

Guidelines for Services for Young People (14–25 Years) with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviours

Quick Reference Guide (QRG)

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www.ldtransitionguide.bham.ac.uk

UNIVERSITY OF
BIRMINGHAM

September 2006

supported by

The
Health
Foundation

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Introduction

These Guidelines concern people with learning difficulties/disabilities with mental health problems and behaviour problems/challenging behaviour that have a Statement of Special Educational Need (SEN), for each of whom there exists a prescribed programme of planning for transition from year 9 (age 14), the SEN Code of Practice (DfES 2001). We expect the schools and the local education authority to be aware of this population.

We recognise that many children who have learning difficulties/disabilities and mental health problems/challenging behaviours do not have a Statement of Special Educational Needs, and therefore lack access to the kind of transition review programme that is prescribed in the SEN Code of Practice and in Valuing People (DH 2001). These children risk leaving school with no background of coordinated multi-disciplinary transition planning.

We also acknowledge that there will be some whose mental health problem(s) may not have been recognised. We are concerned that a lack of a SEN may effectively preclude a child with learning difficulties/disabilities and mental health problems/challenging behaviours from a multi-disciplinary review that is focussed on preparing for life after school. Better mechanisms have to be in place to detect this hidden population and to address the severe problems many face for lack of a planned transition out of school/paediatric services and into adult services.

We are also concerned at the apparent gap in provision that affects many young people as they pass 16 years of age, when many paediatric services cease, and before they reach 18 years, which represents the threshold for many adult services. The pattern of age thresholds seem to vary to some extent from place to place, some paediatric services 'holding on' to individual cases, others experiencing a sudden shortfall in provision. Indeed, the difficulty of ensuring that a timely recognition of the needs of those individual young people who are likely to require lifelong support would appear to be widespread (though not universal) both geographically and by service type.

There is a group who have Autistic Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) with or without associated learning difficulties. Controversy exists as to whether diagnoses such as ASD and ADHD constitute mental health problems. Mental health problems such as anxiety, depressive disorder and behavioural problems are common co-morbidities associated with these diagnoses.

Aims

These guidelines have the primary aim of addressing in one volume the problems of transition for this group of young people who, though they are relatively few in number, often require substantial support to achieve both social well-being and good health, and who are often poorly served by a lack of effective and coordinated multi-agency service planning. This appears to be the case in spite of much good work that goes on within agencies and by individual staff and services.

The guidelines draw upon a wide range of sources to provide advice to professionals working in the field of service planning, commissioning and provision, though it is hoped others such as family members and carers may find it useful too. It is divided into a series of sections each covering a specific theme or aspect of the transition process at the levels of strategic planning for this client group as a whole, and for transition planning for individuals. To a degree, the issues that pertain to one are also relevant to the other. For example the principles of Person Centred Planning (PCP) should apply equally at each level, though implementation of PCP makes different demands and brings different challenges depending on whether one is working for a group or with an individual.

The Guidelines have been produced using methods derived from the National Institute for Health and Clinical Excellence's (NICE) criteria for guideline development (nice.org.uk). As such, they represent the views and experience of the Guideline Development Group (GDG) and the research team, which have considered the evidence available at the time and consulted widely before writing this document. Professionals are expected to take the principles, recommendations and audit criteria into account when exercising their professional judgement.

Each section contains a brief outline describing the nature of the problems and challenges facing those who plan for and provide services for this group of young people, plus a series of recommendations for good practice, and a series of 'audit points' by which good practice may be recognised and measured.

Health and social care policies are subject to change over time. It is therefore possible that some of the

recommendations in this guideline may have to be adapted accordingly. They cannot, nor should they, override the responsibility of professionals to make decisions appropriate to the circumstances of the individual situation. Such decisions must be taken after careful consideration of all the relevant factors, including the wishes of the individual and their family or carers, alongside the possible benefits and risks involved at the time.

An 'easy read' guide (Moving On & Feeling Happy), based on the findings and recommendations of the guideline development process has also been produced. A full account of the research and a detailed discussion of the findings is available on the website listed on the front cover.

The Guideline Development Process¹

An initial scoping conference was held to clarify the terms and conditions of the project based on its original proposal. Four sources of evidence were then drawn upon:

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| i) An extensive review of the literature pertaining to this client group and to the policies, practices and philosophies that influence transition in the UK | Literature was obtained by a systematic search of electronic data bases and a comprehensive hand-search using internet search engines and library sources. |
| ii) A series of focus group interviews to draw upon the experiences and views of a wide range of people involved in a professional or family carer role with the client group | Data from focus groups were recorded on audio tape and analysed for key themes.

Data from telephone interviews were recorded as hand written notes on a prepared form and transcribed to computer. The data set was then analysed for key themes. |
| iii) A programme of in-depth interviews with professionals and family carers by telephone | |
| iv) A regular programme of meetings with a panel of experts, collectively known as the Guideline Development Group, has reviewed evidence as well as provided comment and advice on the development of the guide | Comprehensive minutes were taken at each Guideline Development Group meeting and written up by one or more of the authors. These were then circulated at the next meeting and approval or advice for correction sought. |
| v) Comments were received from a wide range of stakeholder groups and organisations on the draft guidelines | Comments from various sources were recorded on computer file and included in GDG discussions. |

¹ A full account of the methodologies and findings of each stage of the research process can be found on our website, listed on the front cover.

