

FRIDAY 13 MAY 4.30-4.50 PM

## **TRANSFORMING CHILDREN'S SERVICES**

**DR JOHN LOW**

**Chief Executive, RNID**

### **INTRODUCTION**

Early Support is a Government programme involving the Department for Education and Skills, the Department of Health, and Sure Start. Its purpose is to improve the delivery of services to disabled children under three and their families. It promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector.

Early Support is a working example of a cross-sectoral partnership delivering positive change for families and children across England. RNID is proud of the contribution the programme has made and believes many of the lessons we learnt in developing it have application across Europe.

I will:

- i. highlight how the Early Support programme is transforming children's services and leading to the enhancement of the experiences of parents and children;
- ii. demonstrate how partnership working between voluntary organisations and Government can effect genuine and lasting improvements;
- iii. examine lessons learned for the future.

In England, there is a gap between expectation and reality in the delivery of children's services. In seeking to bridge that gap, Government is beginning to focus on the added value the not-for-profit sector brings to the modernisation of public services.

The Government wants to bring about radical change in public service delivery. Parents want to see more flexible support for young children – support that is better co-ordinated and more holistic – in other words, more attuned to family need. The voluntary sector can play a major role in helping achieve these aims, not just as an alternative service provider, but as a catalyst for change.

As a result of our closeness to service users, we have the ability to leverage resources, apply expertise and focus campaigning energies. This energy and passion for change can be harnessed to break down the barriers that prevent modernisation taking place.

## THE ISSUE

So what are the problems to be addressed?

In England, families with very young children who have a disability often experience:

- information and support provided by different agencies that is not well-coordinated
- delay in the process of assessing their child's support needs
- support services that are not adequately resourced.

This has been a consistent message from families over the last twenty years and it informed both the development of **Together from the Start**, about which I will say more later, and working party activity leading to the **National Service Framework for Children**, the Government's 10 year plan for health services.

Despite clear examples of good practice in some places, and the passionate commitment of many front line professionals, parents often find it difficult to access the necessary information and support. On an everyday level, poor multi-agency working translates into multiple contacts with people who do not appear to talk to one another, poor flow of information about the child's disability, and inadequate, fragmented support provided by a number of different agencies.

Parents in this situation tell us that their lives are a 'constant battle'. As one parent put it:

*'I remember thinking if only you could get everybody together. I was constantly ... going off and having a conversation with one person and then going off and having a conversation with another person. If only I could have got them together, it would have been easier.'*

And, in the words of another frustrated parent:

*'In the early days it was like living in a 'fish bowl', people looking in on our lives, appointments here and appointments there, knocks on the front door with another professional asking us the same questions about our son.'*

*'My son doesn't receive a co-ordinated package of therapies. Many 'experts' see him and deal with their part of him and send him back to me for re-assembly.'*

Poor co-ordination of the many agencies involved with some of these families lies at the heart of these problems, which are at their most acute for parents with children who have multiple or complex support needs.

The situation is further complicated by difficulties attracting and retaining high quality staff, and the relatively low priority accorded these services where budgets are under pressure.

As the Audit Commission noted last year:

*'Services for disabled children are still 'Cinderella' services. Their level of priority remains low, with other priorities experienced as more pressing.'*

The Early Support programme has developed over the last three years to become a national initiative, impacting on the lives of many populations of children with disabilities or special educational needs and their families.

I want to focus on issues that are particularly relevant for **deaf children** and talk about:

- how newborn hearing screening acted as a trigger to focus attention on early intervention services
- how organisations in the voluntary sector have facilitated partnership working between government departments, service users and the professionals who work with families
- maintaining the interests of a particular population of service users (deaf children and their families) at the heart of larger, pan-disability initiatives.

## **CAMPAIGNING FOR CHANGE**

As we have already heard today, the introduction of newborn hearing screening brings new opportunities and has the potential to transform lives. Research from America suggests the lifetime costs for those with pre-lingual onset of deafness exceed \$1 million. Government has a legitimate interest in the potential of earlier identification and intervention to lessen the long-term cost to the public purse as well as improving services.

Early identification makes it possible to intervene in a number of different ways before language and communication deficit develops, and to support very young children with digital hearing aids and cochlear implants where appropriate. It also allows more time for families to absorb information about their child's situation and the full range of communication, amplification and surgical options available to them.

