

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

Technical Document -

Chapter 2 Background to the Project

Nick LeMesurier; Research Fellow,
Niyati Bathia; Research Associate,
Shoumitro Deb; Clinical Professor of Neuropsychiatry and Intellectual
Disabilities, and
Gemma L. Unwin; Research Associate

Correspondence to:
Shoumitro Deb, MBBS, FRCPsych, MD,
University of Birmingham,
Division of Neuroscience,
Department of Psychiatry, UK.
Email: S.Deb@bham.ac.uk

www.ldtransitionguide.bham.ac.uk

May 2007

Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour – Chapter 2 Background to the Project

Different professionals including paediatricians, community paediatricians, child and adolescent psychiatrists, psychiatrists specialising in learning disability, clinical and educational psychologists, social workers, and therapists are involved in the management of mental health problems in children and young adults with learning disability. It is not uncommon for individuals to lose specialist involvement in the transition between childhood and adulthood because of lack of appropriate hand over from one specialist team to another. Also, in some places uncertainty exists as to which specialist team should provide service for this client group (See the recently published report by the Mental Health Foundation: '*Count us in*').

Recent evidence suggests that indeed many of this vulnerable group do not have their needs met. In the UK, McCarthy and Boyd (2002) reported findings from a prospective follow up of 80 young people with learning disability from childhood and adolescent to adulthood. They found that the great majority (64%) of individuals with persistent challenging behaviour from childhood into adult life and those with an established childhood psychiatric disorder received no specialist mental health care. They stated that the development of mental health services for this vulnerable group with complex psychiatric and behaviour disorders has been poor for a number of reasons, including lack of recognition at the primary care level and insufficient number of trained professionals within specialist services. These findings have ramifications not only for those with the mental health needs but also their carers.

In a recent study in the USA, McIntyre and colleagues (2002) reported on behaviour/mental health problems in young adults with learning disability and their impact on the families. They found that behaviour and/ or mental health problems of the clients significantly predicted the mother's perceived negative impact of the young adult on the family, even after controlling for other young adult characteristics. These problems also predicted the family's steps towards seeking out-of-home placement, as did better young adult health and the mother's higher educational attainment; stress did not predict additional variance in placement. These findings have obvious implications for service provision to families of young adults with learning disability and additional mental health problems.

These reports highlight major gaps in the service provision for this client group. Cumella and colleagues (2002) found in a recent study of children with learning disability who were leaving schools that inter-agency planning did not occur and little such planning occurred until leaving school was imminent. Health and social needs were not appropriately addressed. Few had accessed social care services after leaving school. Reasons for this policy failure were the lack of staff with designated responsibility for planning and implementing transition with responsibility before and after leaving school, and the impact of perverse funding incentives. Bouras (1999) has also shown that the implementation of good practice has been a serious problem despite several policy announcements over the last ten years. For example, early assessment of adolescents who have been statemented occurs with variable frequency across different Local Authorities.

The rate and type of functional psychiatric illnesses seen among adults with learning disability are similar to that seen among the general population (Deb et al, 2001a). However, if a broader definition of mental health problems is used to include diagnoses such as behaviour disorders, personality disorders, autistic spectrum disorders, Attention Deficit Hyperactivity Disorder (ADHD), the rate becomes significantly higher among adults with learning disability compared with the general population (Deb et al, 2001b, c). For example, Deb & Prasad (1994) found the DSM-III-R diagnosis of autistic disorder among 17% of school children with learning disability in Northeast Scotland, and Morgan and colleagues (2002) found autism among 30% of adults with learning disability who are known to various service providers. Although it is known that certain childhood onset disorders such as autistic spectrum disorders and ADHD that are commonly associated with learning disability tend to persist in the adulthood in a proportion of individuals, these diagnoses are rarely recognised among the adults. According to some estimates the rate of any type of mental disorders among children and adolescents with learning disabilities varies between 38 and 50% (Dykens, 2000; Einfeld and Tonge, 1996).

