrence of disorders are similar in England, Scotland and Wales 151. Also, the ONS research, together with data from the former health authorities in Wales, led to the predictions in Everyday’s Business that:

• More than 40% of young people have recognisable risk factors;
• 30-40% may at some time experience a problem;
• Up to 25% may have a disorder.

The scale of this problem is, therefore, substantial and sets a challenge to responsible agencies in Wales to raise service availability, co-ordination, capacity and capability through a programme of jointly agreed action by all key stakeholders, including children, young people and their families. An Implementation Advisory Group is working on implementing Everyday’s Business 150 and these standards are the next step in that programme of action.

The NSF standards are derived from the CAMHS Strategy for Wales Everyday’s Business 150, and serve to put into practice the values, principles, aims and objectives of the strategy, based on the three key components of Welsh Assembly Government’s vision:
• A joint working approach between different organisations;
• The Four Tier Strategic Concept;
• Partnership working between children, young people, their families and professionals.

The standards are also informed by consultation exercises carried out with children, young people, parents and carers on their views of the services they receive and how they could be improved \(^{53, 250}\). The Welsh Assembly Government extends its sincere thanks to young people from the Barnardo’s Malborough Road Project who attended one of the early External Working Group meetings to give their personal accounts of their experiences of services. Their views have been a strong influence on the development of these standards.

This chapter should be read in conjunction with Chapter 2, which sets standards for all children and young people, and in all the settings in which they find themselves.

This chapter contains 2 standards:

1. Access to Services 68
2. Quality of Services 74
STANDARD – ACCESS TO SERVICES

STANDARD:

Children and young people have equitable access to a comprehensive range of services according to assessed need, delivered in a co-ordinated manner.

RATIONALE:

The key actions within this standard set out criteria for access to services across the four Tiers as described in Everybody’s Business. All services providers must take opportunities to recognise and respond as early as is possible to mental health problems and disorders in children and young people, with the intention of reducing individual suffering and the accumulation of long-term problems. Also, the burden of young people’s mental health problems and disorders and the negative results of failing to provide adequate services for them falls on their families and carers. The results may be long-term, and the high personal as well as the financial costs do not respect sector or budgetary boundaries. Additionally, all children’s service providers should recognise that they, and not solely those identified as mental health services, have key roles to play in a co-ordinated programme of responsive early intervention services.

Another reason for joint provision of a tiered range of services lies in the very high levels of co-occurrence of more than one problem or disorder (termed co-morbidity in the NHS). For example, physical disorders are more common in young people with mental disorders and vice versa, and use or misuse of substances co-occurs with mental health problems and disorders. Once a child’s needs have been assessed, services must be found to meet those needs.

Research studies have shown that 1 in 1000 of the general population of the UK have a learning disability to the extent that they will require specialised services during their childhood, and that 50% of this group will have a significant psychiatric disorder. The range of disorders found is similar to those found in children in general. Some disorders occur more frequently such as hyperactivity, pervasive developmental disorders and self-injurious behaviour. The rate of disorder is highest in the more profoundly affected children. The Children’s NSF is based on a core philosophy of delivering services to meet a child’s specific assessed needs. As such, it is not acceptable to refuse a child access to services based on their IQ. However, this NSF recognises that there are particular skills and services that children who have a learning disability may require if they are to receive effective mental healthcare.
There is overwhelming evidence that Looked After Children have greater mental health needs than the general population of children. There is evidence that, currently, many of the needs of children who are looked after are not met. No doubt, the lack of continuity and stability in the lives of these children is a strong contributory factor. Elsewhere in the UK, research by Saunders and Broad found that 17% of young people leaving care had mental disorders and that 35% had deliberately self-harmed since the age of 16 years. Research by Meltzer et al also demonstrated that over half (57%) of Looked After Children who were clinically assessed as not having any disorder were viewed by their carers as having emotional, behavioural or hyperactivity problems. As with children with learning disability, Looked After Children have high levels of unmet mental health needs. The challenge for local services is to ensure that these children and young people, as all others, have their needs assessed and services delivered to meet those needs. Ensuring better continuity of primary care services will play a key role in this respect.

There is good evidence that the prevalence of behavioural and emotional problems in pre-school years may predict problems in adolescence and adult life, and that mental illness in childhood left untreated can have long-term effects which last throughout adulthood. The ability of CAMHS in Wales to respond to these demands is patchy and at times inadequate. It is the aim of the key actions within this standard to introduce some equity of service provision to all children and young people in Wales.

“We need to better understand the needs of children in care and the extent to which these needs are met”
(Quote from parent consultation, Fostering Network Wales, Dec. 2003)
### KEY ACTIONS:

**Tier 1 (Primary or direct contact services)**

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<tr>
<th>4.1. Service providers ensure that staff who deliver Tier 1 services are able to:</th>
<th>LHBs</th>
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<td>• Identify mental health problems and mental disorders early in their development;</td>
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<td>• Provide general advice and treatment for mild and minor problems;</td>
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<td>• Ensure that children, young people and families are referred to other agencies within Tier 1 or to other tiers within the specialist services where and when this is appropriate;</td>
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<tr>
<td>• Continue to provide services for children, young people and families in co-ordinated partnership with other services including the specialist services;</td>
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<td>• Provide the primary care component of care programmes for individual children and their families that are shared with Specialist CAMHS, and/or other healthcare services and/or other agencies;</td>
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<td>• Reduce escalation of young people’s problems by identifying risk factors and taking opportunities to reduce them, and taking steps to promote the resilience of vulnerable children, young people and their families.</td>
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<tr>
<th>4.2. Professionals delivering services at Tier 1 level have direct access to professionals at Tiers 2 and 3 for consultation, training and joint work.</th>
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<th>4.3. Commissioners and providers have a protocol that defines how consultation, training and joint work is provided by Tier 2 for Tier 1, including:</th>
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<td>• Criteria for routine and urgent cases;</td>
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<td>• Provision of routine consultation to Tier 1 practitioners within three weeks of contact;</td>
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<td>• Access to advice within 3 working days of request for urgent consultation.</td>
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## Tier 2 (Services provided by individual practitioners in Specialist CAMHS and in support of Tier 1 services)

4.4. All referrers to specialist CAMHS receive feedback on the outcome of their referral within 3 weeks. When the referral is considered to be inappropriate, the referrer receives a response and redirection to an appropriate service if necessary.  

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## Tier 3 (Services provided by teams of staff from specialist CAMHS)

4.5. Children and young people have local access to specialist CAMHS at Tier 3. A specialist multidisciplinary/multi-agency team provides day care and community intensive care services.  

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4.6. Commissioners ensure provision of specialist forensic CAMH, substance misuse and learning disability services for young people across Tiers 2, 3 and 4.  

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4.7. Children and young people referred to specialist CAMHS at Tier 3 are seen according to the following criteria:  

- **Routine** cases are seen by day care/community intensive care teams within 4 weeks of acceptance of a referral. When the referral is considered to be inappropriate, the referrer receives a response within two weeks of completion of the assessment and redirection to an appropriate service if necessary;  
- **Urgent** cases are seen by day care/community intensive care teams within 3 working days of acceptance of a referral. Feedback to the referrer is provided within one working day of completion of the assessment, indicating case management advice.  

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**Emergency Services**

4.8. Children and young people have access to emergency and out-of-hours consultation, which is provided 24 hours per day/7 days per week, as well as effective interventions and the availability of appropriate expertise for risk management.

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**Tier 4 (Very specialised out-patient, in-patient and other residential services)**

4.9. Children and young people referred for admission are seen according to the following criteria:

- **Routine** cases are assessed for admission within 3 weeks and where admission is clinically necessary it occurs within 8 weeks. When referrals are considered to be inappropriate, the referrer receives a response within one week of completion of the assessment and redirection to an appropriate service if necessary;

- **Urgent** cases are assessed for admission within 2 weeks and where admission is clinically necessary it occurs within 3 weeks. When referrals are considered to be inappropriate, the referrer receives a response within 3 working days of completion of the assessment and redirection to an appropriate service if necessary;

- **Emergency** cases referred are assessed for admission within 6 hours and where admission is clinically necessary it occurs within 12 hours. When referrals are considered to be inappropriate, the referrer receives a response within same day of assessment and redirection to an appropriate service if necessary.

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### Referral to services out of area

4.10. If it becomes necessary to place a child or young person in residential or inpatient services out of the home area, the case co-ordinator ensures that:

- Placement arrangements are agreed between organisations with responsibility for the child or young person and the relevant body in the area where the placement is made;
- Necessary services are available;
- Funding arrangements are agreed;
- There is a nominated lead practitioner in the receiving area who is responsible for monitoring each child’s progress, evolving needs and return to their home area.

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STANDARD – QUALITY OF SERVICES

STANDARD:

*Children and young people with identified mental health problems or disorders receive services to meet their needs which are timely, effective and co-ordinated.*

RATIONALE:

Whenever possible, the services offered to children and young people should be guided by known effectiveness (evidence-based) and efficiency (good value for money). In common with most other health, education and social services, the evidence about current effectiveness is expanding rapidly but is far from complete. Services should not be denied on the basis of insufficient evidence alone. But, as the evidence-base expands, it will become increasingly appropriate for services to be clear about their client groups, the interventions required of comprehensive CAMHS, effective and efficient pathways for care, the roles assigned to agencies within planned programmes of intervention and care, and the staff training consequently required.

High quality services cannot be delivered without sufficient staff and coherent education and training programmes that include continuing development programmes. All CAMHS should be evaluated with regard to their contribution to the intended framework of competencies and all contributing agencies should be able to demonstrate planned activities to continuously improve the governance of delivery of their services. User feedback from children, young people and families should inform plans to improve service delivery.

The literature now indicates that the most potent risk factors for children developing problems relate to the experiences of their parents. These risks include mental disorders and/or substance misuse, social exclusion and criminality. Therefore, all services for adults must recognise the wider roles of the adults as parents, carers and family members by actively considering the needs of the children of adult service users. Services for adults must have the capacity and capability to intervene where and when necessary or have good and effective relationships with services for children so that they can arrange joint intervention plans.

“There are some very good individual professionals in all services (pity there aren’t more!).”
(Quote from parent consultation, Fostering Network Wales, Dec. 2003)

“For goodness sake, can’t we have some clear structures to help meet these children’s needs.”
(Quote from parent consultation, Fostering Network Wales, Dec. 2003)
Service users, carers and professionals, are disadvantaged by fractured inter-agency arrangements and organisations and individuals within them who work in isolation. Children and their families are better served when commissioners and providers from all sectors work together to establish effective partnerships, which include children, young people and their families, in order to construct networks of comprehensive and appropriate services.

The nature of most direct work in CAMHS requires children and young people to trust and actively engage with the professionals involved. Professional relationships of this kind impact positively on the effectiveness of interventions. Research shows that children and young people engage better and are more satisfied with services in which they see the same professional(s) at each contact, and who can provide them with adequate time and actively listen to what they say. Experience shows that young people engage better with services that have these characteristics.

Many young people with mental health problems or disorders will require on-going support after their 18th birthday. Chapter 5 lists key actions under a Transitions Standard for those young people who will eventually require input from adult services. Although this standard is listed under the Disabled Child chapter, the key actions within this standard apply to any young person who will require support or services after their 18th birthday.

