

Making sense of SEN

Special educational needs

a guide for donors and grant-makers

February 2004

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Sector: Education

Sub-sector: Special Educational Needs

Executive Summary

- This report provides a guide to grant-makers and donors seeking to understand and support children with special educational needs. Its findings show how wellplaced philanthropy can have a significant effect on the lives of a large number of children.
- One child in six in England has special educational needs, which range from requiring additional support from their teacher in the classroom to requiring permanent full-time care. The number of children is growing in certain categories. Children who are not receiving adequate educational provision risk impairing their academic, personal and social development, which shape their life-chances and the contribution that they are capable of making to society.
- Central Government expresses commitment to special educational needs, alongside their education policy commitment, and much has been done in recent years. However, there remain significant numbers of children not receiving all the support they require in the most appropriate fashion due to inconsistent local delivery. Inadequate support is in part due to inevitable funding constraints.
- The involvement of government in special educational needs should not deter donors. We have identified a number of roles for the voluntary sector which are essential if children are to achieve their potential more fully. These are additional to the responsibilities of schools.
- Including all children in mainstream schools has created additional tension in the system. The teaching expertise and confidence required to address the needs of all children has not always been well provided for in the mainstream schools. The voluntary sector has a vital role here in transferring their expertise to schools.
- The assessment of a child's needs is also highly variable and the process of gaining provision from the local education authority has become one of the greatest issues for parents to face when their child has special educational needs. Our research has revealed that there are major inconsistencies here that can be addressed through targeted support from the voluntary sector.
- There are a number of other diverse roles for the voluntary sector, which range from advocacy to academic research and from supporting families to supporting teaching staff themselves. We have in all instances identified roles that are additional to commitments of the state or which lead to leveraged influence through encouraging additional state spending.
- We recommend funding those organisations and activities that can leverage the state's resources, enhance the capacity of schools to deliver education, improve the understanding of each condition and the teaching methods required, and support the parents that are dealing with a complex and changing picture of provision. Our recommendations are more fully outlined in Sections 3 and 4, together with the Conclusion, and we would welcome the opportunity to review these with interested donors and grant-makers.

Introduction

The purpose of this report

This report provides a guide for donors interested in funding projects to help those with special educational needs. Its purpose is to provide the information and analysis required to understand more fully the extent of the issue, and the types of response offered by the state and by voluntary sector organisations. The outcomes generated by such interventions are covered in order to guide donors towards those with the greatest likelihood of fulfilling an unmet need.

This report is addressed to all donors ranging from private individuals, who may be relatively new to the subject, to grant-makers with extensive experience in the area. When we refer to 'donors' we include grant-makers, private individuals, companies or anyone else wishing to donate funds or provide grants, goods or services.

Funding projects in this field can be far from straightforward. There are numerous views regarding best practice in the education of children with special educational needs, for example. This means donors need to be well informed before making their funding decisions. We have aimed to guide donors to the greatest gaps in provision and delivery that we have uncovered in the course of our research. This enables donors to target their resources more efficiently. We have detailed reports on specific organisations to assist in grant-making which we would be happy to discuss in detail should a funder wish to develop grants.

The scope and content of this report

The report is based on research carried out through extensive meetings with voluntary organisations, academics, education authorities and schools. We have made use of primary research, charities' reports and evaluations, as well as interviews with experts in the field. We have concentrated on children aged from 5 to 18 (although are also aware that much effective practice occurs at pre-school age and would reserve this for future research) and on those charities that are working to provide educational input, or to improve children's access to education in their schools, rather than those who are working in a more recreational sense. The different UK education systems and the quite different legislation and regulation mean that on many occasions it was necessary to focus on the English system only.

There is a pressing need for special educational needs to be better understood and better provided for in our education system. As the process of including more children with these needs into mainstream schools accelerates, there are problems arising that may be ameliorated by the voluntary sector. Expertise and experience from the voluntary sector are able to bring benefit to the state sector, to the teaching staff and support staff in schools, and to the children themselves. Since it would be impossible to cover all of the myriad projects that have been effective in their aims and operations, we have aimed to provide a practical guide to the subject. We give examples of organisations that are involved in varied ways. (Owing to the enormous range of work that is happening, it should be noted that organisations are mentioned as examples and omission does not imply a negative assessment.)

There are several categories of special educational needs that formed the starting point for projects to visit. For practical reasons, we have aimed to cover the categories with greatest prevalence and growth. We have not been able to visit every organisation that works in the field but have set out to cover those where their aims are either directly educational or very closely involved with education. We will continue to research effective projects in this area in the future in order to increase our coverage.

The report sets out, firstly, the need for provision and the trends in prevalence of the main categories. Secondly, we cover the role of government and where the system contains gaps. The third section covers the role of the voluntary sector, where services have evolved over time to fill these gaps and improve provision. The outcomes that result from various interventions are then covered in the fourth section. We provide a listing of many of the organisations at the end of the report for reference. Precise funding recommendations are available separately and we welcome enquiries from donors wishing to enlarge on this. We believe that the report will both inform and guide donors, firstly on the case for support, and secondly on the approaches that can be used to give effective support. Should you wish to discuss our findings please contact Eleanor Burton (eburton@philanthropycapital.org).

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Section 1: Need

One in six children

educational needs.

has special

In this section we outline the nature of special educational needs. In total, one in six children has special educational needs. Without an adequate response these children will not fulfil their educational and social potential, often imposing considerable costs on society. Although this subject is fraught with complex conditions and processes, the basic need is for every child to receive an appropriate education and exercise the right to access to the curriculum.

Schools have identified almost one child in six (around 1.4 million children in England alone) as having some aspect of learning difficulty which requires 'additional or different' educational provision – the definition of a special educational need. Many learning difficulties are not well understood and some are more common among poorer socio-economic groups – exactly the groups which find it hardest to understand their rights and to secure the provision their children need in the complex system that has been created to address special educational needs. It is vital that these children have their needs identified correctly and receive an appropriate education. Poor educational provision compromises both a child's future contribution to society and their interaction with that society.

Defining special educational needs

The term 'special educational needs' captures children with a broad range of learning difficulties¹ from mild reading difficulties through to difficulties arising from serious medical conditions such as cerebral palsy. The definition of special educational needs is that the child's learning difficulty requires 'additional or different provision' in school, for example support from a speech therapist, a differentiated curriculum or extra classroom assistance.² The many distinct learning difficulties can be grouped into four main areas:

- Cognition and learning needs vary from 'significant and persistent' difficulties in an area like reading through to profound and multiple learning difficulties for which pupils need permanent support for both learning and personal care.
- Behavioural, emotional and social development needs cover a full range of abilities, but require that the behaviour presents a barrier to learning and persists despite appropriate interventions.
- Communication and interaction needs include speech and language difficulties as well as the range of conditions on the autistic spectrum
- Sensory and/or physical needs range from visual and hearing impairments through to physical disabilities.

It should be remembered that many (if not most) children have complex/multiple difficulties which cover a number of the areas outlined.³ For example children may simultaneously have physical and behavioural difficulties. Many of the conditions cannot be cured, and although many children will lead perfectly 'normal' lives with appropriate interventions, some children will require support and assistance for the duration of their lives.

Aggregate statistics on the number of school children with special educational needs are provided by the pupil level census conducted each year by the Department and Skills (DfES). This gives a snapshot of the number of children with all conditions. The most recent such census (January 2003) shows 17% of children (one in six) with some form of special educational needs. However, changes in the definitions make interpretation of trends difficult.

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¹ This phrase should not be confused with "learning disabilities," which is a term the World Health Organisation define as covering people with incomplete intellectual development causing significant impairment of intellectual functioning

There are no accurate breakdowns of exactly how many children have each learning difficulty (though an improved survey technique recently introduced by the DfES should remedy this). A selection of the available data is shown in Table 1, highlighting that some conditions are very low prevalence (e.g. visual impairment at between two and five per 10,000) while others are relatively common (e.g. behavioural, emotional and social difficulties at between 300 and 700 per 10,000).

Table 1: Approximate prevalence of conditions

Special educational need	Condition	Examples	Approx. prevalence per 10,000 ⁴	
Cognition and learning needs	Specific learning difficulty	Dyslexia Dyspraxia	100 – 400	
	Moderate learning difficulty	Down syndrome Those with IQ score of 50		
	Severe learning difficulty	Those with IQ score 20-50	100	
	Profound and multiple learning difficulty	Those with IQ score less than 20		
Behaviour, emotional and social development needs	Behaviour, emotional and social difficulty	Attention deficit disorder Mental health difficulties	300 – 700	
Communication and interaction needs	Speech, language and communication needs	Specific language impairment	100 – 400	
	Autistic spectrum disorder	Autism Asperger's syndrome	5 ⁵ – 91 ⁶	
	Visual impairment	Blindness	2-57	
Sensory and / or physical needs	Hearing impairment	Deafness	13 ⁸	
	Multi-sensory impairment	Deafblindness	Not available	
	Physical disability	Cerebral palsy	600	

This data illustrates that the most common special educational needs relate to mild and moderate learning difficulties (including conditions like dyslexia), behavioural difficulties and physical difficulties. While exact data is not available, surveys of Local Education Authorities (LEAs) have revealed significant trends in recent years in a number of conditions. Primarily they found perceptions of:

- Significant increases in the number of children with autistic spectrum disorders, speech and communication difficulties as well as some evidence of increases in profound and multiple learning difficulties.
- Few categories with **decreases**, except moderate learning difficulties and specific learning difficulties, but only a minority of respondents detected these trends.

