

# What do parents of deaf children think about SEN reform?

National Deaf Children's Society briefing (February 2013)

In 2011, the Government first announced its proposals to reform the special educational needs (SEN) system in England. Since then, NDCS has run a series of consultation exercises with parents of deaf children to explore their response and identify what impact the proposals might have on deaf children. With the Government's final proposals for reform recently published through the Children and Families Bill, this note summarises out what parents have told us. It also sets out the key issues that we want parliamentarians to consider as they debate and discuss the Bill.

## Summary of key points

- **Parents of deaf children do not believe the reforms will be successful, largely due to funding cuts and existing capacity constraints.**
- **Proposed new Education, Health and Care plans need to be parent-friendly and accessible but with a clear and objective focus on the needs of the child. There also needs to be stronger accountability against health services.**
- **Parents want more and *specific* information about services for deaf children through the local offer. They also want more information about the quality of services.**
- **Parents question the point of a local offer if each local authority isn't required to provide a basic minimum service for all deaf children, regardless of where they live.**
- **Above anything, parents want to be listened to and meaningfully involved.**

## Anxiety and concern over cuts

Very few parents we spoke to were aware of the detail of the Government's proposals. In an online survey, just 12% of respondents had heard that SEN reforms were underway and were familiar with what the changes might mean for deaf children.

Even where parents lived in an area where SEN reforms are being piloted – the “pathfinder” areas – just 17% had heard about the reforms and were familiar with what the changes might mean for deaf children.

When asked what one thing parents would like to see come out of SEN reform, many pointed to the need for more support. Responses included:

*“For funding not to be so difficult to get hold of when it comes to installing and training of specialist equipment required.”*

*“More support available for my daughter as she has to work and concentrate so much more than a hearing child and this leaves her exhausted.”*

Parents recognised a need for change. Recent government figures on GCSE attainment – where 63% of deaf children failed to achieve 5 GCSEs (including English and Maths) at grades A\* to C, compared to just 31% of children with no identified SEN – also supports this. However, a majority were suspicious that the Government's current proposals would address the fundamental issues around lack of capacity and funding in the system.

In our online survey, only 6% believed that the proposed changes would mean that deaf children in their area would get better support. 72% felt that the real aim was to reduce spending. This rose to 80% of respondents who were familiar with what the changes involve for deaf children.

*“What is the reason for making this change? Is it to save money?”*

A number of parents were sceptical that SEN reforms could be taken forward at a time when significant spending cuts are being made. NDCS’s Stolen Futures campaign has found that in the two years running up to April 2013 a third of England’s councils will have made cuts to the vital education support for deaf children. This includes cutting funding for Teachers of the Deaf and Teaching Assistants who help deaf children understand in school.

The extent of the funding cuts and the considerable anxiety that parents of deaf children feel suggest that the Government has considerable work to do to reassure parents that its ambitions for SEN reform will not be thwarted by spending cuts.

*“The system is utterly broken. Central Government needs to compel local authorities to meet the child’s needs, and needs to give local authorities the resources to meet them.”*

**NDCS is calling on the Department for Education to intervene and hold councils to account for decisions that are leaving deaf children without a future.**

The Children and Families Bill currently sets out a requirement on local authorities to review their provision for children with SEN. NDCS is calling on parliamentarians to amend the Bill so that local authorities are also required to consider whether they have adequate funding in place to meet the needs of children with SEN.

## **Education Health and Care Plans (EHCPs)**

The Department is proposing to replace statements of SEN with Education, Health and Care Plans. Young people with SEN up to the age of 25 may be eligible for a Plan. Parents generally supported this change in principle and particularly supported the extension to 25. However, many had a number of questions and concerns, as set out below.

### Accountability and contribution from health services

Although the Department has stated that existing statutory protections around statements and local authority education services will be protected, there will be no extension of these protections to health services. A number of parents questioned this.

*“I think more clarification is needed around the legal entitlements to health and social care services. This seems to be the area that currently lacks depth, and needs to have more substance in the new plans. The way in which it is enforced is critical. Currently everything is separated and it is very hard to bring the services together. Although our son is statemented, our speech and language therapy is involved in individual education plans but constantly reminds us that they have no legal ties to the statement and will not over commit to the support of our son.”*

*“Where does the accountability lie with the new plan? How legally binding will the EHCP be when it comes into action?”*

*“It needs legal teeth, otherwise what’s the point?”*

### Implementation

Parents recognised the significant upheaval these proposals will create and queried whether there was sufficient capacity and staffing in the system to implement these changes:

- *“Who is going to write the reports? Professionals to be more involved – do they have the time for this?”*
- *“If there are no social workers – who will be providing input into this?”*
- *“Where I live is the cheapest borough in the country, with no funding for training for social care for example. So even if social care support was in the plan I don’t think our kids would get it.”*
- *“Who will train and provide support to parents who are getting to grips with this process and new procedures?”*
- *“This pathway has to be sustainable and realistic – in terms of how families use this.”*
- *“Need clear transparency over who we need to contact.”*
- *“What is the qualifying threshold?”*

### Ending a Plan

Some parents expressed frustration that in the current system their child had to fall behind before they got the support they need to achieve their potential.