**KEY ACTIONS:**

*Equitable services*

| 4.11. Parents/ carers of children with mental health problems or disorders are offered an assessment under the powers given by the Carers and Disabled Children Act 2000 | NHS trusts LAs |

“I’ve been consistent. You get a different doctor each time at the clinic. Consistency is so important if the child is to open up.”

(Quote from parent consultation, Fostering Network Wales, Dec. 2003)

“Great difficulty from 16 to 18 because the medical team are trying to push him out to the adult’s services and social services are keeping him as a child.”

(Quote from parent consultation, Fostering Network Wales, Dec. 2003)
### Comprehensive services

4.12. When making decisions about service provision, risk assessments are undertaken in respect of all children whose behaviours may place others at risk of harm, or whose vulnerability may place them at risk of harm from others and themselves, and appropriate services commissioned.

| LHBs | NHS trusts | LAs | HCW |

4.13. All services and settings, which receive and treat children, have agreed robust liaison arrangements with other professionals and organisations to deal with the management of intentional overdoses and deliberate self-harm, as well as possible psychosis and seriously challenging behaviour.

| LHBs | NHS trusts | LAs | HCW |

4.14. The age and maturity of children and young people are considered when planning and providing services to meet their mental health needs.

| LHBs | NHS trusts | LAs | HCW |

### Co-ordinated services

4.15. The Children and Young People’s Framework Partnerships Plans recognise under Core Aim 3 the need for a co-operative approach to CAMHS that includes:

- Agreement between agencies about the contribution that each will make to providing comprehensive and well co-ordinated CAMHS;
- Joint assessment and planning;
- Co-ordinated criteria for service provision;
- Integrated early identification and intervention with children and young people who have problems with psychological well being, mental health problems, or mental disorders;
- A comprehensive range of co-ordinated and targeted parenting programmes.

| CYPFPs | LHBs | NHS trusts | LAs |

4.16. Staff who make decisions under the Children Act 1989 and the Mental Health Act 1983 have direct access to competent advice from a children’s lawyer who is a member of the children’s and mental health panels.

| LHBs | NHS trusts | LAs |
4.17. All cases referred to specialist CAMHS will be subject to case management as defined in Everybody’s Business.\footnote{150}

NHS trusts
LHBs
LAs

4.18. Each child or young person who is under consideration for admission or placement has an identified case manager who:
- Monitors their progress and needs and assures the quality of the care they receive;
- Ensures there are adequate arrangements to meet their needs prior to and following discharge.

LHBs
NHS trusts
HCW
LAs

4.19. Whenever young people over the age of 14 years are assessed or the review of their plan identifies potential continuing needs for CAMHS beyond their 16th birthday, their care and treatment plans will describe the arrangements for engagement with and provision of services for young adults.

LHBs
NHS trusts
LAs
HCW

Training

4.20. All staff who provide Tier 1 functions have access to:
- Training that will assist them in assessing the need for referral to specialist services and ensure appropriate levels of intervention;
- Training in assessing and managing emotional and mental health problems in children, young people and their families.

LHBs
NHS trusts
LAs
4.21. Staff delivering services at Tiers 2, 3 and 4 receive regular multi-agency training programmes (in addition to the core training referred to in Chapter 1), which includes:

- Principles of the CAMHS Strategy for Wales *Everybody’s Business* ¹⁵⁰;
- Information about mental health problems and disorders;
- Use of cognitive and behavioural therapies;
- Psychiatric interventions, including use of medication;
- Knowledge of the *Mental Health Act 1983* ⁶₀.

4.22. Multi-disciplinary teams, which are trained for the purpose, deliver all in-patient assessments, care and treatment.
CHAPTER 5

DISABLED CHILDREN AND YOUNG PEOPLE

INTRODUCTION:

Medical advances in general, and particularly in neonatal care, have led to improvements in life expectancy of children born with severe disabilities. Many families are now caring for children with complex health needs at home, who a generation ago would probably not have survived, and half a generation ago would probably have remained in hospital on a long-term basis.

Disabled children are entitled to be valued and have the same chance to succeed and participate in society as their non-disabled peers. They have legally enforceable rights as children and their families have the right to have their family life upheld and respected. However, there is a compelling body of evidence from research and inspection reports that disabled children and their families face many social and physical barriers to full participation in society. It is not only disabled children’s impairments which determine their quality of life, but also negative attitudes and a disabling environment, for example, unequal access to education, communication, employment, leisure activities, housing and health care. Disabled children and their families need particular support from health, education and social services, including early diagnosis or identification of difficulties and early intervention. They also need support from housing, transport and leisure services.

The Children Act 1989 clearly states that disabled children are ‘children first’. However, recognising disabled children as children first does not imply denial of a child’s particular needs: The Framework for the Assessment of Children in Need and their Families states that: “Ensuring equality of opportunity does not mean that all children are treated the same. It does mean understanding and working sensitively and knowledgeably with diversity.” The needs of disabled children are also addressed through other specific legislation such as the Special Educational Needs and Disability Act 2001, the Special Educational Needs Code of Practice for Wales, the Carers and Disabled Children Act 2000 and the Disability Discrimination Act 1995.

Providers also need to have regard to the Children (Leaving Care) Act 2000, Human Rights Act 1998 and the Race Relations (Amendment) Act 2000 when planning and delivering services,
programmes such as Children First. More work is needed to develop a fully integrated approach to supporting disabled children which maximises their inclusion in society as identified by the Health and Social Services Committee Review of Services for Children with Special Health Needs and the Policy Review of Special Educational Needs – Early Identification and Intervention currently being undertaken by the Education and Lifelong Learning Committee.

What should a minimum service for disabled children and their families look like?

Too often in the past children have been expected to fit in with the services that are available for them. The Kennedy Report highlighted that children are different, and have a different physiology as well as social and emotional needs from those of adults. Disabled children are no different to other children in this respect and deserve to have services that meet their individual needs. Health services are usually the first point of contact for parents of disabled children, but many agencies are often required to deliver services in a collaborative way to meet the needs of these children and their families.

Services designed to maximise the development of a disabled child should include:

- An assessment of each child’s needs and strengths, including diagnosis, if and when appropriate;
- Prompt delivery of services to meet assessed needs;
- Provision of educational support to maximise cognitive development;
- Encouraging social development through inclusive policies and practices;
- Provision of family support to maximise emotional development;
- Provision of services which respect’s each child’s views, language and culture.

Services designed to support families of disabled children should include:

- Clear and accurate information to empower them to make informed choices, and to gain access to help when they need it;
- Practical support to assist them in caring for their child;
- Access to emotional support when they need it;
- Advice on how to maximise their child’s development and offer of training, if needed;
- Access to affordable childcare and other services to enable parents to return to work, if they wish;
• Provision of short breaks and additional services to enable the family to participate in the same lifestyle that parents of non disabled children experience;

• Access to leisure.

These standards are informed by an understanding of the 'social model' of disability, which uses the term disability not to refer to impairment but rather to describe the effects of prejudice and discrimination, the social factors which create barriers, deny opportunities, and thereby exclude and dis-able people. The standards should be read in conjunction with the standards in Chapter 2, which apply to all children, in all the settings in which they find themselves.

This chapter contains 4 standards:  PAGE

1. Child and Family Centred Services 82
2. Access to Services 86
3. Quality of Services 92
4. Transitions 96

Any child or young person with a life-limiting condition as defined by ACT/RCPCH is considered to be potentially disabled and accordingly is included in any reference to disabled children within these standards.
STANDARD – CHILD AND FAMILY CENTRED SERVICES

STANDARD:

Disabled children, with their families from all communities, are fully supported to participate in valued childhood experiences and have access to the same range of opportunities, life experiences, and mainstream and community services and facilities as other children and their families.

RATIONALE:

The UN Convention on the Rights of the Child (Article 12) states that children have the right to have a say in any decision that affects their lives. Children (including those with communication needs) must be enabled to participate in decisions about services which affect them. Access to information is crucial for disabled children as well as their parents and this needs to come from a number of sources and in a variety of formats. Innovative communication methods need to be used to reach those children with communication difficulties. For example, for some deaf/blind children, the only method of communication is by tactile communication which requires very specialised skills and for some children with learning difficulties or autistic spectrum disorders, the use of Makaton is helpful. Information is needed on directories of local and national services and support networks, benefits, detailed information on conditions and specialist services available, as well as information on education and access to employment and adult living.

As the prime caregivers for children, parents need to be supported in their role and to have their expertise in knowing their child best acknowledged. Their concerns should be listened to and addressed.

Caring for a disabled child requires additional expertise and support, and can also be stressful. Research has shown key resources for parents include financial resources, access to short breaks, social support, and skills to deal with behaviour and sleep problems.

Disabled children need to play to improve their cognitive development and social skills the same as their non-disabled peers, but access to play schemes and leisure facilities is often difficult for them. During holiday periods school and community based programmes often cease and there are no alternatives for

“People let me speak and say what I feel because they have to, but then ignore what I say because it’s not what they want to do.”

(Child quote from NCH Cymru/Barnardo’s Cymru, Sept. 2003)

“There should be a greater recognition of parental expertise in discussions by professionals.”

(Parent quote from Contact a Family, Sept. 2003)
disabled children. As a result, they can become bored and lonely and spend more time watching television than their non-disabled peers.

The needs of disabled children are often wide ranging and require services from health, social care, education and the voluntary sector. Close inter-agency working is therefore vital to the smooth delivery of these services. A key working/care co-ordination service can facilitate the tailoring and co-ordinated delivery of services based on the child’s assessed needs by a named key worker for the child and family. A number of different models of key working exist. The key worker may come from a number of different agencies and may be a “designated” key worker i.e. employed specifically as a full-time key worker, or “non designated” key worker who co-ordinates the care for a few families as part of a wider caseload. This may be delivered through a multi-disciplinary/agency team working out of child development centres.

Whatever model of service delivery is used, parents have highlighted the value of a family key worker to co-ordinate care and provide support and advice. The Welsh Assembly Government is working with key stakeholders to develop national standards for care co-ordination services.

A diagnosis, or recognition that a child may have special health, education or social needs, could lead directly to an holistic assessment of the needs of the child and their family following the Framework for the Assessment of Children in Need and their Families and the SEN Code of Practice for Wales. A diagnosis is not a prerequisite to an assessment of any child’s needs. Prompt assessment should provide identification of areas in the life of the child or family where additional services will enable them to enjoy a high quality of life and maximise the child’s progress. Assessments should identify each child’s strengths as well as factors that are inhibiting their access to a good quality of life, as well as what services agencies can provide to help tackle some of these barriers. The needs of children and their families change over time and so assessment must be carried out as a continuous process and not a single event.

Parents of disabled children and those with life-limiting conditions not only suffer extra financial burdens but also endure an emotional cost. Following diagnosis,
parents not only have to come to terms with an adjustment to the needs of their child but also have to cope with attitudes that disabled people have to cope with and can become marginalised by society and friends \(^{181}\). Lack of support at this time can lead to break down in the family structure and may account for the over-representation of disabled children in the looked after population \(^{259, 182}\).

**KEY ACTIONS:**

*Participation*

5.1. Agencies employ creative and imaginative approaches including the use of new technologies and multimedia or non-verbal communication to provide information and to ensure that the views of disabled children and families are heard.

*Inclusion*

5.2. Disabled children and young people have equity of access to play and leisure services, including holiday play schemes, after school clubs and pre-school provision, with appropriate support if necessary.