One cause of increased prevalence of special educational needs is the modest growth (at around 1% per annum) in the number of babies that are surviving premature birth, resulting in an increase in severe disabilities such as cerebral palsy. ¹⁰ Similarly, the prevalence of Down Syndrome is increasing due to improved life expectancy to school age and beyond.

Notwithstanding these factors and perceptions of growth in prevalence, the Audit Commission concluded in 2002 that, albeit due to lack of monitoring and research, it is impossible to identify for sure whether trends were genuine reflections of changing needs or reflections of developments in diagnosis and awareness of conditions.¹¹

It is impossible to identify whether trends are genuine reflections of changing needs or reflections of developments in diagnosis, awareness and monitoring of conditions.

Identification

Before special education can be provided, individual children's learning difficulties must be identified and appropriate intervention agreed upon. For most children, age provides an appropriate guide as to their necessary education. This does not necessarily work for children with special educational needs since their learning may be delayed (possibly as a result of communication delays due to hearing or sight loss) or they may need particular teaching techniques depending on their condition (e.g. as a result of the different way in which autistic children interpret information). Appropriate intervention will not be apparent until their learning difficulty is correctly identified, and several options may exist for consideration.

Box 1: Nick Hornby - We need all the friends we can get¹²

Behind all the statistics and rhetoric are parents and children struggling with the practical everyday problems faced in navigating a complex system. The well-known author Nick Hornby expresses his frustrations below.

Danny's condition is such that his mother's expertise goes way beyond what one would normally expect from a mum. In the past month Danny has been seen by a paediatric gastroenterologist, an eye specialist, a speech and language therapist, an occupational therapist, he's received an updated Statement of Special Educational needs from the LEA (with reports from two educational psychologists), he attends a special school with the input of a behaviour analyst, and in all he has a team of eight teaching professionals working with him at school and at home.

What has shocked me most is the inescapable sense that many of the professionals that parents have to deal with are regarded as the enemy, and that if parents are to get anywhere, the enemy has to be defeated. I don't believe that these people are bad, so what is going on here? The answer is that they have been forced, by circumstances beyond their control, to turn into gatekeepers: gatekeepers who have always to be thinking of how little they can get away with providing, rather than how much the child needs.

If there was adequate funding in the system, this wouldn't be happening. No parent is going to fight to access speech therapy just for the hell of it. We need speech therapy because we want our children to speak - to say their own name, or to ask for the toilet, not because we want our kids to go to RADA. Professionals become gatekeepers because there isn't enough to go round, not because parents are demanding too much.

Parents of children like my son really don't need enemies, believe me. We need all the friends we can get.

The striking point is quite how difficult this process must be for families without the resources that Nick and Virginia have. As Nick himself says:

Virginia and I are the fortunate ones - firstly because we're well-off, and able to afford the private speech therapy, private occupational therapy, and home teaching to support the publicly funded work that takes place at school and from the NHS. Secondly, we've had enough time to find out what Danny's rights are, and who the specialists are that will take Danny's problems seriously and know how to meet his needs. How many families are this lucky?

There are several biases in the present system for identifying special educational needs that mean certain children do not have their needs identified properly – and so do not get an appropriate education. We have identified several broad areas of bias. Below we discuss the key areas of bias namely, the learning difficulty the child has, the ethnicity and family circumstances of the family, the state provision in the family's LEA and school, and the voluntary sector support that is available.

The particular **learning difficulty** a child has affects the likelihood of children being identified as having special educational needs.

- As might be expected, some needs, such as physical difficulties, are more likely to be identified, whilst difficulties that are more qualitative, such as emotional, behavioural difficulties or dyslexia, often go undiagnosed.¹³
- Some conditions occur more commonly in boys, such as speech and language difficulties, behavioural, emotional and social difficulties and autistic spectrum disorder.

Ethnicity plays a role in a child's likelihood of having certain special educational needs and in the family's actions in relation to those needs. In many cases it is not clear whether trends relate to ethnicity itself or to deprivation-related factors which are correlated with ethnicity.

- The relationship between special educational needs and ethnicity is complex and research is inconclusive, ¹⁴ although some relationships have been proven for example the prevalence of severe intellectual disability is three times higher among the Asian community compared to the non-Asian community. ¹⁵
- Black and minority ethnic pupils are over-represented in the population of children with special educational needs. 25% of black Caribbean secondary school pupils were recorded as having special educational needs, 20% of Pakistani pupils and 18% of Bangladeshi pupils compared with 15% of white pupils. 16

Family circumstances play a significant role.

- The link between some needs and socio-economics has been known for a long time (e.g. 44-50% of intellectual disability is explained by deprivation¹⁷). However the correlation between socio-economics and children identified with having special educational needs in LEAs is weak, which may imply that children from disadvantaged backgrounds are relatively less likely to be statemented.¹⁸ Some schools interviewed by Ofsted even confused the terms social deprivation and special educational needs.¹⁹
- The effect of deprivation on a child's development is certainly a factor in the development of special educational needs in some children, since poverty is a leading risk factor for disability. Poverty and low birth weight are often related, and low birth weight babies are at higher risk of special educational needs. If children's brain development is poor in the pre-school period as a result of lower parental engagement, poor nutrition or other environmental factors, they will be more likely to have some special educational needs. ²¹

Families require an awareness of their rights and often a significant ability to challenge authority and understand complex processes in order to navigate the systems for identification of needs (this is discussed in detail in Section 2). More affluent and better educated families are often better able to navigate the system and to secure more generous provision. This was understood by researchers in 1994, who concluded that 'the wealth of parents and their ability to manipulate the system become the ultimate arbiter of a child's educational opportunities. The Audit Commission confirmed this understanding in its 2002 report:

'... Those with knowledge, resources and confidence to challenge staff in schools and LEAs are more likely to get their child's needs assessed and to secure a more generous package of provision ...'

We discuss variation in school and LEA practice in more detail below. This variance seems to favour affluent parents, since they have the resources to move house to locate to better schools. ²⁴ Therefore, there remain a proportion of children in deprived areas that should be statemented for their needs, but where their families have not been able adequately to pursue the matter with their school and LEA.

LEA and school systems and procedures vary significantly and so families in areas of poor performance are at a significant disadvantage in getting their children's needs met. Several points are worth noting here:

The proportion of children identified by schools as having special educational needs varies by a factor of two across LEAs.²⁵ One implication is that children in

Children in certain LEAs are more likely than others to be identified as having SEN than their peers.

certain areas are more likely than others to be identified as having special educational needs than their peers in other areas.

- Delegation of special educational needs funding to schools is increasing the variability of the educational provision for these children.
- Interpretation of the SEN Code of Practice varies within schools and LEAs.
- Most children with special educational needs have either a medical or mental health need, yet health service and education authority boundaries are not the same and there can be difficulty in delivering multi-agency assessment and intervention. This situation may improve if the Government's policy on Children's Trusts is implemented, since it aims to 'join-up' the relevant health, social and education services.

Another important bias frames the debate in the media, in policy formulation and in schools themselves. This is a bias towards the perspectives of the **voluntary sector groups** that form around some conditions but not others, which skews discussions away from the needs of children without powerful groups. This results in disproportionate spending by LEAs on independent special school places for these children at the expense of children who lack powerful advocates with the time and resources to take their case to the LEA, the Tribunal, the High Court and the House of Lords. In the process of producing this report New Philanthropy Capital talked with groups based around certain conditions which were well connected with policy makers, influencing understanding, policies and practices for those conditions. For other conditions, there were noticeably fewer resources and experts available which translated into less consideration of those conditions in policy making, such as social, emotional and behavioural difficulties. This should not be taken, however, to mean that any group is being over-provided for. The significant gaps, which the voluntary sector partially fills, are detailed in Section 3.

The need for provision

Why are special educational needs special? What happens to children with such needs if they are not catered for? Four main categories of impact of the educational provision on children can be considered: personal, social, academic, and life-chance, as discussed further below. A lack of adequate education has severe impact ranging from exclusion from society and lack of personal skills through to significantly diminished employment prospects and increased likelihood of involvement in crime and antisocial behaviour.

The impact of special educational needs on the **personal** development of a child can be significant. Specific learning difficulties experienced by the child could be significantly improved on or overcome if the correct interventions are provided early enough, such as in speech, cognition and communication. Additionally some conditions, like autism, have secondary behavioural difficulties that can be avoided if interventions happen early. Addressing these needs can materially improve the subsequent life of a child.

