



ISLE OF WIGHT NHS PRIMARY CARE TRUST/ IW COUNCIL

TRANSITION TO ADULTHOOD POLICY

For all children and young people who require Universal, Targeted and Specialist Services on the Isle of Wight

2006-2009

Final Version 3

INDEX

Page Title

- 1. Introduction
- 2. Mission Statement Agreed Definition Purpose Scope
- 3. Principles
- 4. Transition Timeline
- 5. Transition Process Children's Services, Adults Services and Isle of Wight NHS Primary Care Trust Protocols
- 6 7 Relevant Policies, Guidance and Procedures
- 8. List of Transition Documents Available
- 10 16 Appendix Two/1 Transition protocol Sp CAMHS to Adult Mental Health Services
- 18 26 Appendix Two /2 Transition protocol for 16-18 years – Sp CAMHS to Adult Mental Health Services

28 - 30 Appendix Two/3 Protocol between the Children's Disability Team and the Adult Learning Disability Team concerning Transition

32 - 33 Appendix Two/4 Protocol between the Children's Disability Team and Physical Disability and Sensory Impairment Team concerning Transition

34 - 38 Appendix Two/5 Transition to adulthood for you disabled people with 'complex health and support needs'.

40 – 50 Appendix Two/6 Guidelines for Transition of Care from Children to Adult Services for patients with chronic conditions.

- 52 54 Appendix Two/7 Easy Read – Transition to Adulthood Policy
- 56- 77 Appendix Two/8 Young People with Special Educational Needs/LD
- 78 91 Appendix Two/9 Get Sorted Protocol

Introduction

Transition from Children's to Adult Services is an important issue. Good and effective and a seamless transition will set the standard for the future care of the young person and their carers for the rest of their adult life.

The National Service Framework for children, young people and maternity services highlight the importance of ensuring a safe and effective transition. Government Policy emphasises that this is not solely a matter for healthcare professionals but for Education and Social Care. Transition planning must secure that all the wider needs and aspirations for all are taken into account.

This document is a multi disciplinary policy. I has been developed in consultation with all agencies and taken into account the individual protocols of agencies appendixed in the document.

The document has been completed taking into account the National context as documented in Annex One.

It should be noted that some of the protocols are still in draft and this policy will be updated on a regular basis and is the responsibility of the authors.

1. Mission Statement

To facilitate a seamless service in transition for all children who require Universal, Targeted and Specialist services on the Isle of Wight in order they access timely relevant and age appropriate services.

Island Policy is to fully involve the child and young person in the process. Acknowledging all stakeholders to influence the children and young people in the transition process taking into account all Policies, Guidance and Procedures working within each Departments protocol - Appendix One.

2. Agreed Definition

This policy is for 14-25 year olds, where it has been identified that they will be in need of Adult Services on reaching their 18th birthday or thereafter. Every agency will sign up to the Policy, while following individual protocols as laid down by their own service which will identify age specific.

3. Purpose

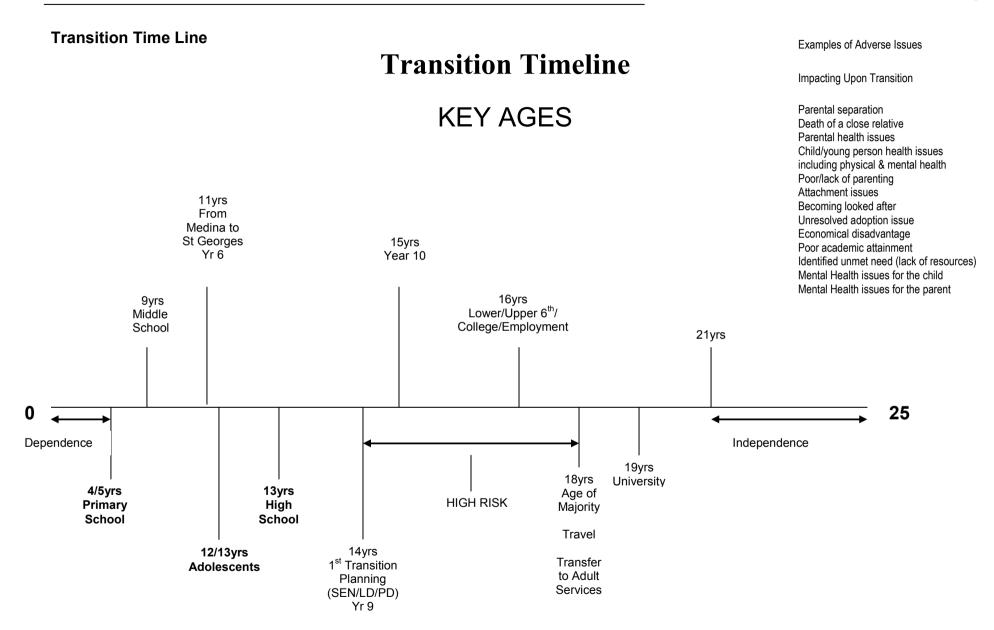
- 3.1 This policy requires the most appropriate care provision for a young person, as well as fully involving them in the process.
- 3.2 To ensure the development of effective joint working between services and will ensure the achievement of Five Outcomes and the priorities of the Children and Young People's Plan:
 - Be Healthy
 - Stay Safe
 - Make a Positive Contribution
 - Enjoy and Achieve
 - Achieve Economic Wellbeing
- 3.3 This policy is intended to reflect individuality and the right to choose.
- 3.4 To inform joint strategic planning and the effective management of joint resources.

4. Scope

This policy is for ALL those individuals and carers involved in transition from children and young people to adulthood.

5. Principles

- 5.1 Children and young people and their carers will be encouraged to exercise choice in the type of service with which they are involved.
- 5.2 Children and young people and their carers will be actively encouraged and empowered to share in the decision making process.
- 5.3 Children and young people and their carers have the right to expect flexibility from all services.
- 5.4 The development of integrated pathway planning will be aligned to the Five Outcomes.
- 5.5 Lead professional responsibility will be made explicit by agreement with all parties and in line with the Common Assessment Framework guidance.
- 5.6 Inter-agency arrangements will ensure that information is shared subject to departmental protocols and information policies.
- 5.7 The underlining principal will be to avoid a delay in providing a service to children and young people through the transition process to adult services.
- 5.8 All professionals will adhere to the policies of the Complaints Procedures within the IW Council and IW NHS PCT.
- 5.9 All professionals must follow the procedure as laid down in the Children Act 2004 in liaison with the Local Safeguarding Children's Board and Adult Protection Policies..



7 Transition process

The Good Practice follows these six steps to ensure smooth transition to adulthood:

- Early Identification of need
- Early Identification of lead professional
- Clarity of transitional arrangements
- Appropriate assessment / transition framework applied
- Timeframe as identified in each protocol
- Evidence of outcomes

8. Children's Services, Adults Services and the Isle of Wight Primary Care NHS Trust should ensure that

- 8.1 Transition planning has as its main focus the fulfilment of the hopes, dreams and potential of the young person, in particular to maximise education, training and employment opportunities, to enjoy social relationships and to live healthily and independently. Transition plans take a person-centred approach, as described in "Towards Person-Centred Approaches guidance".
- 8.2 A multi-agency Transition Group is in place that includes the Transition Champion from the learning Disability Partnership Board and assumes responsibility for overseeing transitional arrangements at both strategic and operational level.
- 8.3 Specific arrangements are made for managing the transition of those who are identified as particularly vulnerable.
- 8.4 Agencies develop local strategies to widen education, training and employment opportunities.
- 8.5 Health services develop appropriate children and young people's services with a view to enabling smooth transition to comprehensive adult multi-disciplinary care.
- 8.6 In commissioning of services all statutory and voluntary agencies will ensure the transition arrangements are key in any service delivery across children and young people and adult services.

9. Protocols

- 9.1 Each service will develop a protocol for transition (Appendix Two)
- 9.2 Each protocol will adhere to the principals of the Transition Policy and the Five Outcomes
- 9.3 Each protocol will be written in a clear language and be accessible to children and young people and carers
- 9.4 Each protocol will be available on request in large print, in Braille and on audiotape.
- 9.5 Each protocol will be reviewed as necessary and at least every three years.

APPENDIX ONE

Relevant Policies, Guidance and Procedures

- 1. *Making Connections: A Guide for Agencies Helping Children and young people with Disabilities Making the Transition from School to Adulthood.* Government bodies and the Prince of Wales' Advisory Group on Disability. Contact: The Prince of Wales' Advisory Group on Disability, Nutmeg House, 60 Gainsford Street, London SE1 2NY.
- 2. Family Fund Trust (1996) *After Age 16 What Next?* Services and Benefits for Young Disabled People. York: Family Fund Trust
- 3. Heslop, P. and Simons, K (2000) Aspects of policy/practice that might make a difference to the experience of children and young people with learning difficulties and their families in the transition to adulthood. Department of Health.
- 4. Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health, Bridging the gaps: health care for adolescents http://www.rcpch.ac.uk
- 5. Viner R, Keane M (1998) Youth Matters: *Evidence Based Best Practice for the Care of Children and young people in Hospital.* Action for Sick Children 1998. London
- 6. Royal College of Nursing (2004) *Adolescent transition Care Guidance for Nursing Staff.* The Royal College of Nursing 2004 London

http://www.rcn.org.uk/publications

7. Direct Payments Guidance - Community care, Services for Carers and Children's Services. The Department of Health have issued new guidance on providing Direct Payments. It provides guidance on how local councils might manage and administer direct payments. Specific chapters refer to making direct payments to 16 and 17 year olds and parents of disabled children. This guidance can be downloaded from:

http://www.doh.gov.uk/directpayments/dpguidance.pdf

- 8. **Valuing People requires** that local agencies will be expected to have introduced person-centred planning for all children and young people moving from children's to adult's services by 2003". In accordance with the PCP guidance this planning should be facilitated independently of professional/agency assessment to determine eligibility for resources and services. For this to be of most use to children and young people it would need to take place in such a way that it could influence assessments which determine eligibility and allocation of statutory resources. This means that local systems will need to look to the timing of the availability of person centred planning and to ensuring the necessary overlap with assessments.
- 9. **The Valuing People White Paper** requires a Transitions Champion to be identified to ensure that effective processes are in place that reflects the needs of children and young people in terms of service development that is user led. There is also a clear expectation that Person Centred Planning is in place before a young person reaches 18.

- 10. National Service Framework for Children, young people and maternity services and Every Child Matters place a strong emphasis on effective transition processes.
- 11. We could also refer to **Audit Commission reports** that identify the need for improved co-ordination of services that respond to the needs of children and young people and place them in the centre of the planning process.
- 12. **Mental Health Policy implementation Guidance (2002)** suggests that age limits are to be determined in line with locally agreed protocols for transitions from adolescents to adults.
- 13. The development of Early Intervention Services in first onset psychosis demands a clear framework for children and young people between the ages of 14-35. Mental Health Policy Implementation Guidance (2001) identifies a need to provide a user centred, seamless service available for those from the age of 14 35 that effectively integrates child, adolescent and adult mental health which works in partnership with primary care, education, social services, youth and other services.
- 14. **Children and young people and substance misuse -** *'Models of care'* focuses on commissioning and provision of drug treatment for adults, that is those aged 18 years and older. The provision of drug and alcohol treatment for adolescents and children and young people is extensively covered elsewhere (Health Advisory Service 1996, 2001b). Commissioning these services should be within the existing frameworks for commissioning health and social care for children and young people, to provide adequate links to generic services for children and families. There should be explicit links to DAT's and commissioning interface services for those in transition from adolescence to adulthood (for those aged 16 to 21).

APPENDIX TWO

Transition documents	Organisation	Department	Reference
Transition Protocol For 16-18yrs Specialist CAMHS To Adult Mental Health Services	Isle of Wight Healthcare Trust	Mental Health & Learning Disability Services	Appendix Two/1
Protocol for admission to Sevenacres for 16-18 year olds Specialist CAMHS	Isle of Wight healthcare Trust	Mental Health & Learning Disability Services	Appendix Two/2
Protocol between the children's disability team and the adult learning disability team concerning transition	Isle of Wight Council	Children's Disability Team	Appendix Two/3
Protocol between the Children's Disability Team and the physical Disability and Sensory Impairment Team concerning Transition	Isle of Wight Council	Children's Disability Team	Appendix Two/4
Transition to adulthood for young disabled people with 'complex health and support needs'	Isle of Wight Council	Oak House	Appendix Two/5
Guidelines for transition of care from children's to adult services for patients with chronic conditions	Isle of Wight Healthcare Trust	Children's Ward, St Mary's Hospital	Appendix Two/6
Outline Strategy for Person- Centred Approaches in Transition	Isle of Wight Council	Adult and Community Services - Learning Disabilities	Appendix Two/7
Protocol for the Transition planning Process for Young People with Educational Needs / Learning Disabilities & Difficulties	Isle of Wight Council	Children's Services	Appendix Two/8
Guidelines for the Transfer of Clients from 'Get Sorted' Young Persons Substance Misuse Treatment Service to Adult Substance Misuse Treatment Services	Isle of Wight Council	Adult and Community Services	Appendix Two/9

NB Electronic versions of the above will be available on the Isle of Wight Council children and young people's website. Could the above authors ensure that any changes made to documents ensure they contact Children's Trust Advisor.