*Co-ordination of services*

5.3. Each LHB/LA area has a Child Development Team to facilitate multi-agency assessments and holistic care for disabled children and their families.

5.4. A hand held record is provided for all disabled children with complex needs that complements the Personal Child Health Record, in line with Welsh Assembly Government guidance to be issued in 2004.

“The words and language that health professionals use is important, if they are positive and give support then the parents feel happier and more positive themselves.”

(Parent quote from Contact a Family, Sept. 2003)
### 5.5. Disabled children with assessed complex needs

Disabled children with assessed complex needs have an individual multi-agency care plan, consistent with the Framework for the Assessment of Children in Need and their Families and the Education Act 1996, which includes arrangements for dealing with emergency situations.  

| LHBs | NHS trusts | LAs |

### 5.6. Parents/carers of disabled children

Parents/carers of disabled children are offered an assessment under the Carers and Disabled Children Act 2000 as required by the Framework for Assessment of Children in Need and their Families.

| LHBs | NHS trusts | LAs |

### 5.7. Service providers

Service providers jointly agree and provide a key worker service for families with disabled children with complex needs. Where appropriate and agreed, this could be the parent.

| LHBs | NHS trusts | LAs |
STANDARD – ACCESS TO SERVICES

STANDARD:

All disabled children and their families receive accessible information about, and equitable and prompt access to, high quality co-ordinated services appropriate to their assessed needs.

RATIONALE:

Care, support and treatment services must ensure that the most vulnerable in our society, including disabled children, receive equitable access to services according to their needs. At present, service delivery for disabled children across Wales has become a post code lottery with many families reaching crisis point before they are able to access the services they need. This inequitable distribution of services for disabled children is made worse by a lack of an agreed definition by of “disability”, and application of different threshold criteria by different areas.

Some disabled children and young people require very specialised services that can be delivered in special schools, however, the majority of disabled children can cope well in mainstream schools with the right additional support. The Welsh Assembly Government has produced a consultation document which forms draft guidance for LEAs on inclusive education 183. Many children with complex health needs have two or more types of disability or special needs 179. Inclusion into mainstream education, where this is appropriate, is important for children with complex and continuous healthcare needs but this presents its own problems in relation to delivery of healthcare and therapy services 180. Many of these problems could be overcome with the development of an effective school health service for Wales as recommended by Clark et al 184, Carlile 18 and Russell et al 185.

Children with learning disabilities are three to four times more likely to experience mental health disorders than children of the general population and have high levels of unmet need. The range of disorders found is similar to that found in the general population of children. The rate of mental

“There should be universal criteria – across Wales for benefits, respite...Criteria vary according to postcode, so there is no parity of access to services.”
(Parent quote from Contact a Family, Sept. 2003)

“I’d like to get rid of the assumption that inclusion without resources is the way forward. Equality means treating people according to their need rather than giving everyone a bog standard service; some people’s needs are more than others.”
disorders is higher in more profoundly affected children \(^{154}\). As with any child in need, children with learning disability should receive an assessment under the *Framework for Assessment of Children in Need and their Families* \(^{37}\) and services delivered to meet their assessed needs. It is not acceptable to exclude any child from receiving a service because of their IQ level. Too often in the past children have been expected to “fit in” with whatever service delivery is available, but the philosophy of the Children’s NSF is that service delivery is focused on the unique and individual needs of each child. Providing effective treatment for psychiatric disorders in children and young people with learning disabilities requires specialist expertise \(^{186}\) and at present these services are inadequately developed in Wales.

Any family can experience housing difficulties but families with disabled children can encounter particular difficulties, especially in relation to space to store equipment, safety and adaptations to meet the needs of the child, such as the need for easy access \(^{176}\). Professionals need to be aware of the effects of housing difficulties on families of disabled children and know how to refer them for assessment of housing need.

Hearing impairment in children can impact upon their communication skills, developmental progress as well as social and emotional development. Since the 1950s, screening for hearing impairment has been carried out on all infants using the distraction hearing test by health visitors but the sensitivity of this test in identification of hearing impairment is variable, ranging from 18% to 80% \(^{273}\). Universal neonatal hearing screening at birth has been shown to be effective \(^{187}\). This is at present being rolled out across Wales and will replace the distraction hearing test. 30-40% of children with hearing loss will also have an additional disability and are at particular risk of visual impairment \(^{188}\), and so vision screening should be carried out whenever hearing impairment is present.

The following key actions are designed to improve equity of access to services for disabled children and young people.

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“The waiting list for home adaptations is far too long, there should be a timed, robust process for grants – no longer than 12 months.”

(Parent quote from Contact a Family, Sept. 2003)
KEY ACTIONS:

Early Identification and Intervention

5.8. Every LHB/ LA area has joint commissioning arrangements which support disabled children being maintained within their local community.

5.9. Disabled children with complex health needs are offered, before statutory school age, ophthalmic and auditory examinations to determine whether these impairments are present.

5.10. Disabled children and their families are offered early contact (before their primary dentition commences eruption between 8 and 13 months of age) with an appropriate member of the dental team for provision of preventative advice and information.

5.11. Children with a learning disability have access to a network of appropriately skilled CAMHS, which can respond to both their mental health needs and learning disability, according to their assessed needs.

Co-ordinated services

5.12. If it becomes necessary to place a disabled child or young person out of area, prior to the child’s placement, both receiving and home agencies agree placement arrangements, ensuring that the necessary services and funding arrangements have been agreed.

5.13. Disabled children, young people and their families have access to services to meet their assessed needs, including short break and other services.
Equipment (including communication aids, medical equipment and supplies)

5.14. There are integrated community equipment services that supply equipment to disabled children and young people, managed by a designated lead agency. The lead agency monitors that the following criteria are met:

- Assessment for equipment for disabled children is carried out by the most appropriate person in the multi-disciplinary team within 4 weeks of referral;
- Equipment is supplied within 6 weeks of assessment according to jointly agreed eligibility criteria for essential equipment;
- The equipment store has dedicated resources for children which are distinct from adult resources;
- A supply of continence equipment is available to meet the assessed needs of children and young people;
- Local emergency supplies are immediately available;
- There are effective mechanisms in place for the retrieval of unwanted equipment. This includes databases that record where equipment is, when it is due for servicing, cleaning or requires repair;
- The child’s equipment requirements are reviewed at least annually in accordance with individual assessed needs.

5.15. Disabled children are able to use the equipment they need in all the places where they spend time e.g. school, home, leisure settings and during short break care.

5.16. There are facilities for personal care available in all locations in hospitals and other health, education and social care settings. Adapted toileting and personal care facilities are available in health and social care locations e.g. toilet chairs and safety straps that meet nationally set standards.
5.17. There are agreed protocols and standards for wheelchair/specialist seating services that include:
- Providing a comprehensive service which meets particular needs of disabled children;
- Provision of clear information for professionals, parents, carers, children and young people regarding access to seating and wheelchair services;
- A single referral process which encompasses services provided through the Artificial Limb and Appliance Services and those provided by rehabilitation engineering;
- Assessment within 6 weeks of the referral being received;
- Provision of a wheelchair or equipment within 8 weeks of assessment;
- Quality assurance systems;
- Repair and maintenance procedures;
- Review of the child’s needs at least annually in accordance with individual assessed needs

5.18. There are agreed multi-agency protocols and standards for the provision of communication aids/tools/systems as follows:
- When a child is judged to have special communication needs by a professional, they are referred for urgent speech and language therapy assessment;
- When referrals are made to speech and language therapy for communication aids/tools/systems, the assessment is commenced within 3 months of referral and the device is provided within 3 months of completion of the assessment;
- There is joint commissioning of communication aids/tools/systems agreed between education, social services and the NHS trust/LHB, enabling the communication device to be used both in school and at home.
### Housing

**5.19.** Where families require housing adaptations, or assistance in moving home, clear information is given to all families about local authority policy and assistance is provided in the completion of forms for those families that require it.

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**5.20.** Local authorities and registered social landlords have up to date registers of adapted properties to assist with transfer requests to appropriate adapted housing without undue delay.

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**5.21.** Information is made available to families of disabled children regarding entitlement to Disabled Facilities Grants, including the increased flexibility provided by the new Regulatory Reform Order (RRO) arrangements.

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STANDARD – QUALITY OF SERVICES

STANDARD:

Disabled children are provided with appropriate high quality, timely services in an environment that is suited to their needs, age and stage of development. Well co-ordinated multi-agency services are delivered to address all types of need.

RATIONALE:

Early identification of problems results in improved health and social care outcomes for children. While effective screening methods exist for recognised conditions, high prevalence – low severity conditions such as delayed speech acquisition, clumsiness and minor behaviour problems are normally detected through professional review, routine and follow up examinations, and as a result of parental concerns rather than through formal screening tests. This emphasises the importance of listening to and acknowledging parental concerns.

There is now a growing number of children with severe complex health needs in education settings, including mainstream education. Policies for carrying out medical treatments and interventions for children in schools need to be developed. A recent report to the National Assembly for Wales in relation to resuscitation policies and practice has highlighted the need for clear policies for schools in relation to monitoring and evaluation of care plans, staff training and multi-disciplinary working.

The Special Educational Needs and Disability Act 2001 extends the Disability Discrimination Act 1995 to all aspects of education, including further and higher education. This is to ensure that young disabled people are not disadvantaged with regard to their education compared with young people who are not disabled. The Special Educational Needs Code of Practice for Wales provides practical advice to LEAs, schools and other agencies in the support of high quality education for all children with special educational needs.

“If a mainstream person went on to college they could pick what course they wanted to do (more choice) and if they didn’t want to do PE they wouldn’t pick it. However there are limited courses for people with special needs and they still have to do subjects they don’t want to do as in school.”

(Young Person quote from NCH Cymru/Barnardo’s Cymru, Sept. 2003)
KEY ACTIONS:

Early and Effective Intervention

5.22. Following diagnosis or identification of additional needs, families receive:

- Time to ask questions, and continuing opportunities to participate, in an informed manner, in decisions that affect the care of their children;
- Assessment reports which record a description of the child’s additional needs or diagnosis, written in a language that is easily understood by parents;
- The opportunity for a follow-up contact 7-14 days later by an appropriately trained professional to discuss any queries;
- Contact details to enable the family to contact a professional for advice when they need it;
- Contact details for local and national support organisations, if appropriate.

Children with complex and continuous health needs

5.23. Children with complex healthcare needs who attend special schools have access to school nurses, who are employed by the NHS, and are on-site at all times when children are on the premises. These school nurses also act as an expert resource for disabled children in mainstream schools.

5.24. Children and young people who need palliative care, whether in the chronic or terminal phase, are supported at home, whenever possible. Alternative or additional sources of support, for example, provided by children’s hospices, are available for families who require them.

Therapies

5.25. Therapists involve families as active partners in setting goals for their children and agree the methods by which these can be achieved and the most appropriate location.
### Oral health care

**5.27. Disabled children** and young people are offered annual oral health assessments and preventative advice by professionals with appropriate expertise, and in settings appropriate to each child e.g. using mobile services at home or in school, as well as care in hospital or community practices.

*Authors and responsible bodies: LHBs, NHS trusts*

### Education

**5.28.** There are clear protocols on the early referral to education for children below the age of 2 years who have severe, long-term and complex needs. Health, social services and education jointly agree on each child’s assessed needs and how those will be met, so that no child is delayed from starting school.