For any individual, self esteem derives from achievements and new experiences. Without proper support and targeted learning, many pupils with special educational needs are simply not expected to achieve very much or are set targets that are unachievable. Similarly, interaction with peers with and without special educational needs is vital for the development of personal skills required to live in an integrated society. Such personal aspects of a child's development do not necessarily all have financial or academic benefits. However, they are no less important for this.

There are **social** costs to not addressing special educational needs. Lack of proper inclusion (see Box 2 for definition) among peers during school age risks longer-term lack of inclusion in society. Personal relationships come through shared experiences which are difficult for children who do not have adequate opportunities to learn with and spend time with their peers. Costs can be borne by the family also. Family breakdown is more common where a child has special educational needs since there is additional stress and confusion over optimal provision. Reducing the stress and confusion may well prevent some of this family breakdown.

Interaction with peers is vital for the development of personal skills.

Box 2: A Definition of inclusion

There are many differing definitions of inclusion, but the underlying principles are agreed on by most. This is that inclusion involves:

- the education of pupils with special educational needs alongside their peers in mainstream schools.
- appropriate support in place, both among teachers, carers and physical equipment.
- participation in school activities without causing disruption to other pupils.

Besides the evidence base for providing for special educational needs, many people view inclusion as a basic human rights issue and believe that inclusive education is the best preparation for integrated life. Government believes that special educational needs should normally be met in mainstream schools, however almost 7% of children with special educational needs (almost 94,000²⁷) remain in special schools. Research by the Centre for Studies on Inclusive Education shows that many children do better both academically and socially in more integrated settings²⁸ and Ofsted research stated recently that 'effective schools are educationally inclusive schools'.

Many children with special educational needs, if properly supported, will take **academic** tests with their peers. Others with special educational needs will never achieve regular academic performance and, even with adequate interventions, achievement for some will remain below Level 1, which is the first recognised attainment test, of the National Curriculum.¹

Additionally, there are straightforward economic reasons to want to provide for special educational needs. Employment opportunities are maximised if children are able to develop to their fullest during school years, which requires adequate support. The **life chances** for those who cannot read in a mature, knowledge-based economy are increasingly poor. For example:

- The Institute of Education, part of the University of London, concluded one study saying that 'the single most likely destination for many disabled people appears to be poverty.'³⁰ Unemployment claimants with disabilities are in double jeopardy disproportionate numbers have limited qualifications and work experience which create barriers to securing work in addition to their disability.³¹
- Teenage pregnancies occur with much greater frequency in girls with learning difficulties and lead to poorer employment and mental health outcomes for them and their children.³²
- The economic consequences for parents of having an autistic child living at home is estimated to include an annual loss of earnings estimated as at least one-sixth of the average disposable income. ³³
- The mental health of those who are unemployed or leave school with no qualifications is worse than average.³⁴

While it is not possible to measure in financial terms all of the impacts of special educational needs, some aspects are amenable to such an economic analysis. For example the Centre for the Economics of Mental Health estimates that the lifetime cost to the public purse of a child with autism in 2000 was about £2.9 million, and that even a moderate increase in educational provision could potentially result in major savings in later living costs. 35

Many children with special educational needs, if properly supported, will take academic tests with their peers.

¹ This would normally be expected of a child at age five or six.

Trends in prevalence

Around one child in six has some kind of special educational need, while one child in 30 (around 250,000 children) has needs which are severe enough, relative to the provision available in their school, to require extra provision, tied to a formal assessment and a 'statement' from their LEA.³⁶

The number of children identified as having special educational needs in England has been rising since 1997 at 5.6% per annum, or around five percentage points above the rate of increase of the number of children $(0.4\% \text{ per annum}^1)$. As mentioned previously, this is mainly due to:

- Improved understanding of the conditions, particularly mental health and behavioural conditions, resulting in more children who might previously have been regarded as merely 'problematic' now being considered as having special educational needs. Given that many conditions are still not well understood, this trend can be expected to continue for the near future.
- Increased survival of premature children has increased the number of children with serious special educational needs. For example, extremely low birth weight babies have a 50% chance of requiring special educational services and 20% are significantly disabled.³⁸

This is set against a reported decrease in needs and in particular the number of statements issued as a result of some children's needs being reduced or resolved as a result of recent emphasis on early intervention (although it is too early in the process to see the magnitude of this effect). The principle behind data for 'children with special educational needs' and data for children with 'statements' is that they require those labels because the provision available is otherwise not sufficient. With improving provision towards accommodating more diverse educational needs in mainstream classrooms, the number of children with either label should fall.

A statement means very different things across different LEAs. For example in one LEA to obtain even 2-3 hours of speech therapy may require a statement, whereas at another school or LEA more help is available in the school without the need for a statement. This reflects whether LEAs choose to spend their resources on making services available at school level to children generally, or restrict resources to the LEA level and link them to statements. As such, the percentage of children with statements of special educational needs varies from around 1% to around 5% across LEAs. Despite this, the typical variance among LEAs in the percentage of children with statements was between 2.3% and 3.9%, which equates to around 250 children in an average LEA.

In January 2002, most LEAs had between 17% and 26%^{II} of children classified as having special educational needs, equating to around 1,400 children in an average LEA.⁴¹ The same data is available at a school level and shows a more fragmented picture. Most primary schools had between 10% and 35% of their children classified as having special educational needs, while most secondary schools had between 5% and 30%.⁴² Statementing in schools varies significantly. Most had between none and 5% of their children with statements.⁴³ The number of statements issued by a given authority may be changing as a result of changing needs in the populations as well as for reasons of local policy. It is not possible to extract from the data, therefore, whether the needs of children are actually growing or not.

Improved understanding has resulted in more children previously regarded as merely 'problematic' being included within the SEN figures.

¹ Due to changes in the categorisation of children with special educational needs but without statements, it is only possible to calculate growth up to 2001.

^{II} Note that this most recent data at school and LEA level is for January 2002, and so can not be compared with the 17% of children known to be identified as having SEN as at January 2003.

Summary: The need for a response

We have outlined in this first section the scale of the need for special educational provision. A significant proportion of school children have these needs (as many as 17%) and we might expect that the number of children represented by these figures under-estimates the real scale of the issue due to the complexities of identification – particularly among those from disadvantaged backgrounds who are less able to navigate the system. There appears to be growth in certain categories (such as autistic spectrum disorder and cerebral palsy) which means that additional capacity to deliver appropriate services should be provided.

The range and complexity of the subject means that better understanding is also needed in the assessment and identification of best practice. This is necessary in order to avoid wasted effort and resources. We will outline the process by which state assistance is provided in the next section, before moving on to discuss the role of the voluntary sector in Section 3.

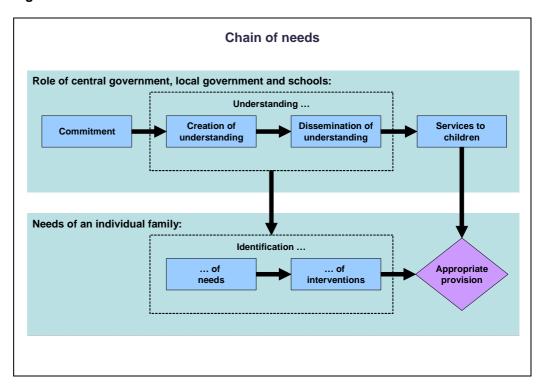
The range of situations in which a child has additional needs and the growth in understanding of certain conditions has led to a significant rise in the cost of education for this group. This has led to funding constraints in the special education needs sector which are themselves a source of confusion for parents and schools. Clearly, it is the responsibility of the state to provide an education for all children, and so the next section will review the Government's delivery of education to children with special educational needs. This is provided in order to improve understanding of the boundaries between state and voluntary sector.

Section 2: Delivery - the role of government

In order to understand the role of the voluntary sector, we must first look at the role of central and local government in meeting special educational needs. Although the Government is committed to education for all, many children with special educational needs do not receive an adequate education – that is, they are not receiving sufficient provision to allow them to achieve their full potential. Additionally, the complexities of the system for identifying special educational needs prevent many children from disadvantaged backgrounds from receiving the provision they require, creating a role for voluntary sector intervention.

Government has a legal responsibility to provide education, asserted through a series of parliamentary acts. Having assumed a responsibility to provide education, it is natural for Government to be held to account on how well it fulfils this responsibility. This section discusses the Government's approach to special educational needs. We examine how special educational needs are assessed and funded as well as the contentious assessment and appeals processes. Our purpose is to consider how the statutory approach to special educational needs creates a role for the voluntary sector, whose role is discussed more fully in Section 3. Our approach, outlined in Figure 1, is to follow a 'chain of needs' that must to be satisfied in order for appropriate educational provision to be available.

Figure 1: Chain of needs



Commitment

The vast majority of

children in the UK

educational needs

are educated in the

with special

state sector.

