Child Studies Group report

UK Mental Health Research Network commissioned this group together with Professor Clair Chilvers to report on the research priorities in Child and Adolescent Mental Health Services (CAMHS).

The need comes particularly from the unsatisfactory nature of the evidence base for common interventions. CAMHS research has been very successful in describing the problems in the community, and has produced distinguished work on the risk and protective factors that affect the initiation and course of disorders. The translational research into clinical practice, however, has been taken up by only a few centres, and is now a key task for the NHS. The expansion of CAMHS is a governmental priority, and the need for research on mental health has been emphasized by the National Service Framework for Children.

The group was recruited from psychiatry, clinical psychology, developmental psychology, and social science; individuals were approached on the basis of a search for investigators who had successfully completed substantial trials in England. Our key focus has been *the development of reliable evidence about the treatment of common mental disorders in childhood and adolescence that continue into adult life and impair functioning.*

We went about the task by:

1. Making recommendations for priority areas. This has involved:

a) Collating current research in England and Wales. Academic departments have been circulated and research databases consulted.

b) Reviewing the existing literature on CAMHS interventions and grading each intervention for the quality of evidence available now.

c) On this basis, identifying key gaps. The full committee met for two day sessions, wrote and critiqued reviews of subject areas, produced a consensus on priority areas, and contributed the result to a Department of Health national conference on developing R&D within CAMHS (in January 2005). The outcomes of this conference have in turn been incorporated into these recommendations.

2. Considering how to develop trials capacity. Information was collected from trials investigators on the obstacles that have been encountered; in training, attitudes, finance and organizational systems.

3. Attempting to contact users' groups; this experience suggested that further development in this area will be needed. We will continue to work with SURGE, and it is clear that creating such groups will require a systematic approach.

We are making our recommendations in three main areas:

The development of trial infrastructure, which we think is the highest priority; a set of general priorities for future research, which specific projects should bear in mind; and suggestions for a small number of specific projects for which bids might be invited.

1. Developing an infrastructure for research and development on child and adolescent mental health

Children, adolescents and their families suffer greatly from mental disorders, and the effects endure into adult life. Most adult mental illnesses have their origins in childhood or adolescence. Unlike the situation in adults many mental disorders in young people are increasing in frequency. If this increase goes unaddressed then we can expect to see a subsequent increase in the level of adult disorder in future years. In short, child and adolescent disorders represent a major health policy target.

The basic science response to this need is advancing quickly. First, the disciplines of neuroscience, genetics, psychology and social science have provided a much more complete understanding of the risk factors that interact to lead to mental disorder than that previously available. Second, a substantial and increasing number of scientifically grounded, evidence-based, treatments are now available. In spite of this, and in spite of increasing CAMHS funding, most affected young people are not receiving appropriate interventions. This is because there is a striking and alarming gap in clinical trials, and related research in the UK that could provide the evidence base to help improve this situation. Our survey identified only a handful of randomised controlled trials. Even trials funded by pharmaceutical companies are scanty.

This group's work has identified some major obstacles to ensuring a proper evidence-based solution to this lack of appropriate interventions and therefore achieving the situation, envisaged by the National Service Framework, in which children with disorders have access to scientifically proven therapies. The obstacles are great, even greater than in adult mental health and require a sustained commitment to overcoming them if progress is to be made. We are proposing a set of feasible actions, some of which can be made directly by MHRN, and some for which the MHRN could be influential through its partners in the NHS and local authorities.

a) Technical improvements are required for trials to be more effective and these need to be commissioned – especially, the development of measures of quality of life for young people and families, and process measures e.g. relating to the fidelity to treatment.

b) Specialist statistical advice should be commissioned for the planning of some trials. Most of the mathematical and design issues are common to those in other specialties of psychiatry, but some are not: referees increasingly expect that the techniques of developmental research should be incorporated, such as the use of growth curves and individual trajectory analysis, and this in turn creates demands for new techniques in the handling of missing data or brought-forward end points. We suggest the steering group making funding available for those planning a trial to commission such advice from a senior academic.

c) Training is seen as crucial. PhD studentships in interdisciplinary departments should be created for applied research; postdoctoral fellowships should be created for basic scientists to work on clinical topics alongside clinicians. Mid-career fellowships should be expanded, to allow NHS clinicians and managers to advance their knowledge of research approaches.

The above recommendations are cast primarily in terms of NHS issues because they seem feasible. Very similar considerations apply to the necessary interdisciplinary partnerships with social care and education, but it is clear that even greater change is needed here to achieve a wider commitment to R and D for mental health.

- General technical support is needed, but for the most part is not different in kind from that required by adult mental health and will fit naturally into existing hub systems. In contrast, *specialist trained recruitment co-ordinators* will be needed to work with services that are usually quite separate from adult mental health.

- Development of new treatments has been a weakness in UK research by contrast with other scientifically active nations. Most evidence-based therapies have been developed by researchers and practitioners in the USA, and it is often unclear how appropriate these are for use in a non-USA setting. Development of interventions appropriate to the environment of the NHS requires strengthening of working links between basic scientists (developmentalists and neuroscientists) and clinicians with good ideas.

- Medium – and long – term perspectives have to be included. Many potential interventions claim their economic justification on the basis of benefits during working life or reduction of future service expenditure. If this is to be judged rigorously, mechanisms are needed for longitudinal study.

- Translational research was a main priority throughout the Group's process of consideration and consultation. It is notorious, and demonstrated by meta-analysis, that effect sizes in real-world practice are very much smaller than those achieved in efficacy trials. We think that this calls for a new kind of research, of which so far there are few instances: the study of the factors promoting or obstructing the achievement of effectiveness. This must include detailed knowledge of the communities into which interventions are to be introduced, and active user involvement will be essential. The involvement of service users throughout the R & D process should be developed with urgency.