ISLE OF WIGHT HEALTHCARE NHS TRUST Mental Health & Learning Disability Services

TRANSITION PROTOCOL SPCAMHS TO ADULT MENTAL HEALTH SERVICES

DRAFT

Transition Protocol SPCAMHS to Adult Mental Health Services

Background

The absence of transition agreements between Adult Mental Health and SPCAMH services can cause lack of clarity about service responsibility, differing views of clinical need and incompatible eligibility criteria. Agreeing the point at which young people move from children's services to adult services is one aspect of ensuring a seamless service. Mental Health Policy implementation Guidance (2002) suggests that age limits are to be determined in line with locally agreed protocols for transitions from adolescents to adults.

The development of Early Intervention Services in first onset psychosis demands a clear framework for young people between the ages of 14-35. Mental Health Policy Implementation Guidance (2001) identifies a need to provide a user centred, seamless service available for those from the age of 14 - 35 that effectively integrates child, adolescent and adult mental health which works in partnership with primary care, education, social care, youth and other services.

This protocol encourages us to consider the most appropriate care provision for a young person, fully involving them in this process. It also encourages joint working between adult mental health services and SPCAMH services to help us achieve a 'seamless service'. This protocol applies to all transfers from SPCAMHS to Adult mental health services including that of the younger person experiencing an early onset of psychosis.

It is understood that traditional age cut offs can be unhelpful to the younger person, and may not reflect individual need and the right to choice over care.

Principles

- 1. Young people and their carers should be encouraged to exercise choice in the type of service with which they become involved.
- 2. Young people and their carers should be actively empowered to share in the decision making process.
- 3. Young people and their carers have the right to expect flexibility from mental health services.
- 4. Care plans should be consistent with the principles of the Care Programme Approach.
- 5. Clinical responsibility must be made explicit to all parties.
- 6. Inter-agency arrangements should be made in ways which are consistent with the right to confidentiality.
- 7. Delay in assessment or treatment is detrimental to a young persons mental health and future engagement with services.

8. When a client is currently cared for within SPCAMHS and they are nearing their 18th Birthday, this protocol should be followed: -

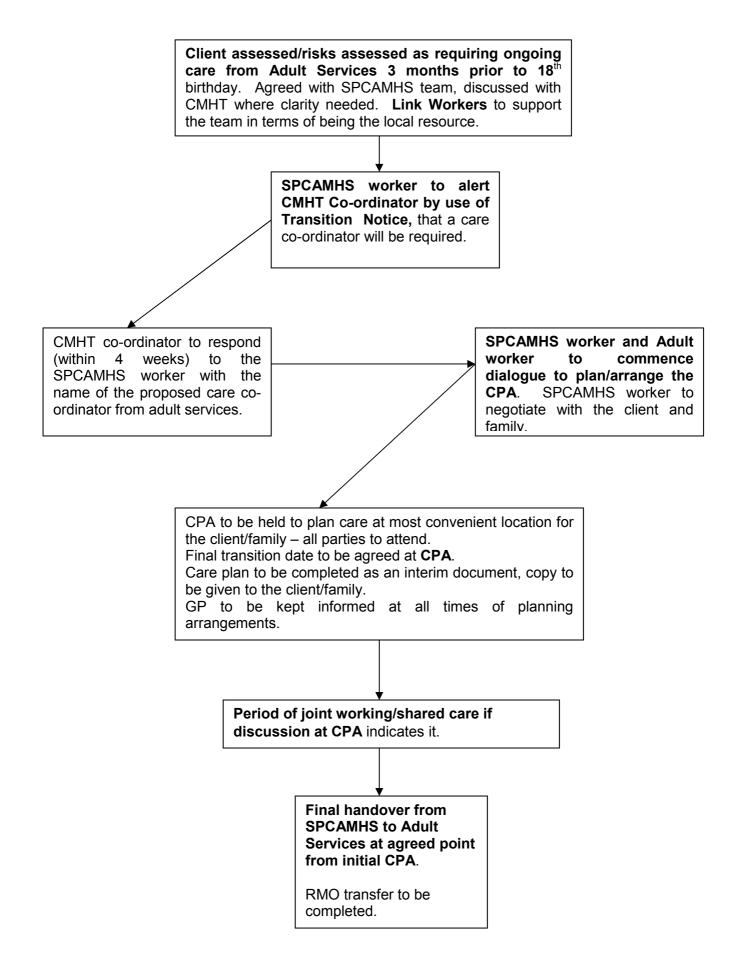
- 9. At three months before the impending birthday, SPCAMHS worker to consider options for future care needs, i.e. do they require transit to Adult Mental Health Services? What are the risks associated with the individual? Can their needs be met by an outside agency or support system? What are the clients/families/GPs feelings about a transition?
- 10. Should there be agreement that the client requires further input from mental health services at their 18th birthday, the SPCAMHS worker will approach the SPCAMHS/Adult link persons to discuss the transition pathway. The link worker will be able to advise on how to commence the dialogue with CMHT if unsure. For young people looked after, the process needs to link with the statutory looked after children review and leaving care planning process. Plans need to be holistic, seamless and inclusive.
- 11.SPCAMHS worker to alert the CMHT co-ordintor that a care co-ordinator will be required. This would be useful in writing (see transition notice form) as an initial point of contact, but in the context that the rest of the planning is to be carried out in "face to face" meetings, involving the client/family/carers at all times.
- 12. At this point it is the responsibility of the CMHT Co-ordinator to ensure a Care Coordinator has been allocated from the Adult Mental Health Services to prepare for the eventual handover. The CMHT co-ordinator should respond to the SPCAMHS worker with a name and a contact number of the proposed care co-ordinator within 2 weeks of the transition notice.
- 13. At this point a CPA date should be negotiated and agreed with the individual, family SPCAMHS worker, proposed care co-ordinator and other agencies for the initial CPA.
- 14. A Care Programme Approach (CPA) meeting should be held at least six weeks prior to the 18th birthday to promote communication between teams and allow for all the interested parties to meet and share concerns and anxieties and formulate a care plan that reflects the changing needs of the clients and the family. This would be an opportunity to explore issues such as confidentiality, expectations of future care and how the individual's care will be managed. This CPA should be arranged in the most convenient place for the client and family. It is the responsibility of the SPCAMHS worker and the proposed new Care Co-ordinator to establish an effective channel of communication that allows for the containment of any anxieties that a transition may cause. CPA documentation should be used to document the agreed plan of care. It is important to consider a period of joint working to enable the services to dovetail and to avoid an abrupt ending (i.e. to promote the concept of a seamless service). Again, for looked after young people, the process is to include the relevant looked after care worker and young people leaving care mentor.

- 15. Consultant responsibility remains with the SPCAMHS Consultant until agreed date of handover that meets the needs of the client. However, joint working between SPCAMHS and Adult Mental Health clinicians should enable a seamless transition. In practice when a client is with adult services, care is likely to be co-ordinated by a CPN, OT etc, and not necessarily by a Consultant Social Worker. Psychologist/Psychiatrist. If the SPCAMHS Consultant holds a case (with no other worker involved) that requires transfer then they should also use the Transition Notice to alert the CMHT and liaise with the newly allocated care co-ordinator from the Adult Mental Health Services on how to organise a CPA to transfer the care. This meeting could be held during outpatient appointments, which the care coordinator could attend until a relationship is established and a care plan is in place. Should the individual's needs be such that it would be easier for them to see an Adult Consultant during the transition period, (i.e. if they are attending the CMHT day hospital as part of their care plan over a 2-3 month period), then the Adult Consultant should take responsibility earlier. This should be needs led rather than service driven, organised on a case-by-case basis and put the needs of the individual first at all times.
- 16. The SPCAMHS worker should continue to assume responsibility for the coordination of the individual's care plan until the handover has been completed at the final CPA meeting. This enables a clear sense of responsibility with the period of joint working, allowing for the sharing of skills and practices between services.
- 17. Should a young person be discharged from SPCAMHS, who in the future may need a service from the Adult Mental Health Services, then the re-referral route in the event of further mental health difficulties should be made explicit to the original referrer (i.e. GP). It should be made clear that Adult Mental Health Services would be the appropriate service following an 18th birthday. This should also be agreed and made explicit to the individual and the family/carers as part of a crisis/relapse plan on discharge. (Please note clinical guidelines on follow up care for early onset of psychosis).
- 18. In the case of an individual experiencing early onset psychosis, best practice guidelines suggest a three-year watching brief thus reducing the impact of the disorder on their daily lives and futures. In such cases it would be appropriate to always use the transition protocol to move into adult services and have a period of joint working sooner than the 18thyear.
- 19. Be aware at all times of the Child Protection needs of the individual. Ensure links with child protection staff.
- 20. Should the client experience a crisis/relapse in this period then the SPCAMHS worker would continue to assume responsibility until the situation is assessed as being more stable. This should not exclude joint working for the client but gives a clear sense of clinical responsibility in a difficult period. Best practice indicates that handovers/transitions are most effective in terms of engagement in future care when the individual is experiencing a settled period in their mental health. Thus, it is advisable to avoid handover of care when a client is unable to contribute in their usual way to the process.
- 21. Should a young person need to be transferred to from an inpatient adolescent unit to an adult inpatient unit, an identified link person from the adult unit will provide a

liaison/communication role with the adolescent unit to enable a planned, safe transfer for the younger person and the family.

- 22. Should a client be transferred outside of the Trust service, i.e. they are moving to another area, then clear transition arrangements should be negotiated prior to the actual handover to ensure the safe and effective transfer.
- 23. This protocol will be the subject to an audit process within 6 months of incept to ensure that any particular difficulties can be identified and problem solved.

SUMMARY FLOW CHART OF TRANSITION PROTOCOL – SPCAMHS TO ADULT MENTAL HEALTH SERVICES



Isle of Wight Healthcare NHS Trust Mental Health & Learning Disability Services

SPCAMHS TO ADULT MENTAL HEALTH SERVICE CPA/TRANSTION NOTICE FORM

Name of Client:

Date of Birth:

Age:

Address:

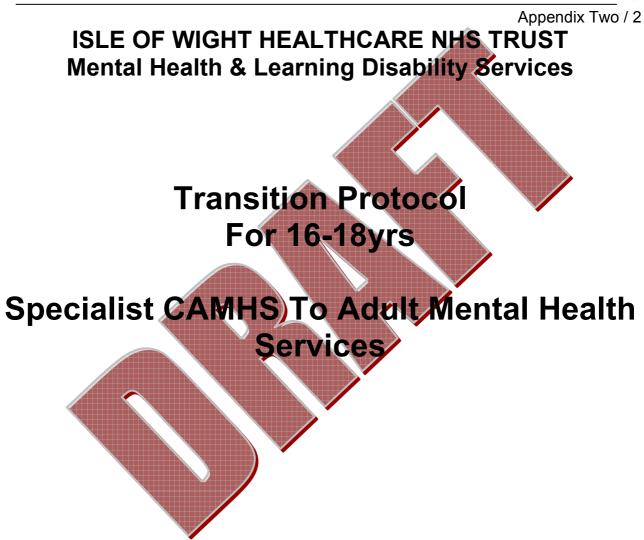
GP:

Diagnosis/Mental Health Difficulties:

Current SPCAMHS Worker/s:

Other Professionals Involved:

Date Notice Received by CMHT:
Care Co-ordinator Allocated:
Date SPCAMHS Worker Informed:
Agreed CPA Date and Venue:
Date Transition Completed:



Authors:

Su Whorwood – Service Leader – Adult In-patient and Rehabilitation Services

Version: 2

Status: Draft review

Date: January 2005

Review date: January 2006

1. Relevant Policies and Procedures

1 Department of Health Improvement, Expansion and Reform: the Next 3 Years, Priorities and Planning Framework 2003-2006 September 2002 www.dh.gov.uk

2 Department of Health. National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/06 – 2007/08 2004 www.dh.gov.uk 3 Gale F, Vostanis P The primary mental health worker within child and adolescent

mental health services Clinical Child Psychology and Psychiatry April 2003; vol 8; no 2; p 227-240

4 Department for Education and Skills, PK Research Consultancy, National Children's Bureau Building a Culture of Participation: Involving children and young people in policy, service planning, delivery and evaluation Department for Education and Skills. 2003

5 Chambers H., Howell S., Madge N. and Ollie H. Healthy Care Building an

Evidence Base for Promoting Health and Wellbeing of Looked After Children and Young People National Children's Bureau 2002 www.ncb.org.uk

6 Malek M and Joughin C. (Editors) Mental Health Services for Minority Ethnic Children and Adolescents London: Jessica Kingsley. 2004

7 Home Office, Implementation of Council Directive 2003/9/EC of 27 January 2003 Laying Down Minimum Standards for the Reception of Asylum Seekers.

