

Workshop to Review Arrangements for Commissioning Services for Children with Disabilities & Complex Health Needs

Wednesday 13th September 2006, Royal Society of Medicine, London W1

Chairman - Chief Executive of The King's Fund

1. Introduction

The workshop was organised by Andrew Ross of the Children's Trust, Tadworth and Francine Bates of Contact a Family. A list of the participants is attached.

Against the background of NHS reform, new proposals for the commissioning of specialised health services (Carter Review) and developments in joint commissioning with local government, we wished to focus attention on the needs of the relatively small generation of 'new survivors', children with multiple disabilities and complex health needs, whose families face a diverse and costly range of needs and will need long-term support. Our aim is to develop effective service commissioning for this population, whose needs are often very poorly served.

2. Summary of key themes and points to be communicated to the Treasury/DfES Review of Services for Disabled Children and to help inform the second phase of the NHS Commissioning Framework to be published in December 2006.

- Improved commissioning of services for disabled children and their families will depend partly on the availability of better data. There needs to be some investment in better epidemiological data. To plan services better we need to define, categorise and quantify need. A more numerate approach to planning would facilitate the measurement of outcomes and develop the evidence base for further service change (C. Wells: 'decide what has to be known to justify changing the way we do things'). The Child Health Mapping exercise underway in the NHS should be used to help quantify and define the populations of children with exceptional needs.
- Present systems designed to address multi-faceted complex health needs seem extraordinarily complex and present too many examples of failure with inadequate clarity about who is responsible for what, resulting in bureaucratic and time-consuming turf wars, sometimes over small amounts of money.
- There was a strong consensus behind the principle of joint commissioning. The Carter Review puts forward a model of specialised commissioning allied to newly configured Strategic Health Authorities, thus spreading risk between PCTs. The meeting expressed some concern about giving specialised commissioners in the NHS all the responsibility for meeting the needs of disabled children with even the most complex conditions. We saw it as a challenge to link specialised regional health commissioning with local action and local assessment of need. The ideal would be a joint approach to commissioning at all levels, local, regional and national.
- There was a consensus that children's trusts are an important innovation, a sound model upon which to base the development of joint working. The meeting

noted that the Government has not followed through their initial enthusiasm for this concept by calling local authorities to account for their progress in implementing the 2004 Children Act.

- The meeting shared the view that obstacles to joint commissioning of children's services are largely attitudinal – a matter of culture and history. There is no longer any legislative barrier to joint working but there is evidence that a coherent holistic approach to service commissioning often breaks down because of narrow and short-term preoccupations with budget restrictions applying to just one aspect of service need. There should be a coherent and long-term view of service delivery, seen through the eyes of service users – children and their parents. This is about promoting shared values and a sense of outrage when a disabled child's basic requirements for daily living are not being met because of what can be quite small budgetary considerations. There was a sense that children's needs in general have not had a sufficiently high profile nor sufficient priority in commissioning health services.
- Much more attention should be given to the development of an integrated 'pathway' approach with skilled and experienced professionals providing children and families with a plan for the journey ahead of them. Children with multiple disabilities and their families are frequently subjected to a series of episodic interventions from diverse agencies, insufficiently linked together. A pathway leading to better health and fulfilling educational opportunities must take account of very diverse needs including housing, various equipment needs, respite care, opportunities for employment, etc. The National Service Framework Exemplars of 'Complex Disability' and 'Acquired Brain Injury' describe this well. The meeting did not determine whether better joint commissioning should be based on health, social services and education or whether it should bring together access to the whole gamut of needs including housing and youth justice. However, there was a united commitment to the need for a holistic and long-term view of service commissioning – a whole system approach.
- There needs to be a key professional to hold it all in place. There needs to be renewed emphasis on giving families access to an effective key worker.
- There is merit in systems for pooling budget responsibility to spread the financial risk associated with relatively low incidence and higher cost cases which can 'bust the budget' held by individual commissioners. Pooling responsibility is not just about reducing financial risk though. There needs to be more expertise applied to commissioning of highly complex cases and along with joint funding should be a system of accumulating experience which should lead to better outcomes and better value for money. There is useful experience to be had from local authorities' Regional Partnerships in SEN which preserve local autonomy but combine experience with a shared system for monitoring quality.
- There was some polarity of views around the idea of 'ring-fencing' commissioning arrangements for children with multiple disabilities and complex health needs. Obviously drawing boundaries with criteria to include or exclude certain cases would bring its own problems. Some kind of special case can probably be made for several different groups but the balance of opinion here was that families bringing up highly vulnerable children with multiple disabilities and very complex

health needs have such diverse and poorly understood problems that they deserve to be given special attention. They have most to gain from a holistic integrated pathway approach. If we can develop a system which works for these children and their families then it is likely to work equally well for families with less challenging sets of need. We heard evidence that where money for CAMHS services has been ring-fenced, it has produced better outcomes for the children involved. At the moment specialised commissioning of health services is based on a defined list of some thirty-five specialised hospital services. One item on that list refers simply to 'specialised services for children'. This gives no useful guidance as to what constitutes a specialised service for children, nor does it recognise the long-term nature of disabled children's health needs. Our concern is not with short term medical intervention to provide a cure but with long-term quality of life. If we are to make holistic joint commissioning work for children with very diverse needs we must surely have some definition of the target population whose needs have to be budgeted for. One contributor showed how a workable definition of 'complex needs' can be arrived at.

3. An outline proposal for a joined-up model of specialised service commissioning. (This idea evolved in discussion amongst a small group of participants at the end of the workshop but draws on recommendations from all three break-out groups).

- We recommend the creation of a small infrastructure at regional level to develop joint commissioning for the most expensive and complex cases of need. This would take the form of new posts accountable jointly to new Strategic Health Authorities and regional Government Offices. They would administer a fund whose purpose would be to help the small but growing population of 'technology dependent' children with very significant health needs to leave hospital so they can be cared for at home. The money could be used for intensive rehabilitation programmes or transitional care packages while arrangements are made to provide adequate support to help a family care for their child at home and perhaps also to contribute to those longer term packages of care.
- Money would be made available from the Fund to subsidise care and rehabilitation packages for a limited number of children, but only provided there is evidence of an integrated care pathway which joins up local services and gives the family a coherent plan which they can rely on. The regional post holders would thus have at their discretion a financial incentive to improve joint commissioning for those high cost cases most in need of it and which present the greatest challenges to budgets held locally. A fund of, say, £200 million nationally could be used to top up local budgets with amounts of up to, say, £50,000 for cases likely to cost in excess of £100,000 per annum.
- This model should build on DfES experience with the SEN Regional Partnerships. They would act as catalysts for the negotiation of better joint commissioning arrangements, supporting and extending networking amongst the members of a 'purchasing club'.
- Ventilated and other technologically dependent children are currently spending long periods in the inappropriate environment of a PICU. This hospital care costs

more than twice as much as a package of appropriate care in the community, provided the family has the right training, support, equipment and housing to enable them to look after their child at home. The proposed Complex Disability Fund should therefore produce a return on investment by freeing up costly places in PICU's and providing an outcome which is better for both child and family.