2. Priorities for Research

Delivery and effectiveness of interventions with trial evidence

- Real-life condition trials: pragmatic establishment in clinics, effectiveness trials
- Overcoming barriers to multi-agency working
- Assessment of value of protocols and fidelity to them in improving outcomes
- Self-administered therapy: trials of effectiveness
- Proof of concept studies for delivery outside clinics.
- Use of established treatments in clinics: service comparison studies

- Improved outcome measures esp. quality of life measures.
- Economic analyses: including model development for costs

Population Based Interventions
- Schools: trials of health-based interventions in school settings
- Early Family Support: e.g., extending trials of parent training or support
- Public Heath Information: developing methodology for assessment
- Primary Care interventions: proof-of-concept studies of mental health interventions

Disorder-related issues

Anxiety
- Extend and evaluate delivery of known treatments

Depression
- Comparison of CBT and antidepressant medication
- RCT of medication in severe adult-type depression

Conduct disorder
- Modification of US treatment programmes for evaluation in routine practice
- Proof-of-concept studies for intervention in severe adolescent problems
- Continuities from adolescence to adult personality disorder – to develop targets for intervention

ADHD
- Proof-of-concept studies for non-drug therapies
- Prevention in preschool
- Transition to adulthood

Obsessive compulsive disorder
- Effectiveness trials for psychological therapies

Tourette and tic disorders
- Proof-of-concept trials for psychoeducation

Autism
- Large-scale multi-site RCT of best-evidence social communication intervention -
- Longitudinal study of factors predicting outcome

Psychosis
- Safety of anti-psychotic drugs
- Trials of psychosocial interventions

Bipolar Disorder
- Clarification of diagnostic criteria for 'pediatric' bipolar disorder

Substance misuse
- Effectiveness trials of approaches such as multi-systems family therapy, motivational interviewing

Other Disorders: areas for general recommendations
- Eating Disorders
- Attachment Disorders
- Early childhood problems of feeding and sleeping
- PTSD

3. Specific topics for which to encourage funding and bids

a) Development of treatments for anxiety in young people. Problems such as social anxiety in teenagers, specific phobias at all ages and separation anxiety have been treated successfully in research trials, but surveys suggest that the effective treatments are rather seldom applied. A programmatic approach would include, in early stages, the development and evaluation of widely disseminable therapies, including self-instruction, primary care interventions, training existing professionals to use behavioural and cognitive approaches. As trials clarify, the factors that make for treatment resistance, developmental and neurobiological research designs should clarify the mechanisms involved so as to lead to a further operation of trials – and to proceed to clarification of the differences between childhood and adult depression.

b) Early interventions for anti-social problems. Early studies would include trials of parent- and school-based interventions for oppositional and conduct disorders; referral process and outcome at CAMHS; later studies to include identifying factors responsible for adolescent to adult continuities and neurobiological causes of conduct disorders.

c) High risk and hard-to-reach groups. Young people known to be at very high risk of adverse outcomes need particular attention, not only because of their current level of suffering and costs to health; but also because of the future severe health and social burden that they will represent. Trials of interventions for these groups are therefore needed - e.g. young people in care, young people with multiple complex disorders (such as those treated in inpatient settings). Complimentary to this work should be investigation of the best form of intensive care provision in CAMHS for different groups, for instance inpatient vs assertive outreach services

d) Development of assessment and therapy for ADHD. The current situation is changing, in that the diagnosis has become more common, with uncertainties about the boundaries of the disorder; and an efficacious treatment (stimulant medication) has been applied increasingly widely, but outcome remains poor. A series of studies will be needed (i) to assess psychological methods of enhancement of treatment (e.g., compliance training), (ii) to research the influences determining development through adolescence and develop treatments in the light of results, and (iii) to increase reliability and decrease cost of assessment.

e) Depression treatment. Cognitive behaviour therapies have received “some evaluation, but their place needs to be assessed in the light of (i) recent concerns over the alternative of antidepressants, (ii) the need to achieve effectiveness on real-world situations. This is likely to require further trials of cognitive approaches. The long-term follow-up of treated children should be encouraged because of the very high rates of adult depression in the later course of diagnosed young people. The existence of small numbers of children who show a typical adult-type depressive illness entails the need for a separate trial for them of the SSRI drugs whose contra-indication is based on the general run of less severely depressed children.

f) A paediatric psychopharmacology group should be formed to develop research projects.

g) A group should be formed to develop a strategic approach to recruitment methods, and methodological improvement (e.g., in measures of quality of life and economic models for analysing outcomes). This group should advise MHRN on child and adolescent mental health issues; and should meet (perhaps annually) to review development of the field.

h) A means should be established for statistical experts to advise MHRN on the analyses of developmental studies.

The DH theme of "Antenatal and postnatal care; identification of predictive, modifiable risk factors for mental ill health in the offspring" will call for collaborations between basic and clinical scientists to identify early vulnerability (e.g., through fetal measures, DNA variants, and exposure to potential pathogens such as drugs and toxins in pregnancy) together with longitudinal study of outcomes; full notice should be taken of major ongoing projects in the USA and Netherlands to assure complementarity rather than duplication.

The DH theme of "How to overcome barriers to multi-agency collaborative working" will call for collaborations with social science, e.g., for economic incentives or disincentives to joint working and for the description of attitudes towards joint work by policy makers, managers and practitioners.

Projects within all these areas should take account of the general issues outlined above. In particular, a focus on interventions that are feasible in the ordinary conditions of practice, trialling them in real-world practice as soon as is reasonable, including health economic dimensions, and assessing mediators and moderators of outcome and process measures such as therapist skill and treatment fidelity.

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