*Authors and responsible bodies: LHBs, NHS trusts, LAs*

**5.29.** A school health care plan is designed for every child with complex needs to identify the child’s needs and how they will be met in the school setting.

*Authors and responsible bodies: LHBs, NHS trusts, LAs*
Training for Professionals

5.30. There are agreed joint education and training programmes for professionals who work with disabled children (in addition to the core training referred to in Chapter 2), which includes:

- Training on the social model of disability;
- Information about the health conditions or impairments;
- The social, emotional and material needs of families with a disabled child;
- Communication with children who do not use speech or who find interaction difficult;
- Management of challenging behaviour, including restraint training;
- Disability Discrimination Act 1995 and inclusion policies;
- The Special Education Needs Code of Practice for Wales;
- Legal and professional indemnity of staff providing health/nursing care procedures;
- Manual handling training.

5.31. Parents/carers and other non-professionals are offered appropriate and on-going training to assist them in meeting the needs of their disabled child. As a minimum this includes:

- Appropriate training in the use of equipment. The arrangement of this training and support is co-ordinated by the person ordering the equipment in collaboration with the supplier;
- Manual handling training;
- Specialist parenting skills and understanding child development;
- Management of challenging behaviour if needed, including restraint training;
- Communication with children who do not use speech, if needed;
- Specialist administration of medication if needed.
STANDARD - TRANSITIONS

STANDARD:

Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.

RATIONALE:

The key actions in this standard apply to all young people who require additional services beyond their 18th birthday. This may include young people who are disabled, have a learning disability, have autistic spectrum disorder, are chronically ill (including those with life limiting conditions), have persistent mental health problems or disorders, or are young people in special circumstances e.g. young people who are leaving care.

Improved healthcare has resulted in more disabled young people or those with complex health needs surviving into adulthood. Some of these have high levels of need that require health, social care and other support services. Transition to adulthood is a particular stage of life, which is usually seen to happen during the years of 14 to 25. It is a time when physical and psychological changes take place. There is evidence that health and social services often fail to meet the needs of these vulnerable young people at the time of transition into adult services.

Becoming an adult is a difficult time for all young people but it creates additional challenges for disabled young people that require help to overcome them. It is also a significant change for carers and family as the young person needs to achieve autonomy and independence and carers may need help to make this happen.

Transition into adulthood should be viewed as a process and not an event. Disabled young people and their families entering and moving through transition from child to adult services require specific information and assistance. Above all, close working is needed between services for children and adults or there is a danger that

“Parents need time to prepare for transition – it can be a traumatic time for parents to come to terms with.”

(Parent quote from Contact a Family, Sept. 2003)

“One person to be responsible for transition from 14 years to adult services, an independent key worker to co-ordinate all the agencies involved and support the family.”

(Parent quote from Contact a Family, Sept. 2003)
young people can be left with disjointed services, or at worst, no services at all. “A person-centred approach” is used as a tool to inform the assessment and transition plan for the young person and their family that relates to both the Unified Assessment and the Children’s Assessment Frameworks.

Some groups of disabled young people experience additional barriers such as those from black minority ethnic communities, those with complex health care needs and those with mental health or challenging behaviour issues. Children and young people in residential schools/placements, often some distance from home, can be isolated and find it difficult to access services outside their placement.

Currently, transitional planning takes place separately within different agencies and the process should be brought together into one system that is initiated by the transition instigated by the Special Educational Needs Code of Practice for Wales.

A questionnaire survey of 283 families and in-depth interviews with 27 young people and 27 parent carers in England, found that, despite legislation and guidance, services do not meet these requirements:

- A fifth of all youngsters had left school without a transition plan;
- Almost half of the young people had little or no involvement in planning their future;
- Lack of planning led to uncertainty and stress for some families;
- The quality of transition planning varied widely; in some cases it was ad hoc, confused and uncoordinated;
- The topics covered in transition planning were often quite different from those families considered to be important;
- For many young people, key issues (e.g. transfer to adult health or social services) had still not been addressed by the time they left school;
- Whether or not youngsters had received transition planning made little difference to what happened to them after they left school;
- There were few post-school options available to young people particularly in relation to housing and employment;
- There was lack of easily accessible information for parents and young people about what future possibilities might be;
• Concerns raised by the young people and their families which inhibited greater independence focused on:
  ➢ Personal safety and risk;
  ➢ Money matters (Including benefits);
  ➢ Transport.

(Heslop et al 2002 195)

The key actions within this standard have been designed to address the most important problems that are currently encountered by young people who require services beyond their 18th birthday.

In the case of care leavers, the arrangements for transition on leaving care at age 16 or later are set out in Welsh Assembly Government regulations 196 and guidance 197. For these young people, the Personal Advisor fulfils the role of transition worker referred to in the key actions which follow, and planning is achieved through a statutory Pathway Plan. For disabled children who are looked after at age 14, early planning through the care planning process will pave the way for later transition arrangements and Pathway Plans. For disabled care leavers the Pathway Plan should embrace the key actions set out below.

**KEY ACTIONS:**

5.32. There is an inter-organisation system to identify children who will require transition into adult services in the year before their 14th birthday (in year 8). This informs the strategic planning for all organisations.

5.33. A **key transition worker** is appointed to all disabled young people at age 14. It is their responsibility to ensure that the young people, their families and all relevant agencies are appropriately involved in the planning process. The **key transition worker** co-ordinates the planning and delivery of services before, during and after the process of transition and will continue to monitor and have contact with the young person until the age of 25 years.
5.34. Information about how to gain access to services and facilities is available to disabled young people in the local community includes information about:

- Employment;
- Housing;
- Training;
- Leisure;
- Educational opportunities;
- Access to independent living;
- The process of transition to adult services within the local authority and health service;
- Support to maximise the use of Direct Payments to 16 & 17 year olds;
- Health promotion.

5.35. There is one joint organisations transition plan produced for each disabled young person which forms the basis of the Unified Assessment within adult services and specifies arrangements for continuing support and services, including:

- Personal assistance;
- Housing requirements (including supported housing);
- Education, training and lifelong learning, including opportunities for work experience;
- Careers including specialist advice;
- Employment;
- Social relationships including leisure activities;
- Short breaks;
- Practical and other skills;
- Health needs including genetic counselling and sexual health;
- Continuing care;
- Appropriate transport;
- Communication needs.
- Domiciliary and day care;
- Financial support (including benefits and direct payments);
- Details of financial arrangements for specialist services required to address particular needs.
5.36. The joint organisations transition plan is reviewed at least annually or, in the case of young people who are looked after, every six months in accordance with statutory regulations Children (Leaving Care) Act 2000. During the year before their 18th birthday the plan is reviewed each term.

5.37. Aggregated information derived from joint organisations transition plans is sent to the area’s Young People’s Framework Partnerships to inform strategic planning.
CHAPTER 6

CHILDREN AND YOUNG PEOPLE IN SPECIAL CIRCUMSTANCES

INTRODUCTION:

Within the context of the Children’s NSF the scope of children in special circumstances includes all ‘children in need’ but is more broadly defined than in the Children Act 1989. Some of the groups of children and young people addressed within this chapter therefore include:

- Refugee families and asylum seeking children who are unaccompanied or with families;
- Young people in the youth justice system, or who participate in risk taking behaviour;
- Children living away from home, including, children who are looked after by local authorities, privately fostered or awaiting adoption and young people who live independently or who go missing from home or care settings (this also applies to children placed by Welsh local authorities outside of Wales);
- Children and young people who are or have been abused, neglected or involved in prostitution and those demonstrating sexually inappropriate behaviour;
- Children living in refuges;
- Children living in families where there is domestic violence;
- Children with parents who are in prison;
- Children whose educational needs are not being met or those with low self esteem;
- Children living with parents who have mental health problems or disorders;
- Children with drug and alcohol problems, or who have these problems within their families;
- Travellers’ children and those from minority ethnic groups;
- Young people who are gay or lesbian;
• Children and young people who are geographically isolated;
• Young carers;
• Young parents and their children;
• Truants or pupils excluded from school.

It should be emphasised that not all children within the above groups will be children in need, but these groups of children tend to be more marginalized by society and so are more at risk of achieving poorer outcomes than their peers. Neither should this list be considered to be exhaustive. Children who would fall within the remit of children in special circumstances should be identified locally through the Health Needs Assessments carried out to inform the local Health, Social Care and Well Being Strategies. It is likely that different groups of children may be identified in different areas according to local need.

While acknowledging that not all children in special circumstances require additional services there is significant evidence that these children often have additional unmet needs. These may include access to mainstream services such as health and education, and requirements for proactive interventions to manage issues that arise from the circumstances that they find themselves in. Mainstream services may also need to be tailored to the needs and circumstances of children and young people.

Targeted support is provided to children in need through the Children First Programme to transform services for these children and their families and enable them to gain maximum life chances and benefit from educational opportunities, health and social care so that they may lead fuller, more successful lives as adults. 4,382 children in Wales were looked after by local authorities on 31st March 2004, the majority of those (3,516) in the care of foster parents. Sharp increases in the numbers of children looked after in Wales presents challenges for local authorities and other agencies to find suitable quality placements that allow children to maintain links with their communities and have stability in education and health care.

Evidence suggests that children in special circumstances are more likely to have poorer outcomes in terms of health and education than children in the general population. For example, children who are looked after are at greater risk of mental health problems and disorders are more likely to have unmet health needs, poorer educational attainment and contact with the criminal justice system than the general population.

This chapter is designed to improve service delivery so that children in special circumstances achieve comparable outcomes to the general population of children. It should be read in conjunction with the standards in Chapter 2, which apply to all children, in all the settings in which they find themselves. Chapter 2 also contains a
standard on Safeguarding, which is important for all children, but particularly so for children in special circumstances because of their increased vulnerability.

This chapter contains 3 standards:

1. Child and Family Centred Services 104
2. Access to Services 106
3. Quality of Services 109
STANDARD – CHILD AND FAMILY CENTRED SERVICES

STANDARD:
The care and services that each child or young person receives is centred on the particular needs of the child, their family and carers. All children and young people feel respected and receive support and information appropriate to their needs and ability, which allows and encourages them to make decisions about the care that they receive.

RATIONALE:
“Fundamental to establishing whether a child is in need and how those needs should be met is that the approach must be child-centred. This means that the child is seen and kept in focus throughout the assessment and that account is always taken of the child’s perspective.”

(National Assembly for Wales/ Home Office 2001 37)

Holistic assessment should consider all aspects of the child’s life in the context of the family. It should build and concentrate upon the positive attributes of children and young people, parents and families to provide services which maximise their social, emotional, physical, intellectual and behavioural development within, where possible, stable family settings 37. The Data Protection Act 1998 38 requires that personal or sensitive data cannot be disclosed from one agency to another. Information can however be shared with the consent of the patient, and agencies must be fully aware that they have a duty to share information where the protection of children is an issue 18.

Research undertaken by Williams et al 201 found that children who were looked after by local authorities for more than 6 months had significantly worse health than children living in their own homes and were more likely to have incomplete immunisations or receive inadequate dental care. They were four times more likely to have experienced a change of GP and usually had no-one with an overview of their health needs and history.

Inclusive services are those that prioritise children and their individual needs within the mainstream and ensure that services are designed and delivered to meet the needs of all children. Health inequalities among children in special circumstances need to be addressed to improve health outcomes during the course of a child’s life and into the next generation 39.

