



Department of Health and Department of Children, Schools and Families: Consultation on a National Framework for Assessing Children and Young People's Continuing Care
Response of the Association of Child Psychotherapists.

Submitted: 19 December 2008 Deadline: 31 December 2008

Introduction

1. The Association of Child Psychotherapists (ACP), the professional body for child and adolescent psychotherapists in the United Kingdom, welcomes this consultation by the Department of Health and the Department for Children, Schools and Families, which is aimed at improving the quality of care for children with complex, long-term health needs. We welcome in particular the consultation's focus on the emotional and psychological needs of children and young people, which should not be overlooked.
2. The University College London Hospital (UCLH) Child and Adolescent Psychotherapy team as members of the ACP's Hospital Group have put together this submission on behalf of the ACP. The Hospital Group is made up of child and adolescent psychotherapists who work in hospital liaison teams throughout the country, including the Royal Free, UCLH, Bristol Children's Hospital, North Middlesex, Borders General Hospital and St Andrew's Centre for Plastic Surgery & Burns at Broomfield Hospital. They meet on a regular basis to discuss the general and psychological wellbeing of children, young people and their families in hospital settings.
3. Child and adolescent psychotherapists working in hospitals perform a variety of functions. These include working with children or young people individually or with parents or other family members to address the emotional impact of the illness on the child and those around them; signposting the needs of the child and family to hospital staff; and supporting the staff who are involved with the child or young person, including doctors, ward nurses, clinical nurse specialists, physiotherapists, dieticians and other clinical and support staff.
4. Examples of the day-to-day work of a child and adolescent psychotherapist in these settings include seeing children and young people on a short- or long-term basis who are in hospital for minor procedures, those who have had accidents and those who have long-

term, serious, life-threatening conditions; working in neonatal units and later seeing those children who have been born with special needs - both physical and emotional; offering bereavement work to families after their child has died; representing the child or young person's perspective in multi-disciplinary team meetings; offering training and supervision to staff who often face traumatic and difficult situations and decisions.

Responses to questions in Annex B

5. This submission is concerned with addressing how to assess the continuing psychological needs of children and young people who have for a variety of reasons needed hospital treatment. Annex B contains several relevant questions which we have considered with this in mind, as follows.

Q. Are the four areas of assessment process the correct ones (p44)?

6. Yes, we felt that the four areas of assessment were thorough and inclusive. The principles of assessment were also felt to be helpful and we were pleased to see that the child or young person's emotional needs figured prominently. This is a complex area and as stated practitioners skilled in working with children should carry out this part of the assessment. An assessment of a child, young person or family's resilience is important in making the judgement about their capacity to manage at home. By resilience we mean the child and family's capacity to cope with the difficulty of the child's illness and ability to find the practical approaches and emotional strength to deal with them.

7. In area 3, reports and risk assessments, we would like the list of who may submit reports to include child and adolescent psychotherapists so that this group is not overlooked. Child and adolescent psychotherapists are experienced in writing reports and letters to doctors, consultants and other agencies about the impact of the illness on the child's emotional wellbeing.

Q. Does the diagram above help demonstrate the shared approach to continuing care (p54)?

8. As the diagram illustrated, contributions from health bodies and local authorities will vary according to each child and the severity of their medical condition, but there will always be a shared dimension. We feel that perhaps the diagram does not reflect, however, the complexity of children's needs on discharge. Children and young people who are in recovery from a serious condition may have high ongoing health needs after leaving hospital. Others who have had treatment and have recovered medically may need a great deal of emotional support in getting back to normal life. Still others may relapse emotionally some time later as the ongoing impact of their illness on family life is felt – it is not uncommon for family breakdown to occur under these circumstances.

Q. In assessing the care domains, is the rating of 3 highs or 1 priority or 1 severe the correct level to indicate a continuing care need? If not what should it be (p54)?

9. No. We believe that this could disadvantage many patients who, whilst generally managing their condition, continue to need support in certain areas. In our experience, children who have completed life-saving or other treatments for serious conditions need support beyond physical recovery. In particular children who have had cancer or other physically disfiguring or disabling conditions often experience difficulties around their self image, socialising, returning to school or even eating an ordinary diet once treatment has ended. For many children and young people, the life they expected to have has been altered and they are faced with coming to terms with the impact of their illness alongside rethinking their futures. They often need skilled support to enable them to do this.

10. Children may appear to be coping very well, and have what could be termed under these ratings a 'low' level of psychological and emotional needs. But fluctuations are common, particularly at periods of transition such as leaving school or starting university. Ongoing re-evaluation of how the child and family is coping is important, and doctors and other hospital staff should be encouraged to include an assessment of psychological and emotional needs as part of continuing care. This assessment must acknowledge the complexity and likely fluctuation of psychological and emotional needs over time.