Consultation Document (anticipated publication 2004)

8 Office of the Deputy Prime Minister Mental Health and Social Exclusion Social Exclusion Unit Report June 2004 www.socialexclusionunit.gov.uk

9 Department for Education and Skills Every Child Matters The Stationery Office 2003 www.dfes.gov.uk/everychildmatters/

10 Department for Education and Skills Removing Barriers to Achievement: The Government's Strategy for SEN 2004

www.teachernet.gov.uk/wholeschool/sen/senstrategy/

11 Pettitt B. Effective Joint Working between Child and Adolescent Mental Health Services (CAMHS) and Schools. Research Report 412 Mental Health Foundation 2003

12 Department of Health, Department for Education and Employment, Home Office-Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children The Stationery Office 1999 www.dh.gov.uk

13 Department of Health National Service Framework for Mental Health- The Stationery Office 1999 www.dh.gov.uk

14 Royal College of Psychiatrist's Research Unit Quality Network for Inpatient Care – Standards 2002-2003 www.rcpsych.ac.uk/cru/qnic.htm

15 Kurtz Z, James C. What's New? Learning from the CAMHS Innovation Projects Department of Health. Forthcoming publication 2004

16 University of Durham, Department of Health National Child and Adolescent Mental Health Service Mapping Exercise. www.camhsmapping.org.uk

17 NHS Health Advisory Service- Together We Stand: Thematic review of the Commissioning, Role and Management of Child and Adolescent Mental Health Services- The Stationery Office 1995

18 Office for National Statistics Mental health of children and adolescents in Great Britain London: The Stationery Office. 2000

19 World Health Organisation The ICD-10 Classification of mental and Behavioural Disorders Clinical Descriptions and Diagnostic Guidelines Geneva: WHO 1992

20 The Audit Commission Children in Mind: Child and Adolescent Mental Health Services- 1999 www.audit-commission.gov.uk

2. Background

Clarity about service responsibility, differing views of clinical need and incompatible eligibility criteria between Specialist CAMHS and Adult Mental Health services is of absolute priority. Agreeing the point at which young people move from children's services to adult services is one aspect of optimising patient care. Mental Health Policy implementation Guidance (2002) suggests that age limits are to be determined in line with locally agreed protocols for transitions from adolescents to adults.

The development of Early Intervention Services in first onset psychosis demands a clear framework for young people between the ages of 14-35. Mental Health Policy Implementation Guidance (2001) identifies a need to provide a user centred, seamless service available for those from the age of 14 - 35 that effectively integrates child, adolescent and adult mental health which works in partnership with primary care, education, social services, youth and other services.

3. Purpose

- 3.1 This protocol encourages consideration of the most appropriate care provision for a younger person, fully involving them in the process.
- 3.2 This protocol can be used for 16-18yr olds where it has been deemed appropriate they are in need of Adult Service sooner than their 18th birthday i.e.: they are living an adult lifestyle.
- 3.3 Joint working between Adult Mental Health Services and Specialist CAMHS Services will ensure patient care.
- 3.4 This protocol applies to all transfers from Specialist CAMHS to Adult Mental Health Services including the younger person experiencing an early onset of psychosis.
- 3.5 This protocol is intended to reflect the individuality of a person and their right to choices over their care.

4. Scope

This protocol is for **ALL** professionals working within Mental Health and Learning Disability services, and with vulnerable service users.

5. Guiding Principles

5.1 Young people and their carers should be encouraged to exercise choice in type of service they are involved in.

- 5.2 Young people and their carers should be actively empowered to share in the decision making process.
- 5.3 Young people and their carers have the right to expect flexibility from the mental health services.
- 5.4 Care plans should be consistent with the principles of the Care Programme Approach. (CPA)
- 5.5 Clinical responsibility must be made explicit to all parties.
- 5.6 Inter-agency arrangements should be made in ways, which are consistent with the right to confidentiality.
- 5.7 Delay in assessment or treatment is detrimental to a young persons mental health and future engagement with services.
- 5.8 When a client is currently known to Specialist CAMHS and they are nearing their 18th Birthday, this protocol should be followed;

6. PROCEDURAL GUIDANCE

- 6.1 Not less than 6 months before the 18th birthday, Specialist CAMHS worker to consider options for future care needs, i.e. do they need transit to Adult Mental Health Services? What are the risks associated with the individual? Can their needs be met by an outside agency or support system? What are the clients/families/GPs feelings about a transition?
- 6.2 Should there be an agreement that the client requires further input from the mental health services at their 18th birthday, then the Specialist CAMHS worker to approach the Specialist CAMHS/Adult link persons to discuss the transition pathway. The link worker will be able to advise on how to commence the dialogue with CMHT if unsure. For looked after young people, the process needs to link with the statutory looked after children review and leaving care planning process. Plans need to be holistic, seamless and inclusive.
- 6.3 Specialist CAMHS worker to alert the CMHT Co-ordinator that a Care Co ordinator will be required via MATs. This should be in writing (appendix 1) as an initial point of contact, but in the context that the rest of the planning is to be carried out in "face to face" meetings, involving the client/family at all times.
- 6.4 MATs should identify appropriate CMHT and pass on referral.
- 6.5 At this point it is the responsibility of the CMHT Team leader to ensure a Care Co-ordinator has been allocated from the Adult Mental Health Services to prepare for the eventual handover. The CMHT Team Leader should respond to the Specialist CAMHS worker with a name and a contact number of the proposed care co-ordinator within 4 weeks of the transition notice.

- 6.6 At this point a CPA date should be negotiated and agreed with the individuals, family Specialist CAMHS worker, proposed care co-ordinator and other agencies for the initial CPA.
- A (CPA) meeting should be held at least six weeks prior to the 18th birthday 6.7 to promote the communication between the teams and allow for all the interested parties to meet and formulate a care plan that is reflective of need. This would be an opportunity to explore issues such as confidentiality, expectations of future care and how the individual's care will be managed. CPA should be arranged in the most convenient place for the client and family. It is the responsibility of the Specialist CAMHS worker and the proposed new Care Co-ordinator to acknowledge any anxieties caused by transition through communicating effectively. The care plan from the CPA documentation would be used to document the proposed, agreed plan of care. Consideration should be given to a period of joint working to enable the services to dove tail and to ensure continuity of care. For looked after young people, the process is to include the relevant looked after care worker and young people leaving care mentor.
- 6.8 Responsibility remains with the Specialist CAMHS Consultant until agreed date of handover that meets the needs of the client. In practice when a client is under the adult services the care is likely to be co-ordinated by a Social Worker, CPN, OT etc and not necessarily by a Consultant Psychiatrist. If the Specialist CAMHS Consultant holds a case (with no other worker involved) that requires transfer to the Consultant they should also use the Transition Notice to alert the CMHT and liaise with the allocated care co-ordinator from the Adult Mental Health Services on how to organise a CPA to transfer the care. This could be held in an outpatient appointment which the care co-ordinator could attend on a few occasions in this three month period until a relationship is established and a care plan is in place. If the individuals needs are such that it would be easier for them to attend to see an Adult Consultant during the transition period, this should be 'needs'

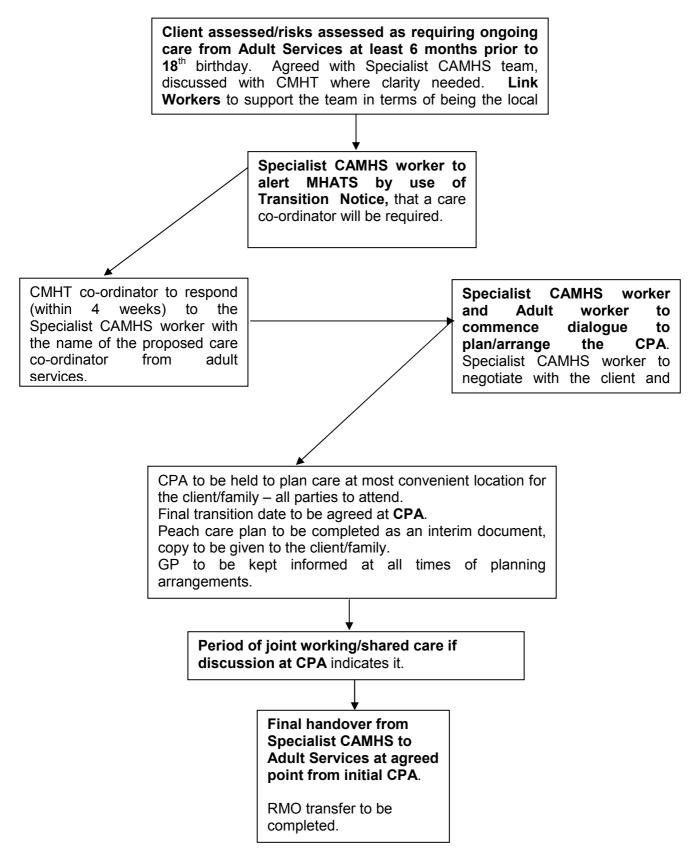
see an Adult Consultant during the transition period, this should be 'needs led' not service driven, organised on a case to case basis, that puts the needs of the individual first at all times.

- 6.9 The Specialist CAMHS worker should continue to assume responsibility for the co-ordination of the individual's care plan until the handover has been completed at the final CPA meeting. This enables a clear sense of responsibility with the period of joint working allowing for the sharing of skills and practices between services.
- 6.10 Should a young person be discharged from Specialist CAMHS, require input from Adult Mental Health Services, the re-referral route in the event of further mental health difficulties should be made explicit to the original referrer (i.e. GP). It should be made clear that Adult Mental Health Services would be the appropriate service following an 18th birthday. This should also be agreed and made explicit to the individual and the family of carers as part of a crisis/relapse plan on discharge.
- 6.11 In the case of an individual experiencing an early onset of psychosis, the best practice guidelines suggest a three-year watching brief for people experiencing psychosis thus reducing the impact of the disorder on their daily

lives and futures. In such cases it would be appropriate to use the transition protocol to move into adult services and have a period of joint working sooner than the 18^{th} year.

- 6.12 To be aware at all times of the Child Protection needs of the individual, that adequate supervision is in place for the worker and that referral and liaison plans are known and acted upon as appropriate.
- 6.13 Should the client experience a crisis/relapse during transition the Specialist CAMHS worker would continue to assume responsibility until the situation is assessed as being more stable. This should not exclude joint working for the client but should give a clear sense of clinical responsibility in a difficult period.
- 6.14 Best practice indicates that handovers/transitions are most effective in terms of engagement in future care when the individual is experiencing a settled period in their mental health. Thus, it is advisable to avoid handover of care when a client is unable to contribute in their usual way to the process.
- 6.15 Should a younger person need to be transferred from an inpatient adolescent unit to an adult inpatient unit, then an identified link person from the adult unit will have a liaison/communication role with the adolescent unit to enable a planned, safe transfer for the younger person and the family.
- 6.16 Should a client be transferred to out of the Trust area, clear transition arrangements should be negotiated prior to the actual handover to ensure safe and effective transfer.
- 6.17 Once this protocol has been improved a 6 month audit process will be used to ensure that any particular difficulties can be identified and problem solved.

SUMMARY FLOW CHART OF TRANSITION PROTOCOL SPECIALIST CAMHS TO ADULT MENTAL HEALTH SERVICES



8. Keys for Transition Protocol

Link Persons – Those identified clinicians from each CMHT and Specialist CAMHS services on the Isle of Wight.

CPA – Care Programme Approach. The established care planning, evaluation, risk assessment tool. Used to communicate care plans to all parties.

Handover – the final completion of the transition of care from one element of the service to another.

Care Co-ordinator – an established term for the individual clinician, through the CPA procedure who is the main worker with a client and whose responsibility it is to manage their care.

Joint working – when a client benefits from the skills and experiences of more than one individual worker. This can take on many forms, but in terms of transition pathways, joint working implies a period of work that enables a smooth and effective sharing of care to ensure the least disruption for a service user.

Appendix 1

Isle of Wight Healthcare NHS Trust Mental Health & Learning Disability Services

SPECIALIST CAMHS TO ADULT MENTAL HEALTH SERVICE CPA/TRANSTION NOTICE FORM

Name of Client:

Date of Birth:

Age:

Address:

GP:

Diagnosis/Mental Health Difficulties:

Current Specialist CAMHS Worker/s:

Other Professional Involved:

Date Notice Received by CMHT:
Care Co-ordinator Allocated:
Date CAMHS Worker Informed:
Agreed CPA Date and Venue:
Date Transition Completed:

Appendix Two / 3 PROTOCOL BETWEEN THE CHILDREN'S DISABILITY TEAM AND THE ADULT LEARNING DISABILTY TEAM CONCERNING TRANSITION

This protocol sets down the expectations and timescales for the transition of those young people that require services as an adult and fall within the criteria of the Adult Learning Disability Service.

It is recognised that the eligibility criteria for the Children's Disability Team and the Adult Learning Disability Team are not the same. This means that there will be a number of young people where it is not clear whether they meet the criteria for a service from the ADLT.

It is important, for planning purposes, that information is shared with Adult Services regarding numbers of young people coming through. To assist in this the Team Manager, CDT, will maintain a database of young people open to the team who are aged 13 plus. This will then be shared with Adult Services on a 6 monthly basis. A Transition Monitoring meeting will be held in January and July with Managers of the ALDT and CDT, and Clinical Service Manager LD to monitor the progress of young people and identify any areas of difficulty.

For cases that are already open to a social worker in the CDT:

- Social worker/social work assistant to attend the SEN Transitional Review which starts at age 14.
- Social worker will form a view as to whether the young person is likely to meet the ADLT criteria.
- Social worker will identify when it is anticipated that the young person will leave full time education.
- If the young person is planning to leave full time education at 16, and the social worker believes that they fall within the ADLT criteria, a referral is to be made immediately to the ALDT for a transitional worker. It is not anticipated that there will be many young people leaving full time education at 16.
- If the young person is planning to stay in full time education till 18/19, and the social worker believes that they fall within the ADLT criteria, a referral is to be made to the ADLT for a transitional worker at age 16. The aim would be for a transitional worker to attend the 16+ SEN Transition Review.
- Case responsibility will remain with the CDT until the young person's 18th birthday. The role of the transitional worker is to undertake assessment, and will arrange for Person Centred Planning to be initiated, to determine the services or resources required after the

young person has reached 18. Close liaison between the CDT worker and Transition worker is essential.

