

Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

Technical Document -

Chapter 1 Aims of the Study

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Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour – Chapter 1 Aims of the Study

This guideline concerns people with learning difficulties/disabilities with mental health problems and behaviour disorders/challenging behaviour that have Statements of Special Educational Need (SSEN), 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 disabilities and mental health problems / challenging behaviours do not have Statements of Special Educational Needs, and therefore lack access to the kind of transition review programme that is prescribed in the SEN Code of Practice. These children risk leaving school with no background of coordinated multi-disciplinary transition planning at all.

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 SSEN effectively precludes a child with learning 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 into adult services.

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.

With this in mind this Guideline has the primary aim of highlighting some of 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 pro-active service planning. This is in spite of much good work that goes on within agencies and by individual staff and services.

It is therefore intended to be read by professionals working in the field of service planning, commissioning and provision. 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.

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, and a series of recommendations for good practice, and a series of 'audit points' by which good practice may be recognised and measured. Each of these elements have emerged from evidence gathered during the fieldwork programme and the regular meetings of the Guideline Development Group

The guideline development process

Four sources of evidence have been drawn upon to produce this Guideline:

- 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.
- 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.
- 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.
- v) Comments were received from a wide range of stakeholder groups and organisations on the draft guideline.

General principles influencing the guidelines:

In consultation with members of the Steering Group and Guideline Development Group, it was agreed that the Guideline should:

- Focus primarily on and provide a pathway for 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 (interchangeably) 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 Department (SSD), 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
- Engage Person Centred Planning (PCP) principles to identify priorities
- Indicate that the Local Authority must make available to carers and the young person information on eligibility, rights and procedures, 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 in each case
- 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 acknowledging 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 the 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
- Argue for effective mechanisms to identify children and young people with learning disability, mental health problems and behaviour problems
- 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.
- Recognise and refer to the vital contribution that is made by parents, family members and carers.