

# This is what we want



## Introduction

These guidelines have been developed by children and young people with learning disabilities and their families in response to the comprehensive Child and Adolescent Mental Health Services (CAMHS) targets for 2007. Moving towards the guidelines will show that the voice of young people is being heard.

The guidelines are based on five consultation exercises with young people in a variety of schools and youth organisations in London, and evidence from previous work by the Foundation for People with Learning Disabilities. We have also taken into account key messages found from other organisations' consultation exercises with young people with and without disabilities.

The major issues that arose from the consultation were that:

- Most young people were not aware of the term mental health.
- Families were suspicious of the label of 'mental health' because it emphasised a need for a separate label in addition to having a learning disability.
- Most of the young people had never heard of CAMHS.
- Most young people turn to their teacher, parents or youth worker for advice over their mental health issues.
- Neither the young people nor the people they go to for advice are particularly well informed about mental health or mental health problems.
- For those from minority ethnic communities the situation was even more difficult to address because of the stigma associated with mental health problems in some cultures.

These guidelines follow the same areas as the QINMAC standards developed by the Royal College of Psychiatrists' College Research and Training Unit.

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## Referral and access

### *We want:*

- To know where to look for help. Services need to be directly accessible to young people
- Information about how CAMHS can help us. For example, a leaflet could be produced by young people to explain clearly what CAMHS do
- Services that are easy to contact.

### *Our families want:*

- To know where they can get advice for their son/daughter, preferably through a single referral point.

## Location, environment and facilities

### *We want:*

- Flexibility in where we see our therapist, for example at a youth club, school, non-stigmatising facility within a town
- If we use a service, waiting rooms must be welcoming with a range of activities such as an X-box or Playstation 2, refreshments and magazines for parents as well as children and young people.



Professionals in regular contact with young people (for example, teachers and youth workers) have said how useful it would be for mental health professionals to visit them offering a surgery approach on a regular basis.

## Assessment

### *We want you to:*

- use language we understand when describing mental health problems
- use photographs and symbols to aid our understanding.



Our parents want professionals to assess our needs by observing our family in familiar settings rather than always see them in a clinic type setting.

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## Information and rights

### *What we want:*

- Information about the service we are being referred to through a range of accessible formats – leaflet, website or posters
- Information about the range of professionals that we will come into contact with
- The right to change therapist if we feel uncomfortable with our existing one. The relationship with the therapist is of paramount importance
- A new therapist immediately if our existing therapist leaves the service
- If our family is from a minority ethnic background, they need information (in an audio or visual format) in their first language and may need someone to explain what the service can offer.

## Care and intervention

Making appointments is a problem for some of us who live in more than one address and find it difficult to attend appointments, particularly if we live in rural areas. Also, we don't always want to explain to our friends or teachers/employers that we are seeing someone for help with our mental health problems.

### *So we want:*

- A convenient time and place for appointments
- A drop-in service with more flexible hours, in non-stigmatising accommodation
- To agree how to keep in touch for example, mobile phone, texting or letters
- Services that provide social opportunities and time to talk to other young people with similar problems.



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## *Our families want:*

- More proactive strategies to cope with challenging behaviour and information on mental health problems so that they are aware of possible changes in our behaviour
- Services to be sensitive to the religious and cultural beliefs of the young person and their family and to be flexible in sources of support. For example, from some communities, a teenage girl should be seen by a female, or short-term break centres should not be of mixed sex accommodation
- If medication is being used the young person and their parents should be informed of the side effects and an explanation why it has been prescribed
- We and our families need to have access to professionals who have expert knowledge about our disability or difficulty
- Support– often families too are very stressed and require emotional support.

## **Pathways on**

### *We want:*

- Information about activities, clubs and other opportunities to meet friends in our local area
- The transition to adult services to be smooth and coordinated, with locally set protocols.

### *Our families want:*

- On-going support rather than short episodic treatment approach to care
  - To be put in contact with other local services on discharge, for example, support groups, voluntary organisations, leisure opportunities.
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## Enabling frontline staff

### *What we want:*

- Better awareness in schools and colleges so that staff understand us better and can help when we are in distress. Then they will be able to work with us more effectively and help us get appropriate support if we need specialist help
- CAMHS staff should be involved in training and supporting primary care services, as well as informing them of who to refer to for those presenting with more complex problems.

## Multi-agency working

### *We want:*

- better coordination between services as we often are in contact with numerous services and professionals.

### *Our families want:*

- regular contact with a key worker or link person who can help them access services and coordinate care on their behalf.

## Commissioning

When developing new services, speak to us and our families to find out what we want

When existing services are reviewed, we want to be involved in them.

*We are very grateful to the pupils and staff at Paddock, Marjorie McClure and The Glebe schools, and the youth club run by Generate for giving up their time to talk to us.*

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If you would like more information on the work undertaken by the Foundation on young people and mental health log on to **[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)**

We also carry out consultancy work in this area.

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## Sources of evidence

1. Consultation with five groups of young people (2005/6). Foundation for People with Learning Disabilities.
  2. Foundation for People with Learning Disabilities (2002). Count Us In: the report of the committee of inquiry into meeting the mental health needs of young people with learning disabilities. London: Mental Health Foundation.
  3. Foundation for People with Learning Disabilities (2005). Making Us Count. London: Mental Health Foundation.
  4. Foundation for People with Learning Disabilities (2004). Developing Connexions: Young People with disabilities, mental health needs or autistic spectrum disorder. Web based report.
  5. Mental Health Foundation (2001). Turned Upside Down: Developing community-based crisis services for 16-25 year olds experiencing a mental health crisis. London: Mental Health Foundation.
  6. Investing in Children Newsletter – Issue 65 (Feb 2005) Tees and North East Yorkshire.
  7. National Children's Bureau (2004). Mental Health Services - What children and young people want. Highlight no. 210.
  8. Department of Health (2003). The Mental Health and Psychological Wellbeing of Children and Young People: Report from consultations with users of Child and Adolescent Mental Health Services for the National Service Framework for Children, Young People and Maternity Services (England).
  9. Department of Health. Consultation with Disabled Children in Derbyshire, prepared by the National Children's Bureau for the National Service Framework for Children, Young People and Maternity Services (England).
  10. Welsh Assembly (September, 2003). Are you listening? What disabled young children and young people in Wales think about the services they use. A consultation to inform the children and young people's National Service Framework (Wales).
  11. Our Mental Health: the support people with learning disabilities want for their mental health. A report by the Tuesday Group, Lewisham (2003).
  12. Consultation on integrating services for disabled children, young people and their families (2006). University of York: Social Policy Research Unit.
  13. Welsh Assembly (2003): National Service Framework (Wales). Consultation with Parents and Carers of children and young people with mental health and psychological well-being needs. Summary report.
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