General Principles Influencing the Development of the Guideline

The Guideline should:

- Focus primarily on those children with Statements of Special Educational Need for whom the formal Transition Review process starts at year 9 (age 14).
- Use the term learning disabilities/difficulties as this is acceptable to health, education and social services.
- Work within the current transition review process, starting with a first transition review at year 9.
- Recognise current legislation, recommendations and requirements of Valuing People and the relevant National Service Frameworks.
- Emphasise the responsibility of adults' services (health, social services, further education) to lead the transition process, and to start to take this lead long before the young person actually becomes eligible for their services.
- Reflect the principles and ethos of *Valuing People* (DH, 2001).
- Follow Person Centred Planning (PCP) principles throughout the transition process and beyond.
- Indicate that the Local Authority must make available to carers and the young person information on eligibility, rights and procedures, and that guidance must be provided on sources of support and advice.
- Identify ways in which the voices of those who cannot communicate are heard so they too can claim to have a 'Person Centred Plan'.
- Use ordinary language – avoid jargon and acronyms.
- Encourage implementation of a carer's assessment for each individual.
- Emphasise the importance of good quality and accessible epidemiological information at a local level.
- Encourage a common understanding of planning processes among staff from different agencies.
- Recommend champions to foreground the needs of this group of people.
- Recommend continuity of care by identifying a key person to liaise with service users and carers throughout the whole period of transition.
- Emphasise the importance of on-going good working relationships between service users and carers and a key person responsible for co-ordinating planning and implementation of the transition plan.
- Emphasise the important contribution that health services can play for this group.
- Identify the full range of professionals who might be involved at each stage and their respective roles.
- Acknowledge the experience and the range of needs of those children without SSEN but who may have a learning disability and mental health problem(s).
- Recognise and refer to the vital contributions that are made by parents, family members and carers.

Issues, Recommendations and Audit Criteria

A: Mechanisms and Structures for
Strategic Planning at the Local Level

B: Good Practice in Joint Strategic Planning

C: Roles and Responsibilities of the Agencies
involved in Transition Planning Processes

D: Assessment of Needs and Eligibility for Services

E: Transfer of Support for Mental Health Problems
from Children's to Adult's Services

F. Empowering Young People with
Learning Difficulties/Disabilities and their
Family/Carers in the Transition Planning
Process: Person Centred Planning

G: Recording and Sharing of Information

A: Mechanisms and Structures for Strategic Planning at the Local Level

For the purposes of these Guidelines, strategic planning refers to forward planning by social services, health and education services (perhaps in conjunction with Connexions, private and voluntary sector agencies) for the provision of services to a population of people with learning difficulties/disabilities approaching eligibility for adult services in each of these sectors.

Statutory, and many private/voluntary agencies, are organised to serve populations living within or originating from certain geographical boundaries. In most instances these will be coterminous with the local authority boundaries, but in some cases where the health service is primarily involved it may mean health-commissioning boundaries. Many private and voluntary sector services are contracted within a 'free market' so that providers of specialist services such as residential, education or care for people with high support needs, will sometimes be sought 'out of area' where no suitable local provisions exist. This is the case in spite of many stated policies to contract all services within the geographical areas covered by the commissioning agency. The main groups of organisations involved with this client group are:

- **Local Authorities**
(Education; Social Services; Housing Services)
- **Health authorities**
(Primary Care Trusts; Health Trusts; Health Service providers)
- **Connexions**
- **Voluntary and Private Sector providers**
(Housing Associations; Residential and other Care and Support Providers; Independent Schools; MENCAP; Advocacy Groups; People First)
- **Learning & Skills Council**
- **Valuing People Support Team**
(Since April 2005 part of the Care Services Improvement Partnership)

In spite of a few outstanding examples of good practice there seems to be little evidence of transparent organisational structure influencing the

planned development of services for people with learning difficulties/disabilities and mental health problems/challenging behaviours at a local level. This causes confusion regarding the identification of clear roles and responsibilities of different organisations in relation to the client group.

Examples of some of the existing and proposed future mechanisms that might involve strategic planning for this client group at the local level include:

- **Children's Trusts**
- **Local Strategic Partnerships (LSPs)**
- **Health and Social Care Partnership Boards**
- **Learning Disability Partnership Boards (LDPB)**
- **Learning and Skills Council**
- **Mental Health Locality Implementation Teams**
- **Strategic Health Authorities,**
- **Primary Care Trusts**
- **Health Trusts**
- **Regional Valuing People Implementation Teams**

An essential pre-requisite for strategic planning is comprehensive, accurate and accessible data. Examples of mechanisms that may be used for collecting information on the client group include the GP Reed code, and Information Referral Tracking (IRT) recommended in the 2004 Children's Act. At a local level, local agreements to bring together agencies to identify in good time individuals who are likely to need multi-agency support and to designate planning and funding responsibilities can help to highlight the needs of individuals.