State commitment to provision

The vast majority of children in England with special educational needs are educated by the state, as shown in Table 2. The state's commitment to education ensures that an education in some form is available to every child, with or without special educational needs. The difficulty for children with special educational needs then is not that they do not receive any education at all, but that they do not receive an education that is appropriate to their needs (the caveat to this concerns children who are excluded from school, which is discussed on page 23). Through delegated responsibilities, LEAs provide education to children with special educational needs in a range of schools, but there are three main types:

- State maintained schools are operated by the state and maintained either by the LEA or by a grant from the DfES. Most children with special educational needs are educated in mainstream nursery, primary and secondary schools, but a number are educated in the almost 1,100 special schools in England (86,000 pupils, or 34% of statemented children).⁴⁴
- Non-maintained schools are non-profit-making schools run by charities and funded primarily through pupil fees paid by the LEA (therefore indirectly funded from the public purse). There are 63 non-maintained special schools, which typically provide for children with exceptionally severe and/or low incidence difficulties that require a level of specialism that LEAs find impractical or not cost-effective to provide. 45
- Independent schools are wholly funded by pupil fees and can be run on a profit-making basis. The almost 150 independent special schools have most pupils placed in them by LEAs, although parents can also meet the costs of a place privately. 46 Only 89 are approved as suitable for the admission of children with statements of special educational needs. 47

Table 2: Schooling of children with special educational needs (2003)⁴⁸

	Thousands of pupils			
Type of school	Pupils with statements of special educational needs		Pupils with special educational needs	
	Number	Percent	Number	Percent
State nursery	1	<1%	5	<1%
State primary	71	28%	756	53%
State secondary	79	32%	509	36%
State special	86	34%	88	6%
State pupil referral units	2	1%	8	1%
Independent	7	3%	50	3%
Non-maintained special	5	2%	5	<1%
Total	251	100%	1,420	100%

There is a strong policy commitment to meeting special educational needs and doing so within mainstream schools. The initial piece of legislation in this area was the Education Act of 1981, although this has since been updated with the Education Acts of 1993 and 1996. Special educational needs legislation was updated again by the Special Educational Needs and Disability Act (SENDA, 2001).

As a result of such a differentiated and fragmented education system, interpretation has been varied. Moving education provision from separate special schools towards a more inclusive approach in particular has been slow and is difficult for LEAs to manage. Difficulties can be compounded by local opposition to the closure of special schools and a shortage of trained teachers with knowledge of special educational needs. More general difficulties in implementing the sheer quantity of change have emerged from interviews with both schools and the voluntary sector. Margaret Hodge, Minister for Children shared this view in a discussion on special educational needs in October 2003, saying:

"... We can only move at the pace of people's willingness to contribute ... the will is there I can promise you, but with the best will in the world it takes time to get there ... we need a cultural change in the system ... *49

LEAs and schools are required to 'have regard to' the Special Educational Needs Code of Practice ('the Code'), which explains how LEAs should fulfil their duties under the Education Act 1996 and the accompanying Regulations. The Code also gives guidance to schools on how they should meet the needs of pupils with special educational needs who do not have statements. The Code is not legally binding on schools, as such, but is best considered as 'strong advice'. As a result, a number of varied interpretations of the Code are found in different LEAs, causing inconsistency in interpretation and yielding confusion for parents. Schools have appointed SEN Co-ordinators (so-called 'SENCos') who may be members of senior management or may be relatively junior members of the teaching staff. This in turn leads to varied adoption of the Code throughout schools.

Inclusion

By far the most important factor in the provision that children with special educational needs receive is the school they attend. The shift to inclusion which was first brought in as a legal duty on LEAs with the 1981 Act and strengthened under the SENDA 2001, affects this markedly.

Government believes that special educational needs should normally be met in mainstream schools. Only around 7% of children in the UK with special educational needs (almost $94,000^{50}$) are educated in special schools. Inclusion is not a straightforward issue. For many children it involves the support and expertise of a special school for part of the week. The only official data on the varying level of inclusion comes from Scotland, and applies to children with a record of needs (the Scottish version of a statement). Figure 2 shows that in Scotland, encouragingly only around 4% of children with a record of needs spend no time at all in mainstream classrooms.

In the early 1900s a separate education system based on special schools was built for pupils classified as 'handicapped,' which expanded until the 1980s. The Education Act in 1981 placed a legal duty on LEAs to include pupils with special educational needs into mainstream education where appropriate. 'Appropriateness' required that children should be educated in mainstream schools so long as the needs of the child are properly met, other children's education is not adversely affected, resources are efficiently used, and parents are in agreement (see Box 3). The 1994 UNESCO Salamanca Statement, as agreed by 92 governments and 25 inter-governmental organisations, called for inclusion to be the norm and stated that learning must be adapted to fit the needs of the child rather than the child to the process.

Only around 7% of children in the UK with special educational needs (almost 94,000) are educated in special schools.

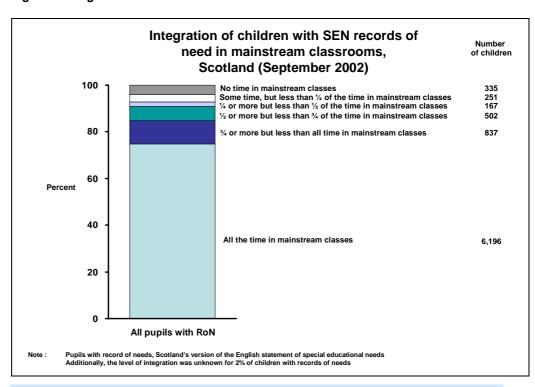


Figure 2: Integration of children with a record of needs in mainstream classrooms⁵¹

Box 3: Statutory framework for inclusion and disability discrimination

The Government's commitment to inclusion was most comprehensively outlined in the 1997 Green Paper 'Excellence for all children: meeting special educational needs' (1997). The Special Educational Needs and Disability Act 2001 amended the law on special education to remove two of the three qualifications which had previously been used to block parental wishes for mainstream education for their children. As a result, LEAs must now include children with special educational needs unless this prejudices the education of other children and there are no reasonable steps which could be taken to prevent this prejudice. ⁵²

The Disability Discrimination Act 1995 was amended by the Special Educational Needs and Disability Act 2001. This required schools not to treat disabled pupils 'less favourably' than their peers and to make 'reasonable adjustments' for them. Specifically, discrimination against disabled children in admissions, education and other activities (such as after-school clubs, trips and orchestra) or through exclusion was banned.

Guidance for implementing this legislation is contained in the Code of Practice for Schools, from the Disability Rights Commission.

Despite the shift towards inclusion, there are a number of problems. The Audit Commission found in 2002 that schools are often reluctant to accept special educational needs students because of their league table position, ⁵³ which creates a disincentive to take students unlikely to succeed academically. Fortunately, there are now examples of schools that have a high level of inclusion as well as a rising level of attainment, suggesting that fears may be unfounded and that good practice on inclusion does not impair the improvement of results. ⁵⁴

It is clear that different special educational needs entail different levels of adaptation by mainstream schools. Teachers believe that the easiest to include in mainstream education include pupils with physical difficulties and sensory difficulties. Unsurprisingly pupils with emotional and behavioural difficulties and severe learning difficulties are thought by teachers to be among the most difficult to include. ⁵⁵

Schools are often reluctant to accept special educational needs students because of their league table position.

Lack of understanding seems to be the biggest barrier to inclusion To favour and successfully implement inclusion, a great deal of understanding is required on behalf of all involved. In reality the lack of such understanding seems to be the biggest barrier to inclusion and although it is easy to achieve this in principle, establishing such understanding in a system the size of the education sector is a mammoth task. Difficulties in the practice of inclusion were outlined by the Audit Commission. ⁵⁶ Of the head teachers, SENCos and LEA officers interviewed:

- Most head teachers knew of schools that had a reputation for not accepting children with certain special educational needs and some head teachers admitted reluctance to accept children with certain special educational needs.
- Parent partnership officers (PPO), who are employed by the LEA to provide independent advice to parents, most commonly experienced problems gaining admission for children who had been excluded with social, emotional and behavioural difficulties or with autistic spectrum disorders.
- There was concern about the 'magnet effect' of being seen to deliver well for certain conditions leading to a level of demand that could not be met.

Teacher training currently includes very little information or guidance on special educational needs, despite one child in six having such needs. To achieve qualified teacher status, students must satisfy criteria relating to special educational needs and it is expected that more detailed work with pupils with special educational needs will be part of induction. However, Ofsted recently reported that a shortage of appropriate staff training was a major concern of a majority of schools. The Additional research has shown that a large proportion of teachers feel ill-prepared and wish to have more knowledge and training on special educational needs. Ongoing debate surrounds the requirement for continuous training throughout teacher's careers and is another area of under-funding.

This need is recognised by the Government, and research has been initiated to address it, but will take time. The Government committed in 2001 to a program of training only SENCos and then only committed to providing 'an average of' three days training by 2004. ⁵⁹

Some LEAs have taken steps to reduce the number of special schools, moving more children into the mainstream (78 schools closed between 1997 and 2002 – 16 per year). Other LEAs have done little to close schools and a few have opened more special schools (in most cases for children with behavioural, emotional and social difficulties). It is important to note that in some cases children are dual registered at both mainstream and special schools, receiving part of their education in each.

It is unlikely that special schools will be abolished completely in the near future, in fact government see some as having a long-term future as centres of excellence, helping other schools to develop inclusive practices. But such schools will increasingly be seen as a last resort for students whom schools and LEAs feel would be better off in a segregated setting.

