

**Call for evidence: DfES/HM Treasury Joint Policy Review on Children and Young People  
Comprehensive Spending Review 2007**

**NDCS Response**  
Review of disabled children strand

<b>Contact details for respondent</b>	
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Do you represent an organisation?  (if so, name of organisation and type: e.g. voluntary, public body, private company).	Yes  The NDCS National Deaf Children's Society Voluntary sector organisation
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	<b>Which area of the review are you responding to? (please mark X)</b>
Prevention strand	
Review of disabled children	X
Strategy for youth services	
Review of high cost, high harm families	

## Introduction

*NDCS is the only national charity that is dedicated to the support of the UK's 35,000 deaf children and their families. NDCS also has an international wing that works with deaf children in developing countries.*

## Consultation response

### General:

- *At present parents of deaf children continue to experience a postcode lottery of services with wide variations of what might be available depending on their location. This arises out of entirely localised decision making processes and absence of national guidance to local commissioners.*
- *A central commissioning framework is required to ensure all families benefit from the same high standards of provision throughout the UK. This framework would be sufficiently narrow to ensure consistency of provision but also enable local authorities to reflect the diverse nature of their communities.*
- *Chief among the services urgently required are specific parental support services, designed to equip parents to cope with the demands of a disabled child. The voluntary sector, including NDCS, has designed and delivers such parent support programmes but there is inadequate national provision or full geographic coverage. Equally mainstream child voluntary sector organisations need to further develop the support they offer to parents of disabled children.*
- *The system of direct payments is not well known or understood by many parents of deaf children.*
- *There is a lack of national data on the achievements of deaf children despite a large number having been educated in mainstream settings since the 1970s. This results in inconsistencies in the breadth of provision across the UK. Resources are not allocated according to need across the country but rather according to individual health authority and LEA policies and practices. These policies and practices are based on belief systems as opposed to quantifiable data on deaf children's achievements following all possible interventions.*
- *There is no register of deaf children held either centrally or locally enabling forward planning of service provision*
- *Quality Standards for Education and early years already exist and should be universally adopted. These standards represent models of*

*best practice for professionals working with deaf children, their parents and wider families.*<sup>1</sup>

Key review questions and response:

Q. The changing profile of disabled children, for example, due to increases in complex disability and rise in Autistic Spectrum Disorders, profound and multiple learning disabilities and low birth-weight babies and the challenges this poses to services.

A. *The recent roll-out of the Newborn Hearing Screening Programme will mean a significant increase in children diagnosed with significant permanent hearing loss in the early years. While this presents a challenge for existing services to deal with the greater numbers it also presents an opportunity to ensure that adequate and integrated support services (medical, educational, social) are in place to support parents in the choices that they need to make as a result.*

Q. What progress has already been made in addressing the needs of disabled children and their families?

A. *Newborn hearing screening has led to the routine early identification of deafness in children and, through the Early Support Programme, a standardisation of information given to parents and families of newly diagnosed children. While this has been positive the dissemination of this information is not as good as it could and should be. Every family should receive this information as early as possible in order to make genuinely informed choices on behalf of their deaf child, contributing to greater positive outcomes later in life and reducing the likelihood of later interventions being required.*

Q. What are the barriers currently restricting access to services and therefore effective intervention?

- A. *A chronic shortage of qualified Teachers of the Deaf and other specialist staff, further exacerbated by a postcode lottery of service provision.*
- B. *Local authorities find it difficult to plan for low incidence disabilities, particularly in rural areas, which results in a low level of provision. This is further exacerbated by local systems of schooling provision, for example cross-boundary catchment areas for schools (i.e. those with a resource base for deaf children) excluding pupils who would benefit from special educational provision.*
- C. *The exclusion of audiology services from the make up of Children's Trusts. These services are classed as "acute" and therefore one of the most fundamental services affecting the development of deaf children*
- D. *The absence of any evidence base for professionals and families to decide on which medical intervention is in the best interests of the deaf child. Depending on where the family lives the local health authority will advocate different interventions to parents, based on the professionals'*

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<sup>1</sup> Available at:

[http://www.ndcs.org.uk/information/professional\\_focus/professional\\_publications/education\\_professionals/quality\\_standard.html](http://www.ndcs.org.uk/information/professional_focus/professional_publications/education_professionals/quality_standard.html)

*belief in one system as opposed to quantifiable data on the subsequent achievements of deaf children following the various possible interventions.*

*E. A lack of advocacy services available to parents, who in many cases do not have access to all of the information they are entitled to receive.*

*F. A chronic shortage of qualified human aids to communication such as BSL-English interpreters and Communication Support Workers.*

Q. Are services sufficiently co-ordinated at local level to allow families to access sufficient support to meet their needs?