RECOMMENDATIONS

- a) At a local level there should be a closer working relationship between the commissioners and service providers for mental health and people with learning difficulties/disabilities. One such example is the Mental Health Locality Implementation Team and the Learning Disability Partnership Board working closely for the client group by setting up joint working practice and groups.
- b) The joint working groups should liaise regularly with the commissioners and providers of Adult's and Children's services.
- c) There should be a local strategy for this client group. The responsibility for developing and monitoring this strategy along with the mechanism for implementation will depend on local circumstances.
- d) The strategy should emphasise the need to increase awareness of mental health needs in the population of people with learning difficulties/disabilities among policy makers, managers and practitioners in order to ensure that there are mechanisms to address these needs within their localities.
- e) There should be a local mechanism for collating information regarding the service needs of this client group for the period of the next 2-3 years. Professional and carers working directly with this client group are best placed to provide this information.
- f) There should be local mechanisms for appropriate commissioning bodies to decide and agree on appropriate budget allocation in anticipation for this client group for the period of the next 2-3 years, although it is recognised that different organisations will have different ways of budget allocation depending on different eligibility criteria.
- g) Where possible, the experience and aspirations of people with learning difficulties/disabilities and their carers should inform service planning.

AUDIT

- a) There is an effective joint commissioning structure in place locally for young people with learning difficulties/disabilities and mental health needs.
- b) There is a local strategy in place for this client group.
- c) The local strategy is effectively implemented.
- d) There is a mechanism to monitor the effectiveness of the strategy.
- e) There are one or more agreed mechanisms to routinely gather and disseminate information on the needs of individuals with a learning difficulty/disability who are in receipt of children's/paediatric services and to feed this information into local planning procedures.
- f) There is an accessible database of information on this client group available to commissioners to assist in the planning of services.

B: Good Practice in Joint Strategic Planning

We have identified five primary areas of joint working and overlap among organisations. They are:

- Joint working and overlap among education, health and social services.
- Joint working and overlap between social services and health services.
- Joint working and overlap between mental health services and learning disability health services.
- Joint working and overlap between commissioners of services and providers of services.
- Joint working between children and adult services.

For all that the networks between agencies working with people with learning difficulties/disabilities and mental health problems are dense, there are significant gaps or barriers that inhibit the transfer of information and the formation of joint policies and working practices.

There are a number of factors that may contribute to this unfortunate situation.

- Each service sector has different concepts of 'need' and of eligibility, and even of ways of defining problems, which inhibit joint working.
- In many cases the primary cause or difficulty is hard to establish, and thus responsibility for treatment or support is hard to assign.
- There is considerable local variation between the range of services available and the mechanisms by which they are accessed.
- Paradoxically, the fact that these children and young people represent a 'low volume/high cost' group, - albeit one for which an extensive array of assessments and interventions will probably have been applied since early childhood — seems to contribute to a widespread lack of forward planning and an over-reliance on crisis interventions.

It is noticeable that the quality of transition at a strategic level depends to a large degree on principles that apply equally at an individual level. Good leadership, commitment to joint working and communication between agencies and the young person and their family, and flexible access to planning and resources count at every level.

RECOMMENDATIONS

- a) One organisation may lead the strategic transition planning at a local level in partnership with others. The lead organisation will depend on the local circumstances and on agreement among the local organisations.
- b) There should be a single pooled budget for this client group to which health, mental health and social care purchasers within a locality should contribute.
- c) This group of young people should be recognised by eligibility criteria for services that are appropriate to their needs and are agreed and applied across all services. In effect there should be a jointly agreed eligibility criteria for this group of people.
- d) A better understanding of different rules and cultures within different organisations should be encouraged in order to facilitate joint planning and working. At a practical level these could be enhanced by opportunities for staffs from different organisations to participate in: a) joint working groups, b) joint training, c) joint away days, d) sharing office space, and e) regular liaison at a managerial level from different organisations. This list is however, not an exhaustive one..
- e) Commissioners and providers should work closely and have regular dialogue in order to create a better 'providing market'. The providers may include statutory organisations such as Health and Social Services as well as voluntary organisations and private sector providers.
- f) Commissioners and providers of services should look into a variety of provisions and different models of provision at a local level, and be willing to seek alternatives to existing provisions.
- g) In order to plan effectively, commissioners and providers of services should have information available on the population of young people with learning difficulties/disabilities to help them plan at least two to three years ahead.
- h) There should be a jointly agreed protocol for quality control, and long term monitoring and evaluation of services provided by various organisations and through various models.
- i) Commissioners and providers should be involved jointly in the implementation and monitoring of the strategy.

AUDIT

- a) There is an agreement among agencies regarding who should lead the planning at a local level.
- b) There is a pooled budget with funds from health, including mental health and learning disability services, and the local authority to cover the commissioning of services / support needs of young people with learning difficulties/disabilities experiencing mental health problems/ challenging behaviour.
- c) Opportunities for joint multi-disciplinary training exist, featuring mental health needs as a significant component.

C: Roles and Responsibilities of the Agencies involved in Transition Planning Processes

The SEN Code of Practice provides the only national framework specifying duties to young people with learning difficulties/disabilities at transition. It applies only to children with a Statement of Special Educational Need (SSEN), under the SEN Code of Practice the Local Education Authority (normally via the child's school) has a statutory responsibility to start the formal process of transition planning at the age of 14.

It is the duty of the Head Teacher of each child's school to ensure that planning for transition is included as part of annual reviews of progress for every child with a SSEN. A representative from Connexions *must* be invited *and* attend the first transition review at year 9 (age 14). At that time and thereafter the head teacher *may* seek advice and intervention from other agencies, including health and social care agencies. There is no obligation under the SEN Code of Practice for any agency other than Connexions to be present at the Transition Review.