The DfES recently produced a long-term strategy for the development of special educational needs provision, reflecting the long time-scale over which improvements in provision must inevitably take place (although ministers have been quoted as saying that changes should be visible in two to three years). ⁶⁰ It is unlikely that it will produce a step-change correction in the nature of state special educational needs provision. ¹ The key themes in the strategy are:

- Focus on early intervention, in terms of identifying a child's needs at an early age and providing better targeted resources at the early stages of the Code of Practice.
- Improve provision for children with special educational needs in mainstream schools, including rolling out best-practice models for educating children with well understood conditions.
- Raise expectations and achievements for children with special educational needs by developing teachers' skills.

¹ For example, there will not be a comprehensive re-training of teachers in mainstream schools

Increase resources for provision for children with special educational needs, including more speech and language therapists, co-ordination across multiple agencies (health, education and social services) and co-ordinating good practice.

The strategy is emblematic of Government's commitment to the area. However, the practical implications of this commitment are inevitably constrained by funding. In this regard the system creates a number of tensions.

Funding special educational needs

The sum of the

many government

funding streams for

special educational

needs was at least

£3.6bn in 2001/02.

A considerable proportion of all state education spending is on special educational needs. It is very difficult to disentangle special educational needs funding from other education funding, however The Audit Commission estimates the sum of the many government funding streams for special educational needs to be at least £3.6bn in 2001/02. This is incremental to the cost of providing education generally and alone represents 15% of total education spending. Allocating a share of the mainstream education spending suggests that total resources consumed by special educational needs are nearer 30% of the total education budget. This represents an increase of around 7% from 2000/01, helping to correct for previous under-funding. Table 3 shows estimates of additional spending per pupil with special educational needs in different types of schools based on Audit Commission and DfES data. These estimates show the material increase in resources which, on average, are available for children with special educational needs. We estimate that educating pupils with statements of special educational needs in the mainstream costs on average around twice that of their peers, as shown in Table 3. Of total spending on special educational needs, the Audit Commission believes that around 70% is focussed on children with statements. 61

Table 3: Estimated average spend per pupil, England (2001/02) 62

School Type	Average non-SEN £	Average SEN without statement £	Average SEN with statement £
Pre-primary / primary	2,700	3,500 +27%	7,500 +174%
Secondary	3,300	4,200 +26%	6,500 +97%
Special	n/a	n/a	21,100

Percentages are increases relative to non-SEN figures.

Government provides funding for special educational needs through DfES allocations to LEAs. The formula for this funding makes allowance for factors such as number of families receiving working family tax credit, on income support and pupils for whom English is an additional language. Each of these factors is a reflection of an underlying factor – be it deprivation or ethnicity – which is correlated with special educational needs. The only factor used which is directly related to special educational needs is the number of children of low birth weight. Government spending on education makes some allowance for special educational needs, but this allowance is imperfect.

It should be emphasised that not all funding is utilised in providing education or support for the children for whom it is intended. For example the Audit Commission estimated the cost of producing a statement at £2,500. In 2002 around 31,000 statements were issued by LEAs in England and Wales, implying expenditure of around £78m on statementing alone. ⁶³ Some claim this represents a significant waste of money, however it is a small percentage of the total cost of provision for children with statements.

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Although some of this funding may not come from DfES budgets.

[&]quot;This varies by condition. Ofsted recently estimated the cost of educating a child in the mainstream with autistic spectrum disorder to be between £3,700 and £9,000, while the cost of educating a child with emotional, behavioural and social difficulties is estimated to be between £1,000 and £3,000. It appears that Ofsted calculations exclude the costs of shared services.

Central government funding to LEAs therefore does not react perfectly to the numbers of pupils with special educational needs or to the (much smaller) number of pupils with statements. More precisely, funding allocations do not adjust exactly to match the increased spending needs of LEAs which result from special educational needs.

There is an obvious reason for this. If funding allocations did adjust perfectly so as to immunise LEA budgets against increases in pupils with special educational needs, this would create an incentive for schools and LEAs to encourage registering pupils as having special educational needs. Per pupil spending could be markedly increased in this way. Government, and particularly the Treasury, is understandably reluctant to create such an incentive. However, the corollary is that by not making an adjustment there is an incentive for LEAs to resist the demands for additional resources that come with special educational needs. This can be particularly difficult since some children require expensive residential provision (up to £165,000 per annum) and many require out-LEA placements (around £30,000 per annum) costing many times the average cost of educating a child without special educational needs. It can also cause problems for children with less acute needs and is felt most keenly through the statementing process, as discussed below.

Within special educational needs, there is a continuum of severity of need which is reflected in a continuum of cost of provision. Some children will need only a small number of hours of additional help per week, while some will require the assistance of a full-time support worker. Children with statements on average receive significant extra funding from the LEA budget, but an individual child progressing through the system may only obtain a moderate increase in funding in moving to statemented provision depending on his or her needs. The majority of children with special educational needs have no safeguard of the funding they require and are left in the hands of variable school practice created by the devolved and fragmented funding system.

LEAs decide how much funding they allocate to and devolve to schools, although the DfES expects that LEAs will 'delegate where possible.' Special educational needs funding is usually allocated to individual schools using a mixture of social deprivation factors (e.g. free school meals), school results and, in only some cases, is based on the numbers of children with special educational needs or proxies for such needs. Each LEA devises its own school funding formula taking into account local needs and circumstances and so different allocations are found in different LEAs and even within the same LEA for children with similar needs.

Delegation has caused severe problems for some disability groups as central resources have disappeared without adequate provision replacing them at local levels. For example sensory specialist services have been withdrawn in a number of LEAs. 68

Within schools there is little consistency in methodology or quality of special educational needs spending. School budgets are used to fund SENCos, salaries for learning support assistants and even for extra teaching time for all pupils in lower sets. ⁶⁹ Schools have traditionally been poor at accounting for expenditure and checks have not been in place at LEA or central government level.

There are a number of additional funding streams that central government uses to catalyse and encourage best practice in special educational needs, including the Standards Fund (£81m) for children with special educational needs and other disabilities, ⁷⁰ the Schools Access Initiative (£100m) for school accessibility ⁷¹ and the Small Programmes Fund (£2m) which provides small grants, the bulk of which is distributed to voluntary organisations. ⁷² However, these sums are all small relative to the totality of spending on special educational needs.

Each LEA retains a budget which covers items relating to its statutory responsibilities, such as funding interventions identified on statements and conducting statutory assessments. Additionally, it retains a central special educational needs team which provides advice to schools and offers parents 'independent' support in the form of parent partnership services. A recent Ofsted report found that although children with special educational needs are well served in mainstream schools, LEA support itself varies greatly. The discussion about funding for special educational needs is set against a backdrop of general school under-funding. The funding situation for education in the UK was generally described as 'in crisis' during 2003 as increased National Insurance and pension fund contributions for teachers were not adequately covered by the increase in public expenditure. Funding

Funding at a school level is not based on the type of learning difficulties that the school's pupils have.

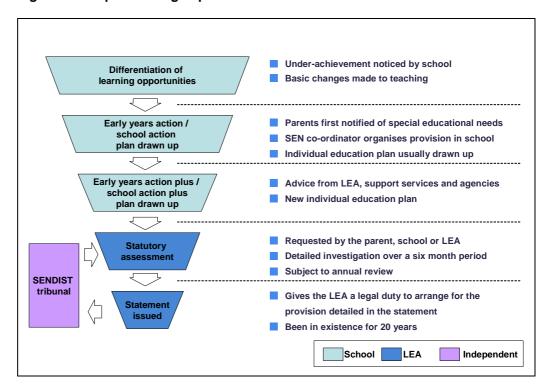
guarantees were recently announced for 2004/05, however many professionals believe this is not sufficient to restore education funding to an adequate level.⁷⁵

There is suggestion that in the recent schools funding crisis, pupils with special educational needs are affected more significantly than their peers. The Vice President of the National Association of Head Teachers was quoted as saying 'the first staff to go are the support staff that are instrumental in helping children with special educational needs.'⁷⁶

Identification of special educational needs

There are several processes that a child with special educational needs must pass through to identify and understand their needs and the appropriate interventions, as outlined in Figure 3. The system is long and complex, resulting in significant numbers of children failing to have their needs identified and met. (We will describe in Section 3 how this process has produced an important role for the voluntary sector where support and donations are needed.)

Figure 3: The path through special educational needs



The process presented in Figure 3 may take considerable time. At all stages in the process, to test whether pupils' needs are being met, schools must question whether the child is making 'adequate progress', meaning that the system must fail the child for him or her to get additional support. Children with more severe needs may progress more quickly or will not need to move through all of the steps. To Given the complexity of the system, this can result in long periods of unsatisfactory provision.

Even if it is immediately obvious that a child requires the extra advice, support and resources that a statutory assessment can bring, the statutory assessment process alone takes 28 weeks to complete – a long time if you are a family waiting to discover the result and if you are a child waiting to receive the education that you require.

