

Meeting Service Needs

Meeting the service needs of young people with learning disabilities and mental health problems

SUMMARY

Young people with learning disabilities experience the same range of mental health problems as other young people but are at a higher risk of developing such problems, especially at times of stress and change. They need high quality, responsive services to help them cope with these difficulties. Yet services are often inappropriate, pathways to care are unclear and there is a shortage of trained staff.

Service commissioners need to ensure that services respond to individual needs and that they are more inclusive (Department of Health, 2001; Scottish Executive, 2000).

BACKGROUND

Young people with learning disabilities were identified as at risk of developing mental health problems in the Mental Health Foundation inquiry report, *Bright Futures* (The Mental Health Foundation, 1999). The Foundation for People with Learning Disabilities convened a committee of inquiry in October 2001 led by Professor Barry Carpenter, chair, and Dr Mary Lindsey, vice chair, to look at meeting the mental health needs of people with learning disabilities aged 13 to 25. It considered evidence from professionals, families and young people with learning disabilities.

Updates: Research and Policy Briefings Volume 4, Issue 8 gave an overview of the inquiry report, *Count Us In: The Report of the Committee of Inquiry into Meeting the Mental Health Needs of Young People with Learning Disabilities*. This *Update* focuses on the service needs of young people with learning disabilities who also have mental health problems. A future *Update* will explore ways of promoting emotional well-being.

EVIDENCE

Despite the vulnerability of young people with learning disabilities and mental health problems the committee repeatedly heard families report delays in obtaining help or unwillingness on the part of services to listen to them and take their problems seriously. Often symptoms were seen as an unavoidable aspect of the learning disability. 'The most common approach to responding to needs of young people with learning disability is "no response" until problems have escalated to the point of significant risk,' (evidence to the inquiry).

Families reported that it was often unclear how they could get access to mental health services and indeed what services were available to them. Moreover, criteria that determined whether or not someone would be referred to a service often seemed designed to exclude people rather than include them.

People aged 16 to 18 face particular difficulties in that they may fall between child and adult services. It is not always clear if they should be seen by the learning disability service or the adult mental health services and sometimes they end up with neither service. 'They were finding it difficult to find anywhere to send him to as, at 16 and with no verbal communication, he fell between child and adult services,' (evidence to the inquiry).

Primary health care staff, especially GPs, are often the first point of call for families when difficulties arise. However, they are often ill equipped to deal with people with learning disabilities and mental health problems and there is no consensus about how care should be provided (Lennox & Kerr, 1997).

The inquiry heard how changes to the environment of the young person often led to improvements in their mental health. Psychological and counselling approaches are valued, although talking therapies are often not available to someone with learning disabilities. In particular, cognitive behavioural therapy has been used effectively with some people with learning disabilities for anxiety, depression and anger management (Lindsay, 1999). While medication undoubtedly has a role to play, the inquiry heard that there was anxiety about an over-reliance on drugs and a lack of knowledge about appropriate dosages and side effects.

MAIN FINDINGS

- The committee believes that radical changes are needed in policy and services if young people with learning disabilities are to access the support they need.
- Young people and their families must be listened to; young people value being treated with respect.
- Schools need better and quicker links with specialist services. School nurses have a role in assessing individual children's health needs.
- Primary care teams need access to specialist advice and training, which should include communication skills.
- The English Connexions service, the health facilitator role in the *Valuing People* English white paper and the local area co-ordinator in *The Same As You* Scottish review have significant potential in supporting the mental health needs of these young people (Department of Health, 2001; Scottish Executive, 2000).
- Getting to know the young person and their circumstances should underpin assessment and diagnosis and treatment should be holistic. Social interventions – such as social skills training and circles of support, which bring together a group of people committed to supporting a person with learning disabilities in realising their wishes – should always be considered as part of a treatment package.
- Early diagnosis and intervention are vital to prevent further deterioration, such as a worsening illness or a breakdown in living arrangements. Professionals should, wherever possible, use interventions that have been shown to work ('evidence based'). They need to keep up to date with research findings, network with their peers, develop outcome measures for their work and contribute to research.

- Joint commissioning by health and local authority agencies is the best way of ensuring that the different needs of young people with learning disabilities are met. Commissioners must also consider how best to meet the needs of minority ethnic communities in their area, which may change as new groups arrive (such as refugees).
- Services need to be flexible, for example in the use of eligibility criteria, particularly for 16 to 18 year olds, who often fall between child and adult specialist services. Young people also need mental health services close to their home. However, multi-disciplinary, specialist services are required for those with the most severe and complex needs and they should aim to restore mental health and return young people to local facilities.
- More research is needed into assessing mental health problems in young people with learning disabilities and into the effectiveness of treatments, including therapies other than medication.
- There should be better identification of, and appropriate support for, the minority of young people with learning disabilities who offend. Wherever possible treatment should be delivered within the community.
- Information needs to be made accessible to young people with learning disabilities and their families, particularly when their first language is not English. The Foundation for People with Learning Disabilities is publishing booklets for young people and their families about seeking help for mental health problems.
- Families whose children with learning disabilities develop mental health problems need support, such as short breaks, practical help and counselling.

SUMMARY OF RECOMMENDATIONS

- Each general practice should have access to a lead person/adviser in its area on the needs of young people with learning disabilities.
- Each primary care organisation needs to map staff competencies and provision for young people with learning disabilities and mental health problems, so that services can be effectively planned.
- In discussion with other agencies (such as English learning disability partnership boards), each primary care organisation should create clear referral protocols and care pathways, which set out the roles of services.
- Each primary care organisation should ensure that local services are sensitive to the needs of minority ethnic communities and they should monitor uptake of services.
- Child and adolescent and adult mental health services, and strategic agencies should identify a senior member of staff to lead on learning disabilities.
- Schools and colleges should have plans for improving access and inclusion for students with learning disabilities and mental health problems. A designated lead (for example the SEN co-ordinator) should provide information and support to young people with learning disabilities experiencing mental health problems.

REFERENCES

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century* London: The Stationery Office.

Lennox, N.G. & Kerr, M.P. (1997) Primary Health Care and people with an intellectual disability: the evidence base *Journal of Intellectual Disability Research* 41, 5, pp. 365-371.

Lindsay, W.R. (1999) Cognitive Therapy *The Psychologist*, 12, pp. 238-241.

The Mental Health Foundation (1999) *Bright Futures: Promoting children and young people's mental health* London: The Mental Health Foundation.

Scottish Executive (2000) *The Same As You? A Review of Services for People with Learning Disabilities* Edinburgh: Scottish Executive.

This Update was written by Linda Steele and edited by Anna Hewitt and Hazel Morgan. It is based on findings from *Count Us In: The Report of the Committee of Inquiry into Meeting the Mental Health Needs of Young People with Learning Disabilities*, published by the Mental Health Foundation.

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