• A Senior Practitioner in the CDT will take responsibility for monitoring the progress of young people from age 14 onwards to ensure that actions are taken at the appropriate time.

For cases that are not open to a worker in the CDT:

- If a request to attend an SEN Transition Review for a young person aged 14 is received the CDT Manager will need to consider the following:
 - 1. From the information provided does the young person fall within the criteria that would deem them as disabled? If yes, the CDT Manager would identify a worker to attend the Transition review. A full referral and assessment may be required to identify services required. Consideration would also be given as to whether a transitional worker is required.
 - 2. If the young person would not be deemed as disabled then this decision would be passed to the school for inclusion in the Transition Review. No further action is required.

Where there is uncertainty about whether a young person meets the ALDT criteria.

When completing the Transition referral form it is important that the worker provides as much information as possible to assist in the determination of whether the criteria is met or not. Useful documentation includes SEN review reports, any information from Health that supports a diagnosis or view of severity of learning disability, any assessment from an Educational or Clinical Psychologist.

If, in the Team Managers (ALDT) view there is still uncertainty a referral may be made to the Clinical Psychologist (Leaning Disability Service) to determine the young person's level of functioning.

If this assessment identifies that they meet the ALDT criteria the referral is accepted.

If the assessment identifies that the young person does not meet the ALDT criteria, the referral will be declined. It is acknowledged that the young person may well be considered as a vulnerable adult and will therefore be eligible for assessment under S47 Community Care Act once they have reached 18.

It is important to remember that other services such as Connexions also have a key role to play. See also the Transition Protocol for Physical Disability and Sensory Impairment.

Appendix Two / 4

PROTOCOL BETWEEN THE CHILDREN'S DISABILITY TEAM AND PHYSICAL DISABILITY AND SENSORY IMPAIRMENT TEAM CONCERNING TRANSITION

This protocol sets down the expectations and timescales for the transition of those young people that require services as an adult and fall within the criteria of the Physical Disability and Sensory Impairment Team.

It is important, for planning purposes, that information is shared with Adult Services regarding numbers of young people coming through. To assist in this the Team Manager, CDT, will maintain a database of young people open to the team who are aged 13 plus. This will then be shared with Adult Services as required.

For cases that are already open to a social worker in the CDT:

- Social worker/social work assistant to attend the SEN Transitional Review which starts at age 14.
- Social worker will form a view as to whether the young person is likely to meet the Physical Disability and sensory Impairment Team criteria.
- Social worker will identify when it is anticipated that the young person will leave full time education.
- If the young person is planning to stay in full time education till 18/19, and the social worker believes that they fall within the Physical Disability and Sensory Impairment Team criteria, a referral is to be made to the Physical Disability and Sensory Impairment Team at age 17.
- Case responsibility will remain with the CDT until the young person's 18th birthday. The role of the Physical Disability and Sensory Impairment Team worker is to undertake assessment and planning to enable appropriate resources to be identified for post 18 provision.

For cases that are not open to a worker in the CDT:

- If a request to attend an SEN Transition Review for a young person aged 14 is received the CDT Manager will need to consider the following:
 - 3. From the information provided does the young person fall within the criteria that would deem them as disabled? If yes, the CDT Manager would identify a worker to attend the Transition review. A full referral and assessment may be required to identify services required. Consideration would also be given as to whether a transitional worker is required.

4. If the young person would not be deemed as disabled then this decision would be passed to the school for inclusion in the Transition Review. No further action is required.

What information would be useful when completing the transition referral.

When completing the transition referral form it is important that the worker provides as much information as possible to assist in the determination of whether the criteria is met or not. Useful documentation includes SEN review reports, any information from Health that supports a diagnosis or view of severity of disability, any assessment from an Educational or Clinical Psychologist.

If the assessment identifies that the young person does not meet the Physical Disability and Sensory Impairment Team criteria, the referral will be declined. It is acknowledged that the young person may well be considered as a vulnerable adult and will therefore be eligible for assessment under S47 Community Care Act once they have reached 18.

The transition worker from the Physical Disability and Sensory Impairment Team will attend CDT Team Meetings when appropriate to support communication between the teams.

Appendix Two / 5 Transition to adulthood for young disabled people with 'complex health and support needs'

Although the term 'complex health and support needs' covers a wide range of impairments and conditions, young people with high levels of health and/or support needs experience some common difficulties in their access to services during their transition to adulthood. A review of research, consultation with six local authorities and interviews with young people themselves found:

- Increasing numbers of children with health and support needs are surviving into adulthood.
- Health and social services organisations generally have inadequate and incomplete information about the numbers of young people with health and support needs.
- Information about medical conditions, treatments and impairments was important to young people but they did not always receive the information they needed, or in ways which were useful to them.
- Young people who need high levels of support continue to be at risk of moving into segregated (institutional) accommodation as they reach adulthood.
- Young people sometimes lose contact with specialist healthcare services when they cease to use paediatric (children's) services.
- Some young people would benefit from health services specifically geared to transition to adulthood. However, there is very patchy provision of such services across the country.

Introduction

There are increasing numbers of young people who have a range of physical, sensory and cognitive impairments, many of whom also have continuing health care needs associated with their impairments. There are also young people who, while they do not have 'multiple impairments', have quite high levels of need in terms of continuing health care. Over recent years, children with conditions associated with poor life expectancy (such as cystic fibrosis) have been surviving into adulthood because of more effective interventions and better quality care.

These young people share a number of experiences, both in terms of their general transition to adulthood and their relationships with services. A key common characteristic is that they all require a combination of health and support services in order to access a good quality of life, and that existing services seem to find it a complex matter to meet their needs. The young people are particularly vulnerable to a failure of health and social services to meet their needs in the context of the transition to adulthood. This review identified a number of important issues

Inadequate information about the numbers of young people concerned and their needs One of the biggest problems facing planners is that local sources of information have varying ways of gathering data: health, social services, education and voluntary organisations work with different definitions of disability and health needs. There is no nationally agreed categorisation which applies across agencies. Another problem is that registers of disabled children and adults often do not allow for the identification of those with 'multiple impairments' or for those with continuing healthcare needs.

Most information gathered does not focus on the actual needs of the young people concerned. Instead planners tend to establish numbers of people who fall into various service categories (physical, sensory, learning disabilities, disabled children), diagnoses (e.g. cystic fibrosis, haemoglobinpathies) or eligibility criteria (banding according to levels of dependency).

Present systems for gathering information about the performance of health and social services organisations are not based on measuring the things which are important to young people themselves, such as: the provision of information about their condition; being able to go out with their friends; access to communication equipment for those who need it.

Access to information and peer support

Young people wanted accessible information, given directly to them rather than to their parents. Peer support was also important, particularly for those who required ongoing treatment and/or whose conditions were life-limiting. However, this support was not always available or recognised as important by service providers.

Education

Some young people interviewed had clearly been discriminated against in their access to education. A number were struggling with the legacy of poor standards of education and spoke of how they had not been given the opportunity for continuing with education and learning in the way they would wish.

Accommodation and support

People with high support needs face very few options other than some form of residential care because:

- there is a dearth of good quality services in community settings for people who have high support needs, particularly for those identified as having 'challenging behaviour' and those with continuing nursing care needs;
- a shortage of wheelchair accessible housing is still a major barrier to independent living for those with mobility impairments;
- the cost of providing the high levels of support that some young people need can mean that health and social services purchasers will look for 'economies of scale' and are reluctant to consider even small-scale group homes;
- while there has been progress in the provision of supported living projects for people with learning difficulties enabling them to live in 'ordinary' houses in the community these initiatives often do not cater for people who also have mobility impairments and/or health care needs.

Young people were interviewed who are effectively being 'warehoused' in residential provision: they have little opportunity for making friends, being involved in their local community, or doing anything meaningful during the day. To a large extent the scope for any personal development has ceased. Some of the young people placed in residential establishments have little or no continuing contact with their social services department. This includes young people like Jennifer, whose parents were just offered a list of residential establishments when she left school, and who only goes out when she attends a day centre twice a week or to visit her parents:

I only keep in touch with one friend from school. I'm not really happy with what I'm doing here, I want to go out more.

Some young people require housing and support services which are knowledgeable about and sensitive to issues relating to their particular impairments. One service provider interviewed talked of how important it was that those working with, for example, a young man with brain injury, who also had sickle cell anaemia, understand the consequences of these two conditions: 'If they don't know how to recognise and respond to his needs, his life expectancy will be shortened'.

Health

Many young disabled people cease to have access to specialist health services once they pass out of paediatric services. In recent years a few 'transition' clinics have been set up but the picture is still patchy across the country and many young people have the kind of experience described by Simon:

When you get to 16 they get rid of you. ... I haven't been to the hospital for a check-up since I was 16. I know I'm OK at the minute but a lot could happen. No one's mentioned to me what happens to my condition as I get older.

Most people with physical or sensory impairments and/or learning difficulties have the same kind of health needs as the rest of the population but they may also have some specific health needs related to their particular impairment or condition. There are a number of barriers to good quality health care - experienced in common by people with widely different impairments and conditions. For example:

- access to primary health care may be poor because the service creates barriers: for example, a GP may not take the time to understand someone with a communication impairment; one local authority reported how a group home for people with continuing health care needs found the local GP refused to allow them to register with him;
- one label gets in the way of recognising other needs: for example a failure to recognise sight problems for people with learning difficulties or, if recognised, failure to address them seriously;
- a lack of understanding amongst health care professionals about specific conditions: for example, young people with diabetes spoke of how general practitioners often had little knowledge about their condition, and they would prefer to attend specialist clinics.

Communication needs

Transition to adulthood can mean losing touch with the people who know how a young person communicates. Young people may need communication aids and it is not clear who is responsible for funding these or for their maintenance and updating. Many young people and their families are paying for communication equipment themselves or raising money through charities. There is confusion over whether social, health, education or employment services have statutory duties in this area. Young people may continue using the equipment they were issued with at school and not have access to updated technology and methods.

Access to employment and leisure opportunities

Young people talked about the barriers that get in the way of employment opportunities, including prejudicial attitudes held by employers about people with conditions such as cystic fibrosis. There is also evidence of disincentives to paid employment created by the means-testing of personal assistance (through social services charging policies and eligibility criteria for Independent Living Fund grants). Lack of transport and inadequate access to support were key barriers to young people going out and enjoying themselves. Michelle had hoped that moving into a bedsit attached to a residential home would give her greater freedom and ability to socialise than she had previously had, but unfortunately faced the same problems:

I was very isolated. Transport was a major problem - if you could get the vehicle you couldn't get the driver - 'we're short-staffed' ... Although I saw it [moving into the bedsit] as a new start, it hasn't been that - it's the same short-staffing, no transport and I still feel isolated.

Listening to young people

Young people interviewed stressed the importance of listening to them. As Charlotte said:

If anyone were to ask me what message I might have for others I would tell them that they should listen to, believe and respect young people. In my experience it is very difficult to tell anyone how you feel when they won't listen; if you aren't believed then you stop believing in yourself; if you're not respected then you lose your self-respect and everyone needs self-respect.

Young people had clear views on how organisations and professionals could do things better. All of the local authorities said consultation with young people was an area that could be improved upon: 'This is an area we need to develop', said one officer. What consultation there was tended to be with parents and to focus on services rather than on needs.

Conclusion

This review concerns a group of young people who have a wide range of conditions and impairments but whose common characteristic is that they all require a combination of health and

support services in order to access a good quality of life. There is evidence that many of these young people experience a failure of health and social services to meet their needs as they grow into adulthood.

A more integrated and needs-led approach to both commissioning and the provision of services is required. The current fragmentation in responses to their needs is not only caused by the divisions between health and social services but also by inadequate liaison with housing, leisure, education and employment services, and the experience of being transferred from children's to adult services within health and social services organisations.

About the study

The review was carried out by Jenny Morris, an independent researcher. She summarised what is known from existing research about transition to adulthood for young people with 'health and support needs'. Information was also gathered from six local authority social services departments about policies concerning this group, including joint work with health and education services. The report included material from 14 accounts by young people about their experiences and aspirations and 2 accounts by parents of young people who have significant learning and communication difficulties.

How to get further information

The full report, *'Hurtling into a void': Transition to adulthood for young people with complex health and support needs* by Jenny Morris, is published for the Foundation by Pavilion Publishing (ISBN 1 84196 001 2, price £16.95).

Click on the 'order report' icon in the left margin to order online.

Publication title:

NSF for Children, Young People and Maternity Services

Next Previous Contents

7.1 Assessment and planning for transition from child to adult services is often unsatisfactory. For many, there is a lack of co-ordination between the relevant agencies and little involvement from the young person. Some disabled young people are not transferred from children's to adult services with adequate care plans, resulting in their exclusion from adult services. In addition, some disabled young people experience a decline in the services they receive. This can lead to a regression in their achievement and/or deterioration in their condition. Disabled young people need high quality, multi-agency support to allow them to have choice and control over life decisions, and to be aware of what opportunities are open to them and the range of support they may need to access.