The difficulties the system causes for parents are significant. Many parents are forced to fight as a result of limited resources in the education system just to understand what interventions their child needs, before they even begin the fight to get the state to provide those interventions. The difficulties outside of the educational needs (e.g. medical difficulties) are outside the remit of this report, but should not be forgotten since they add significantly to the stress and difficulties experienced by the parents.

The difficulties the system causes for parents are significant. Many parents are forced to fight.

The reality behind the rhetoric on special educational needs often involves parents facing the frustrations illustrated in Box 4. An inevitable cause of these frustrations is the fixed pool of funding for education. Variation in policy across LEAs compounds the problem. There is a clear role for external, voluntary sector support for parents navigating the path to getting their children's special educational needs met.

Box 4: Sticking up for Katie⁷⁸

Katie is a delight much of the time but at times she disappears into a black hole where no one can reach her. Katie was born prematurely and with so much cocaine and heroin in her bloodstream that she had to be weaned off. She spent her early life in an environment in which drugs, inappropriate sexual activity and violence were the norm.

Shortly after joining reception year at primary school we had to put her back into nursery because she suffered severe anxiety: cut lumps off her hair, hid in corners, put scissors near her eyes and coloured her tongue with felt pens until there was no sign of its natural colour. Her teachers could not watch her all the time - they had 29 other children to look after.

I made a formal request to the LEA to assess her with a view to providing her with a statement. I had to provide a detailed dossier, including reports from one of the country's top child psychologists and historical documents from social services, but the LEA rejected our application on a technicality – it said it was unable to determine whether the school had placed Katie on School Action and School Action Plus. The LEA had made no attempt to determine from the school whether it had implemented these procedures. But the school SENCos said School Action and School Action Plus were so new that they did not have to be implemented for another month.

I was left with the impression that the LEA was looking for any excuse to avoid granting a statement. Several SENCos in the borough alleged the LEA's new children's officer had put a blanket ban on all new statements because of a funding crisis which the Education secretary, Charles Clarke, admitted had arisen because of a government "mistake".

I studied the 217-page Special Educational Needs Code of Practice and, when I got to page 80, I found a gem I could use, and I was also able to argue, with the help of Katie's teachers, that the school had fulfilled the spirit of School Action and School Action Plus even if it had not formalised it as such.

The LEA agreed to give Katie a Statutory Assessment and it awarded her a statement. It was inadequate and I successfully argued to increase the number of hours of inclass help. But the school refused to implement the statement saying it was one of the "losers" under the new funding formula and it was a simple choice between making teachers redundant or recruiting staff to help children with special educational needs.

Katie was caught in a vicious circle. The school said the LEA had not provided it with the funds to implement statements; the LEA blamed the DfES and the DfES blamed the LEA for holding back money. My fight for Katie became full-time. I wrote to anyone I thought might be able to help and hounded LEA officials so that they knew I was not going to go away.

The LEA's chief education officer at one point told me she would go through the school's budget line by line and that as a last resort she would threaten to remove all funding from the school unless it complied with the statement. I felt she was deliberately trying to make trouble between me and the school when I genuinely believed it was the LEA at fault. At various stages there were commitments to implement some of the hours stipulated by the statement but this was woefully inadequate and did not comply with their legal obligation.

Katie continued to deteriorate, so I hired a City-based law firm who got a judicial review at the High Court. I was exhausted, emotional, frightened for my daughter's future and outraged at an education system that seemed to put finance before the welfare of genuinely needy children. The intervention of solicitors got things moving. The school finally confirmed Katie would receive all but about an hour of the provision specified in the statement.

I was left with the impression that the LEA was looking for any excuse to avoid granting a statement.

When I picked Katie up from school on the first day of the new school year she ran out of the classroom and threw her arms around me in the most glorious hug, her face beaming. I found myself wondering about all the other children affected by the funding crisis who had no one to champion them.

The path to identification

The first stage for children falling behind their peers is differentiation of learning opportunities, where children are presented with different opportunities and alternative approaches to learning. Should this not work children have action plans drawn up for them (these are referred to as Early Years Action Plans or School Action Plans depending on the child's age). At all stages a child's parents can seek help from the LEA parent partnership officer (PPO) who is employed by the LEA to provide independent advice.

Under action plans, additional or different provision is offered, which might comprise of extra adult time in considering appropriate interventions, different learning materials, individual/group support or staff development and training. From the time an action plan is drawn up the child is deemed to have special educational needs and the school has a duty to inform the child's parents of that.⁷⁹

Action Plus plans are drawn up following a lack of adequate progress at action plan stage and is the first point at which external support services (such as educational psychologists and speech therapists) are brought in from the LEA to assess the child. (This stage is called Early Years Action Plus or School Action Plus depending on the child's age.)

During the action plan stage, an Individual Education Plan (IEP) drawn up by the school is used to monitor and review the child's progress. IEPs are required to be drawn up and used before LEAs will consider the one remaining stage of assessment – the statutory assessment process.

Statutory assessment and statementing

A minority of pupils with special educational needs (around one in seven⁸⁰) require support beyond that available from their school. To obtain this support, children must go through a statutory assessment process and obtain a statement of special educational needs (a 'statement'). Around 30,000 were issued in 2002 in England and just over 250,000 were in place as at January 2003.⁸¹ The number of new statutory assessments in England has been declining at around 3% per annum since 1996. The number of assessments that do not result in a statement being issued is declining faster (at 6% per annum), suggesting a better targeting of the assessment process to children who need it.

The statementing process is a big step that consumes LEA resources and causes significant stress for the family. There are two main reasons why families pursue statutory assessment for their children. Firstly and fundamentally a statement places a legal obligation on the LEA to provide the educational interventions it outlines. This is the only way the child can be legally guaranteed the provision he or she requires. It is important to note that a statement itself will not lead to the substantial increases in resources implied in Table 3 which showed the average resources for a child with a statement compared with a child without a statement. In practice, the marginal increase in resources that comes with a statement compared with a child on the verge of the statementing process will be far less.

Secondly a number of parents pursue the process simply to obtain a better understanding of their child's needs and of the appropriate interventions, believing that the long and complex process will yield further insights through the involvement of additional expertise and professional insight. The Statementing by LEAs is restricted primarily as a result of the funding restrictions outlined above. Minister for children Margaret Hodge said in October 2003 that 'there is not enough money, infrastructure and trained people – take that as read ... I need more [money] for every aspect of my portfolio, but this is limited by people's willingness to pay taxes. Additionally, Baroness Warnock, whose committee set the pattern for today's provision 25 years ago, recently criticised the statutory assessment process for its lack of public money as well as its ideological rigidity, bureaucracy and litigation. Symptoms of the funding restrictions include:

The start of additional or different provision is the point at which the child is deemed to have special educational needs.

- A number of children with special educational needs who require statements are refused either statutory assessment by the LEA or refused a statement at the end. This can be seen by the large number of children who appeal to the Special Educational Needs and Disability Tribunal (SENDIST) only to have the LEA back down and give a statement without actually going to appeal. A large number of these involve the LEA backing down at the last minute suggesting that they seek to use the difficulty of the appeals process as a method for restricting the number of statements issued.
- Some LEAs choose not to specify the entitlement on children's statements to avoid a commitment to providing that entitlement. This process was recently clamped down on by the DfES as a result of a court action brought by a voluntary sector organisation, the charity Independent Panel for Special Education Advice (IPSEA).⁸⁸
- Statements are sometimes not implemented owing to a lack of resources. The General Secretary of the Association of Educational Psychologists felt that it was 'only too common' that statements were not implemented.⁸⁹ Even once the LEA has been beaten in a tribunal there are significant problems with implementation one recent survey found that 29% of parents who were successful contacted a solicitor concerning implementation.⁹⁰

Appealing against LEA decisions

Parents may appeal to the Special Educational Needs and Disability Tribunal (SENDIST)^{II} if they are unhappy with the provision offered in a statement or to force the LEA to carry out a statutory assessment.⁹¹ The appeals process by its very nature imposes significant strains on parents. These strains may explain why few parents choose to take up their right to appeal. In 2002/03, almost 3,800 appeals were received (which represents 1.5% of children with statements), of which over half were withdrawn before they were heard (often, as noted above, as a result of the LEA backing down).⁹²

According to SENDIST, parents had legal representation at around 30% of hearings during 2002/03 and had other representatives (e.g. friends or advocates from the voluntary sector) at an additional 37% of hearings. 93 Data from a parent survey of children with autism in 2003 suggested that 88% of people had used legal representation at their appeals, averaging a cost of almost £4,300 – a sum available only to a small minority of families. 94 Although this survey and another by a large autism charity in 2003 were small, the results are very concerning. The surveys found that:

- 68% of parents contacted another parent for help, 61% had contacted a charity (such as Peach which helps parents with children who are autistic), 48% had contacted the Independent Panel for Special Education Advice and 24% contacted the National Autistic Society helpline. 95
- 63% of parents felt that the appeal process had caused them financial hardship^{III}, of which: 19% had re-mortgaged their house, 19% took out bank loans, 14% had borrowed from family and 4% had used their savings.⁹⁶

The stress that the process puts the family under is great, resulting in parents not taking up the process in the first place or backing down before they are happy with the result. Surveys in 2003 found that:

78% rated their stress levels during the process as eight or above on a scale up to ten.⁹⁷

63% of parents felt SENDIST had caused them financial hardship.