Many children and young people find themselves in special circumstances because of the needs, beliefs or attitudes of their parents. Child-centred care therefore involves looking more widely at adults who have a parenting responsibility and are receiving
services for their own needs and assessing how this impacts on their parenting capacity.

KEY ACTIONS:

**Assessment**

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<th>6.1.</th>
<th>A health care plan is generated for each Looked After Child following an effective holistic assessment which complements and builds on information obtained through the Framework for Assessment of Children in Need and their Families.</th>
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**Service planning**

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<th>6.2.</th>
<th>Peer-support groups for children in special circumstances are jointly funded and facilitated in each locality.</th>
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STANDARD – ACCESS TO SERVICES

STANDARD:

All children and young people in special circumstances have equitable access to appropriate high quality health and social care irrespective of where they live, their ethnic group, culture or other social circumstances.

RATIONALE:

There is extensive evidence that access to services is one of the most difficult problems facing children in special circumstances. This includes access to universal services as well as access to specialised services to meet specific needs. Refugee children are an example of children who require specialised services. Many refugee children, who comprise roughly one quarter of asylum seekers, have been exposed to violence, forced displacement and multiple losses – all risk factors for poor mental health. Some have to act as head of the household because they develop better language skills, some have carried weapons and fought and find it difficult to adjust to school, many live in fragmented or reconstituted families and some come to this country alone. There is evidence that they have significant morbidity, though there have been few studies of their health.

Young carers who take on adult roles in caring for a parent or sibling with needs, often have their own needs neglected and as a result can suffer emotional problems. Research commissioned by the Assembly Government highlighted the need for better systems for identifying young carers in the community and for assessing and meeting their needs. In particular, schools were often unaware of the caring roles of some of their pupils and as a result they often did not receive the support they required to achieve their educational potential. Young carers themselves want to receive better support services, information and dialogue with service providers, and social and emotional support for themselves. Caring About Carers: A Strategy for Carers in Wales focuses on the needs of young carers. The Assembly Government has also established a Young Carers Advisory Panel and a Young Carers Focus Group to look at some of the issues that affect young carers.

All children have a right to access education, and the value of educational well being in helping children achieve their full potential in later life cannot be understated. Children in special circumstances however do not always have their educational needs met.

Unfit housing and homelessness can have a devastating impact on the health and well being of children, young people and their families. Homeless children and young people are more likely to suffer from mental health problems, behavioural problems and developmental delay than those who are not homeless. Domestic violence is a major cause of homelessness for young women and their children.
The forthcoming Domestic Violence Strategy that is being produced by the Welsh Assembly Government will attempt to address this as well as other important issues that affect this particularly vulnerable group of children and their mothers. The Assembly Government has also produced a National Homelessness Strategy which recognises homelessness as the most serious form of social exclusion and has put forward an Action Plan to address the problem. Certain vulnerable groups of young people are particularly susceptible to homelessness. It is a requirement of Young People’s Framework Partnerships to investigate the housing needs of young people in their areas and to work with local strategic housing services to meet those needs.

**KEY ACTIONS:**

*Service Planning*

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<td><strong>6.3.</strong></td>
<td>There is joint planning to ensure that Looked After Children are placed within their local community, whenever possible and appropriate.</td>
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<td><strong>6.4.</strong></td>
<td>Organisations provide inclusive services, and additional targeted services, that meet the needs of children in special circumstances and their families. Take up of service provision is regularly monitored and service planning revised accordingly to ensure equitable access.</td>
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<td><strong>6.5.</strong></td>
<td>Children and young people who have an urgent need for help (e.g. those who have experienced, or are alleging, severe abuse or who are demonstrating sexually inappropriate behaviour) do not have to wait for the completion of formal assessment procedures before appropriate services are provided.</td>
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<td><strong>6.6.</strong></td>
<td>All school-aged children in special circumstances are offered an allocated school place in the locality in which they are living whenever possible and appropriate. The young person’s choice of school is followed whenever possible. Their attendance and requirements for additional support at school are monitored, and actions are taken to ensure their needs are met.</td>
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### Housing

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<td>6.7.</td>
<td>Parents who are of school age are offered additional support to assist them in accessing learning opportunities to meet their educational needs.</td>
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<td>6.8.</td>
<td>Local authority housing departments and social services ensure that <strong>vulnerable young people</strong> such as care leavers, travellers, asylum seekers and those leaving the Youth Justice System are housed in appropriate and safe accommodation.</td>
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<tr>
<td>6.9.</td>
<td><strong>Homeless families</strong> with children are not placed in bed and breakfast accommodation, except in emergencies. Where bed and breakfast is the only available option, they are re-housed into accommodation suitable for families within 2 weeks.</td>
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STANDARD – QUALITY OF SERVICES

STANDARD:

Children and young people in special circumstances receive timely high quality care delivered in an environment which is safe and well-suited to their age, need and stage of development. The care is evidence-based or innovative with a structured evaluation. Their care is well co-ordinated and managed across the various providers and systems, with a clear point of contact for each element of support.

RATIONALE:

There is evidence to indicate that the average physical health status of asylum seekers on arrival in this country is comparable with the average health status of UK residents. However, their health status has been shown to worsen in the 2 to 3 years after arrival in the UK. This is a sad reflection on the quality of care provided to a group that often has particular health needs resulting from impoverished living conditions and restricted freedom.

Runaway children rank among the most vulnerable in our society, with many becoming involved in stealing, begging or prostitution in order to survive. Children run away from their families and care settings for a variety of reasons, though the most common triggers are family conflict, abuse, neglect and bullying at school. It has been estimated that in the UK as a whole one in nine young people run away from home before the age of 16 years and that this is linked to episodes of repeated homelessness in adult life.

In work commissioned by the DoH to ascertain children’s views in relation to the implementation of the Children Act 1989 it became apparent that children had clear views on the qualities in social workers and other professionals that enabled them to discuss their feelings and take part in decision-making. These included reliability (keeping promises), practical help, the ability to give support, time to listen and respond, and seeing children’s lives in the round rather than just the problems.

Many young people in special circumstances require on-going support after their 18th birthday, and this is particularly the case for Looked After Children. Chapter 5 lists key actions under a Transitions standard heading for those children who will eventually require input from adult services. Whilst this standard is listed under the Disabled Child chapter, the key actions within the transitions standard apply to any young person who will require support or services after their 18th birthday.
### Key Actions:

#### Training

6.10. All organisations agree local protocols covering training, competence and indemnity for staff in children’s homes and secure units, as well as for foster carers, to administer invasive medical procedures, as required, in a variety of settings used by the child e.g. administration of rectal diazepam.

| LHBs | NHS trusts | LAs |

#### Co-ordination of services

6.11. Arrangements are in place to notify the LHB, General Practitioner and education authority when a child becomes looked after or their circumstances change.

| LAs |

6.12. All Looked After Children have access to a specialist health practitioner in the area in which they are residing to co-ordinate the health care plan and address their health needs.

| LHBs | NHS trusts | LAs |

6.13. Every Looked After Child has a Personal Education Plan produced within 20 days of entering the care of the local authority or joining a new school.

| LAs |

6.14. When a child is accommodated in a health or education setting for longer than 3 months (or this has been planned), a referral is made to social services to determine whether an holistic assessment is required under the Framework for Assessment of Children in Need and their Families.

| NHS trusts | LAs |

6.15. The safety and well being of children who go missing from home or care is addressed through agreed joint protocols that set out the respective responsibilities of all appropriate service providers.

| LHBs | NHS trusts | LAs |
CHAPTER 7

ACUTE AND CHRONIC ILLNESS OR INJURY

INTRODUCTION:

Most children will become ill at some time in their lives but fortunately they are for the most part resilient and bounce back to good health very quickly. However, for those children who suffer serious or chronic illness, the effects on them and their whole family can be devastating. To have a sick or seriously injured child is every parent’s worst nightmare. When the worst scenario occurs, parents want to feel secure in the knowledge that their child will receive the very best care that is available, delivered in an environment that assists their child’s recovery and by staff who are competent and sensitive to their child’s needs.

Professor Kennedy’s report *Learning from Bristol* highlighted that excellence in service provision for children was often lacking and described fragmented service delivery in which the quality of care was less than it should have been, where children’s rights and vulnerability were often overlooked and where there was absence of an open and honest relationship with children, young people and their families. Children’s physiology and emotional needs are different to those of adults and services need to take account of this. Too often in the past, children’s services have been delivered as a scaled down version of adult services, instead of designing them to meet their unique needs.

This chapter is intended to improve service delivery and achieve better health outcomes for children and young people who become ill or suffer injuries. It should be read in conjunction with the standards in Chapter 2 which apply to all children, in all the settings in which they find themselves. Some young people with chronic illness will require on-going support after their 18th birthday. Chapter 5 lists key actions under a Transitions Standard for those young people who will eventually require input from adult services. Although this standard is listed under the Disabled Child chapter, the key actions within this standard apply to any young person who will require support or services after their 18th birthday.

This chapter contains 3 standards:

1. Child and Family Centred Services  
2. Access to Services  
3. Quality of Services

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STANDARD – CHILD AND FAMILY CENTRED SERVICES

STANDARD:

Children receive care centred on their particular needs. All children, young people and parents/carers receive support and information to enable them to understand their condition, treatment and care and are encouraged to be active partners in decisions that affect them. Their care is well co-ordinated across the various providers and systems, with a clear point of contact for the key elements of support.

RATIONALE:

“A good quality service for children provides for the child as a whole, for his or her complete physical and emotional well being and not simply for the condition for which treatment or care is required.”

(Welsh Office 1991 219)

The Kennedy Report 17 criticised hospitals for operating in a vacuum that detached the child from their previous life with a family, friends, school and community to which they belonged and for paying little heed to how the child would be integrated back into their home environment following discharge. Contact with family members while a child is in hospital can help to promote their recovery, but appropriate facilities need to be available to enable parents to sleep overnight in the same room or close to their child and still get adequate rest for themselves. The responsibilities of parents to other children in their family, work and home commitments, should not be ignored. Visiting children in hospital, especially for parents of children who attend hospitals frequently, can impose stress and financial hardship on families 220, 221. Staff should be aware of the needs of families and know how to refer them for support and assistance if needed 222.

With the reducing size of families in recent years, it is now quite common for children to be used to having the privacy of their own bedroom at home. The importance of privacy for children, and especially young people, should be respected at all times 223. It is often not possible to nurse children in individual rooms, and indeed from the point of view of social interaction, it is often not desirable. It should still be possible to respect a child’s right to privacy by, for example, asking them if they want curtains drawn around the bed and asking their permission before a student is allowed to observe or participate in their care.

“Respect the pressure on parents, if treated as partners in care – in hospital, give them a break, an opportunity for a cup of tea – without feeling guilty.”

(Parent quote from Contact a Family, Sept. 2003)
Growing up into adulthood is a time of increased vulnerability for young people in which they often feel self-conscious and confused by their developing physical and emotional maturity. Young people are individuals who mature at different rates and so need to be cared for on adult or paediatric wards that are most appropriate to their developmental state.

Providing an appropriate environment for children and young people is important in both primary and acute care services and is essential for the delivery of services which focus on the needs of children and young people. A core requirement is that settings where children and young people spend time provide an environment that is protective and safe. An environment that is lively and cheerful and appeals to the senses of children and young people can be achieved by involving them in designing settings. This doesn’t always have to involve a great deal of expense, primary care practices, for example, could involve local schools in creating children’s waiting areas in surgeries.