7.2 Disabled young people who are looked after have the same entitlement to care when leaving services as other looked after young people. They need a pathway plan setting out the services they will require to achieve their potential as young adults. See Standard 4

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

• Transition planning has as its main focus the fulfilment of the hopes, dreams and potential of the disabled young person, in particular to maximise education, training and employment opportunities, to enjoy social relationships and to live

independently. Transition plans take a person-centred planning approach, as described in Towards Person-Centred Approaches – guidance28, and which is consistent with the Special Educational Needs Code of Practice14.

• A multi-agency Transition Group is in place. This could be taken on by an existing group that has developed a multi-agency transition strategy. The group: a) Includes a Transition Champion from the Learning Disability Partnership Board;

b) Has representatives from Connexions Service, the local authority including social care, education and housing, the Learning and Skills Council, health, user representatives and voluntary organisations, and

c) Assumes responsibility for overseeing transitional arrangements at both strategic and operational level and for agreeing inter-agency protocols;

- Young disabled people aged 16 years and above are supported to use direct payments;
- Specific arrangements are made for managing the transition of those with high levels of need, those in residential schools/living away from home, looked after young people leaving care, and those with rare conditions;
- Agencies develop local strategies to widen education, training and employment opportunities for disabled young people, and
- Health services develop appropriate adolescent/young persons services with a view to enabling smooth transition to comprehensive adult multi-disciplinary care.

Transition to Adult Policy

Appendix Two / 6

ISLE OF WIGHT HEALTHCARE NHS TRUST FAMILY AND PRIMARY CARE SERVICES.

GUIDELINES FOR TRANSITION OF CARE FROM CHILDRENS TO ADULT SERVICES FOR PATIENTS WITH CHRONIC CONDITIONS

Dated October 2006

Author: Matt Powell – Children's Nurse Status: Draft 5 Version: 1 Review: October 2008

Children's Ward St Mary's Hospital Newport Isle of Wight NHS Primary Care Trust P030 5TG

1. <u>PURPOSE</u>

- **1.1** To provide guidelines to enable medical and nursing staff to smooth the transition process for young adults with chronic conditions between paediatric and adult care.
- **1.2** To provide information for the young adolescent and their parent(s) to allow them to develop a healthy relationship with adult medical specialties to ensure appropriate, timely and safe continuing care following discharge from paediatric services

NOTE: The word parent has been used throughout this document, but this also encompasses carers.

2. RATIONALE

- 2.1 In today's world of improved rates of mortality in many chronic conditions, many patients that previously were not expected to live into early adulthood are now surviving and some currently have minimal standards of healthcare from adult services, simply because adult healthcare teams have neither the knowledge of childhood disease aetiology nor sufficient data about long-term outcomes to allow progressive, patient centred healthcare plans to be made. This guideline has been developed to address this issue, allowing the young adult patient with a chronic condition time and a framework in which to develop a good working relationship with healthcare providers in primary and/or secondary care.
- **2.2** With today's emphasis on patient empowerment and the government addressing the issue of previous poorly addressed transition processes, there is a growing requirement for NHS Trusts to formulate a process of transition for these young adult patients with chronic conditions. This is backed by national government policy and local requirement. This guideline has been formulated as a result of these policies and local needs and the fact that there is no standard procedure within this trust for transition.

3. <u>SCOPE OF THE DOCUMENT.</u>

- **3.1** The target audience is all medical professionals involved in the care of young adults. This list includes medical consultants in both paediatric and adult medicine, GP's, nursing staff and any other specialist paediatric allied health professionals, and their adult counterparts routinely involved in the care of the young adult.
- **3.2** It should be noted that if an acute episode occurs whilst the young adult is going through the process of transition and the individual requires hospitalisation that they should be admitted to the Children's Ward under their paediatric consultant. They should not be admitted to an adult ward until the process of transition is complete.

4. BACKGROUND.

4.1 Young people aged between 10 and 20 account for up to 15 per cent of the UK's total population (Royal College of Paediatrics and Child Health, (referred to as RCPCH) 2003), and statistics suggest that numbers will grow by 8.5 per cent by 2011 (RCPCH, 2003). An increasing number of chronically ill children are surviving into young adulthood. With over 85 per cent of children with chronic illnesses (Betz, 1999) and 90 per cent of those with disabilities (Bloomquist et al, 1998) surviving into adulthood, there is a growing need for specialised care to ensure a seamless transfer and transition from Children's to Adult Health Care Services. There is also a need for greater attention towards transition within Mental Health Services for 16 to 18 year olds.

- **4.2** The transfer of young people from Child to Adult Services requires special attention. Evidence shows that a properly planned transition programme may result in better disease control and improved patient satisfaction. Currently, there is a lack of specific, discrete provision for transfer, never mind the longer process of transition for adolescents. Young people report feelings of being "dumped, cut off and abandoned" as they reach the transition period. (Shaw, Southwood, McDonagh, 2004).
- **4.3** Transition is a lengthy process and should continue on into adult care. The responsibility for ensuring effective transition does not stop at the point of transfer of the young person to a different consultant / GP. Joint multidisciplinary working is essential and longer consultation times are required for adolescents working through transition than in children's or adult clinics (RCPCH, 2003).
- **4.4** The National Service Framework (NSF) for Children and Young People (DH, 2003) recognizes that transition should be a guided, educational, therapeutic process, rather than an administrative event. Effective transition must also allow for the fact that adolescents are undergoing changes far broader than just their clinical needs. The full NSF (2004) attempts to cover transition in its broadest sense to include social care, education and employment rather than just within hospital services.

5. COURSE OF ACTION REQUIRED.

5.1 There is no set "right" time for transition of care. The Royal College of Paediatrics and Child Health state that: "Young people should not be transferred fully until they have the necessary skills to function in an adult service and have finished growth and puberty."

Transitional care planning must take into account:

- > The patient's disease severity
- > The level of medication compliance
- The psychological impact of moving from Children's to Adult Services and whether the patient is emotionally developed enough to interact with both primary and secondary Adult Services.
- > Self-ownership of patient's condition.
- An appropriate period of time in disease progression when the patient and clinicians feel it is safe to transfer them to adult services.
- **5.2** Identification of a key worker in the transition process is fundamental. This can be anyone from within the Multi-disciplinary Team, but the key worker must be able to identify, plan and prepare and ultimately educate the young person in the differences between paediatric and adult medicine. For this to be effective, an initial assessment of the young person must be carried out in order to ascertain base knowledge and any knowledge gaps, in order that these gaps may be filled.
- **5.3** Key qualities identified by the Royal College of Nursing that are considered to enhance transition between paediatric and adult services include:
 - > Leadership
 - Successful collaboration and cross boundary working
 - Resources
 - Acquisition of skills and knowledge
 - Robust documentation and appropriate administration

- **5.4** Training for the key worker needs to be supported by clear written guidance and should remain within the hospital setting.
- **5.5** There should be an agreement between young person, the key worker and the parent(s) to initiate the transition programme.
- **5.6** The transition process should follow the transition plan and transition flowchart as detailed below, utilising the "assessment of readiness" checklists

The transition programme must be continually reviewed. A debriefing session should be carried out once the transition process has been completed and allow for targets to improve the process to be developed.

- N.B. If a patient is treated within the hospital during the process of transition they should be seen by the paediatric team. Only once formal handover to an adult physician or GP has been completed should they be seen under the adult teams. After any period of treatment handback should be given to the appropriate medical discipline, not the medical team on take for the day of admission.
- 5.7 Reference needs to be made to the unique position the Isle of Wight NHS Primary Care Trust. Due to geographical and financial limitations many adult specialities do not exist within the secondary healthcare system. Therefore it is imperative that we use the excellent existing primary healthcare interface. It is envisaged that the care of many adolescents will be handed over to their GP at the end of their paediatric episode and the GP will refer to appropriate adult services.

6. <u>REFERENCES:</u>

Betz CL (1999) Adolescents with chronic conditions: linkages to adult service systems, *Paediatric Nursing*, 25, pp. 473-476.

Bloomquist KB, Brown G, Peerson A, Presler EP (1998) Transitioning to independence: challenges for young people with disabilities and their caregivers, *Orthopaedic Nursing*,May/June, pp. 27-35.

Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health, Bridging the gaps: health care for adolescents. <u>http://www.rcpch.ac.uk</u> (accessed 25 May 2005)

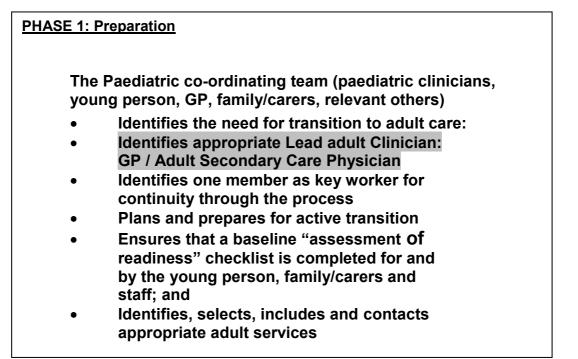
Shaw KL, Southwood TR and McDonagh JE (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a Delphi study. *Rheumatology* 2004 Aug;43(8): pp.1000-6

7. OTHER POLICY/DOCUMENTS TO READ IN ASSOCIATION.

- **7.1** Department of Health (2003) *Getting the Right Start: National Service Framework for Children. Standard for Hospital Services.* The Stationary Office 2003. London
- **7.2** Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health, Bridging the Gaps: health care for adolescents. <u>www.rcpch.ac.uk</u> accessed 6 June 2006
- **7.3** Bennett, D L, Towns, S J and Steinbeck K S (2005) *Smoothing the transition to Adult Care*. <u>www.mja.com.au</u> accessed 20 June 2006.
- **7.4** Viner R, Keane M (1998) Youth Matters: *Evidence Based Best Practice for the Care of Young People in Hospital.* Action for Sick Children 1998. London

- **7.5** Royal College of Nursing (2004) *Adolescent transition Care Guidance for Nursing Staff.* The Royal College of Nursing 2004 London
- **7.6** Department of Health (2006) *Transition: Getting it right for Young People.* The Stationary Office 2006. London.

Transition Plan:





The Key worker:

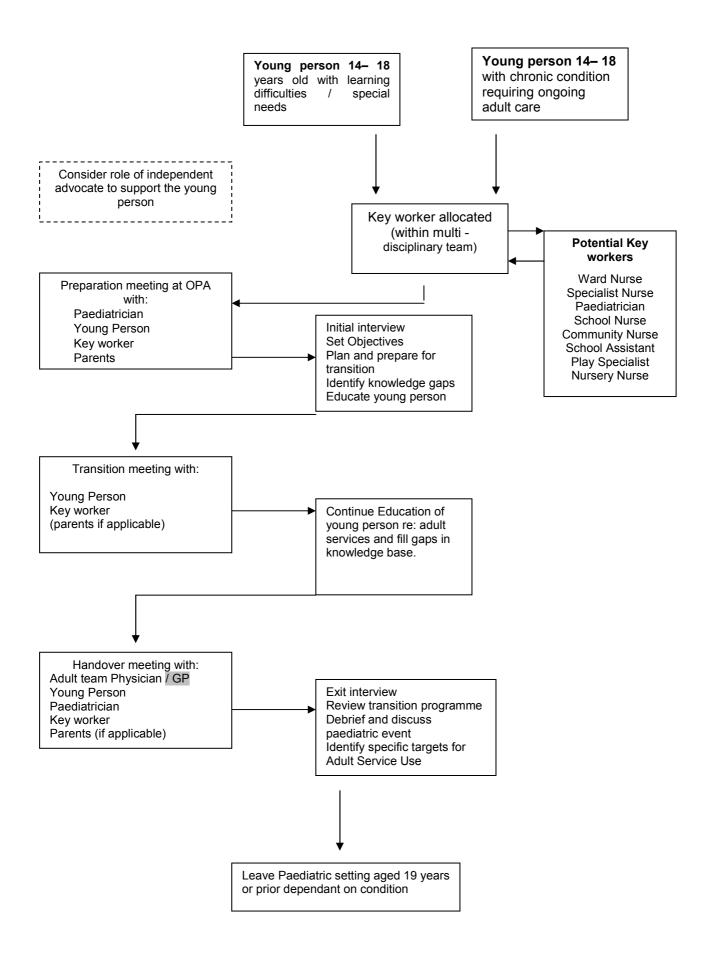
- Evaluates "assessment of readiness" checklist on an ongoing basis;
- Engages a combined paediatric and adult transition team in partnership with the young person and family/carers; and
- Ensures successful transfer to adult services

Phase 3: Integration

The Key Worker

- Ensures that transfer is completed and that care is integrated into adult services, including designation of a new case manager
- Evaluates quality outcomes; and
- Evaluates "assessment of readiness" checklist for indicators of success

Transition flow chart:



Defined Outcomes:

- Each young person requiring transition to adult services follows a pre-determined transition pathway, specifically tailored to their individual needs.
- Each individual young person moving through the transition pathway will have a single key worker as a point of reference throughout the whole process.
- A full evaluation of their transitional needs is carried out at the beginning of the transition process and an exit interview is carried out after handover to their GP / Adult Services to allow for a formal reassessment of whether these transitional needs have been met.
- Following completion of the pathway by a young person audit needs to be carried out at a period between six months and a year later to ensure the system is working and that the young person is continuing to engage with their GP / Adult services. This allows for evaluation of the care pathway and to keep a firm record of all patients that have undergone the transition process.