¹ One survey by the National Autistic Society showed that in 56% of cases the parent withdraws the appeal, often as a result of the LEA backing down and settling. Furthermore, in 40% of these cases (i.e. almost one quarter of all appeals) this happens in the last six weeks of a four to six month process, implying considerable strain and resource cost in the interim.

SENDIST also hears appeals about disability discrimination within the education system.

Legal Assistance (formerly known as Legal Aid) is limited to people who are on income levels around state benefit eligibility level, but only covers preparation, not representation at the SENDIST hearing.

Children with special educational needs from low income families are less likely to receive the education they require and are entitled to receive.

Of those parents that had settled with the LEA, 48% reported that they were not happy with the outcome and 66% felt that they were 'too worn down' to continue.⁹⁸

It is inevitable that families with low incomes are under-represented within the appeals process. The potentially considerable financial costs involved make it prohibitively expensive should they be unable to locate free voluntary sector help or to navigate the complex system on their own. Children with special educational needs from low income families are less likely to receive the education they require and are entitled to receive. The fact that SENDIST does not collect data on household circumstances of those making appeals is striking. Charities play an important role providing support to low income families going through the appeals process, but there is considerable anecdotal evidence that more such support is needed.

Box 5: Exclusions

A serious consequence of inclusion not being implemented or resourced properly is exclusion. The total number of children with special educational needs in England who are excluded is estimated to be in the region of 40,000 at any one point in time. ⁹⁹ Children with statements are four times more likely to be permanently excluded from school than other children, which is particularly alarming given that these children have documents placing a legal obligation on the LEA to provide a certain standard of education. ¹⁰⁰ There does not appear to be any marked difference in the likelihood of exclusion between statemented and non-statemented children with special educational needs. Around 6,000 pupils with special educational needs were permanently excluded in 2002 (60% of all permanent exclusions). ¹⁰¹ Additionally it is estimated that around 20,000 children with special educational needs are unofficially excluded per annum (not included in government statistics) and that the numbers of children with special educational needs who are subject to fixed term exclusion far exceeds those permanently excluded. ¹⁰²

Charities working in the field argue that children with special educational needs are usually excluded as a result of their additional needs not being met. ¹⁰³ Usually, these are children whose needs arise from conditions which do not in themselves predicate difficult behaviour (e.g. dyslexia and many of the language and communication problems) but where the frustration they experience when their needs are not met causes challenging behaviour and/or anxiety and depression. ¹⁰⁴ Alternatively, they are children whose needs arise from conditions which do give rise to behaviour which can be difficult to manage in the classroom (e.g. attention deficit and hyperactive disorder and some autistic spectrum disorders), but which can be helped given appropriate provision. ¹⁰⁵

A future report from New Philanthropy Capital will address in detail the subject of school exclusions and the role of the voluntary sector. This will look at what charities are doing and how they are tackling the links between special educational needs and exclusion. However, a number of charities described in Section 3 provide support to parents whose children are excluded.

Links between exclusions and special educational needs are also the subject of a research report by NFER (commissioned by the DfES).

¹ Fixed term exclusions can be and often are repeated for up to a total of nine weeks in any one year, representing a sizeable chunk of any child's formal education.

Summary: The need for the voluntary sector

Government commitment to adequate provision for children with special educational needs is clear and welcome, but there is evidence of a gap between policy and delivery. Getting correct educational provision for children is often time consuming, stressful and expensive. Though many children with special educational needs appear to be receiving 'good enough' education in their schools, there remains a large number for whom securing proper provision is a struggle.

The statementing process is the most visible battlefield for this struggle. Out of the around 32,000 statutory assessments taking place in 2002/03, 96% resulted in a statement. ¹⁰⁶ A small proportion of these appealed to SENDIST, probably to clarify the statement or to secure increased provision. Half of these withdraw their appeal but, as noted above, this is often the result of the LEA backing down. SENDIST upheld 75% of parents' appeals. ¹⁰⁷

The numbers involved in the SENDIST process are small in absolute terms – fewer than 3,800 appeals were started and only around 1,200 were completed in the last year. ¹⁰⁸ But for these parents going through the process the strains are considerable. It is difficult to match the rhetoric of adequate provision for special educational needs with the trials and tribulations of the SENDIST process. It is not known how many parents baulk even from pursuing an appeal.

Many parents face difficulties securing adequate provision long before the statementing process. The fixed pool of resources available for education spending produces in-built tensions which work to undermine the professed commitment to provision for all. In addition, the behaviour of many LEAs does not match the commitment of central government to providing for special educational needs. Schools themselves may lack this commitment since they do not have the trained staff to provide for all needs, and the recent pressure to perform well in league tables has influenced some attitudes to accepting those with more limited ability. There is reason to believe, as suggested by the Audit Commission, that low income families suffer particularly from these shortcomings.

It becomes apparent that the provision for special educational needs is complicated and confusing for many parents. Access to good advice is very important. LEA parent partnership officers (PPO) can play a role in this, in principle an independent role. However, Ofsted has remarked on the variability of LEA support to parents. A parent without a good understanding of the field may encounter poor advice, a difficult school or an intransigent LEA without being aware that they should be given better support and their children a better education. As long as this situation can arise there will be a crucial role for the voluntary sector, both to educate and to support, in a multitude of ways. The next section provides a review of the interventions that are offered by voluntary sector groups, meeting visible needs that are being over-looked or under-resourced by the state.

Shortcomings create a role for the voluntary sector.

Section 3: Delivery - the role of the voluntary sector

Despite the fact that the state has overriding responsibility to provide education for children with special educational needs, it is clear from our research that the voluntary sector has a significant role to play in this area. Donors and grant-makers have the opportunity to fund exciting ventures that are making a real difference to the prospects and lives of children with special educational needs. This section of the report sets out the main education-related interventions that are provided by the voluntary sector.

Introduction

Since the Education Act of 1944, the state has taken responsibility for the education of children within the UK. As a result, the primary role of grant-makers and donors is not to provide education, nor to provide teachers or buildings. We estimate that within the top 10,000 charities alone there are over 300 registered charities in the UK that have some involvement with special educational needs, with total income in 2002 of around one billion pounds. This clearly includes large charities that exist to support people with a specific or a range of disabilities, and for which the education of children with special educational needs is only a small part of their wide-ranging work. It is interesting to note that despite the apparent statutory obligation of the government to provide an adequate education for all, there are still a number of critical interventions that the voluntary sector makes in this area. In addition, it is important that donors only fund work that is additional to state commitments, as outlined in Box 6.

Box 6: Additionality

Charities are frequently contracted to provide services that are paid for by government, usually through LEAs or even by schools themselves. A special school, for example, may well have charitable status but will charge fees to an LEA in order to recover the cost of providing education to its pupils. In these cases, the charity is acting essentially as outsourced service provider, but complexities occur when the charity provides additional services which it regards as crucial for the good of the beneficiary (i.e. the child) but these are not formal statutory obligations. This concept of 'additionality' is important for any funder to consider, as a charity may typically agree to fund part of a service itself whilst charging the state for the rest of the service.

Worryingly, the voluntary sector has not always been efficient at charging out the full cost of a required service to the state. This leads to donors subsidising statutory authorities. For many charities, the portion of their costs that cover innovation, research and strategic development is the hardest element to cover in their contract negotiations with statutory authorities. Funding capital projects is another area where charities have difficulty in covering their costs. For example, if a private contractor was to build and operate a school, the capital expenditure would likely be financed with loans and the cost of depreciation of the asset would be re-charged to LEAs on a per-pupil basis over the asset's lifetime. The voluntary sector however, has typically fundraised to cover the cost of construction and in doing so has allowed LEAs to evade payment of the full cost of the service of educating its children.

All charities are developing a better understanding of these costs in order to allocate more effectively the full and relevant portion to each project. One of the main umbrella bodies in the voluntary sector, the Association of Chief Executives of Voluntary Organisations, has produced a widely disseminated template to help organisations in this regard, which is being increasingly used. ¹⁰⁹ As New Philanthropy Capital's individual charity reports make clear, our recommendation is always for grant-makers to fund those activities of the voluntary sector that are providing a key intervention, but that are truly additional to the current obligations of the state. There is often a compelling argument for a private donor or grant-maker to

Over 300 registered charities in the UK have some involvement with special educational needs, with total income in 2002 of around one billion pounds.

We have concentrated on those charities whose work is mainly in the educational sphere.