*“Although our son made extremely good progress in his first year in his new school, this seemed to be a trigger to reduce the levels of assistance from all other departments. His speech and language therapy stopped, everything stopped. It was as if he no longer needed it and he just dropped, his development went completely backwards.”*

*“I feel that because my daughter has done so well they have taken all her support away from her. She does not have a Teaching Assistant in class or any additional support. I think that they should give additional support in class even if it was an hour a day because with that extra support she would do even better and not just be middle of the road. There is only so much support we can offer at home.”*

*“So far, because he is “average” for some things and “just below average” for others, this has meant that his needs are not considered great enough to provide additional support to the below average areas. It could be a lot better.”*

*“Should allow statements for children even if they are doing well at school, they still need extra help.”*

The Children and Families Bill currently proposes that a local authority can end an Education, Health and Care Plan if the child’s set outcomes have been achieved. This fails to recognise that it is only through ongoing support that a child’s outcomes can be maintained. **NDCS recommends that the Bill be amended so that local authorities can end a Plan if a child’s outcomes have been achieved and ongoing support is not needed to maintain those outcomes.**

### What should the ECHP include?

SEN pathfinders have been testing out different approaches to EHCPs and a range of templates are now available. In a couple of recent focus groups, we asked parents to compare a statement of SEN with a couple of template Plans that had been developed by the voluntary and community sector.

We asked what parents liked about statements. They felt that this document had a range of strengths, which they would want to see retained:

- Legally binding.
- Published step by step process.
- Can be reviewed and re-written if and when required.

- Structure is clear when written properly.
- The right of parents to ask for implementing actions on the SEN report.
- *“You know where you stand i.e. if it is in the statement, you will get it.”*
- Encompasses input from all so everyone gets the opportunity to contribute.

When asked what doesn't work about statements, many parents referred to the constraints imposed by limited resources:

- Lack of suitable experts.
- Parental choices can be limited to accessibility to services.
- Low number of Teachers of the Deaf limit availability – one respondent highlighted that in her area there was just 1 Teacher of the Deaf for 90 deaf children and limited specialist provision available.
- Lack of specialist services.

Others mentioned that statements could be unclear but recognised this was about how the statement was written rather than the format of the statement itself:

- *“Often written badly and unclear so local authority etc can reduce the care provided.”*
- *“Can be very obtuse if not handed well.”*
- *“The statement of SEN needs to be simplified and more concise. Requirements should be summarised and to the point and not lost in text.”*

Parents were then asked to look at template Education Health and Care Plans developed by two voluntary sector organisations. Parents generally indicated that they saw strengths and weaknesses in both. Parents wanted to see a new template that combined the parent friendly tone and accessible language of the first template with the focus on outcomes and targets and a document that had a clear legal basis.

*“Must be accessible to parents, including child but be robust, detailed and able to hold professionals to account.”*

Factors that were important to parents included:

- Accessible language for both parents and young people
- Specifies children's needs
- List of contacts so that parents can see who is working with child, their role and their contact details
- Clear targets for their child to reach and evidence of child's progress to date.
- Information and evidence from assessments
- The fact that it was and clearly looked like a legal document
- Had health and care input to add to educational information

Some parents felt one of the templates asked for too much information about family background and was too long:

- *“Want to keep some family background private – feel uncomfortable.”*
- *“Invasive to personal information and life and not sure how it will help with child support?”*
- *“Not fair to ask some questions e.g. favourite person in family – goes too far from actual support for the child's needs.”*
- *“It is too big a document and may be discouraging to read and understand by parents.”*

Other points raised included the need for transparency over money, stressing the involvement of the child and ensuring that transport is adequately covered in the Plan.

### Case studies from pathfinder areas

NDCS's team of Regional Directors and Family Officers has been working with the SEN pathfinder to explore how the changes will impact on deaf children. To date, the known number of deaf children involved appears to be relatively low. Of those that have been involved, a number of concerns have been expressed about the process.

- Lack of involvement or input from health services. In one case, a child's lead paediatric consultant had been invited to contribute to a child's assessment as well as representatives from audiology, speech and language therapy and CAMHS. None did.
- In some cases, no clearly designated 'navigator' or key worker.
- The capacity of the pathfinder team being undermined by cuts. In one area, core members of the pathfinder team were currently having their own posts reviewed, and have seen members of their team made redundant.