Just as an appealing environment is important to children and young people, so too is the availability of play and recreation facilities. Play is a natural part of childhood which is essential for physical, mental, social and emotional growth and has been shown to speed the recovery of children. While there is growing recognition of the need to provide toys in waiting areas, the needs of young people for recreation are often overlooked. A little creativity and the involvement of children and young people can ensure that the needs of all ages, abilities and cultures can be met.

KEY ACTIONS:

Appropriate settings

| 7.1. When a child or young person is admitted to hospital, appropriate arrangements exist for family members to stay with their child. | LHBs |
| | NHS trusts |
| | HCW |
## Play and recreation

### 7.2. The use of play techniques is used across the multidisciplinary team caring for children, with appropriate numbers of play specialists taking a lead in techniques that other staff can adopt, including preparation of children for surgery.

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### 7.3. All A&E departments which treat more than 18,000 children a year employ a dedicated play specialist. Other A&E departments have access to a play specialist when required.

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STANDARD – ACCESS TO SERVICES

STANDARD:

All children and young people receive equitable access to appropriate, high quality health care irrespective of where they live, their ethnic group or their social circumstances. They are treated as close to home as possible, while ensuring that their care is of the highest quality.

RATIONALE:

The NHS Plan 227 committed the government to “ensure equitable access to effective and appropriate healthcare according to need.” In Wales, there are particular challenges which can make this difficult. Kennedy 17 stated that ease of access should be a secondary consideration to service quality, particularly where tertiary services are concerned. All families want the highest quality care for their children and understand that sometimes this means travelling long distances to centres that can provide specialised services. For families living in rural areas of Wales, this can mean very long journeys that are compounded by increased levels of poverty in rural areas and poor public transport systems. A round trip to the local DGH for a 20 minutes outpatient appointment can take a full day on public transport and this can be a miserable and costly experience for parents who have to take all the children in the family with them because they cannot afford childcare. It is little surprise that children and their families often fail to turn up for appointments 228, a factor which has impacted on NHS waiting times. Creative and imaginative solutions need to be found for these problems with delivery of services provided as close to home as possible, whenever possible. The Review of Tertiary Children’s Services for Wales 229 revealed that some specialised services for children in Wales were confronted by numerous problems that included gaps in service provision and difficulties with recruitment and retention of the highly skilled staff that were needed to provide these services. In some cases this had led to unsustainable service delivery. To address these problems the Children and Young People Specialised Services Project was established so that in future specialised healthcare delivery would be provided as part of a Managed Clinical Network model (http://www.wales.nhs.uk/cypss). This means that there will be equity of access and quality wherever a child or young person lives, through effective communication and partnership working across primary, secondary and tertiary care services.

Availability of children’s community nursing services in Wales are patchy at present and yet research has demonstrated the value of this service to both children and their families as well as demonstrable cost savings to the NHS 230, 231. Benefits include

“Children’s community nurses provided excellent follow-up care for the taught procedures from specialist centres like Alder Hey.”

(Parent quote from Contact a Family, Sept. 2003)
Improved emotional health in children and less stress for families by minimizing unnecessary separation. Nursing children at home also gives parents more control and allows them to learn new skills, with the support of children's community nurses, enabling them to fully participate in caring for their children.  

Children can become ill very quickly and it can be difficult for parents, especially first time parents, to distinguish between a minor illness such as a viral infection and a serious one such as bacterial meningitis. Healthcare services at GP surgeries and A&E departments can be tied up unnecessarily when parents often just need reassurance. Giving parents information to manage minor childhood illnesses and to know when and how to access healthcare services will ease the burden on scarce resources as well as easing the stress that parents feel when their children are unwell.  

**NHS Direct** plays a key role in delivering this service to parents, as well as community pharmacists, health visitors, school nurses, practice nurses and community paediatric nurses. Analysis of contacts made to **NHS Direct** in Wales from 2001-04 revealed that the most common concerns in relation to babies from 0-12 months were crying (18.3%), vomiting (14.6%), fever (13.7%) and rash (13.6%). In children from 1-4 years the most common concerns were fever (23.5%), rash (19.9%) and vomiting (15.1%), and in children from 5-16 years the most common concerns were rash (16.9%), abdominal pain (15.6%) and fever (13.2%). GP consultation patterns across England and Wales have revealed increased numbers of consultation for allergic conditions. International comparisons between 1994 and 1996 showed that young people aged 12 – 14 years in Great Britain had some of the highest prevalence of symptoms for eczema, asthma and hay fever. Whilst the number of children diagnosed with asthma has risen annually between 1990 and 2000, the number of children either seen in GP consultations or admitted to hospital with asthma has dropped, indicating improved management of the condition.

The first point of contact for access to the health service is often via the ambulance service. This is often a distressing time for both parent and child. While providing a prompt service, the ambulance service also has to ensure that it provides a service which is sensitive to the needs of children and their families. Paramedics and technicians need to receive core training in relation to delivery of services to children as detailed in Chapter 2, as well as more specialised training in the provision of paediatric life support and appropriate pain control in children.

The need for ongoing education of children in hospital with better information sharing between health and education services was highlighted in consultation exercises carried out with parents. Sufficient education at home is also important, especially for children with long-term chronic illness.  

“After 7-14 days in hospital there should be an education plan in place, provided in consultation with the child’s teacher.”

*(Parent quote from Contact a Family, Sept. 2003)*
regained and can have a long-term impact on self-esteem, career paths and life chances.

**KEY ACTIONS:**

*Access to treatment and care close to home*

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<td><strong>7.4.</strong></td>
<td>A Children’s Community Nursing Service is available to meet local needs in every area of Wales.</td>
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<td><strong>7.5.</strong></td>
<td>An appropriate range of outreach services is provided as close to home as possible, particularly to meet the needs of families living in rural areas.</td>
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<td><strong>7.6.</strong></td>
<td>Children and young people have access to a full range of appropriately trained Paediatric Allied Health Professionals according to their specific needs. If provided by generic services, it is provided in partnership with specialist paediatric colleagues.</td>
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<td><strong>7.7.</strong></td>
<td>An appropriate amount of on-going education, in a suitable environment, is provided for all children and young people who are well enough to receive it, including those in hospital. Education is provided in liaison with each child’s school, and is appropriate to their age and stage of development.</td>
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*Medicines*

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<td><strong>7.8.</strong></td>
<td>Hospital pharmacists communicate directly with colleagues in other hospitals and in the community, who are involved in the care of a child, to ensure that appropriate information is readily available when medicines are unlicensed or specials.</td>
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### Improving equity of access

7.9. Clinics are offered at times and in locations which result in minimum disruption to schooling. Families/carers are given the option of attending an **outreach clinic**, where available, or travelling to a **specialist centre** for follow up, if they would prefer.

7.10. Systems are in place so that children with **complex conditions** who require multiple appointments can be seen on the same day and in the same setting. Coordination of care for all children, to minimise disruption to their lives, is planned for whenever possible and appropriate.

7.11. Families who have children in hospital, or who have to attend out-patient appointments, are provided with information about eligibility and arrangements for claiming travelling subsistence.

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STANDARD – QUALITY OF SERVICES

STANDARD:

Children and young people receive timely high quality, and where possible, evidence-based care delivered by appropriately trained staff in an environment which is safe and well-suited to their age and stage of development. The transfer from children’s services to adult services is planned with the young person and their parents/carer to ensure a smooth transition.

RATIONALE:

“Setting, monitoring and reviewing national standards of care is a key component of our strategic approach to improving quality…. NSFs aim to significantly improve primary, secondary and tertiary services for patients and should see an end to unacceptable variations in practice whilst also delivering year on year clinical quality improvements.”

(National Assembly for Wales, September 2001 236)

Children have distinctly different needs when it comes to treatment and should not be simply regarded as small adults, as can so often happen. Their physiology is different from that of adults and is changing as they develop. Children suffer from a different range of diseases and disorders from adults and this includes a higher proportion of rare and often complex congenital and inherited disorders. The progress of illness can also be very different and a child’s condition can deteriorate much more rapidly than that of an adult.

The small size of children can require special skills to carry out interventions, such as surgical or intravenous procedures, as well as to assess the correct doses of drugs to use. Those who deliver children’s services therefore require specialised skills.

There is evidence to suggest that there may be better outcomes for children with conditions that are rare, intractable, complex, severe or complicated if they are referred to tertiary service for diagnosis and treatment 237, 238. Tertiary services for the children of Wales are provided by a number of English as well as Welsh NHS Trusts. Some of these services (such as liver transplantation) may only be provided in as few as two to six hospitals in the UK.

Young children can be very frightened by separation from their parents or carers and finding themselves in a strange environment in which they may experience pain. Such a traumatic experience could have an emotional impact on them for many years. Pain control and reducing anxiety in children, especially young children, may not be used because of lack of sufficient knowledge about techniques and fear of adverse effects 239. The management of pain/anxiety, in partnership with children, should be a routine part of any treatment or procedure carried out in any clinical setting 240, 241, 242, 255.
Recovery from illness and surgery is dependant upon sufficient nutritional intake. While children’s diets need to be balanced and healthy it is important to remember that the nutritional value of food not eaten is nil. Children need to be tempted to eat by offering plenty of choice from food that is attractively presented and takes account of different cultures and family traditions. The availability of healthy snacks and drinks, including fresh water, will assist children in meeting their nutritional requirements.

A review carried out by the Welsh Assembly Government into the provision of services for children and young people in accident and emergency and minor injury units (MIUs) in Wales found many excellent areas of practice, but also highlighted a number of areas in which improvements were needed. Issues of particular concern included lack of facilities for young people, particularly following self-harm or alcohol abuse, poor protocols for administration of Post-coital Emergency Hormonal Contraception and poor information systems at MIUs. The report also highlighted the need for public education with regard to which type of unit should be used for different types of emergencies, to avoid unnecessary delay in treatment.

Standards for the care of critically ill children were published by the Welsh Assembly Government in 2003 and aim to improve outcomes for critically ill children by ensuring that they receive the level of specialist care that they need, regardless of where they live. These standards are not repeated within this document but there is an expectation that they will be delivered by all NHS trusts, Local Health Boards and Health Commission Wales.

**KEY ACTIONS:**

**Nutrition**

7.12. The nutritional needs of children in hospital are met through the provision of appropriate menus designed for children and young people, and the provision of freely available healthy snacks and drinks. Hospital dietitians work with children and young people to design these menus.

**Use of equipment**

7.13. Equipment used is the correct size for each child, and its design is tailored to different needs at different ages and stages of development.

7.14. Staff who use equipment receive specific training in correct use and evidence of training is documented.
Training

7.15. At every location where care is provided for sick children, staff are trained to provide basic paediatric life support. Appropriate equipment is available to resuscitate, stabilise and hold a collapsed child, appropriate to the levels of risk.

Surgery

7.16. Units that provide day surgery for children and young people have a child and young person friendly environment and access to play specialists.

Specialised services

7.17. Delivery of highly specialised services for children is achieved through managed clinical networks, as recommended in A Special Service: the future of specialised healthcare for the children of Wales 246.

7.18. All commissioners and providers implement the recommendations of Caring for Critically Ill Children: Standards 246.

Emergency services

7.19. Information regarding every child or young person’s attendance at an A&E department is sent to the child’s GP, health visitor, school nurse or social worker as appropriate. The person sending this information must have received child protection training.