The SEN Code of Practice urges that the young person and their parent(s) or carers be present at each transition review and be fully involved in preparing for it.

Although Connexions has a duty to coordinate the transition process for young people with learning difficulties/disabilities, this duty extends primarily to transfers from school to further education/other training/employment or service provision. It is recognised that in general Connexions staff may not have the resources or the expertise to work closely with children with complex needs, who may have additional health and communication problems. Connexions can only request or recommend that assessments be made for health/social care services. For some people the roles of health and/or social services are as important as that of Connexions.

An example, which may provide a role model, is the process known as the Team- Around-the-Child.

This sets up a multi-disciplinary 'team' around each individual child and designates an appropriate lead agency.

In some cases, adult services should play an active role from the very beginning, but in most cases it would be expected that the adult services would intensify their involvement towards the end of transition. A significant threshold occurs around the age of 16 when, for example, eligibility for access to children's health services ceases, and some children with learning difficulties/disabilities leave full-time education.

Various agencies and regions have devised transition frameworks for transitional planning. The West Midlands Care Pathway is an excellent example of a person centred approach to the framework of transitional planning. The Regional Partnerships (formerly called Special Educational Needs Regional Partnerships), Eastern, North Eastern and South Western regions have produced guidelines in various forms.

In certain areas there are specialist transition teams and transition workers involved within health and social care teams. This is seen as a good practice, but we also acknowledge that these teams and these social workers are not available everywhere in the country. Where they exist, they may play an important role in helping to gather information on this client group and the nature of their service needs over the period of the next 2-3 years.

RECOMMENDATIONS

- a) Depending on the individual circumstances, one or more of the organisations or a professional representing these organisations should take up the role of the co-ordinator for the transition process.
- b) All the relevant parties should agree at the outset of the formal transition planning process which organisation(s)/ professional(s) should co-ordinate transition planning. This should not affect the duty incumbent upon Connexions or the Local Education Authority.
- c) The organisation/professional co-ordinating the transition planning may change over time. For example, children's health or social services may hand over the responsibility for co-ordinating the planning towards the end of the transition process to adult services. Also, it is possible that in some cases Connexions may hand over the responsibility of co-ordinating transition planning to a health professional or a social worker as appropriate.
- d) Leadership of the transition planning process should be managed by an organisation or professional from an adults' service by the time the young person reaches 17 ½ years of age. The organisation / professional should make contact with the young person and their family / carer in good time before they take over the role formally.
- e) The process of hand-over of responsibility should be formally recorded and the identity of the key worker / lead agency made known to all parties.
- f) Adult services should get involved in the transition planning process as early as possible and should take up the role of co-ordinating the process as soon as deemed necessary by all the relevant parties.

AUDIT

- a) There is a properly drawn out transition plan for everybody by the time the person reaches 17½ years of age.
- b) Adult services are in charge of transition planning by the time the person reaches 17½ years of age.
- c) Every young person with learning difficulties/ disabilities has a named coordinator or lead worker. The identity of this person is recorded and is known to other key staff and agencies involved in supporting the person.

D: Assessment of Needs and Eligibility for Services

Assessment of needs can enable access to services: it can also deny such access.

Young people with learning difficulties/disabilities and mental health problems often present with a complex mixture of problems that do not 'fit' the eligibility criteria of many services (those with autism and 'mild' learning disability are a case in point).

Such people require sympathetic assessment and a common recognition of need.

Assessment of mental health is an important aspect of general health care for everyone, including people with learning difficulties/disabilities that may be overlooked. A mental health assessment should be carried out by a qualified person, such as a psychiatrist, community paediatrician, clinical psychologist, or community psychiatric nurse. Other professionals are also likely to be involved with this group of young people and may be in a position to recognise a problem and to refer. These include those staff defined within *Every Child Matters: Change for Children* (DfES 2004) as Tier 1 mental health workers: GPs, health visitors, school nurses, teachers, social workers, youth justice workers, voluntary agencies, as well as educational psychologists, residential care staff, day care staff, parents and other carers, each of whom may have on-going contact and may be in a position to recognise problems and to refer to others for assessment.

We present a brief list of some of the assessment mechanisms currently in use. Web links and further information are included in Appendix 2.

Community Care Assessment: is used to determine eligibility for local authority social services

Common Assessment Framework (CAF), described in the Green paper, *Every Child Matters* (DH 2003) provides a single, standardised approach to assessing children's needs for services. It focuses mainly on physical and mental development and the factors affecting these, as well as actions and services needed to support them.

Health Action Plans (HAP) for adults (over 18) with learning difficulties/disabilities should be based on a

comprehensive health check by a health professional. A HAP should contain advice on healthy living as well as a summary of a person's state of health, and should list additional sources of help

NHS Continuing Care Assessment for people who may require full time nursing care by qualified staff (for example in a nursing home).

Carer's Assessment, provided by the Local Authority to anyone who provides a regular and substantial amount of care for someone aged 18 or over.