At the time that newborn hearing screening was first introduced in England, the argument for developing services for deaf children and their families was helped by an increased emphasis on early intervention and better multi-agency working in key policy documents, like the SEN Code of Practice. More recently, the Government's formation of a new Children's and Young People's Directorate, cutting across old departmental boundaries has also helped. These developments made it possible to argue that the service development needs of deaf children simply required the application of current policy priorities to a particular population.

However, none of this would have been persuasive without the ability of a wide range of stakeholders and partners to work together, repeating the same messages clearly and consistently to make the case for change.

From RNID's point of view, this has involved building and developing a working relationship with Government over a number of years, the secondment of staff into the Department for Education and Skills, and secondment of civil servants out to head up service development initiatives from a physical base in our organisation. However, this working relationship has only been effective in so far as it has facilitated much broader partnership working across the voluntary sector, with families who use the services involved and professionals who work with families with young children with disabilities. It is this partnership which is delivering practical solutions to obstinate and familiar problems.

## **FROM CAMPAIGNING TO THE IMPLEMENTATION OF SERVICE CHANGE**

RNID was active, alongside many other voluntary organisations and agencies, in campaigning for service change in 2000 and 2001, as newborn hearing screening was being introduced across England. This activity led to broader working party activity and the issuing of a key piece of guidance by the Department for Health and the Department for Education and Skills in May 2003. The guidance was called:

*Together from the start – practical guidance for professionals working with disabled children (birth to third birthday) and their families.*

At the same time, 'sister' guidance, focusing on the particular support needs of deaf children identified by newborn hearing screening was also issued:

*Developing early intervention/support services for deaf children and their families.*

Unusually and significantly, the second piece of guidance was published jointly by the Department for Education and Skills and RNID – an organisation in the voluntary sector.

The Early Support programme puts the principles outlined in *Together from the Start* into operation. To date, the Department for Education and Skills has invested a total of £13 million to support the development of the programme. 45 multi-agency partnerships across England are currently funded by Early Support as 'pathfinders', to implement service change at local level and to feed back their experiences of implementing multi-agency service change to central government. You can read about the activity of these 'pathfinders' on the programme website – [www.earlysupport.org.uk](http://www.earlysupport.org.uk)

The steering groups for the Early Support programme include voluntary sector partners working alongside Government agencies. This has brokered a dynamic and new method of delivery, which brings the expertise and practical knowledge of organisations that work directly with families and children together with Government policy, initiatives and resources. Key to these developments has been the capacity of voluntary sector organisations to facilitate and manage consultation with families and the professionals who work with them. The suite of materials produced by the programme over the last two years has directly involved many hundreds of families who use services and professionals who work with families. Voluntary organisations have been key to this process, providing a network through which Government has been able to consult directly with parents, who have piloted the use of prototype materials and made suggestions for how they could be improved, to meet the needs of parents better.

For example, the *Early Support Family Pack*, which provides information about how services work and a standard family-held file, which helps the co-ordination of service delivery in practical ways, was driven by a steering group involving 15 different voluntary organisations, representing the interests of many different populations of children. Their participation enabled progressive refinement of the material over time, in response to what families who had 'been there before' said was useful and what was not, because they managed the consultation with families and fed back comments to the centre. This complemented perfectly the wide-ranging consultation with professionals from health, education, social services and voluntary organisations that was also running, in parallel, through 2003.

For those thinking about deaf children identified by newborn hearing screening, the contribution of the National Deaf Children's Society, to this multi-faceted, national initiative, alongside other organisations will be of particular interest. At the same time as other organisations were asked to work with parents to develop family-friendly information, NDCS was commissioned to develop standard information on deafness to support early discussions between families and professionals, following identification of deafness. This material is now in use across the country and it is a powerful means to ensure families everywhere have the information they need to make important decisions as understanding of their child's situation grows during the first three years of life. You can view the **Early Support Information**

**Booklet for Parents** on deafness on-line or at the Early Support exhibition stand.

Early Support has also worked directly with more than 120 families with deaf children under 3 in 2003 and 2004 to develop a new, standard, developmental profile for deaf babies and children. The material is family held and it enables parents to observe and celebrate their child's development though the first three years of life. It directly supports partnership working between families and professionals, by underpinning discussion with rich evidence that is transparent and jointly-owned, because it uses the observations of full-time carers. Another organisation in the voluntary sector, the Ewing Foundation, was a key player in these developments, through the involvement of Sue Lewis, who lead and managed this project, while employed by them.