7.20. Paediatric advice is available, at a senior level, for any child or young person who attends an A&E department and for whom there are child protection concerns.
7.21. All A&E departments collect data on children’s attendances by age bands and case mix (diagnoses). These data are sent to the All Wales Injuries Surveillance System.

7.22. All commissioners and providers implement the recommendations of the Royal College of Paediatrics and Child Health document on A&E services 247.

7.23. A&E departments providing services for children have a consultant in post who has undertaken a recognised training programme in Paediatric Accident and Emergency Medicine, and there is a designated consultant paediatrician who liaises with the consultant in A&E medicine.

7.24. When attending an A&E department or children’s ward, children are triaged on arrival to ensure that the sickest or most injured child is treated quickly and pain relief offered promptly. All infants and children receive an immediate assessment of life threat on arrival.

7.25. Seriously injured children have a paediatrician involved in the initial resuscitation and stabilisation in the A&E department and are then transferred to the care of a consultant paediatrician/surgeon in a specialist facility that includes paediatric intensive care, unless there is need for immediate life-saving surgical intervention.

**Pain/ anxiety management**

7.26. Clinical settings that provide services for children use evidence-based guidelines for the management of pain or sedation, including non-pharmacological methods.

**Discharge**

7.27. Children with complex health needs are not discharged from hospital without a written care plan. Systems are in place between health, social services and education to ensure that equipment suitable to the child’s needs, and follow-up care, is provided in a timely fashion.
### Transition services

**7.28.** Every lead health professional has adequate arrangements for transfer of young people to adult services, preferably via specific transition clinics involving staff from both paediatric and adult services.

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## GLOSSARY OF TERMS

**All Wales Injuries Surveillance System (AWISS)**

A&E departments send regular downloads of all attendances to this central clinical database, though only injuries are coded. AWISS does not contain patient names but does contain addresses that are used to identify postcode areas which may have higher injury risks. Aggregated data are used to develop strategies and interventions to reduce injuries.

**All Wales Medicines Strategy Group (AWMSG)**

The All Wales Medicines Strategy Group (AWMSG) provides advice to the Minister for Health & Social Services in an effective, efficient and transparent manner on strategic medicines management and prescribing. The AWMSG, acting in a strategic and advisory capacity, is the conduit through which consensus can be reached on medicines management issues, especially those affecting both primary and secondary care.

**Area Child Protection Committee (ACPC)**

An inter-agency forum composed of representatives from the each of the main agencies and professionals responsible for helping to protect children from abuse and neglect. Their role is to ensure that different services and professional groups co-operate to safeguard children in their area. Under the Children Bill, ACPCs will be replaced by Local Children Safeguarding Boards.

**Balanced Scorecard**

The Balanced Scorecard was developed by Kaplan and Norton in the early 1990's and arose from research into performance measurement approaches in a number of leading international companies and over the last 10 years has been developed for use in the public sector. The overall purpose of the scorecard approach is to enable managers to develop a robust set of performance measures that provide a comprehensive view of the overall performance of the organisation but that are also visibly linked to the key strategies and priorities of the organisation.

**Care plan**

A document which details the assessed needs of an individual and the type and level of services required to meet those needs, as well the person responsible for delivering the actions identified in the plan, the objectives and potential outcomes that can be achieved. This is normally planned in partnership with the individual or family concerned.
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<th>Glossary Term</th>
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<tr>
<td><strong>Case management</strong></td>
<td>The activity of co-ordinating a care plan for a patient.</td>
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<td><strong>Case manager</strong></td>
<td>A nominated member of a multi-disciplinary Child and Adolescent Mental Health Services Team who co-ordinates the care plan for the patient.</td>
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<td><strong>Children and Young People’s Framework Partnerships</strong></td>
<td>These partnerships, in each local authority in Wales, develop plans to ensure coverage of children’s and young people’s services in Health, Social Care and Well Being Plans developed by Local Health Boards. Partnerships are made up of local authorities, health services, other statutory bodies such as the police, and voluntary organisations.</td>
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<td><strong>Challenging behaviour</strong></td>
<td>Abnormal behaviour of such an intensity, frequency or duration, that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in, the person being denied access to ordinary community facilities.</td>
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<tr>
<td><strong>Child development team</strong></td>
<td>A multi-disciplinary team which provides assessment, diagnosis and treatment of children with neuro-developmental disorders and disabilities, communication, learning and behavioural difficulties and associated sensory problems. Following assessment, the team works closely with each child and their family to design a programme that enables them to achieve their full potential.</td>
</tr>
<tr>
<td><strong>Child Protection Register</strong></td>
<td>A central register, maintained by local social services departments on behalf of the local Area Child Protection Committee, of all children and young people who are resident in the area, who are considered to be at continuing risk of significant harm and for whom there is a child protection plan.</td>
</tr>
<tr>
<td><strong>Children’s home</strong></td>
<td>A home which provides care and accommodation (wholly or mainly) for more than three children at any one time and can include: private, voluntary and local authority children’s homes, and both mainstream and specialist boarding schools accommodating or arranging accommodation for any child over 295 days per year. All children’s homes must meet with national standards.</td>
</tr>
<tr>
<td><strong>Children’s hospices</strong></td>
<td>A service dedicated to the provision of palliative care for life-limited children and young people.</td>
</tr>
<tr>
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<td>Definition</td>
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<tr>
<td>Communication aids/ tools/ systems</td>
<td>Communication aids/ tools/ systems are forms of communication offered to those who cannot speak or whose communication attempts are unintelligible. Systems which are described as being high-tech aids are operated by electronic or computerised means. Low-tech aids and systems comprise of sign languages, communication boards and communication books.</td>
</tr>
<tr>
<td>Community intensive care</td>
<td>Services provided to children and young people who have complex mental health problems, normally requiring day or in-patient care, who instead receive services from a multi-disciplinary team in their own home or other community facility.</td>
</tr>
<tr>
<td>Complex conditions</td>
<td>A child or young person with more than one medical diagnosis.</td>
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<tr>
<td>Complex needs</td>
<td>A child or young person has complex needs when they require services from more than two agencies, not including the universal services which all children receive.</td>
</tr>
<tr>
<td>Contractor practices</td>
<td>Services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.</td>
</tr>
<tr>
<td>CRB checks</td>
<td>Checks against the Police National Computer (centralised information point for police force in England and Wales) and records held by DoH and DfES about people considered unsuitable to work with children and young people.</td>
</tr>
<tr>
<td>Disabled Child</td>
<td>A child who is restricted or lacks ability (due to an impairment) to perform an activity in a manner or range considered normal for a child of a similar age.</td>
</tr>
<tr>
<td>Disabled Facilities Grant</td>
<td>Disabled Facilities Grants (DFGs) are the only mandatory grants from local authorities. They help with the cost of adapting disabled people's homes. To make sure that they are received by those in the greatest need a means-test is applied. One of the main advantages of DFGs is that they enable disabled people to continue to live in their own homes. Housing and Social Services departments of local authorities work together closely in assessing the needs for DFGs and in providing the adaptations.</td>
</tr>
<tr>
<td>Emergency supplies</td>
<td>Equipment which is necessary to maintain a child's life e.g. ventilators and parenteral feeding equipment.</td>
</tr>
<tr>
<td>Essential equipment</td>
<td>Equipment which is necessary for a child to function in day-to-day living e.g. special seating aids and mobility equipment.</td>
</tr>
</tbody>
</table>
Foster care
A child under 16 years of age, and cared for and provided with accommodation (in excess of 28 days) by someone other than a parent, a person having parental responsibility, or a relative.

Hand held record
A health or care record which details information concerning a patient/client and which is kept by them rather than a professional or organisation.

High Risk Pregnancy
Where there is a likelihood of an adverse outcome to the woman and/or her baby that is greater than the incidence in the general pregnant population.

Holistic assessment
An evaluation of the needs of the child in the context of the family and the community in which they live. The evaluation includes social, physical, emotional, educational, cultural and spiritual aspects of the child’s life.

Housing Health and Safety Rating System
The current Housing Fitness Standard, which sets out the basic conditions houses should meet has been in place since 1990. The standard has 9 items and if a house ‘fails’ on any one of them it is not considered to be fit for human habitation. The Government intends replacing the current fitness standard with a new Housing Health and Safety Rating System (HHSRS) based on risk assessment and vulnerability. Overall, the new system will be more sensitive to the needs of the 21st century and will be more linked to health and safety. The HHSRS is contained within the Housing Bill that is currently before Parliament.

Homeless families
Where the family have no accommodation available for their occupation which they have a legal right to occupy.

Independent advocacy
An individual or service that acts exclusively on behalf of the child or young person and has no conflict of interest or pressures. For example, they should have sufficient independence and distance form policymaking, service provision, complaints services, planning and resources. Current practice to achieve independence is to contract a service from a provider external to the organisation, often from the voluntary sector.