Interdisciplinary transition planning checklist and evidence record for:
ADDRESSOGRAM
Consultant
Named Nurse / Key Worker
Specialist Nurse
Dietician
Psychologist / Psychological Support
Community (e.g. GP)
Education (e.g. teacher / college tutor)
Other
Transition Process
Start date
Finish date

Assessment of readiness checklist 1

Patient No:

Name

Self Advocacy:

- Educate young person in describing their health condition
- Encourage young person to ask questions during each visit
- Encourage parents to participate
- Make sure young person knows how to access information about their condition, for example through support groups, the Internet or condition specific organisations
- Explain all the available adult care options
- Provide details of all relevant adult care providers, including the differences between paediatric and adult care

Action:

Evidence:

Signatures:

Date:

Assessment of readiness checklist 2

Patient No:

Name:

Independent health care behaviour:

- Make sure young person understands what medication they require, and discuss potential problems / barriers
- Ensure young person knows where to get help
- Make sure young person understands the principles of confidentiality
- Young person should maintain a personal health record to keep track of appointments, health information, medication, treatments and health care providers
- Ensure young person knows when and how to access emergency / medical help
- Young person meets with adult consultant / specialist nurse before discontinuing paediatric care

Action:

Evidence:

Signatures:

Date:

Assessment of readiness checklist 3	Patient no:	Name:		
 Psychosocial support: Give parents an opportunity to discuss for the future 	s their feelings about tr	ransition and any concerns		
 Talk to young person about friends and supportive relationships Encourage young person to join a social group, such as a club or youth group Encourage young person and parents to set positive goals Identify any need for assistance in personal care If young person's condition is potentially life-shortening, identify any need for help in dealing with this 				
Action:				
Evidence:				

Signatures:

Date:

Appendix Two / 7

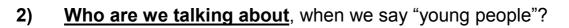
Easy Read - Transition to Adulthood Policy

(How we will help vulnerable children as they grow up)

1) What this is for

It is to make sure that all young people who need help from our services get that help when they need it and in a way that suits them.

We have to follow government policies and local procedures, and there are certain people we have to consult, but we will always involve the young person as far as possible in planning for their future.



In general we mean 14-25 year olds who need some kind of help from Health or Social Services as they grow from childhood to adulthood ("transition"). There are lots of different groups of people (agencies) who can help, and they all have their own rules about who they can work with and how.

3) Why we have written this

- 3.1) We want to make sure that each young person gets the care and help that is right for them, and that they feel we have taken their views into account.
- We want to recognise that young people are not all the same 3.2) and that they should be able to choose how they want to live their lives as far as possible.
- We want all the agencies to work well together so that, 3.3) as they become adults, young people:
 - stay safe
 - are healthy
 - can contribute to the community they live in
 - enjoy what they do and achieve their goals
 - have enough money to live on and are free from exploitation
- 3.4) We want people high up (who plan services) to know what young people really need, so that they put money into the right things.







4) <u>Who have we written this for?</u>

This policy is for all vulnerable young people growing into adulthood, and their carers.

5) <u>Key Ideas</u>

- 5.1) Young people and their carers will be helped to choose the kind of service they get.
- 5.2) Young people and their carers will be helped to express their views every time a decision is made about them.
- 5.3) Services must adapt the way they work to meet the needs of young people and their carers, if they possibly can.
- 5.4) Agencies must find a way of working together so that the "five outcomes" (in 3.3 above) can be achieved for every young person.
- 5.5) There must be one key professional who is responsible for transition planning with each young person. Everyone involved with that young person must agree who the key professional is, and this "lead responsibility" must fit with the rules laid down in a document called the 'Common Assessment Framework'.
- 5.6) When different agencies are working together, they can only share information that is really needed for the young person's transition plan to make sense.
- 5.7) Plans must be put into action in good time, because if people do not get services when they need them it can be very bad for them.
- 6) (Time line as previously)

7) Things that must happen

- 7.1) Services need advance warning of every vulnerable child who is approaching transition.
- 7.2) The "lead professional" must be chosen as early as possible.
- 7.3) The young person's needs must be assessed in the way that suits them best, and a "transition plan" put in place that they and their carers understand.
- 7.4) The transition plan must be clear to everyone involved, and must say clearly who will do what, and when. (Each agency has set times when they must do certain things.)
- 7.5) There must be a way of recording if things are happening for the young person as the plan says, and putting things right if not.







8) <u>In working together:</u>

- 8.1) We will focus on the hopes, dreams and potential of young people, as expressed by the young people themselves. No aspect of life should be off limits if the young person wants to consider it.
- 8.2) Those young people who are especially vulnerable (for whatever reason) must have specific and extradetailed arrangements made for their transition.
- 8.3) We will broaden the range of opportunities for young people growing into adulthood.



- 8.4) Adult Health Services will get information from Children's Health Services so that they can take over care smoothly.
- 7.6) A "Transition Group" from all the different agencies will meet regularly to check that this policy is making transition planning work for everyone.

APPENDIX TWO/8

Protocol for theTransitionPlanningProcess

For Young People

With Special Educational Needs / Learning Disabilities & Difficulties

SEPTEMBER 2006







Foreword

Transition planning is an important activity for young people to ensure a smooth transition between services and to help the young person move towards their longer-term goals.

Young people with Statements of Special Educational Needs have a wide range of needs and many young people need support from a range of agencies. The Transition planning process, therefore, needs to bring together these agencies' systems into a single protocol to ensure good co-ordination.

A multi-agency task group has developed the following Protocol. This task group's purpose is to improve the transition planning process on the Isle of Wight.

This work has resulted in the Protocol for the Transition Planning Process for Young People with Statements of Special Educational Needs. The Protocol builds on the statutory framework for agencies.

Signatories for Agency:

Index

1.0	Introduction		
2.0	Summary of Transition Planning		
3.0	Information and Advice to Parents / Carers		
4.0	Information and Advice to Young People		
5.0	Procedure for Notification		
6.0	Key Responsibilities and Actions of each Agency		
6.1	 Responsibilities of LA and/or Schools 		
6.2	 Responsibilities of Social Care Services 		
6.3	 Responsibilities of Connexions 		
6.4	 Responsibilities of Health 		
6.5	• Responsibilities of the Learning and Skills Council		
6.6	Responsibilities of Housing Services		
7.0	Strategic Planning		
Appendix A	Transition Plan		
Appendix B	Transition Policy for young people with disabilities moving from Children to Adults services		

1.0 Introduction

This document has been produced by the Isle of Wight Transition Group.

This is a locally agreed interagency protocol based on acknowledged good practice.

Text in boxes indicates a statutory requirement

This protocol has been written against a background of considerable change in this area of work. The following pieces of legislation have influenced this protocol:

- Chronically Sick & Disabled Person Act 1970
- Disabled Persons (Services, Consultation and Representation) Act 1986
- National Health Service & Community Care Act 1990
- Education Act 1996
- Learning and Skills Act 2000
- Children (Leaving Care) Act 2000
- Carers & Disabled Children Act 2000
- Special Educational Needs and Disability Act 2001
- Code of Practice on the Identification and Assessment of Special Educational Needs (DfES) 2002
- Homelessness Act 2002
- Disability Discrimination Act 1995 (Amendment) 2003
- Children Act 2004
- National Service Framework for Children, Young People & Maternity Services Care Standards 2004.

Legislative Framework explained

The Education Act 1996 and Code of Practice require that, for all children with a statement of special educational needs, the Local Authority Children's Services (LA) ensures that the Year 9 annual review includes a focus on planning for school leaving and draws up a Transition Plan which is reviewed at subsequent annual reviews. This responsibility rests with the school under the new Code of Practice. The LA must involve other relevant agencies, including the IOW NHS Healthcare Trust, IOW Council departments, Connexions and the Learning and Skills Council (LSC) in the transition planning process where appropriate. Section 5 and 6 of the Disabled Persons Act 1986 require the LA to seek an opinion from the Social Care Services as to whether a young person with a statement is disabled, as defined in the Act, and, if they are, the LA must inform Social Care Services of their expected school leaving date. Social Care Services must then offer the young person an assessment of their needs before they leave full time education. Various pieces of legislation (e.g. National Health Service and Community Care Act and Chronically Sick and Disabled Person Act) place a duty on Social Care Services to provide services for disabled people. These services should be provided following the assessment of need under the Disabled Persons Act 1986.

This protocol is intended to ensure that all agencies, which have a role in supporting young people as they prepare to leave school, are able to make an effective contribution to the transition planning process. The protocol aims to ensure that relevant agencies are involved at the start of the process so that the young person, their parents/carers and the agencies themselves are clear what the specific responsibilities of each agency will be at each stage of the process. The protocol explains the roles of the LA, schools, LSC, Health, Connexions, Housing and Social Care Services in working together to support young people with special educational needs in the transition from childhood to adulthood. The process of transition planning should start when the Young Person is in Year 9, that is the school year in which the Young Person has their 14th birthday. The protocol will need regular review as the statutory framework and best practice is constantly changing.

Produced October 2006.

2.0 Summary of Transition Planning

The annual review of the statement in Year 9 must also include the completion of a Transition Plan and it is the drawing together and implementation of this plan, which is the focus of this protocol. The Transition Plan identifies:

- The young person's aims and aspirations for the future
- The options which are available to the young person after leaving school
- The support the young person may need as they prepare to leave school and when they have left
- The support carers need to continue in their role.

The aim is to ensure that the young person and their parents/carers have a central role in this process.

A recommended format for the Transition Plan is attached as Appendix A to this document.

The LA, Health, Connexions and Social Care Services undertake in consultation with the young person and his or her parents to:

- Contribute to the Transition Plan
- Assess the needs of young people likely to require support
- Provide information for annual review meetings about the young person's needs
- Attend the Year 9 annual review meeting where the young person is considered likely to need support after leaving school and subsequent annual review meetings where appropriate
- Inform the young person, his or her parents and other agencies of the support that will be available as the young person prepares to leave school and beyond
- Make provision to meet the assessed needs of young people during the transition period
- Involve Further Education providers in this process.

3.0 Information and Advice to Parents/Carers

Schools will involve parents/carers in the transition planning process as key participants.

Parents/carers will be encouraged to express their expectations of their child's adult life, how they can help their child develop new skills and what their own needs are as carers.

The Connexions Manager will arrange for the parents and carers of young people with Statements of Special Educational Needs entering Year 9 to be sent copies of a leaflet, introducing them to the transition planning process.

The parent partnership scheme offers a source of impartial advice and support to parents to enable them to understand and participate in the transition process.

The school will organise evenings for young people and their parents/carers to find out about their options post 16 and develop links with relevant local providers.

Providers of post school provision will hold open events to encourage parents to become more familiar with the available options.

Parents can request a Carers Assessment under the Carers Act when assessing the young person's needs. However, the Core Assessment /Short Term Break Assessment incorporated the carer's needs automatically.

4.0 Information and Advice to Young People

Young people themselves will be treated by all agencies as central to the transition planning process. All young people will be supported in expressing their views and aspirations for the future and services will work with them to realise these.

The school should ensure that the young person is well prepared for the first transition-planning meeting.

Young people, as appropriate, will be supported to attend link courses and/or open events in local post school provision.

Young people in transition will have opportunities to view options to meet their needs and aspirations.

An advocacy service is available for young people with disabilities to assist in this process.

5.0 Procedure for Notification

The LA will notify schools, Health, Social Care Services, and Connexions of young people due a Year 9 review, including those educated off the Isle of Wight, and those in subsequent years whose transition plans are due for review.

Notification containing the following information will be sent out by a Special Needs Officer (Review and Monitoring) in the summer term of year 8:

- Name of young person
- Date of birth
- Home address and telephone number of young person
- Name of school
- Type of school
- Details of any current joint funding arrangements
- Category of special educational need and profile of need
- Whether the young person is regarded as disabled by Social Care Services
- Expected school leaving date
- A copy of the young person's most recent review

Where a young person with a statement of special needs moves into the authority during Year 9 or beyond, the LA will notify colleges in the area, Health, Social Care Services and Connexions and send the information above.

In addition, the LA will remind all schools that at the Year 9 review and subsequent reviews the need to invite representatives from:

- Social Care Services
- Health
- LA
- Connexions

6.0 Key Responsibilities and Actions of Each Agency

6.1 Responsibilities of LA and/or Schools

It is the responsibility of the LA and schools to:

•	Arrange the Year 9 review meeting and invite other agencies where appropriate
•	Ensure that the Year 9 review meeting focuses on beginning to establish a Transition Plan
•	Produce and update the Transition Plan in consultation with the young person, their family and other agencies where appropriate
•	Make provision to meet the young person's educational needs

It is the responsibility of the LA to:

- Ensure that the correct procedures are followed
- Ensure that other agencies are aware of and invited to contribute to appropriate reviews
- Ensure there is consistency in terms of the standard and quality of service families receive
- Identify unmet need to inform strategic planning
- Ensure a representative attends all transition planning meetings in Year 9 and at subsequent reviews where necessary
- Fulfill any functions that cannot be delegated to the school for young people educated outside of the area
- Send a Year 9 cohort profile to the Learning and Skills Council (LSC) in the summer term of Year 8 and co-operate with the LSC strategic planning processes

Action to be taken by schools (including Pupil Referral Units etc.)

