



Children and Young People's Specialised Services Project (CYPSS)

Consultation Document
2005



All Wales Universal Standards for
Children and Young People's
Specialised Healthcare Services



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

**CHILDREN AND YOUNG PEOPLE'S
SPECIALISED SERVICES PROJECT (CYPSS)**

**All Wales Universal Standards for
Children and Young People's Specialised
Healthcare Services**

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Foreword

Brian Gibbons, AM, Minister for Health and Social Services



The Welsh Assembly Government is committed to the children and young people of Wales. This document is one of a series which follows on from the recent consultation document, The National Service Framework for Children, Young People and Maternity Services. It addresses the specific needs of Children and Young People who need to access specialised healthcare.

The series of consultation documents will be published over the next 12 months and we believe that service commissioners and providers can work in partnership to deliver on these standards.

We ask that you participate in this series of consultations to help us develop the standards further and to ensure that they have the maximum impact on the health of children and young people with specialised healthcare needs.

Ensuring that quality services provided for our children and young people is the best investment we can make for the future of Wales.

A handwritten signature in black ink, appearing to read 'Brian Gibbons'.

Brian Gibbons AM
Minister for Health and Social Services

Consultation Questions

Responses are invited to this consultation document by **8th June 2005**.

Responses can be sent to the address at the end of the list of questions or sent electronically to: eiri.jones@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 identified for early implementation and for delivery within 1 year of publication of the standards. 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 implemented, in many areas.

Do you agree that the early implementation key actions are the right ones to prioritise for early delivery? Please state which of these key actions you do not believe can be delivered by this deadline and why. Please also state if there are any other key actions which you believe could be delivered by the end of the first year following publication.

3. Each key action has the organisations which are responsible for the 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 or another organisation could contribute to delivering that have not been listed next to a key action?

4. When you read this document (both the universal and service specific) you will notice that they address either universal or service specific issues.

5. ***Are there any important universal or service specific NEEDS of children, young people and their families which you feel have not been addressed by the key actions in this standards document?***

6. When writing the key actions, and in the Quality Assurance process, 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?

7. These documents are aimed at service commissioners and providers, however we have developed the documents with the help of children, young people and their families and therefore hope that they are easily understandable. We have identified some key words in the glossary of each standards document.

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 identified for early implementation (i.e. developmental key actions) please select the three that you feel will have the greatest impact on the specialised services for children and young people or are essential to develop and rank them in order of priority.*

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

Please post your consultation responses to:

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Children and Young People's Specialised Services

Introduction

Currently, specialised services for the children and young people of Wales are delivered in an ad hoc and fragmented way. This was identified by the Specialised Health Service Commission Wales, when they undertook a review of specialised services^{1,2}. Following this review, the Minister for Health and Social Services announced that the future of specialised services for children would be through the development of Managed Clinical Networks (MCNs)³.

The Children and Young People's Specialised Services Project (CYPSSP) was established by the Welsh Assembly Government to take this work forward. The project's remit was to:

Develop high quality, equitable and sustainable specialised children's health services across Wales based upon the best available evidence and with children and their carers at the centre of all planning and provision.

This would be achieved by the following aims:

1. To develop service specific standards for Children's specialised services for the children of Wales
2. To enable equity of access for all children in Wales requiring specialised services through effective managed clinical network models.

The agreed specialised services for the project are:

- Neonatal Services
- Paediatric Neurosciences
 - neuro-surgery
 - neurology
 - neuro-disability
- Paediatric Oncology and Palliative Care
- Paediatric Critical Care (standards already published)

- Paediatric specialist surgery
 - General surgery (including neonatal surgery)
 - Trauma and orthopaedics
 - Ear Nose and Throat
 - Ophthalmology
 - Maxillo-facial

- Paediatric specialist medicine
 - Nephrology
 - Cardiology (and access to cardiac surgery)
 - Endocrinology
 - Gastroenterology/hepatology and nutrition
 - Metabolic
 - Respiratory

- Paediatric plastic surgery and burns

The Standards Document.

The standards document is written from an All Wales perspective and applies to all children and young people with that health need, wherever they live in Wales^{4, 5, 6}.

There is an universal standards document that applies to all specialised services included in the project.

In addition to the universal standards, there is a document of service specific standards and key actions that apply only to the relevant speciality.

These standards should be read and used in conjunction with the Children's National Service Framework (NSF)⁷, in particular Chapter 2 which is relevant to all services and all children and young people.

To aid effective communication across the Primary, Secondary and Tertiary interface, it is proposed that a Directory of Specialised Services will be developed which will be updated annually.

Purpose of standards

The standards and their key actions have been developed to provide a foundation for service commissioners and providers to plan and deliver effective services⁸. They are to be used to benchmark current services and then inform the

development of robust future services to meet the specialised health needs of children and young people across Wales⁹.

Developing the standards

The standards for each service have been developed by an External Working Group (EWG) representative of the key stakeholders. The relevant membership detail is included as an appendix in each of the standards document.

The EWG members have given of their time and effort and their contribution is greatly appreciated. We are particularly grateful to all the children, young people and parents who have been involved in the development of this work^{10,11}.