The recent White Paper from the Department of Health (DH) entitled, 'Valuing People: A New Strategy for Learning Disability for the 21st Century', clearly identifies the need for implementing individual care plan for young adults (14-25 years) who have learning disability and additional mental health problems (DH, 2001) with their active involvement, need for support for their parents and other carers, and above all to be allowed to live a full life. Often, none of these principles has been implemented in practice. There is, therefore, a clear need to develop a structured framework within which the DH aims can be achieved. It is of paramount importance that our practice is based on valid evidence. The ideal way to develop a guideline on this would be to follow the National Institute of Clinical Excellence's (NICE's) recommendations for guideline development. We therefore propose to develop an evidence-/ consensus-based guideline for service provisions for young adults (14-25 years) who have learning disability and mental health problems, using NICE's criteria.

Plan of investigation.

The research programme has run from January 2004 to October 2006 (33 months).

The study has been conducted in three stages, each of which overlapped with the others in an iterative process. It commenced with:

- 1) A programme of group interviews involving representatives of service users and all other appropriate stakeholders.
 - i. Focus groups of Practitioners (NHS, Social Service, voluntary sector and private sector service providers), Commissioners and senior managers, and also of Family Carers were held in separate groups and then in a combined group
 - ii. A series of telephone interviews was held with providers from all sectors in various parts of the UK. The main aim was to find out what various service providers were providing and were able to provide, and what the service users and carers wanted them to provide.
 - iii. Consultancy and advice was sought from The H Team, a group of service users with learning disabilities in Coventry. Members of the H Team are experienced in providing advice to medical and social work professionals in

health care issues of significance to people with learning disabilities. The resulting document *Moving on and Keeping Happy* was printed in A5 format and made available on the Research Team's website (www.LDTransitionguide.bham.ac.uk)

- 2) A review of the policy, professional and academic literature, and also 'grey literature' from representatives of service users, service providers in statutory and non-statutory organizations. This included other guidelines that have been developed for service deliveries for this client group.
- 3) Information from 1) and 2) above contributed to an on-going and iterative process of review of evidence and consultation through the working of a Guideline Development Group (GDG). This group examined evidence gathered in the course of the research programme and was responsible for the process of refining the focus of the Guideline and eventual content. The workings of the GDG followed the criteria laid down by the National Institute for Clinical Excellence for the development of guidelines (*NICE Document 3: NCCs and GDGs; post-consultation version 08/11/01*).

The working process of the GDG consisted of seven distinct, if overlapping, stages:

- 1: Refining the subject: the subject area of the guideline was continuously refined throughout the development of the guideline.
- 2: Defining questions: Similarly, the questions that the guideline recommendations will need to address were refined as an on-going process.
- 3: Identifying the evidence: evidence from literature searches, including systematic reviews, meta-analysis, randomised controlled trials, and quality of life and economic studies, as well as service evaluations, policy reviews and academic discussion of key issues.
- 4: Assessing and synthesising the evidence in relation to its clinical significance and significance for policy, methodological rigour and validity.
- 5: Translating the evidence into recommendations for practice:
- 6: Audit: key audit criteria were identified for each set of recommendations.
- 7: External review by expert referees.

The project followed the recommendations laid down by the NICE for the process of guideline development. First, we recruited a panel of experts, including members who could represent the perspective of service users and their carers, to form a Guideline Development Group (GDG). The group had at least seven or eight (including the group leader) members who were professionals either directly treating patients or managing services.

The members of the GDG were drawn from a wide background including representatives from the Health Service management and commissioners, Education, Social services, Clinical Psychology, Private sector, Voluntary sector, Psychiatrist, Connexions, Social Science.

The subject areas covered in this guideline were defined in stage 1 and 2. As there are many issues that involve the service delivery for this client group, we concentrated on one or two important areas. We made sure that there was no overlap with other groups in choosing the specific subject area for guideline development.

The GDG met once every 4 to 6 weeks throughout 2005, starting on 28th January 2005 through to 15th November 2005.

Findings from the GDG meetings and elsewhere contributed to a document containing a series of recommendations and audit points, *Guidelines For Services For Young People (14-25 Years) With Learning Disabilities/ Difficulties And Mental Health Problems/ Challenging Behaviours: “Quick Reference Guide”* (Deb et al 2006).