RECOMMENDATIONS

- a) Whatever form the assessment takes it should be based on a 'person centred' approach, in accordance with the principles of *Valuing People*. Assessments should be relevant to the child's or young person's and the carer's lives as a whole, and should include domains significant to each of the services they may use. Formulation of such a framework would help reduce repetition and enhance information sharing. As much time and support as is required to complete a holistic assessment should be given.
- b) A common framework should look at the child's or young person's life at a given point in time, and take into account their physical and mental health needs, as well as their social support needs, and their aspirations and preferences for their adult life, including education and leisure.
- c) Carers' support needs should be prominent in any assessment of a young person with mental health problems and learning difficulties/disabilities.
- d) There should be appropriately trained/experienced professionals available locally to carry out the assessments.
- e) Professionals or organisations able to assess mental health problems should be clearly identified and defined at the local level and should be known to the transition planning team for each individual person.
- f) The option for a mental health assessment should be considered as part of the formal transition review process, and should feed into the general assessment process. The time frame and mechanisms for monitoring should be agreed as early as possible.
- g) Extending the opportunity for Health Action Plans to the children's population will help to detect unidentified mental health needs amongst children with learning difficulties / disabilities.
- h) Training should be available to staff at all levels to raise awareness of mental health problems in young people with learning difficulties / disabilities. These staff should know who to refer to and how to do so.

AUDIT

- Transition planning for every young person with learning difficulties/disabilities is evidently based on the principle of person centred planning.
- An assessment has been carried out of the needs of carers of every young person with learning difficulties/disabilities.
- There is an option for mental health assessment included in each transition plan, as part of health needs assessment.
- There are appropriate mental health professionals/ agencies identified and recorded, along with their contact details, in each individual care plan.
- Training in awareness of mental health problems is available to all staffs with direct contact with young people with learning difficulties/disabilities.
- Every young person with learning difficulties/ disabilities has access to a Health Action Plan at the earliest opportunity.

E: Transfer of Support for Mental Health Problems from Children's to Adult's Services

It is essential that assessment for mental health problems at transition should be supported by effective referral and by a smooth transfer of clinical responsibility from professionals in health services for children and young people to those in adult mental health services. This applies whether referral/transfer is to adult learning disability or adult mental health services: the aim is to achieve access to the most appropriate and effective services to meet the young person's needs.

There are significant boundaries between services caring for the mental health needs of children and those for adults. In most areas, the primary mental health service for children is Child and Adolescent Mental Health Services (CAMHS). This service does not, however, frequently accept referrals in which the primary diagnosis is a learning disability. Much mental health care for children with learning difficulties/disabilities is undertaken within community health services for children and young people, though in many areas, services for psychiatry of learning disability is provided on a 'lifespan' model.

Once a child becomes 16 he or she is no longer eligible in most cases for treatment from paediatric and other health services for young people. Young people of this age who have learning difficulties/disabilities and mental health problems may be referred to

adult learning disability services, which may include psychiatric support. However, the lower age threshold for adult mental health services is usually 18, and some localities are unable to offer access to a consultant psychiatrist for learning disability. Adult 'mainstream' mental health services are often reluctant to accept referrals of people with learning difficulties / disabilities.

These barriers of age and eligibility exist in spite of expectations in Valuing People, the NSF for Mental Health, and the NSF for Children that local service arrangements should ensure that referral for treatment between paediatric and adult services is effective. There is likewise a requirement that unfinished treatments are continued to completion or transferred safely to another practitioner.

RECOMMENDATIONS

- a) There should be recognition within paediatric services of the need to transfer clinical responsibility for mental health care for young people with learning difficulties/disabilities to adult mental health and / or learning disability psychiatry services. This should happen within at least a year before transfer and should likewise be acknowledged by adult services.
- b) There should be transparent and agreed transition pathways that support transfer of responsibility to treat mental health problems, and other health problems, alongside responsibility to assess.
- c) Local arrangements should be developed to ensure that those children and young people who 'fall between the gaps' between services because their needs do not meet eligibility criteria for referral and treatment are recognised and granted the right to treatment. Young people who are particularly vulnerable to this kind of experience are likely to be those with Autistic Spectrum Disorder (ASD) or Asperger's syndrome, or Attention Deficit Hyperactivity Disorder (ADHD).
- d) For young people with learning difficulties/ disabilities and mental health problems arrangements similar to Care Programme Approach (CPA) should be in place. Such a model of care should be available to young people with mental health problems whose primary diagnosis is learning disability.

AUDIT

- a) Referral pathways to adult mental health care are published and available to staff working in paediatric services for children with learning difficulties/disabilities.
- b) There are arrangements to facilitate the exchange of information on mental health problems between health professionals in paediatric and adult mental health services.

F. Empowering Young People with Learning Difficulties/Disabilities and their Family/Carers in the Transition Planning Process: Person Centred Planning

Person Centred Planning' (PCP) offers the primary means and philosophy by which the whole process of supporting people with learning difficulties/ disabilities may take account of their personal wishes and aspirations, as well as defining and recognising their 'needs'.

Person centred planning is a fundamentally different way of seeing and working with people with disabilities, and is at the heart of *Valuing People* (DH 2001). Being 'person centred' or using a 'person centred approach' means ensuring that planning is based upon what is important to a person from their own perspective. Person centred planning provides a conceptual and methodological structure to help professionals and other supporters continually listen to and learn from young people about what is important to them now and in the future, and to act on this in alliance with friends and family. It requires a fundamental shift of thinking from a 'power over' relationship to a 'power with' relationship.

