Autism Speaks Response to the Cooksey Review of UK Health Research

Autism Speaks is the only UK organisation dedicated to discovering the causes of autism. We are a registered charity that raises funds to accelerate biomedical research to determine and understand the causes and biological basis of autism spectrum disorders; and through that understanding to discover and promote new ways of improving the quality of life for all those affected.

Autism is a complex and lifelong brain disorder that significantly impairs a person's ability to communicate, to respond to his or her surroundings and to form relationships with others. Current estimates suggest that 1 in around 166 people has an autistic spectrum disorder and there are estimated to be around half a million people on the autistic spectrum in the UK. The exact cause or causes of autism are at present unknown.

We are led and inspired by people directly affected by autism and began our work late in 2004, rapidly gaining a position of influence as members of the DfES Autism Research Co-ordination Group, DoH Mental Health Research Funders Group and the Advisory Group to the All-Party Parliamentary Group on Autism. We hope to make our first research grants during 2007.

We are pleased to contribute to the review. We have responded only to those questions where we can offer insight into how organisational and procedural changes arising from the review could benefit the millions of people affected by mental illness and developmental conditions such as autism whose needs currently attract little research interest and funding.

We believe that charities representing these groups have an important role to play in stimulating interest and funding ourselves but that this must be in the context of a shared and structured dialogue with government, researchers and other stakeholders about research priorities and the implications of research findings not only for healthcare and health outcomes but for wider government policy and practice.

We would be pleased to meet with the Cooksey team to discuss this response.

1. What are the strengths and weaknesses of the MRC and NHS R&D programmes at present? How do each of these support the research and training needs of the NHS, social care, industry and academia? Does more need to be done?

The MRC has a significant reputation for its portfolio of basic and laboratory-based research and for its wide ranging programmes of clinical trials. The strength of its peer review mechanisms is widely recognised. Whilst its independence from political influence is valued, its 'response-mode' operation weakens its ability to take a strategic view of health research priorities and its inability to build reserves of funding weakens its ability to respond proactively to emerging health concerns.

The NHS is a unique, but under-exploited environment in which to conduct health research. Whilst the new research strategy 'Best Research for Best Health' has begun the process of creating a stronger platform for research, peer review mechanisms are often weak, and research funds are too easily diverted to underpinning service delivery and meeting NHS targets. Any new arrangements will need to ensure that trust concerns about meeting their patient care objectives are addressed before greater commitment to research can be achieved.

Nevertheless we welcome the creation of a single research fund as it will ensure that a higher proportion of current allocations is actually spent on research. In particular we hope that the creation of a single fund will restore interest in pilot and exploratory studies for which it is currently difficult to find funding either through the MRC or through the NHS. Such studies are particularly important in developmental and psychiatric conditions where understanding of the basic science remains weak.

2. What do you believe are the key scientific and organisational challenges facing health research, and underpinning training, in the UK over the next decade? How might the UK Government best help address those challenges? What do you believe should be the Government's objectives for health research, and why?

The distribution of health research funding across a number of government bodies, industry and charities and the poor co-ordination between them has limited UK research capacity and it is imperative that the Government does more to encourage co-ordination and to grow the researcher base.

The government's objectives for health research should be three fold:

- to further our understanding of conditions such that the UK can be at the forefront of unlocking the potential for treatments and interventions
- to further our understanding of conditions such that the costs to the UK of long term conditions can be reduced by more effective prevention, earlier interventions and treatments
- to further improve our understanding of conditions such that the life quality and chances of people with a range of conditions can be significantly enhanced.

In particular there is a need to exploit the opportunities afforded by a unified national approach to health care provision to encourage shared research between bench and bedside. The creation of a unified research structure within the NHS and of the electronic medical record creates an underpinning framework that can be used much more effectively than to date. There is also an opportunity to encourage new entrants in many disciplines to see research as a key theme of healthcare practice rather than as an academic specialism with limited real world application. Training approaches should reflect the centrality of research in knowledge and practice development. The creation of research networks is facilitating data sharing. These are all developments that the government should continue to support and promote.

3. What should be the Government's priorities for health research? Is there anything it should stop doing or funding? What is it not doing or funding that it should do, and, in the absence of further sources of support, what can it lower in order to release the necessary funds?