Arranging the Year 9 review meeting and subsequent annual review meetings,

- a) The school should check with the family and young person whether there are any other agencies or individuals who they feel it would be helpful to involve in the review.
- b) The school will arrange the review meeting with at least one term's notice to facilitate interagency planning, where possible.
- c) The school will ask agencies who are invited to the review meeting to submit any relevant information about the young person
- d) The school will invite:
 - The young person and their parent(s)/carers

- The LA representative
- Other agencies as indicated by the LA and the school's knowledge of the young person's needs and circumstances
- The young person's Connexions personal adviser
- The young person's advocate where one is involved
- The independent parental support as appropriate

e) The school will circulate copies of any information provided to agencies invited to the review meeting 2 weeks before the meeting

- f) Following the Year 9 review meeting, the school will produce a Transition Plan and send a copy to the LA, and to other agencies involved with the young person. The LA has a responsibility to accept and review the plan
- g) The Transition Plan will be reviewed at subsequent annual review meetings. The school will amend the Plan where necessary and send a copy of the latest Plan to the LA and to the other agencies involved with the young person
- h) The school will notify the LA of the proposed school leaving date of all young people with statements of special educational needs.
- i) The school will identify a member of staff who will work with the young person to:
 - Help them identify their goals and aspirations
 - Prepare them to contribute to the transition planning process including participation in review meetings
- j) The school will organise evenings for young people and their parents/carers/supportive others to find out about their options post 16 and develop links with relevant local providers

k) The school will, in partnership with the Connexions Service, develop links with local providers and where relevant and appropriate will ensure they are invited to attend transition-planning meetings.

6.2 Key Responsibilities and Actions of Each Agency

It is the responsibility of Social Care Services to:

•	Identify whether the young person is likely to need support from Social Care Services now or in the future when he/she leaves school
•	Decide at what stage Social Care Services will become involved and indicate what support is likely to be available
•	Inform the Education Department whether the young person is eligible to be registered or is registered disabled and ensure that all are offered an assessment of their needs before finishing full-time education
•	Make provision to meet the needs of young people in accordance with the legislation

• Ensure there are robust procedures for the transfer of responsibility from Children's Services to Adult's services.

Action

a) Social Care Services will designate a local transition co-coordinator if eligible at 16. This local co-coordinator is responsible for ensuring appropriate action is taken for all the young people due Year 9 reviews. He/she must also ensure that the young person's school is informed of the decisions made so that Social Care Services' role can be included in the Transition Plan.

b) All disabled young people must be offered an assessment of need by Social Care Services before leaving full-time education.

c) For young people who are likely to require Social Care Services support in

Adult life, the Adult Team should be represented at the annual review

preceding transfer of the case.

Social Care Services' contribution to the Transition Plan could be summarised in one of three ways:

- To have no involvement
- To take specified action now
- To make an assessment of need at a future (specified) date, e.g.18 months before school leaving date.

d) An assessment must involve an Occupational Therapist (OT) where necessary.

e) The local co-coordinator will ensure there are robust links with the Sensory

Impairment Teams/s.

f) Social Care Services will have a clear protocol (Appendix B) for the transfer of responsibility from Children's to Adult services that:

- Can be clearly understood by young people and their parents/carers
- Ensures that Adult Services participate in the assessment process for those young people who are going to need significant Community Care Services as adults.

6.2 Responsibilities of Connexions

The Connexions Service provides an information, advice, guidance and support service to all young people, aged 13-19 (up to age 25 for young people with learning difficulties and disabilities).

The Special Educational Needs Code of Practice 2002 has given the Connexions Service particular responsibilities for young people with Statements of Special Educational Needs. In addition, the Learning and Skills Act 2000, Section 140, requires the Connexions Service to undertake assessments of the education and training needs of young people with learning difficulties and disabilities, with or without statements, in their final year of education, and up to age 25.

Connexions Personal Advisers work with young people with learning difficulties and disabilities, and their families, to:

- Identify and help meet their needs
- Help them to be engaged in education, training and employment
- Help them to move successfully into adult life.

The local contact for the Connexions Service is the Connexions Manager.

Action

The Connexions Manager will provide to the Special Educational Needs (SEN) Officer of the LA details of the deployment of Personal Advisers to mainstream and special schools.

The Connexions Manager will arrange for the parents and carers of young people with Statements of SEN entering Year 9 to be sent copies of a leaflet, introducing them to the Transition Planning process.

The Connexions Manager will agree the work to be undertaken by the Connexions Service in schools with Head teachers and this will be described in Partnership Agreements.

In the Summer Term, the Personal Adviser and school SEN co-coordinator will meet to:

- Agree dates for Annual Review and Transition Planning meetings
- Identify all the young people in Year 9-11/14, attending the school with special educational needs in the next academic year to ensure that the Personal Adviser has adequate information, for advice and guidance and planning processes.

Further meetings should be held on a termly basis to review progress of individual young people and to agree amendments to the programme of Annual Review and Transition Planning meetings.

Connexions contribution to Year 9 Annual Review and Transition Planning meeting.

The Personal Adviser must be invited by the school and must attend. The Personal Adviser will arrange to meet the young person and, ideally, the parent or carer, prior to the meeting.

Once the Transition Plan has been produced, the Personal Adviser has the responsibility for overseeing its implementation and co-coordinating its delivery. There will be circumstances where it is not possible or appropriate for the Personal Adviser to ensure delivery e.g. where delivery of parts of the plan depends upon the budgets of other agencies.

Connexions contribution to subsequent meetings

The Personal Adviser should be invited to all subsequent Annual Review and Transition Plan meetings and attend where appropriate, especially at the 'final review'.

Attendance at Year 9 and subsequent meetings held for young people attending schools outside the area will be agreed with the 'host' Connexions Service. The Personal Adviser will seek to attend the 'final review'.

Contact with the young person will be maintained through regular meetings during school holidays.

The Personal Adviser's role from Year 11 onwards

The Personal Adviser should undertake with the young person, a Section 140 Assessment in the final year, if the young person is likely to take up post-16 education or training. This assessment will describe the young person's education and training needs and the provision required meeting them.

The Personal Adviser will work with the young person to identify and obtain suitable education, training or employment opportunities. This will include supporting applications to the Learning and Skills Council for funding for specialist provision.

Liaison with 'host' Connexions Services will be maintained for young people attending schools outside the area and they will be responsible for the completion of a Section 140 assessment.

6.4 Responsibilities of Health

It is the responsibility of the Primary Care Trust to:

- Identify whether the young person is likely to continue to have health care needs when s/he leaves school
- Ensure that arrangements are put in place to enable the young person's health care needs to be met when s/he leaves school.

Action

Preparing a medical report

- a) In year 8 the Community Paediatrician will contact the family of a child with a statement, which includes a medical need. This is to offer an appointment to prepare a medical report for that young person when in Year 9. In addition, young people, their parents or the school may request a medical report if a medical problem is causing worry.
- b) In order to prepare a medical report, the Community Paediatrician may need to conduct an upto-date medical examination and arrangements for this will be made. The Community Paediatrician will co-ordinate reports from therapists and other specialist doctors regularly involved with the young person.
- c) If the child attends an "out-of-city" school, the Community Paediatrician may ask the school to obtain a medical report directly from the school's doctor.
- d) The Community Paediatrician will seek, where possible the young person's permission or parent's permission before sharing medical information about the young person with the school and other agencies.

Attending the Year 10 review meeting and subsequent annual review meetings

a) If the young person will require health care support as they prepare to leave school and beyond, the Community Paediatrician or other Health Professional will attend the Year 10 review meeting if invited by the end of the preceding term.

6.5 Responsibilities of the Learning and Skills Council

The Learning and Skills Council (LSC) is responsible for the funding and planning of Post-16 education and training (except Higher Education). For most young people with a learning difficulty and/or disability it is likely that a post-16 course of further education or a training opportunity will be available in the local community, either at a Further Education College, maintained school with a sixth form, a special school with post-16 provision or a Work Based Learning Provider.

Action

The LSC works with its partner organisations to ensure that, wherever possible upon leaving school, young people have the opportunity to continue their education and training locally.

For those young people whose education and/or training needs cannot be met locally there is a network of national independent specialist colleges. These can provide education and/or training courses, with residential provision. The process for requesting that the LSC consider funding a placement at an independent specialist college and the criteria by which such requests are assessed is outlined in 'Funding Guidance: Placement for Learners with Learning Difficulties and/or Disabilities at specialist colleges' and is available on the LSC web site (www.lsc.gov.uk).

6.6 Responsibilities of Housing Services

Isle of Wight Council offers a range of housing and related services for people with learning disabilities. Access to social housing on the island is primarily through the Isle of Wight Housing Register, which is used to allocate properties, owned by the Isle of Wight Council (IWC) and local registered social landlords (RSLs), to applicants.

The Homelessness Act (2002), which amends the Housing Act (1996), requires local authorities to assess whether applicants are "eligible, unintentionally homeless, and in priority need". The Act ensures that people deemed vulnerable due to a disability are considered to be a priority. IWC therefore has a statutory duty to re-house vulnerable applicants where they are also deemed to be eligible and unintentionally homeless.

In terms of the type of housing available, both IWC and local RSL's have a range of properties specifically adapted for people with care and support needs, while properties can also be adapted to suit

the needs of applicants in some cases. In the private sector, Disabled Facilities Grants are available to enable adaptations to be made to properties to ensure that people are able to live safely in their own homes.

Action

- a) Housing Options and Social Services will jointly assess applicants with learning disabilities applying for re-housing. If it is decided that the applicant's learning disability means that they need to be re-housed, their application will be given higher priority through the "banding" system. This system classifies applications for housing according to the type of need. In this case, there is a "Health, Care, and Support" banding, which ensures that applicants with care and support needs are allocated a certain proportion of available properties.
- b) Where support is needed to enable people with special needs to live independently, services funded by the Supporting People programme can be provided. On the Isle of Wight, there is a range of such services available, aimed specifically at people with learning disabilities. The programme currently funds services with combined capacity for over 100 people in the city, either in supported housing schemes, or through the provision of "floating" support services, where support is delivered in the service users' own home. However, it should be noted that many of these services only accept referrals from Social Services.

7.0 Strategic Planning

There is a lot of information about the needs of the cohorts coming through the system.

An annual planning forum through the Transitions Group will consider the overall needs within the Island of changing patterns of need indicated by the cohort data and the need to develop provision to meet those needs. The forum will also consider information about young people's aspirations as they become expressed.

Appendix A - TRANSITION PLAN

Transition Plan

The Annual Review in Year 9, and any subsequent Annual Reviews until a young person leaves school, must include the drawing up, and subsequent review of a Transition Plan. The Transition Plan describes what needs to be put in place to ensure an effective transition to adult life. The Plan will be shared with other people who support transition to help make sure it works.

Section 1: Personal Details

Name:	DOB:						
Address:							
Telephone:							
National Insurance number (if I	known):						
Unique Pupil Number (if know	n):						
Name of parents/carers/person	responsible:						
School:							
Year group (please tick at each	review):	9	10	11	12	13	14
Expected school leaving date:							
Looked after young person:	Yes/No						

List of key people supporting transition:

Name	Contact details

Section 2: Vocational and Additional Education

This is a consideration of the young person's developmental needs in vocational and additional curricular planning and also the arrangements for post-16 education/employment/training.

What(please complete name) wants to do:

Aims	By When

Summary of key issues to be addressed during transition:

Issue(s)	Raised by

Objectives/targets:

Action	By whom	By when	Review date

Section 3: Personal and Social Skills

This is a consideration of what will be necessary to help the young person work towards personal, social and independence skills and take up a role in the community.

Summary of key issues to be addressed during transition:

Issue(s)	Raised by

Objectives/targets:

Action	By whom	By when	Review date

Section 4: Health and Welfare Needs

This is a consideration of the special health and welfare needs that will require planning and support now or in the future.

Summary of key issues to be addressed during transition:

Issue(s)	Raised by

Objectives/targets:

Action	By whom	By when	Review date

Section 5: Additional support arrangements

Practical and technological help required:

Practical help required (adaptations, aids or general support during the transition period)	Reasons
	D
Technological aids required and training needs (record provision for securing technological support on transition)	Reasons
	Reasons
	Reasons
	Reasons

Additional	professional	support required:	
------------	--------------	-------------------	--

Which local services could provide relevant information, advocacy and advice if required?	Services required
Which new professionals need to be involved in planning for transition?	Services required

Head teacher signature:	Date:
Young person signature:	Date:
Connexions Personal Advisor signature:	Date:

ISLE OF WIGHT COUNCIL CHILDREN'S SERVICES DEPARTMENT

Procedure Number:

Title: Transition policy for young people with disabilities moving from Children's to Adults Services

Date of Issue: October 2006

Appendix A

CHILDREN'S SERVICES TRANSITION PROTOCOL: CHILDREN TO ADULT SERVICES

At 14 years:

On a previously unknown case, the Referral and Assessment Team receives information about a young person with care needs that continue from Education and refer to CDT. A negotiated assessment will take place either by R&A or CDT.

Where a child or young person is already allocated to a Social Worker and the relevant assessments have been undertaken the Team Manager for CDT will pass information to Adult Services to ensure long term identification of young people needing transition services are identified, through regular 2 monthly meetings.

The Children's Disability Team will send information on the Children with Disability Register to the family. If appropriate and with the family's consent the child's name will be entered on the register.

At 16 years:

The Children's Disability Team will inform the Adult Learning Disability Team, the Physical Disability Team and the Sensory Impairment Team of young people who have high level or complex needs. The team managers will discuss each referral individually, and agree a joint plan for managing the care of that young person until they are 18 years of age.