PCP requires substantial commitment from all agencies. It is not a 'bolt on' addition to current procedures, but should inform the whole process of supporting people with learning difficulties/disabilities in such a way that they have as much control as possible. This requires a radical approach to service provision and negotiation on the part of agencies and families, and a willingness to relinquish power to the user and their family. PCP is of little value if it does not translate into Person Centred Action. For this to be achieved there have to be resources available or the willingness on the part of provider and commissioning agencies to access or create them.

The empowerment of carers and service users depends heavily on access to information that is timely, up to date, and in accessible form. Such empowerment may come about by many means, but will require at least some face-to-face contact between the significant parties or their representatives.

Negotiating transition is a complex process for which few people without professional expertise are prepared. For this reason, young people and their families may require the help of a 'champion'- someone who can be aware of their situation and help them to prepare for meetings and advise on sources of information. That 'champion' may in principle be anyone, but in practice is likely be the person leading the transition process, such as a social worker, nurse or Connexions Personal Advisor. There are an increasing number of PCP Facilitators – professionals who have been specially trained in supporting young people and their families and in advising agencies on implementing PCP.

RECOMMENDATIONS

- a) Where appropriate young people and their carers should be empowered to either lead or be proactive in the whole process of transition planning.
- b) Sufficient time and resources must be made available to people involved in person centred planning to allow it to work. This often involves much preliminary contact and preparation in advance of transition planning meetings.
- c) Information must be provided to young people and their carers freely, accurately, and in an appropriate and accessible form.
- d) Someone should act as a 'transition champion' for the individual. They must maintain continuity of contact with the young person and their family / carers throughout the transition period.
- e) The person doing this should be the one most appropriate to the person's needs.
- f) They should have some knowledge of mental health issues and be aware of the various mental health services in their area and of how to access them.
- g) The young person and his/her carer should be fully prepared and informed to take part in the transitional planning process from the very beginning.
- h) They should be given the opportunity to express their views in a proactive way in any planning meetings, and where appropriate to ask for information to be provided and for certain things to be done.
- i) The 'transition champion' should de-brief the service users and family carers about the issues that are discussed in various transition planning meetings.
- j) It is important that the professionals use languages, symbols and terminology that are acceptable to service users and family carers in a multi-disciplinary meeting.
- k) Different options for care including access to Direct Payment should always be considered.
- l) The assessment of needs should be based on the young adult with learning difficulties/disabilities and their carers' perceptions of need.

AUDIT

- a) All young persons with learning difficulties/ disabilities and / or their carers agree that they have been sufficiently involved in the transition planning.
- b) All young persons with learning difficulties/ disabilities and / or their carers agree that they have been given adequate information during every stage of the transition planning which they have understood properly.
- c) A transition champion is named for each individual.
- d) Information on help for mental health problems is included as part of health information.
- e) There is an opportunity to access advocacy support where necessary.

G: Recording and Sharing of Information¹

Information sharing is an important part of transition planning. At present local authorities, health services, schools and education departments keep separate databases of information on individual children. The information sharing process also involves educating and training of professionals, service users and carers on the mental health issues of children and adults with learning difficulties/disabilities. The professionals who might benefit from such training would involve teachers in school, nurses, general practitioners, social workers and Connexions Personal Advisors.

RECOMMENDATIONS

- a) There should be either a common database among various agencies or a password protected access to various agencies' databases by people and professionals on a "need to know" basis. Individuals and / or their families / carers must be informed of this database and its function, and give written consent.
- b) Protocols should be established, and training given, to establish mechanisms by which information may be shared and the appropriate form it should take. Such protocols should draw upon a common consensus of responsibility towards young people with learning difficulties / disabilities.
- c) The process of information sharing may be supported through the use of a 'profile' held by the young person. This could be a book or file, but it could also use electronic or visual media to communicate key information. It could contain material developed with the individual themselves, as well as that from professionals.
- d) Information about any assessment and intervention provided by professionals could be summarised in the service users Health Action Plan.
- e) Young people and/or their carers should be informed about the sources including web-based sources from where they can receive relevant information about care provisions and their rights.

AUDIT

- a) There is a mechanism for various agencies to share information on a 'need to know' basis.
- b) Each individual has a Health Action Plan or similar that identifies what health support is being provided and by whom.
- c) Access to information about service users' and also carers' rights is available and included in assessment and other information.

¹ Any transfer of information must be conducted within the requirements of the Data Protection Act

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Appendix 1

The Members of the Guideline Development Group and the Scoping Group.