*A. This is entirely dependant on where you live. Parents fortunate enough to reside in an area with good local provision will have a very different experience to those living in an area with little or no services. Financial delegation from LEAs to schools have worsened this situation by further eroding provision as funding is re-directed towards higher incidence categories of SEN children.*

*Central (LEA) funding needs to be retained in order to forward plan for low incidence SEN provision and to respond to immediate and unplanned needs, (such as a disabled child with specific needs moving into an area). Further, regional SEN partnerships should have a formal role in overall SEN resource planning, and retain an overview of service provision.*

Q. How does the system of support for disabled children and their families compare across the country and abroad? Are there lessons we can learn to improve outcomes?

*A. The NDCS casework service has a number of examples highlighting the impact of postcode lottery provision for parents, families and deaf children themselves. The wide variations of service provision across the country ranges from negligible to highly resourced, cost effective and practical support systems.*

*B. There remains a clear need for enforceable quality standards and guidelines on good practice for professionals working with families of deaf children*

Q. What family support services i.e. key workers, short breaks, sibling support, behavioural management are currently available and how do these relate to other services?

*A. The NDCS runs a number of family support services, which while providing invaluable support for parents, highlight gaps in current statutory provision. These services include our Parenting Programme which offers support and learning opportunities to parents of deaf children in every aspect of their child's social, emotional, and educational development. This can be found at: [www.ndcs.org.uk/parenting](http://www.ndcs.org.uk/parenting)*

*In addition our Supporting Dads and Grandparents to Support Deaf Children programme is based on the first ever programme of research conducted into the needs and experiences of fathers of deaf children. Prior to this work little was known about this crucial yet often marginalised group. This programme offers professional and peer support networks in supporting fathers to participate fully in the care of their deaf child, and enable grandparents to play an important role in family life. This can be found at:*

*<http://www.ndcs.org.uk/information/fathers/>*

*Both of these services offer support to parents, in particular fathers, which has proved to be invaluable to their beneficiaries. They are however time limited, and highlight the need for formal statutory provision in partnership with the voluntary sector.*

Q. What are the most cost effective interventions in delivering better outcomes?

- A. *Effective dissemination of information to parents of newly diagnosed deaf children irrespective of location*
- B. *Parent-parent support networks, which combat isolation*
- C. *Investment and ongoing support of qualified Teachers of the Deaf*
- D. *Investment and ongoing support of Speech and Language Therapists*
- E. *Training of mainstream educational staff in how to communicate effectively with deaf children, and to adjust the school environment to accommodate their needs*

*Early investment and ongoing support of specialist staff, parental support programmes and direct services all lead to better outcomes and lessen the need for costly later interventions*

*It is worth noting the significant resources expended by parents, professionals and the voluntary sector in contesting decisions made by the system as it currently operates. These resources should be invested in improving the system.*

Q. Are there interventions which, if made earlier, could reduce more costly interventions later? How can we identify the need to intervene earlier?

- A. *In addition to the answer given above, it is important to note that there is a significantly higher incidence of mental ill health among deaf people than the national average. Deaf children, therefore, are at greater risk of developing mental health problems.*

*Early intervention and the development of mental health services for deaf children and young people is therefore cost effective. NDCS Northern Ireland, funded by the four Health Boards in the Province, published a report in 2005 which listed the wide range of issues facing deaf children and young people, focusing on the need to develop mental health services in order to prevent difficulties in later life. It outlines preventative measures that should be undertaken through joint working between education, health and social services and the voluntary sector, and details the clinical provision that should be put in place as a matter of urgency. This can be found at:*

[http://www.ndcs.org.uk/information/ndcs\\_publications/developing.html](http://www.ndcs.org.uk/information/ndcs_publications/developing.html)

*B. It is also worth noting that deaf people have a significantly higher rate of unemployment than the national average. The measures outlined in questions listed above in educational support will result in better educational outcomes and therefore employment, reducing the cost of unemployment.*

Q. What lessons can we learn from the legal frameworks in other countries that might inform the review?

A.