The standards for each service have been Quality Assured by a Project Steering Group (SG) comprising of strategic external key stakeholders. The membership detail is included as an appendix (Appendix 1) in this standards document.

A 3 month consultation period will follow the launch of this document which is being circulated widely. Following the consultation period, comments will be evaluated and the final documents published later in 2005.

Delivering the standards

Following consultation, the standards and key actions will be revised and published.

Once published they will be issued to commissioners and service providers who are responsible for the planning and delivery of future services⁸.

Some of the key actions can be delivered within the first year. We acknowledge however that due to workforce and financial constraints others will take some years to materialise. Thus each key action has a guide timescale as outlined in the following table and based on a 10 year plan to mirror the implementation of the NSF standards⁷.

<i>Category</i>	<i>Timescale</i>	<i>Level</i>
Short Term	Less than 1 year	Early implementation
Mid Term	1 – 3 years	Developmental
Long Term	4 – 10 years	Aspirational

Table 1: Timescales for implementation

Monitoring the standards

Standards will be monitored and audited by the relevant Network Group on an annual basis.

Managed Clinical Networks (MCNs)

These can be defined as:

“Linked groups of health professionals from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Trust/Health Authority boundaries, to ensure equitable provision of high quality and clinically effective services.”¹²

Through the formal establishment of an MCN, children and young people requiring specialised healthcare will do so based on the following principle:

“Age appropriate, safe and effective (high quality) care delivered as locally as possible, rather than local care delivered as safely and effectively as possible”¹³.

Work on the proposed service models is currently under discussion at the Welsh Assembly Government and Health Commission Wales.

Standard 1: Access to Specialised Health Care Services

Rationale: All children identified with a specialised health care need will have access to high quality, evidence based care provided by appropriately trained multi-disciplinary teams

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
1.1 Access to specialised healthcare services is readily available for all children and young people identified with a specialised healthcare need ² .	HCW LHBs	1-3 years
1.2 Access to the following specialised support services are available as relevant: <ul style="list-style-type: none">▪ Social Worker▪ Spiritual Adviser▪ Bereavement Counsellor▪ Breast – feeding support staff▪ Psychological / Psychiatric Advice▪ Multi – ethnic health advocates and translators▪ Parent resuscitation training	HCW LHBs Lead Centres Trusts	1-3 years

Standard 2: Resourcing of Specialised Healthcare Services

Rationale: Specialised healthcare services are staffed with appropriate, multi-disciplinary professionals who are fully trained and equipped to deliver care across the network. These staff are supported by other essential resources to deliver this care safely and effectively⁴.

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
2.1 IT links are in place to support the network, including cross border arrangements with the English lead centres ¹⁴ .	WAG HCW LHBs Lead Centres Trusts	4-10 years
2.2 Workforce planning mechanisms are in place to allow for year on year growth and service development.	WAG HCW LHBs Lead Centres Trusts	Less than 1 year
2.3 Resources are available to support parent training ¹⁵ .	HCW Lead Centres Trusts LHBs	Less than 1 year
2.4 Accommodation with appropriate facilities is available for a parent/carer to stay with their child if they wish to do so ^{7,10} .	HCW LHBs Lead Centres Trusts	4-10 years
2.5 Families are aware of how to access funds for travel to and from the specialist centres ^{7,16,17} .	WAG Lead Centres Trusts	Less than 1 year
2.6 Age appropriate and suitable in patient facilities for adolescents are available based on choice. The needs of adolescents are recognised and met within the organisation ^{18,19,20} .	HCW LHBs Lead Centres Trusts	1-3 years
2.7 A child psychologist is available locally within every child health service.	LHBs Trusts	1-3 years

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
2.8 Time and funding is available to ensure the network delivers its remit.	HCW LHBs	1-3 years
2.9 In all units, add on staffing needs have been built in to the establishment to allow for: <ul style="list-style-type: none"> ▪ annual leave ▪ maternity leave ▪ sickness ▪ study time ▪ attendance at multi-disciplinary meetings ▪ CPD 	HCW LHBs	1-3 years
2.10 In all units, support staff are in place to provide administrative support. This is in addition to the clinical establishment.	HCW LHBs	Less than 1 year
2.11 Equipment is in place and resourced to meet the needs of each service.	HCW LHBs	1-3 years
2.12 All equipment in place complies with National Standards with quality assurance processes for all equipment is in place ²¹ .	Lead Centres Trusts	Less than 1 year

Standard 3: Care of the child and family/Patient Experience

Rationale: The child and the family receive holistic, child and family centred care.