Integrated community equipment services
Services, which provide long and short-term loan of equipment, funded through pooled NHS and local authority budgets. Equipment provided includes nursing, daily living and mobility aids but not children’s wheelchairs or buggies (these are provided through the Artificial Limb and Appliance Service [ALAS]).
<table>
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<tr>
<th>Term</th>
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<tr>
<td><strong>Invasive medical procedures</strong></td>
<td>Procedures which involve specific intrusive contact with a patient such as blood testing, passing a naso-gastric tube and giving rectal medication (e.g. to stop an epileptic fit).</td>
</tr>
<tr>
<td><strong>Joint commissioning arrangements</strong></td>
<td>Arrangements for one or more agencies or bodies (statutory or independent) to commission a service or services for an individual or client group.</td>
</tr>
<tr>
<td><strong>Joint organisation transition plan</strong></td>
<td>A plan, based on an assessment of a young person’s needs, which identifies services to be provided by all the organisations involved in the life of the young person to ensure a smooth transfer of care through to adult services.</td>
</tr>
<tr>
<td><strong>Key transition stages</strong></td>
<td>Developmental stages in middle and late childhood when children undergo physical, cognitive, social and emotional transitions. These changes are gradual but are punctuated for most by several key stages such as:</td>
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<tr>
<td></td>
<td>• The change from primary to secondary education;</td>
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<td>• Leaving school and entering work or higher education;</td>
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<td></td>
<td>• Leaving one’s family (or the equivalent, such as LA care) to set up a new, independent home;</td>
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<td></td>
<td>• Becoming involved in sexual relationships, and eventually cohabiting or marrying;</td>
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<td></td>
<td>• Becoming a parent;</td>
</tr>
<tr>
<td></td>
<td>• Becoming a full adult consumer with adult rights and responsibilities.</td>
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<tr>
<td></td>
<td>For some children and young people with long term limiting illness or disability, some of these key transitions may be delayed or incomplete.</td>
</tr>
<tr>
<td><strong>Key transition worker</strong></td>
<td>A key worker who works at the interface between child and adult services to ensure a smooth transfer of care for young people with complex needs into adult services through implementation of the joint organisation transition plan.</td>
</tr>
<tr>
<td><strong>Key Worker</strong></td>
<td>A named person who is both a source of support for children and young people with complex needs and their families, and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and with professionals from services, and for ensuring delivery of an inter-agency care plan for the child and family.</td>
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<tr>
<td>Lead Professional (maternity services)</td>
<td>The professional who will give a substantial part of the care personally and who is also responsible for ensuring that the woman has access to care from other professionals as appropriate.</td>
</tr>
<tr>
<td>Learning disability</td>
<td>A significant, usually long-term, intellectual impairment and deficits in social functioning or adaptive behaviour (basic everyday skills) which are often present from childhood.</td>
</tr>
<tr>
<td>Life-limiting condition</td>
<td>Refers to children who are likely to die in childhood or soon afterwards, and also includes children with severe long-term disabling conditions.</td>
</tr>
<tr>
<td>Looked After Child</td>
<td>A child or young person (less than 18 years old) who is in the care of a local authority under a care order by the courts, or accommodated under a voluntary arrangement as a result of there being no person who has parental responsibility, he is lost or abandoned, or the person caring for him being prevented from providing him with suitable accommodation or care.</td>
</tr>
<tr>
<td>Managed Clinical Networks</td>
<td>Linked groups of health professionals from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Trust/LHB boundaries, to ensure equitable provision of high quality and clinically effective services.</td>
</tr>
<tr>
<td>Marginalized communities</td>
<td>Groups of people who are excluded from full access to the society in which they live for a variety of reasons. Factors associated with the social exclusion include: poverty, disability, black and minority ethnic families, being homeless or lack of permanency (e.g. travellers, asylum seekers, those in the care of the local authority or in secure units). This list is not exclusive and will vary from one local area to another.</td>
</tr>
<tr>
<td>Maternity Services Liaison Committee</td>
<td>A committee set up within an LHB area which provides a forum for all the professionals involved in the provision of maternity care, with representatives of the women who use the services, to discuss issues relevant to the provision and development of maternity services in the area.</td>
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<tr>
<td><strong>Medicines and Healthcare products Regulatory Agency (MHRA)</strong></td>
<td>The executive agency of the Department of Health responsible for protecting and promoting public health and patient safety by ensuring that medicines, healthcare products and medical equipment meet appropriate standards of safety, quality, performance and effectiveness, and are used safely.</td>
</tr>
<tr>
<td><strong>National Patient Safety Agency (NPSA)</strong></td>
<td>The NPSA co-ordinates efforts in the UK to report, and to learn from mistakes and problems that affect patient safety. As well as making sure errors are reported in the first place, the NPSA promotes an open and fair culture in the NHS, encouraging all healthcare staff to report incidents without undue fear of personal reprimand. It collects reports from throughout the country and initiates preventative measures, so that lessons can be learnt from each case, and patient safety throughout the NHS improved.</td>
</tr>
<tr>
<td><strong>Named Midwife</strong></td>
<td>The midwife identified as the person who plans and co-ordinates care with the pregnant woman.</td>
</tr>
<tr>
<td><strong>NHS Direct</strong></td>
<td>Nurse-led telephone helpline for the public, provided by the NHS.</td>
</tr>
<tr>
<td><strong>NICE</strong></td>
<td>The National Institute for Clinical Excellence is a Special Health Authority which promotes clinical excellence and the effective use of available resources in the health service.</td>
</tr>
<tr>
<td><strong>Off-label medicines</strong></td>
<td>Off-label use encompasses use of a licensed medicine which for example: is licensed for use in a different age group, is licensed for a different health problem or is being given by a different route (e.g. injection solution being given by mouth).</td>
</tr>
<tr>
<td><strong>Outreach clinic</strong></td>
<td>Clinics run in primary care and rural hospital settings by specialist medical practitioners. They are designed to increase the accessibility and effectiveness of specialist services and their integration with primary care services.</td>
</tr>
<tr>
<td><strong>Outreach services</strong></td>
<td>Service provision in the service user’s home or other community setting, at times suited to the service user, rather than focused on the service providers’ convenience.</td>
</tr>
<tr>
<td><strong>Palliative care</strong></td>
<td>The active holistic care of children and young people with advanced, progressive illness.</td>
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<tr>
<td><strong>Parenteral</strong></td>
<td>Intravenous administration of medicines (or food).</td>
</tr>
<tr>
<td><strong>Parenting education</strong></td>
<td>Programmes and diverse learning opportunities directed at developing parents and prospective parents' skills in their roles as parents, through better understanding of their own needs and those of their children.</td>
</tr>
<tr>
<td><strong>Parenting support</strong></td>
<td>Services designed to assist parents cope with the demands of parenting, enabling them to fulfil their parenting responsibilities for the benefit of their children and wider society.</td>
</tr>
<tr>
<td><strong>Patient Safety Incidents and prevented incidents</strong></td>
<td>Any intended or unexpected event which could have, or did lead to, harm for one or more patients receiving NHS-funded healthcare. This is also referred to as an adverse event/incident or clinical error, and includes near misses.</td>
</tr>
<tr>
<td><strong>Patient Safety Incident and Untoward Event Reporting</strong></td>
<td>Policies and procedures for the reporting of patient safety incidents and other untoward events which include processes for the immediate operational management, an investigation or review of the incident and the capacity to learn from and implement follow-up actions and solutions to minimise the risk of them recurring.</td>
</tr>
<tr>
<td><strong>Peer support groups</strong></td>
<td>A group of children or young people of similar age and status, or circumstance, who are able and willing to support one another.</td>
</tr>
<tr>
<td><strong>Personal care</strong></td>
<td>Assistance for a child or young person to complete activities of daily living e.g. dressing and toileting.</td>
</tr>
<tr>
<td><strong>Personal Child Health Record (PCHR)</strong></td>
<td>A hand held health record that is given to the parent or carer of every baby within 2 weeks of birth (commonly referred to as the Red Book).</td>
</tr>
<tr>
<td><strong>Primary Care</strong></td>
<td>Services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners together with district nurses and health visitors, with administrative support.</td>
</tr>
<tr>
<td><strong>Professional abuse policy</strong></td>
<td>The policy of an individual organisation about how to deal with allegations of abuse against a professional, carer or volunteer which is consistent with <em>Working Together to Safeguard Children</em> and local ACPC procedures.</td>
</tr>
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<tr>
<td><strong>Psychosis</strong></td>
<td>Severe mental illness in which the sufferer loses contact with reality.</td>
</tr>
<tr>
<td><strong>Registered social landlords</strong></td>
<td>Registered Social Landlords (RSL) is the legal term for a landlord registered with the National Assembly for Wales. Most are housing associations but they may also be trusts or co-operatives. They are run as businesses but do not trade for profit. All RSL activities are regulated and supervised by the Welsh Assembly Government.</td>
</tr>
<tr>
<td><strong>Regulatory Reform Order (RRO)</strong></td>
<td>New arrangements under which local authorities can give grants or loans for acquiring, adapting, improving, repairing, demolishing and replacing accommodation. (<a href="http://www.housing.wales.gov.uk/pdf.asp?a=f16">www.housing.wales.gov.uk/pdf.asp?a=f16</a>)</td>
</tr>
<tr>
<td><strong>Rehabilitation engineering</strong></td>
<td>The clinical application of engineering principles and technology in the provision of services, research and development to meet the needs of individuals with disabilities. It involves the reduction of environmental barriers and improvement of the physical, mental or social function of a person e.g. provision of wheeled mobility, special seating and assistive technology for all activities of daily living.</td>
</tr>
<tr>
<td><strong>Risk management procedures</strong></td>
<td>The processes for the identification, assessment, analysis and management of all risks and incidents for every level of an organisation, and aggregation of the results at a corporate level. This facilitates priority-setting and improved decision-making to reach an optimal balance of risk, benefit and cost. It includes the capacity to learn from and follow up incidents and risks and implement solutions to minimise their recurrence.</td>
</tr>
<tr>
<td><strong>School healthcare plan</strong></td>
<td>Some pupils have medical needs that, if not properly managed, could limit their access to education. A health care plan may be drawn up by the school, following appropriate medical advice, to ensure appropriate access to education and to outline measures that should be taken to ensure that pupils with medical needs and others are not put at risk.</td>
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<tr>
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<td><strong>Short break care</strong></td>
<td>In the context of disabled children: a service that benefits the child and their family and can be anything from a few hours to weekly or monthly stays. Breaks include: day care, sitting services, respite in residential settings (involving temporary accommodation). Short breaks allow parents time for themselves or other children in the family, and allows the disabled child to have a wider social life outside the family and school to gain independence.</td>
</tr>
<tr>
<td><strong>Special school</strong></td>
<td>A special school is an educational establishment specifically resourced to meet the needs of the most complex and challenging young people in communities. Typically they will provide an environment for the delivery of education as well as social and health needs.</td>
</tr>
<tr>
<td><strong>Specialist centre</strong></td>
<td>A centralised service provided for a small number of patients who require assessment, diagnosis and treatment using advanced knowledge, skills and/or technology.</td>
</tr>
<tr>
<td><strong>Specialist forensic CAMHS</strong></td>
<td>A Tier 4 service which offers both psychological and psychiatric assessments, treatment and interventions to young people between the ages of 10 and 18 years who have been involved with the Criminal Justice System and/or pose a risk to themselves or others through their behaviour. This is targeted at high-risk young offenders with mental disorders as well as severe behavioural disturbance, for example violent, sexual or fire-raising offending behaviours.</td>
</tr>
<tr>
<td><strong>Specials (medicines)</strong></td>
<td>A medicine which is not available as a licensed product but which has been produced to the order of a doctor or dentist by the holder of a special manufacturer’s licence for administration to a particular patient.</td>
</tr>
<tr>
<td><strong>Staff delivering services to children</strong></td>
<td>Any person (professional or non-professional) who is involved with the delivery of services to children and young people. This includes staff who do not have direct contact with children, such as administrative staff who have access to children’s records.</td>
</tr>
<tr>
<td><strong>Targeted services</strong></td>
<td>Services directed at a specific group of people or to address a specific area of need.</td>
</tr>
<tr>
<td><strong>Triage</strong></td>
<td>The assignment of degrees of urgency to illness or injury to decide on the order of treatment of a large number of patients.</td>
</tr>
</tbody>
</table>
**Unified Assessment**

A co-ordinated and streamlined approach to assessment and care management which ensures that agencies take an holistic approach to assessment and managing care together. It is person-centred and proportionate to need. Services must be co-ordinated and integrated at all levels. Duplication and paperwork is minimised for patients and professionals. It provides standardised and fairer eligibility criteria across Wales and must be developed and used by all involved in the provisions of health and social care services.

**Unlicensed medicine**

A medicine that has no UK Market Authorisation or Product Licence. When a manufacturer wishes to market a new medicine they must obtain a licence from the Medicines and Healthcare Products Regulatory Agency. The licence restricts the way the medicine can be advertised for use, the conditions it can claim to treat, the doses and the age of the patient. The licence is known as a Marketing Authorisation (previously known as a Product Licence).

**Vulnerable children and young people**

Includes children in need, including disabled children and those looked after by a local authority, as well as care leavers.

**Welsh Risk Management Standard 15**

Maternity services represent a major risk to NHS trusts in terms of litigation costs. Adherence to Standard 15 is a system for controlling risk in hospital-based maternity services. The Welsh Risk Management Standards incorporate and replace the Welsh Risk Pool standards and the Controls Assurance standards. These standards support guidance on risk management for the NHS in Wales.

**Whistleblowing policy**

A policy which sets out how an employee, person working in a commissioned service, or member of the public can raise any concern with confidence and without having to worry about being victimised, discriminated against or disadvantaged in any way as a result.
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