An adult care manager will be nominated to work alongside the child care social worker during this period. This could mean attendance at meetings such as reviews, it could mean giving information about adult services. A copy of all reviews will be sent to the nominated care manager whether or not they attended.

At 18 years:

The Adult care manager will take full case responsibility for the young person at an appropriate juncture around their 18th birthday. If the young person is to remain in full time education then the Child Care Social Worker will continue until the end of that academic year. The date to be agreed between Children and Adult Services, and made explicit in writing for each young person, their carers, and all relevant agencies as appropriate.

Throughout this process:

No decision will be taken to commit resources into adulthood without the agreement of the care manager and their manager.

Generally:

The Team Managers in Adult Services and Children's Services will meet every 2 months to monitor this process, ensure its smooth implementation on an individual care basis.

APPENDIX TWO/9

Guidelines for the Transfer of Clients from 'Get Sorted' Young Persons Substance Misuse Treatment Service to Adult Substance Misuse Treatment Services

The aims of these guidelines is to ensure a smooth and seamless transfer of care for a young person (under 19 years of age), receiving substance misuse treatment from ' Get Sorted' to an Adult (over 19 years of age) substance misuse service.

Identification of Young Person

1. At least 2 months prior to reaching the age of 19 it should be identified if the young person under the care of 'Get Sorted' will need continuing treatment and intervention from substance misuse services.

- a) If it is identified and expected that the continuing treatment required will be short-lived, i.e. 6-8 weeks past the age of 19 then for continuity of care and maintenance of therapeutic relationship it should be expected for this person to continue to be treated under the care of 'Get Sorted', until discharged.
- b) If it is identified that the young person will need longer-term treatment and interventions, then the transfer procedure should be implemented in order to ensure a smooth transmission of the young person to the adult services.
- 2. When it is identified that a young person will need continued treatment and interventions, a multi-agency assessment and referral form should be completed and forwarded to the appropriate adult treatment centre. Accompanying this should be a letter to the team giving an outline of the clients situation and perceived future needs and in addition a request for contact from the identified keyworker from the adult services, in order to establish some joint appointments (please see example letter appendix a).
- 3. Following contact from the identified adult keyworker, joint appointments should be made to visit the young person at their home or choice of venue. The quantity and frequency of these visits should be agreed with the young person, taking into account their individual needs.
- 4. Following these visits, further joint appointments should be made with the adult keyworker at the adult treatment centre or monitoring

clinic. The young person should be transported to and accompanied during these appointments by the 'Get Sorted' worker. Again, the number of these joint appointments required are of an individual nature and should be agreed with the client.

- 5. After the joint appointments at the adult treatment service, following appointments can be made with the 'Get Sorted' keyworker, transporting the young person to the venue but not accompanying the young person in the appointment (this is to ensure that the young person is confident in making their own way to the said appointment).
 - 6. Following the last contact with the client, a letter should be sent to the clients GP informing them of change of keyworker and transfer to adult service, with any additional information as deemed necessary. It may, with the clients' permission, also be necessary to inform other agencies involved in the young persons care.

SAMPLE LETTER

Ref: Client caseload number

Date:

Team (i.e. Cranston / IDAS)

17, Melville Street Ryde Isle of Wight

Dear Team,

Re: Name:, d.o.b: Address:

This young man for whom we are prescribing subutex / methadone has now reached the age of 19 and thus will need to be cared for by your team.

As in the normal manner, I would be willing to facilitate some joint appointments in order to assimilate (Name of Client) into the adult services and as a way of introducing her to her allocated key worker.

If you could contact me at 'Get Sorted on 01983 533474 in order to arrange the smooth transition of (name of client) to adult services, I would be most grateful.

Yours sincerely,

'GET SORTED' TIER 4 PROTOCOL FOR PLACEMENT CRITERIA

A tier 4 placement may be sought in-order to meet a young persons treatment needs. It is imperative that this is seen in the context of an intervention plan, as if an individual requires this level of intervention there will need to be some anticipation of need on completion of such intervention and how this might be met. Please see guidance below:

Key factors

One of the following Assessment revealing established:

- 1. Chaotic poly-drug use
- 2. Mental health problems with significant problematic substance misuse.
- 3. Poor physical health related to significant problematic substance misuse.
- 4. High risk behaviours related to significant problematic substance misuse.

Plus

History demonstrates needs

- 1. Tier III is insufficient at this time.
- 2. Client requires/requests time out of environment and this is identified as part of a structured treatment programme.
- 3. Where residential care/treatment is being requested: there is no other appropriate provision that can be established.

Plus

*Available services

It is important to ensure that appropriate provision/support is provided to those moving through TIV placement. It is vital that there is sufficient support to those returning to the community as risk is increased if appropriate care structures are not in place at this point: For example in cases of detoxification there can be an elevated risk of overdose; individuals may be more sensitive to dysfunctional areas of their lives.

1. An appropriate care structure is available (e.g. care planned thru care, linking with Tiv provider) for return. This will ideally include a named acre coordinator or keyworker.

* Service that would normally be expected to provide a service in the locality of a given individual (this does not relate to in-house TIV services, though a given TIV service may provide an important link with local/community providers as part of the care package).

Appendix A

Our Ref:

Date:

Team at (Cranstoun / IDAS) 17, Melville Street Ryde Isle of Wight

Dear Team,

Re: Name of Young Person d.o.b. Address:

This young person for whom we are prescribing Subutex / methadone has now reached the age of 19 and thus will need to be cared for by your team.

As in the normal manner, I would be willing to facilitate some joint appointments in order to assimilate (name of young person) into the adult services and as a way of introducing her to her allocated key worker.

If you could contact me at 'Get Sorted on 01983 533474 in order to arrange the smooth transition of Honey to adult services, I would be most grateful.

Yours sincerely,

Young Person's Substance Misuse Service 'Get Sorted'

ANNEX 1 TRANSITION PLANNING – THE NATIONAL CONTEXT

This annex summarises key points form legislation and strategy papers relevant to transition for young people with special educational and/or complex needs. It is not a full summary of the legislation

The Disabled Persons (Services, Consultation and Representation) Act 1986

- Places a duty on LEAs to seek information from social services departments as to whether a young person with a Statement is disabled and may require services from the local authority when leaving school
- Social Services have a duty to offer an assessment of needs, but not to provide services

The Education Act 1996

- States that a child with Special Educational Needs should normally be educated in a mainstream as long as this is compatible with:
 - His receiving the special educational provision which his learning difficulty calls for
 - The provision of efficient education for the children with whom he will be educated, and
 - The efficient use of resources
- Places duties on school governors in respect of pupils with special educational and/or complex needs

Subsequent legislation relating to pupils with special educational and/or complex needs builds on this legislation. <u>www.hmso.gov.uk/acts/acts1996/1996056htm</u>

The Learning and Skills Act 2000

- Places a power and a duty on the Secretary of State, through Section 140 of the Act, to make arrangements for the assessment of young people with LDD when they are undertaking or likely to undertake post –16 education or training or higher education. Connexions Partnerships will deliver this responsibility
- Requires the LSC to have regard to the needs of persons with LDD and to any report of an assessment carried out under Section 140

• Sets out the reasons for seeking a specialist residential placement <u>www.legislation.hmfo.gov.uk/acts/acts2000/20000021.htm</u>

Valuing People: A New Strategy for Learning Disability for the 21st Century March 2001

- Sets out the new vision for services under the four key principles of Rights, Independence, Choice and Inclusion
- Highlights the issues young people face in transition and sets an objective "As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment."
- Highlights the role of Connexions, including their responsibilities to young people up to the age of 25
- Describes the responsibilities of Learning Disability Partnership Boards for:
 - Establishing frameworks for Person Centred Planning which will build on the assessment and planning work undertaken by Connexions
 - o Identifying a person with lead responsibility for transition
- Notes the importance of continuity in health care

• Sets an objective "To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work" www.archive.official-documents.co.uk/document/cm50/5086/5086.htm

The SEN Code of Practice

- Describes the annual review process from Year 9 and the place of the transition plan within that process
- Describes the responsibilities of Connexions who
 - Must attend the Y9 review and should attend the Y11 review
 - Are responsible for overseeing the delivery of the Transition Plan; the PA should co-ordinate its delivery
 - \circ Should be involved in the transfer of information
 - Must ensure a S140 assessment is carried out
- Describes the role of Social Services and Health
- Acknowledges that young people with special educational and/or complex needs who have not required a Statement may require support in transition
- Says that there should no be a separate action plan and transition plan and that the Pathway Plan, Transition Plan and Connexions Personal Action Plan should be the same document
 www.teachernet.gov.uk/sen/documents/SENCodeOfPractice.pdf

The Special Education Needs and Disability Act (SENDA)

- Amends both the Education Act 1996 and the Disability Discrimination Act 1995
- Applies to pre and post 16 education

- Makes it illegal to treat a disabled person less favourable than a non-disabled person for reasons related to his/her disability, without justification
- Requires institutions to make reasonable adjustments to ensue that a disabled student is not placed at a substantial disadvantage

N.B. HE and FE institutions and Youth Services are covered by SENDA. Other providers of services including training providers and Connexions Services are covered by Part 3 of DDA, which has similar requirements and makes it illegal to discriminate against a disabled person for a reason relating to their disability.

www.hmso.gov.uk/acts/acts2001/20010010.htm www.disability.gov.uk/dda

Every Child Matters

- Sets out to ensure that children at risk are properly protected within a framework of universal services, which support every child to develop their full potential
- Sets out a vision for early intervention and effective protection which includes improving information sharing, establishing a common assessment framework, identifying lead professionals
- Anticipates the SEN Action Programme Removing Barriers to Achievement
- Says that it will improve the transition to adulthood through the National Service Framework for Children, the SEN Action Programme and the work of Connexions
- Was followed with a consultation and "Next Steps" paper

www.everychildmatters.gov.uk

The Children Act 2004

- Sets the legislative foundation for the actions agreed as a result of Every Child Matters
- Includes provision for the establishment of a Children's Commissioner and for each children's service in England to make arrangements to promote co-operation between the authority, its partners and other appropriate bodies to improving the well-being of children in the authority's area relating to areas which include education and training
- States that arrangements made may apply to the 19-25 age group who have a learning difficulty and are receiving services under the Learning and Skills Act
- Sets out a mechanism for establishing a database and sharing information

www.hmso.gov.uk/acts/acts2004/20040031.htm or www.everychildmatters.gov.uk

Every Child Matters: Change for Children 2004

• Sets out the action that needs to be taken locally to implement the Children Act, and describes the support that will be provided

www.everychildmattes.gov.uk

Removing Barriers to Achievement – The Government's Strategy for SEN 2004

• Revolves around the key areas of early intervention, removing barriers to learning, raising expectation and achievement and delivering improvements in partnership

- Anticipates that most children with special educational and/or complex needs will be educated in mainstream schools
- Makes a commitment to work across Government to improve the quality of transition planning, setting national standards for health and social care through the children's NSF and to work with the Connexions Service and the LSC to expand educational and training opportunities and develop new opportunities for transition work

www.teachernet.gov.uk/wholeschool/sen/senstrategy

Improving the Life Chances of Disabled People – Final Report January 2005-04-05

- Completes a project announced in December 2003 and builds on an interim analytical report published in June 2004; the project recognised that disabled people are faring less well than nondisabled people, set out to find out why and assess what can be done to improve the situation
- Identifies and proposes policies which will remove barriers and improve outcomes for disabled people
- Sets out a vision that "By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society"
- Provides statistical evidence which highlight the increasing numbers and complexity of need in children with disabilities
- Covers four key areas of disabled people's lives
 - o Independent living
 - Early years and family support
 - Transition to adulthood
 - o Employment
- In its section on transition, highlights three key ingredients needed for effective support for disabled young people, to ensure that they enter adulthood able to participate and be included
 - Planning for transition focused on individual needs
 - Continuous service provision

Access to more transparent and appropriate menu of opportunities and choices

www.strategy.gov.uk

National Service Framework for Children, Young People and Maternity Services

DoH, September 2004

- Is a ten year programme intended to stimulate long-term and sustained improvement in children's health
- Part One sets out five core standards which will help the NHS, local authorities and their partner agencies to achieve high quality service provision for all children and young people and their parents or carers. Standard 4 'Growing up into Adulthood' covers transition for all young people.
- Standards 6-10 address children and young people who have particular needs
- Standard 8 relates to Disabled Children and Young People and those with Complex Health Needs. Section 7 of Standard 8 is on Transition to Adulthood. This sets out to ensure
 - A person centred approach to transition planning, focusing on the fulfilment of the hopes, dreams and potential of the young disabled person
 - The establishment of multi agency transition groups
 - Support for young disabled people to use direct payments
 - Support to manage the transition for those with high levels of need, those in residential schools, looked after children and those with rare conditions
 - The agencies develop local strategies to widen education, training and employment opportunities for disable young people
 - The development by Health Services of appropriate adolescent/young person' services with a view to enabling smooth transition to comprehensive multi-disciplinary care

www.dh.gov.uk/PolicyandGuidance/HealthAndSocialCareTopics/Children Services/ChildrenServicesInformation/fs/en

'Our Health, our care, our say: A new direction for community services' DH, 2006-08-01

• Provides the framework to facilitate integration of services across health and social care, shifting the balance from acute to community and primary care and giving greater control of services provided to young people and their families

(will need to chase web reference)