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
3.1 Services are delivered in line with the principles of the UN Convention on the Rights of the child ²² .	Lead Centres Trusts	1-3 years
3.2 Parents/Carers are actively encouraged to participate in care (documented evidence is available) ^{17, 18} .	Lead Centres Trusts	Less than 1 year
3.3 Consent Protocols are in place based on WAG guidance ²³ .	Lead Centres Trusts	Less than 1 year
3.4 Facilities for parents are available on site ^{18, 24} . These should include: <ul style="list-style-type: none"> ▪ Overnight accommodation ▪ Sitting room ▪ Quiet room/area for private conversation ▪ Facilities for making refreshments ▪ Telephone ▪ Access to networking with other parents 	HCW LHBs Lead Centres Trusts	4-10 years
3.5 Information is available for parents/ carers in several formats including leaflets and videos and in a variety of commonly used languages ²⁵ .	Lead Centres Trusts	Less than 1 year
3.6 Arrangements are in place to allow for seamless transition to adult services ^{7, 26, 27} .	HCW LHBs Lead Centres Trusts	Less than 1 year

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
3.7 Information about access to a support group is available ²⁵ .	Trusts Voluntary-Organisations	Less than 1 years
3.8 Education and training is provided for children, young people and their parents who wish to be involved in delivering elements of their own/their child's care ^{24, 25} .	LEAs Lead Centres Trusts	1-3 years

Standard 4: Communication/Clinical Governance

Rationale: There is effective two-way communication from local to specialist care and back and between professionals and children, young people and their families

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
4.1 There is effective two-way communication using a variety of methods between specialist services and secondary and primary care ¹⁴ and between health and other statutory bodies ⁷ .	HCW LHBs Lead Centres Trusts LEAs LAs	Less than 1 year
4.2 There are allocated Information Technology (IT) and administrative services to enable rapid transmission of clinical information across the network ¹⁴ .	WAG HCW LHBs Lead Centres Trusts	4-10 years
4.3 Verbal and written information is available about specific conditions in a variety of commonly used languages and in several formats throughout the pathway of care ⁷ .	Lead Centres Trusts Voluntary Organisations	1-3 years
4.4 Children, Young People and their families have the opportunity to contribute to a patient satisfaction process as part of their annual review of care ^{11, 28, 29} .	Lead Centres Trusts	Less than 1 year

Standard 5: Evidence base, Professional Education and Training/Clinical Governance

Rationale: All members of the Managed Clinical Network are trained to the required standard to deliver a high quality evidence based service.

Key Actions:

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
5.1 An induction programme is in place for all new members of staff.	Lead Centres	1-3 years
5.2 Specialist education is available across the network as an annual programme.	HCW LHBs Lead Centres Trusts Education-Providers	1-3 years
5.3 All non-medical staff are working within a competency framework which is linked to the Knowledge Skills Framework (KSF) and Agenda for Change.	Lead Centres Trusts Education-Providers HPW	1-3 years
5.4 Training is in place for all equipment in use. This is updated annually ²¹ .	Lead Centres Trusts	Less than 1 year
5.5 Individual members of the multi-disciplinary team access speciality training to maintain their knowledge and skills through continuous professional development (CPD).	HCW LHBs Lead Centres Trusts	Less than 1 year
5.6 All members of the multi-disciplinary team have protected time and funding for CPD with specialist education provided across the network ⁷ .	HCW Lead Centres	Less than 1 year*
5.7 As part of the network, clinical pathways, protocols and guidelines are developed for the care and management of children presenting with specific conditions ³⁰ .	HCW Lead Centres Trusts	1-3 years

<i>Key Action</i>	<i>Responsible Organisation</i>	<i>Timescales</i>
5.8 Multi-disciplinary research is an essential component of the managed clinical network.	HCW LHBs Lead Centres Trusts	1-3 years
5.9 Audit programmes are funded as part of the MCN arrangements and include comprehensive audit of: i. Training ii. Practice iii. Compliance with pathways and protocols	WAG HCW LHBs	

Glossary

This glossary should be used in conjunction with the glossary provided in the Children's NSF.

Education Providers	Providers of commissioned health education.
Health Commission Wales (HCW)	Commissioners of specialised services.
Lead Centres	Trusts delivering specialised services.
Local Health Boards (LHBs)	Commissioners of local primary and secondary services.
Trusts	All Trusts other than lead centres delivering children's services.
Universal Standards And Key Actions	Standards and key actions which apply to all of the specialised services.

Project Steering Group Members

Chairs of the External Working Groups (EWG's)

Rhian Davies (Observer) Representing the Children Commissioner's Office

Dr Leyla Al Jader, representing National Public Health Service (NPHS)

Alison Lagier, representing Local Health Board Chief Executives

Becky Healey, representing Welsh Nursing & Midwifery Committee (WNMC)

Angela Hillier, representing Welsh Therapies Advisory Committee (WTAC)

Jane Perrin, representing National Association of Chief Executives (NACE)

Dr Geoffrey Carroll/Andrew Ferguson representing Health Commission
Wales (HCW)

Andrea Matthews representing Community Health Councils (CHC)

Dr Michael Badminton, representing Welsh Scientific Advisory Committee (WSAC)

Sue Greening representing Welsh Dental Committee (WDC)

Dr Eddie Coyle representing Welsh Centre for Health (WCH)

Caroline Crimp representing service users (Action for Sick Children)

Keith Bowen representing service users (Contact a Family)

Irene Allen Head of Branch Welsh Assembly Government

Dr Huw Jenkins Director Children and Young People's Healthcare
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