These materials went into general use across England from September 2004 and Early Support has now delivered 11 training events across England for professionals and families in 2005 in partnership with the Newborn Hearing Screening Programme.

The activity of the Early Support programme as a whole has expanded dramatically over the last 3 years and it is forging new working arrangements at local level in many different places, which are bringing positive benefits to families and children. For example:

Early Support Pathfinders are all actively supporting the development of key worker services as one means to improve the continuity and co-ordination of services.

Face to face awareness raising and conferences and a systematic programme of training on better co-ordinated multi-agency service delivery, using the Early Support materials will involve an estimated 6,000 professionals, managers and parents/carers in the one-year period beginning September 2004.

More than 25,000 **Early Support Family Packs** have been distributed and each of the **Early Support Information Booklets for Parents**, has had to be reprinted in response to the demand. More than 14,000 copies of the booklet on deafness have now been distributed.

Through all this, the participation of voluntary organisations has ensured that the particular interests of young deaf children and their families have been held at the heart of bigger developments, for larger populations of children.

## **INNOVATIVE PUBLIC/PRIVATE PARTNERSHIPS**

Early Support is being delivered through innovative working relationships. Current working arrangements between DfES and RNID have been built up over a four-year period and have progressed beyond lobbying to the joint

management of service change, via inward secondment of RNID staff to DfES and joint partnership working with other key agencies. The Early Support Programme is now based at RNID. This dynamic and new way of working has ensured that the expertise and practical knowledge of the sector as a whole has been brought together with Government policy initiatives and resources to deliver real and lasting change.

## **KEY LESSONS FOR THE FUTURE**

RNID is proud of the pivotal role it has played in developing the Early Support programme and in having been able to facilitate some of the broader partnership working between Government and the voluntary sector that has been a key element in the programme's success. We also have had previous experience of working with a government department through the Modernising Hearing Aid Services initiative.

Our experience demonstrates that voluntary organisations have a continuing, critical part to play in the modernisation of public services. We contribute:

- closeness to service users
- passion and continuity of commitment
- flexibility and speed of response
- practical solutions
- a clear focus on outcomes for service users impact

### **Closeness to service users**

Voluntary organisations are in regular touch with the people who use the services Government wants to improve. The sector can feed back the daily experiences of families and children to the centre and directly facilitate the participation of families and professionals in the discussion, development, piloting and refinement of better ways of working.

### **Passion and continuity of commitment**

We bring passion and the 'vibrant dissatisfaction' of good campaigners to the task of improving the quality of life of our constituent members and can function as a 'critical friend' throughout the process of delivering change.

We are also persistent and bring a continuity of focus to the task of securing effective service change, once the case for action has been made, that it is sometimes difficult for the mechanism of government to sustain – particularly where multi-agency working is concerned. In our experience, partnership working with Government does not restrict freedom to continue with campaigning and advocacy work on other issues – effective campaigning and pressure from many different directions (bottom up and top down) have been essential elements in sustaining momentum behind the Early Support initiative.

### **Flexibility and speed of response**

Not-for-profit organisations can move quickly and act as catalysts for change because we are used to having to take decisions quickly and work with a wide range of stakeholders to agree and implement change. We have to seize and capitalise on opportunities as they present themselves and our independence from statutory processes can also be an important element in building alliances with a wide range of partners.

### **Practical solutions**

Campaigning, however persuasive, is sterile if it does not lead to positive solutions and practical suggestions for how things might be improved. Effective organisations in the voluntary sector are particularly well-placed to involve the people who use and deliver public services in a shared analysis of problems and joint development of practical solutions.

### **A clear focus on outcomes for service users impact**

The only and real test of public sector reform and the contribution of the not-for-profit sector, and indeed the Early Support programme, is whether children and parents looking for information and practical help are better served by services. Voluntary organisations live daily with the need to demonstrate positive impact to donors. This is a useful discipline to bring into partnership working.

### **Conclusion**

In the words of one professional working in an Early Support pathfinder area:

*'This was something that needed to happen a very long time ago.'*

Early Support is a powerful example of how partnership working between Government, service providers, service users and the voluntary sector can lead to more effective, joined up services for children across the country

Put these partners together and you create an unstoppable force for positive change.

Note:

1. RNID publication *Adding Value*.
2. Slides showed variety of children enjoying services.