Additional points

11. There are a number of further points not covered by the questions at Annex B that we wish to raise, as follows.

12. **Transition:** Children aged 16 are often 'transitioned' from paediatric to adult services. We feel that this may be unhelpful as the range of appropriate services available in paediatrics cannot always be accessed in adult services. Some conditions, such as those in the Urology or Endocrine area, can cause feelings of shame, guilt and embarrassment. Whilst we feel that adult services may handle such matters with delicacy, it is unlikely that services will have the degree of understanding that this age group requires, including the presence of child-trained staff. It is often at this point that the type of treatment they receive can influence their long-term coping with their condition. There are examples of good practice in this area which could be adopted elsewhere, including the development at both University College London Hospital and Great Ormond Street Hospital of a transitional service that connects to adult services.

13. **End of life planning:** Difficulties can arise when the child or young person's wishes conflict with the wishes of parents, who wish to continue treatment e.g. chemotherapy or bone marrow transplants. It is important to address the rights of the child whilst at the same time offering support to the family and staff, who are in the centre of difficult discussions.

14. **Ongoing support:** Ongoing emotional support beyond treatment or for parents and other family members after the child has died should be made available as part of the framework. Parents have often stated that a link with the hospital for this type of support is very important, particularly where the clinician has known the child during treatment.

15. **Neonatal trauma:** The babies born prematurely will have continuing physical needs and often have psychological difficulties relating to their experiences in the Neonatal Unit. It is now recognised that babies are often traumatised by the necessary but invasive procedures used to save their lives. After care should include a recognition of the ongoing emotional support that might be needed for some families, and that a clear pathway to services should be in place should the need arise.

16. **Teenage parents:** Teenage mothers will have the ordinary needs of a young person alongside the needs of their infant. Parenting and emotional support for both mother and child should be considered.

17. **Chronic and ongoing conditions:** Where a child or young people has had a diagnosis of cancer or another chronic condition, help and support should be offered to families to process the diagnosis, manage treatment and later to live with the ever-present fear of relapse. Help will often be needed to support children and young people to return to an ordinary life, for example returning to school, rejoining their social life or participating in family life. Their emotional development needs to be part of ongoing care.

18. **Support for parents:** Parents may need support to recover from the enormous strain of caring for an ill child. It is well documented that relationships can be put at risk during this time, and family breakdown is not uncommon. Parents may need to be helped to adapt to allowing their children to return to a normal life.

19. **Post-discharge support:** We are also aware of the raised expectations families have for services that they have received in abundance in hospital to continue to be available on discharge. Local provision varies hugely and often families experience feelings of abandonment and isolation when they finally leave hospital. Child and adolescent psychotherapists within hospitals offer a continuing service but it is not always possible for families to continue to travel long distances to use these resources. Children, young people and families need access to good local psychological services.

20. **Children of adult patients:** Although not exactly part of this consultation, this issue does link in with the continuing emotional health needs of children. Children whose parents have serious disabling, disfiguring or life-threatening health problems often find themselves facing issues far beyond their capacities, including coping with a parent's death. We would like to see a dedicated service for these children that offers them and their parents a supportive service to manage these challenges. Currently the availability of such a service varies enormously from trust to trust.

Background information

21. The **Association of Child Psychotherapists (ACP)** is the professional body for child and adolescent psychotherapists in the United Kingdom. The ACP is responsible for ensuring that the training and practice of child and adolescent psychotherapy is of the highest standard. It is also working to increase its availability to children and young

people within the public sector, including the NHS, children's centres, local authorities and schools.

22. Our 760 members work with infants, children and young people of all ages, as well as their parents, families and wider networks – including teachers and social workers. Most child psychotherapists work within the NHS as core members of Child and Adolescent Mental Health Service (CAMHS) teams. Our members also work in hospitals, social services departments, nurseries, schools, specialist clinics, the voluntary sector and in private practice.

23. Child and adolescent psychotherapists see children and young people individually or with parents or other family members. They are able to treat a wide range of difficulties ranging from problems with sleeping to eating disorders, self-harm, anxiety and depression.

24. They also play an important role supporting other professionals who work with children and young people, like GPs, health visitors, nurses, teachers, mentors and social workers. This support may take the form of training, supervision or consultation. ACP-trained child psychotherapists undergo a rigorous six-year training at doctoral level, including a four-year clinical placement in a multi-disciplinary Child and Adolescent Mental Health Service (CAMHS) team or its equivalent in the voluntary sector.

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