In one area, a parent provided us with a copy of their statement and a first draft of their EHCP, allowing us to compare between the two. This comparison has confirmed some of our worst fears; that many EHCPs are being produced which are lightweight, unsubstantive and a clear downgrade next to the statement. Key concerns include:

- Compared to the statement, very basic and unspecific information about the child provided in EHCP. For example, no information about child's placement or current levels of attainment was shown. Contained vague statements like "child is happy... and progressing at school" with no detail to support this.
- Driven almost entirely by parent and child without real professional input. Appeared that only the mother and the child's Teacher of the Deaf is involved so far. No apparent contribution from health or social care professionals.
- EHCP failed to adequately describe the child's SEN and then to identify the educational provision needed. Only two actions were listed and were not particularly in-depth or well-founded. For example, it noted that child sometimes experiences frustration but did not explore whether this is, as likely, due to communication barriers, and how these barriers could be resolved. No actions listed relating to improving educational outcomes, even though this was identified as a priority by parents.

The work of the SEN pathfinders is still ongoing and many of the above issues may soon be resolved. However, our early experience does not provide us with confidence that the reforms will have a positive impact.

**In light of this feedback, NDCS is calling on the Government to look at the wording of the Children and Families Bill to ensure that the proposed Education, Health and Care Plan:**

- **Will be as legally robust as a statement.**
- **Strike a balance between being parent-friendly and accessible but also specific about a child's needs, expected outcomes and objectives and the support they need to achieve these outcomes.**
- **Ensure that a single Plan has a single means of redress and accountability against health and social care providers.**
- **Allow local authorities to continue to maintain a Plan if a child needs ongoing support to maintain good outcomes.**

## Local offer

The Department is proposing to require each local authority to establish a local offer, setting out what help they will provide to families with children with SEN. Parents supported proposals to improve transparency and highlighted the difficulties they had experienced in accessing relevant information about support specifically for deaf children to date.

*“We have fallen across possible choices and information quite often by chance.”*

*“I got an information pack when my child was diagnosed, but half of it wasn’t relevant to deaf children and it didn’t include information on the local deaf school.”*

We asked parents of deaf children what they wanted to see in a local offer from their own local authority:

- Information about specific areas of disability and specialist support and availability
- Information on support at different stages of life
- Case studies and to see other experiences
- Information on progress of children / achievement
- Communication support available
- Qualifications of staff
- Information that’s accessible and in plain English.
- “Everything in one place.”

One parent felt strongly that the local offer was worthless unless it provided parents with information about quality of services:

*“Parents of hearing children can look at Ofsted reports but they don’t say anything about deaf children.”*

**NDCS is calling on the Department for Education to confirm that the local offer will present parents with specific information about deafness**

**NDCS is also calling on the Department for Education to provide parents with information about the quality of services they receive. This means producing more information about the outcomes achieved by all deaf children and requiring Ofsted to inspect specialist educational support services for deaf children.**

Separately, parents expressed frustration they experienced in accessing basic essentials for their deaf child. A number of parents stated that they had felt obligated to buy this additional support themselves because it wasn’t available locally.

*“We are looking to purchase privately a radio aid which hopefully will improve things for our daughter. This is a considerable sum of money for us as a family (we have one income and four children to support) but really we have no option given the fact that the Teaching Advisory Service has stated that they are ‘not resourced’ to provide this type of help to children with unilateral deafness.”*

*“We are worried about how our daughter will cope with the transition from primary school to secondary school in a couple of years time. This has really been our motivating force to privately purchase the acoustic support that our daughter needs as we are very conscious that at secondary school she will have to change classroom at every lesson and that not all classrooms will have adequate acoustics.”*

Other parents pointed to the consequences of there being a lack of support in their area:

*"I have had to send my daughter to a special school nearly 100 miles away and now only see her at weekends. The amount of support in this area is nearly zero."*

*"Our son left school 2 years ago, having underperformed and failed to reach his potential. We would wish him to have had the same chances as everyone else but for this to happen, he needed more specialist support... We would like deaf children in mainstream schools to receive expert trained help rather than learning assistance. There were no specialist deaf units in mainstream schools in our area and no schools for the deaf in the county. Now he is 20 and jobless, having under-performed again in a Level 3 FE course."*

In our online survey, over 1 in 10 families said they had already moved to access better services for their deaf child. 1 in 4 families would consider moving if cuts affected their deaf child but nearly two-thirds would not be able to move because of the costs involved. One family told us how their deaf son had moved between 4 different schools, involving the whole family moving from Hampshire to Lincolnshire, before they could be confident their deaf child was getting a good education. The son's father told us:

*"All of the delays my son has had to endure have had a cumulative effect on his life and where he is today. It is immeasurable how much damage has been done to his potential."*

Many felt it was unacceptable that the help deaf children was not always determined by what they need but by where they live and wanted to see assurances that the basic essentials would be provided everywhere.