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Appendix 2: Further Information

This section contains a list of web links to organisations that have an interest in or are relevant to transition. It is by no means exhaustive – indeed, new links are constantly becoming available. Inclusion in this list is not intended as a comment on the quality of service or information provided

AFTER16

A website for young disabled people and families. It has information about opportunities and services after school, as well as information on benefits, leisure, housing, relationships, transport, employment, health and more
<http://www.after16.org.uk>

AUTISM.WEST MIDLANDS

This site provides links to information about autism. west midlands, which provides of autism-specific services in the West Midlands region, offering residential and educational services, supported living and employment support for adults with Asperger Syndrome, family support, an information help-line, and training for staff, parents and professionals
<http://www.autismwestmidlands.org.uk/index.html>

BRITISH INSTITUTE OF LEARNING DISABILITIES (BILD)

BILD offers advice, information, advocacy, training, research and consultancy to people with learning difficulties/disabilities, families and professionals. This site contains information on training courses, conferences and easy to read publications
<http://www.bild.org.uk>

CARE PROGRAMME APPROACH (CPA)

This site describes the Care Programme Approach (CPA), introduced in 1991 in England. CPA applies only to people with mental health problems. Hospitals/Trusts have to arrange an individually assessed 'package of care' for all people about to be discharged. Community mental health services (outpatient services, community mental health teams) have to arrange CPA assessments for users of mental health services who live in the community. The Care Programme Approach applies to 'anyone in touch with secondary mental health services (health and social care)'.
<http://www.mind.org.uk/Information/Factsheets/Community+care/Community+Care+2+-+The+Care+Programme+Approach.htm>

COMMUNITY CARE ASSESSMENT

NHS CONTINUING CARE ASSESSMENT

A number of the major charities and organisations provide information on-line that may be applicable. For example:

<http://www.infosci.org/MS-UK-MSSoc/ccassess.html>

<http://easyweb.easynet.co.uk/vob/alzheimers/information/asses.html>

http://www.alzheimers.org.uk/Caring_for_someone_with_dementia/Residential_and_nursing_care/info_nursingassessments.html

CONNEXIONS

Connexions is the Government's support service for all young people aged 13 to 19 in England. It provides support up to the age of 25 for young people who have learning difficulties/disabilities. Connexions provides information, advice, guidance and access to personal development opportunities for young people. This site contains links via Connexions Direct to information on careers, learning, health, housing, relationships and other matters.

<http://www.connexions.gov.uk>

CONTACT A FAMILY

Contact a Family provides advice, information and support to parents of disabled children. It helps to link families locally and nationally, and provides a useful on-line medical directory, information on rights, a 'Dad's Zone' as well as other services.

<http://www.cafamily.org.uk>

COUNCIL FOR DISABLED CHILDREN

Provides a national forum for the discussion and development of a wide range of policy and practice issues relating to service provision and support for disabled children and young people and those with special educational needs.

<http://www.ncb.org.uk/cdc>

DEPARTMENT OF HEALTH

This site has links to the full range of DH policy, publications, consultations and news.

<http://www.dh.gov.uk/Home/fs/en>

DEPARTMENT FOR EDUCATION AND SKILLS (DfES)

This site contains information on a wide range of government initiatives and issues to do with education, and links to a number of government sites, including Teachernet

<http://www.dfes.gov.uk>

DIRECT PAYMENTS

Direct Payments can enable a disabled person or their representative, to arrange and pay for their own care and support services instead of receiving them directly from the local council

http://www.direct.gov.uk/DisabledPeople/FinancialSupport/FinancialSupportArticles/fs/en?CONTENT_ID=10016128&chk=NHagZX

DISABILITY RIGHTS COMMISSION

This site gives advice and information to disabled people, employers and service providers. It also supports disabled people in getting their rights under the Disability Discrimination Act.

<http://www.drc-gb.org>

THE FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES

The FPLD works to promote the rights, quality of life and opportunities of people with learning difficulties/disabilities and their families. It undertakes research and develops projects that promote social inclusion and citizenship; provides advice to support local communities and services to promote inclusion. It advises on services and service development; and disseminates knowledge and information through a variety of media.

<http://www.learningdisabilities.org.uk/index.cfm>

HEALTH ACTION PLANS (HAP)

Health Action Plans are currently available for adults (over 18) with learning difficulties / disabilities. A HAP should be based on a comprehensive health check by a health professional, and contain advice on healthy living as well as a summary of a person's state of health, and should list additional sources of help. In some cases a person may need help to decide what to put in their own Health Action Plan. This can be provided by a Health Facilitator who should

work with them and their carers to find out what help they need to stay healthy. A Health Facilitator can be anyone, though is most likely to be a nurse or other professional.

http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/AdditionalResources/fs/en?CONTENT_ID=4001807&chk=4dHiWO

HELEN SANDERSON ASSOCIATES

Helen Sanderson Associates is a training and development agency specialising in person centred planning.

<http://www.helensandersonassociates.co.uk>

HER MAJESTY'S STATIONERY OFFICE (HMSO):

This site contains full texts of Acts of Parliament.
www.legislation.hmso.gov.uk/acts.html

KEYRING

KeyRing provides supported accommodation for people with learning difficulties/disabilities. It works to enable people to live as independently as possible in 'networks' of independent houses usually located within a single community.

http://www.keyring.org/site/keyring_home.php

LEARNING AND SKILLS COUNCIL

LSCs have a role to develop educational and training provision for young people and a more general role around helping to develop employment.

<http://www.lsc.gov.uk/National/default.htm>

LEARNING DISABILITY

This site provides information, education and services to both members of the public and those with a commercial interest. The site is primarily aimed at providing education information for people with learning difficulties/disabilities, their carers, advocates, friends, professional carers, social and health care workers, students and those who have an active interest in promoting equality of opportunity for people with learning difficulties/disabilities.