What is critical is the creation of mechanisms that allow a range of voices to be heard in determining research priorities. The DoH is essentially target-driven, the MRC investigator-driven and industry market-driven. Charities fund in accordance with their ability to raise funds, which is much greater for life-threatening conditions. Issues such as prevalence and socio-economic impact play little part explaining why mental illness and developmental, learning and language disorders struggle for funding. The annual UK research spend on autism is for example less than the additional lifetime costs of caring for a single person with autism.

The UKCRC is an example of how a range of stakeholders can engage together. Some form of supra-forum to consider research priorities would be beneficial, particularly if it allowed those affected by disease and their representatives to contribute.

6. How might better links be forged between 'basic', translational and applied researchers, working across the whole field of health research, from the laboratory bench to the front line of the NHS? How might better links be forged across disciplines, e.g. with engineers, physicists, and social scientists?

The creation of a number of research networks in recent years has provided a platform for bringing together researchers working across the whole field of health research around an area of common interest. We believe that such networks can be expanded to include a broader range of contributors covering for example not only biomedical research, but intervention effectiveness and best practice. This could in particular help to strengthen the evidence base underpinning health, educational and social services.

8. How can UK health research funding be most effectively used to provide the appropriate infrastructure for basic, translational and applied research, whether funded by the UK public sector or other sectors? How can UK health research funding be most effectively used to support the work of NICE, facilitate innovation and collaboration with industry, and address market failures in the application of healthcare?

One important way in which UK health research funding can contribute is through reducing the barriers that exist between research carried out in academic and clinical settings. One of the strengths of UK health research is the location of university departments either in or in close proximity to clinical settings, but there has not always been the degree of cross-over that this physical co-location might imply. There may need to be specific schemes where funding is only available to a mixed academic and clinical economy.

The creation of a unified NHS R&D structure is a helpful step towards reducing the fragmentation of research within the NHS but thought now needs to be given to how researchers may be able to move more easily (for example through periodic placements and fellowships) between academia, the NHS and industry. Shared web databases and web portals are likely to be increasingly common and effective mechanisms for supporting these multi-disciplinary and multi-participant networks and would be an appropriate use of UK health research funding.

9. What lessons should the UK learn from other countries in making the proposed changes to the institutional arrangements for the funding of health research?

There are valuable insights to be gained from exploring both the US and Canadian models of health research funding.

10. In implementing the single fund for health research, to what extent should the MRC and DH/ NHS R&D be merged or brought together? And to whom should the single, ring-fenced fund be accountable? Please provide reasons and any supporting evidence for your response.

One of the distinguishing characteristics of the MRC is the robustness of its peer review process which is not always replicated within the NHS. It is important that peer review remains at the heart of UK health research and is used to underpin a stronger evidence base for health care and intervention and the work, for example, of NICE. Given that the larger proportion of health

research spend is within the NHS, it would make sense if there were to be a gradual diffusion of MRC practice into the NHS supported through the clinical networks.

Responsibility for the management of a single fund will be a function of the government's conclusions about the ultimate role of health research – economic stimulation or healthcare provision. Maintaining shared responsibility between the DTI and DoH may prove to be the best way of securing continuing but important tension between these roles.

11. To what extent does the success of recent innovations in health research (e.g. Clinical Research Networks) and the proposed structures rely on the new Connecting for Health NHS IT system, and to what extent should it do so?

A strong underpinning technology framework is essential to both healthcare delivery and health research. It remains to be seen how effective the Connecting for Health IT infrastructure proves to be.

12. Given that NHS R&D is currently devolved, but that the work of Research Councils is not, how can these functions work best together to maximise the health and economic benefits to the UK?

The keys to maximising the health and economic benefits of medical research in the UK are co-ordination and communication. We all have a stake in ensuring that publicly funded research is effective, efficient and value for money.

It is important therefore that any new structure allows research findings to be shared. UK universities already have networks that effectively span home country, UK and international activities and any new health research structure should encourage and facilitate collaboration. Mechanisms such as research networks and policy and priority-setting frameworks are the key to ensuring that different organisational structures do not become barriers.