*"Making sure all services and equipment is available to ALL deaf children which ever school they go to."*

*"Should be services that local authority should provide as standard."*

*"Want to ensure that all deaf children are entitled and financially supported to get the right educational provision for them."*

*"Models of help available should be used i.e. deaf children who attend mainstream schools need carpeting, radio aids, one to one help. This could be in a standard model. At the reviews the standard model could be used to tailor the Plan for each child."*

**NDCS believes there should be a national offer for all deaf children, setting out basic minimum requirements that each local authority should ensure is provided**

**This should include:**

- **Access to a specialist education service for deaf children that is adequately staff to meet the needs of all deaf children in each area and meets quality standards.**
- **All specialist units / resource provisions for deaf children to be headed by a qualified Teacher of the Deaf**
- **Specialist equipment, including radio aids, to be provided, as required in each local authority**
- **Spectrum of provision or appropriate pathways to nearby provision available to meet the needs of all deaf children in each area**
- **Access to communication courses, including sign language, for all parents of deaf children**
- **Publication of data on outcomes**

## Personal budgets

When we ask parents for their views on personal budgets and whether they would be interested in taking up the option of greater control over the support their child receives, we have received a range of opinions. Many parents supported the option and could identify several potential benefits:

*“Can identify needs and need to buy in support e.g. counselling.”*

*“Parents would know that the money is benefitting their child, i.e. at school, you know the money is not being used to buy pencils and other materials for other children because the head teacher cannot manage the schools budget efficiently.”*

*“Let parents be in charge of SENCO budget. Had to go private every time to get diagnosis or help.”*

We asked parents what they might use a personal budget for:

- Learn sign language within the family
- Activities tailored for deaf children
- Teacher of the Deaf service
- Speech and language therapy services
- Counselling
- Private medical health care
- Respite breaks
- Transport

Other parents, however, did not want this responsibility and could identify a range of potential concerns or difficulties:

*“Will the budgets be adequate to cover all the services provided at present?”*

*“I already have a personal budget to help my son access activities (e.g. paying for signed support). Almost half of this budget is spent on administration as I have to pay insurance and for payroll service. Parents have enough responsibility without having to deal with budgets and accounts.”*

*“A lovely idea in theory, but in practice it’s a nightmare.”*

*“I’m not a professional Teacher of the Deaf. How can I make these decisions? I’m a mum and I want to be a mum, not a specialist.”*

*“I’m really anti this. How do you know what services are out there? How do you know if they are any good? Where do you get independent, good, clear advice, to know what to get?”*

Other parents felt that the concept of personal budgets and increasing parental choice was flawed if there were already a lack of providers in their area. One parent told us that even if she had the money, the services she needs, for example to support sign language use, don’t exist in her area.

**NDCS agrees with the Department for Education that personal budgets should be optional only. Parents should be provided with support and information on how to access personal budgets. The Department must also set out how it will ensure meaningful choice for parents of deaf children whilst not undermining services for those who have chosen to remain supported by their local authority.**

## Other issues:

### Mediation

We asked parents whether they felt they should be compelled to undergo mediation before they could take any dispute with their local authority over the EHCP to a Tribunal. Parents strongly opposed this and felt it would add to an already stressful process. Many felt it would be pointless, arguing that if a case had got to this point, the local authority would already have “made up their mind”. Parents will be relieved that the Department for Education have now abandoned this proposal.

### Parental involvement

Though parents did not support mandatory mediation, parents frequently raised the importance of meaningful engagement with the local authority, greater involvement in decision making and for their opinions to be taken into account.

*“Want to be LISTENED to!! Rather than having our and consultants written testimony cherry picked and important information dismissed when applying for a statement.”*

*“More supporting parents to have a more informed choice regarding their child's support. Not relying solely on one professional to know everything, and then dictate to the parents what they can or can't have.”*

*“If it was law for teachers to have to communicate more with parents about their child's current work in school, I would be more able to support what my child is learning.”*

*“Really listen to those on the ground who deal with children day by day - the parent.”*

Parents will therefore welcome the set of principles established on the face of the Bill on engagement with parents and young people with SEN.

## Background:

This briefing summarises the outcomes of a range of consultation exercises as set out below.

Online survey (2012)	569 responses.
Focus groups (2012/13)	Exeter and Sheffield. Total parents consulted: 15
In-depth written questionnaire (2012/13)	Total parents consulted: 8
NDCS Family weekends	Deaf parents with deaf children. Total parents consulted: 6
Focus groups (2011)	Derby, Wandsworth and Birmingham. Total parents consulted: 28
In-depth written questionnaire (2011)	Total parents consulted: 9

We would like to thank every parent who has taken the time to give us their views on these important reforms. Above anything, parents want to be listened to and meaningfully involved in their deaf child's education. We therefore hope that the Government will ensure these views will continue to be listened to and acted upon before the Children and Families Bill becomes law.