<http://www.learningdisability.co.uk>

MEDICINES.ORG.UK

This gives details of the manufacturer's information. It can be helpful if you need to know how common the side effects are and what the excipients ('fillers') are in a tablet in case there are allergy problems.

<http://www.medicines.org.uk>

MENCAP

This site provides a wide range of information, research, services and support for people with learning difficulties/disabilities and their families.

<http://www.mencap.org.uk>

MENTAL HEALTH FOUNDATION

This site contains information about a wide range of mental health needs.

<http://www.mentalhealth.org.uk>

MOVING ON UP

A website for young disabled people from minority ethnic communities . It contains information in six languages on work, leisure, money, health, education, housing and culture

<http://www.movingonup.info>

NATIONAL AUTISTIC SOCIETY

Provides information, advice and support on autism (ASD) and Asberger's Syndrome for families and professionals

<http://www.nas.org.uk>

NATIONAL CENTRE FOR INDEPENDENT LIVING

This site contains advice and information on independent living, direct payments and personal assistants.

<http://www.ncil.org.uk>

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE

This site includes information mainly for health professionals. NICE have issued good practice guidelines on mental health issues.

<http://www.nice.org.uk>

NORAH FRY RESEARCH CENTRE

Its principal interests are the evaluation and development of services for people with learning difficulties/disabilities. It produces a number of research and policy documents, many of which are produced with the involvement of people with learning difficulties/disabilities.

<http://www.bris.ac.uk/Depts/NorahFry>

PARADIGM

Paradigm is a consultancy and development agency in the forefront for supported living and person centred planning. This site contains learning disability related articles, links, information on training courses, UK government policy

<http://www.paradigm-uk.org>

PERSON CENTRED PLANNING

Many organisations carry information on person centred planning. The site for Valuing People Support Team contains information and a wide range of links, including research on the impact of PCP.

<http://www.valuingpeople.gov.uk/pcp.htm>

ROYAL COLLEGE OF PSYCHIATRISTS

This site offers a wide range of information on many aspects of mental health, including material accessible to people with learning difficulties/disabilities.

<http://www.rcpsych.ac.uk>

ROYAL NATIONAL INSTITUTE FOR THE BLIND (RNIB)

Provides information, support and advice to people with visual impairments.

<http://www.rnib.org.uk>

ROYAL NATION INSTITUTE FOR THE DEAF (RNID):

Provides information about hearing loss. It also campaigns and lobbies government to change policies.

<http://www.rnid.org.uk>

ST GEORGE'S, UNIVERSITY OF LONDON

This site provides a wide range of information about learning disabilities, including medical and health information, parents issues

<http://www.intellectualdisability.info/home.htm>

SCOPE

This site provides information about cerebral palsy. It provides information on campaigns, research and support.

<http://www.scope.org.uk>

SKILL: NATIONAL BUREAU FOR STUDENTS WITH DISABILITIES

Skill provides information and advice on matters to do with education and employment for individual disabled people and the professionals who work with them. They aim to provide information and advice helps disabled people to overcome financial and physical barriers, ignorance and discrimination so that they can study, train or find work.

<http://www.skill.org.uk>

SOCIAL CARE INSTITUTE FOR EXCELLENCE: (THE ROAD AHEAD)

The Road Ahead is a Guide that provides information for young people with learning difficulties/disabilities and their families at transition. The report can be

downloaded, and there is an easy read and an audio version.
<http://www.scie.org.uk/publications/tra/downloads.asp>

TEACHERNET

This site provides access to the *SEN Code of Practice*, which establishes the duties of schools to provide transition planning for all children with statements of special educational needs.
http://www.teachernet.gov.uk/_doc/3724/SENCodeOfPractice.pdf

TELL US MORE

This site is provided by the Birmingham Learning Disability Partnership Board, and has a wide range of information and links on a variety of issues
<http://www.tellusmore.org>

TRANS-ACTIVE

This interactive site is provided by Mencap for young people with learning difficulties/disabilities who are going through transition. The Trans-active project teams up young people with learning difficulties/disabilities with young people without disabilities in a supportive relationship. The site contains accessible information for participants in the project, teachers and helpers, including advice on developing transition 'passports'
<http://www.trans-active.org.uk>

VALUING PEOPLE

This is the website of the Valuing People support team. It has information for people with learning difficulties/disabilities, as well as resources and a section on health and Health Action Plans. There are links to regional pages
<http://www.valuingpeople.gov.uk>

WELSH CENTRE FOR LEARNING DISABILITY

The Welsh Centre for Learning Disability researches and publishes many articles and papers on a wide range of issues for people with learning difficulties/disabilities.
<http://www.hebw.uwcm.ac.uk>

WEST MIDLANDS TRANSITION PATHWAY

This site describes the West Midlands Transition Pathway project. The Pathway is a Guide that presents clear, comprehensive and easy to follow advice on the process of transition for any young person with

a disability. Based on Person Centred principles, it indicates who should do what and when, and includes useful templates that can be adapted to individual circumstances and needs. It can be used by professionals and family carers, and there is an 'easy read' version.
<http://www.transitionpathway.co.uk>

YOUNG MINDS

This is the website of YoungMinds, a national charity committed to improving the mental health of all children and young people. The site contains a lot of useful links and information for young people, their families and carers, and professionals.
<http://www.youngminds.org.uk>

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