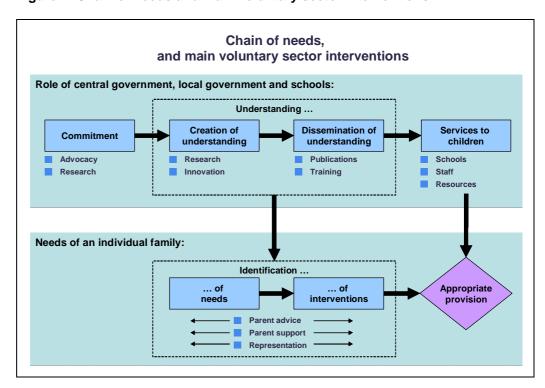
fund a charity that is primarily providing services funded by the state (such as to support a pilot initiative that the charity believes will subsequently be adopted by government), but it is important that the generosity of grant-makers does not allow the government to evade its responsibilities.

For the purposes of this report we have concentrated on those charities whose work is mainly in the educational sphere (rather than in medical research, recreational activities for children, parents' support groups or community-based projects). Many groups offer recreational activities for children or arts-based activities that are particularly beneficial to children with special educational needs but we do not aim to cover these in comprehensive detail in this report.

The intervention cycle

We can demonstrate the various voluntary sector interventions by adding them to the chain of needs originally shown on page 15.

Figure 4: Chain of needs and main voluntary sector interventions



Ultimately the measure of success for any voluntary sector activity is the provision of appropriate education to children leading to improved outcomes for these children (such as literacy or language). The main feature of the chain is that earlier needs on the left need to be satisfied before needs on the right can be. For example a child cannot have appropriate interventions devised, let alone delivered, until his learning difficulty ('condition') is identified. Similarly the state cannot adequately understand the range of interventions required of it until it understands the nature of the conditions among children with special educational needs.

Satisfying a need upstream leads in part to the needs downstream of it being satisfied. Securing a significant commitment to educational provision for children with special educational needs will in part lead the government to the nature of special educational needs and the nature of appropriate interventions as well as to provide adequate services. These downstream needs will never be satisfied completely, but the trickle-down effect may in some cases be significant, though often not measurable.

The main choice facing funders is whether to support a voluntary organisation primarily helping the State to provide better **services to children** (the top half of Figure 4) or to **help individual families** (the bottom half) to navigate the complex system of provision. Another

One choice is whether to help provide services to children or to help individual families. choice is whether to help a few children intensively or to help many by, for example, training teachers and disseminating good practice. Each of these can be done through very direct, measurable interventions such as training teachers better to include children with special educational needs or through helping a particular family through the SENDIST process. Alternatively, each has interventions that are more geared, but correspondingly difficult to measure, such as providing policy advice to government and running a helpline for parents. On the following pages, we review the interventions that are being used by the voluntary sector.

Increasing state commitment

In Section 2 we saw the strong stated government commitment to special educational needs but that this commitment was not adequate to ensure the translation of policy into practice. For example, many schools are reluctant to include children with special educational needs despite a commitment to inclusion, and it is a significant struggle for parents to navigate the system despite a commitment to providing appropriate education to all children. Here we discuss how the voluntary sector plays a vital role in ensuring that national, regional (LEA-based) and local (school-based) commitment is increased in order to ensure the delivery of services to meet the needs of children with special educational needs.

At the outset it is clear that advocacy and lobbying is perhaps the least measurable area of voluntary sector activity. There is no objective way to measure government commitment, and so no way to measure a subsequent increase, let alone attribute any change to a particular voluntary sector activity. Yet without the commitment to special educational needs, clearly children's needs will continue to go unmet.

To translate commitment into provision for children with special educational needs, commitment must stem from the desire to meet children's special educational needs by those running national, regional and local education and must be articulated in the form of policies. We now review the desire to meet special educational needs and the need to articulate this in policy.

The desire to meet special educational needs

The voluntary sector must consistently remind government of the need to provide education to children with special educational needs. Almost every organisation involved with special educational needs maintains some level of dialogue with central Government and at a national level this seems to be very effective. To bridge regional and local gaps in commitment, fewer organisations are able to participate significantly due to the sheer number of people involved: over 200 LEAs and over 420,000 teachers in England alone need to demonstrate this commitment in order for the entire education system to move forward.¹¹⁰

Much of the work that increases commitment does so alongside interventions planned for other purposes. Training teachers in disability awareness, for example, must fundamentally increase teachers' commitment to special educational needs. There are however, some projects that seek to increase commitment of regional and local educators as one of their primary aims. For example, we identified inclusion as the preferable form of education for almost all children with and without special educational needs. We also revealed a serious gap between the ideal and the practical implementation of inclusion. Voluntary organisations that seek to bridge this gap include the Centre for Studies on Inclusive Education who provide practical guidance materials to schools on inclusion and Parents for Inclusion who set up local community groups involving parents and teachers to work through the process of inclusion together:

The **Centre for Studies on Inclusive Education** (CSIE) encourages and empowers professionals in the field of education to work towards inclusion. This is achieved by the provision of information through commissioning specific pieces of research, gathering and disseminating information and through specific advocacy of policy positions.

Parents for Inclusion (Pi) is run primarily by parents and helps children with special educational needs by empowering their parents. Pi provides information to parents of disabled children on issues related to disabilities, with a particular emphasis on inclusion. The organisation advocates the rights of disabled children, both those with

Inclusion is the most preferable form of education for almost all children.

physical and mental disabilities, by working with the media, the government and other supporting organisations.

The **Alliance for Inclusive Education** is run by disabled people and gives a voice to disabled people who are in, or have been through, the education system. The Alliance advocates complete inclusion and produces a number of publications and advocacy projects around this objective.

Policy articulation

Policy must be articulated to translate commitment into provision. Charities are increasingly involved in national policy formulation, especially those with longer histories of working in a particular field and those with the resources to employ staff to attend, and so contribute to, the debate. Organisations with strong policy influence include:

The **Special Educational Consortium** brings together almost 250 organisations and individuals involved in special educational needs to influence policy with a united voice where possible and with a clear articulation of policy differences where not. The consortium retains one member of staff for one day per week and a similar quantity of support staff.

The primary role of the **Independent Panel for Special Education Advice** (IPSEA) is to support parents of children with special educational needs in understanding and accessing state education. This role puts IPSEA in a strong position to identify and apply pressure on schools and LEAs who pursue inappropriate policies. Through applying pressure, IPSEA has achieved blanket changes in policy and practice across many LEAs.

The Centre for Studies on Inclusive Education's most notable piece of work is its 'Index for inclusion' toolkit for schools. All schools and LEAs in England and Wales have copies (through DfES and Welsh Assembly Government grants) and the report is well respected by educators and referenced in six Government documents. The index provides a roadmap for schools to become more inclusive over a five year time-scale.

The National Autistic Society (NAS) has three staff with responsibility for parliamentary affairs. As part of its responsibility, the NAS staff co-ordinate a group of 150 MPs and Peers known as the All-Party Parliamentary Group on Autism. This group, and the access it has to ministers and other policy makers, is undoubtedly a powerful tool of the voluntary sector, helping to shape opinions and policies concerning autism.

Scope has a team with responsibility for parliamentary affairs. The focus of its education-related work is on advocating policies favouring inclusion in the mainstream. Again, it offers a valuable resource because it is well tied in to MPs, ministers, and other key decision-makers.

The main unmet need in influencing national policy formation is the representation of special educational needs that do not have large powerful groups with the resources to have a presence at the policy-making table, such as social emotional and behavioural difficulties. However, in a constructive development, a group of twelve charities involved in emotional and behavioural support has decided to collaborate to influence policy and have formed the **Emotional Health Alliance** to improve dialogue by co-ordination.

Qualifications, examinations and assessments of children with special educational needs are particularly complex and several charities are represented on the various committees that look at examinations. Again, the main unmet need in the qualification and assessment area is the representation of special educational needs that do not have the resources to be represented in these discussions.

The National Autistic Society (NAS) has an education policy expert who sits on the Qualifications and Curriculum Authority (QCA), the Government body setting standards for the provision for special educational needs in schools. This helps to ensure that autism is central to the discussions and is well considered in policies that result.

The **Dyslexia Institute** is involved in the development of the National Literacy Strategy and policies that define rules for children with dyslexia in public examinations. It

conducts research into the teaching methods for those with specific learning difficulties and the policy implications for primary education. The provision of extra time for those children who have been assessed with specific learning difficulties has meant that they are able to complete their papers. This was recently highlighted in the primary school SATs results where better literacy results were achieved and 36,000 children were awarded extra time for the test.

I CAN has jointly developed professional standards for speech and language therapists, as well as working to partner mainstream schools in their policy for children with these difficulties. I CAN participates in the debate around provision and policy, alongside the academic and health professionals from both state and private sectors.

Creating and disseminating understanding

We mentioned earlier in the report that much is still to be done in understanding special educational needs and understanding appropriate interventions, despite having come a long way in recent years. The evaluation of different approaches is particularly complex, and may not be comparable, without the collection of good data at the outset and ongoing evaluation of data in well-designed research studies.

We look at two types of intervention in this section. First we will look at the **creation of understanding**, primarily through research. This can be both understanding of the conditions that give rise to special educational needs themselves, and understanding of the interventions that are appropriate for educating children with those conditions.

Secondly, to increase both understanding of the conditions and of appropriate interventions there is an amount of work to be done in **dissemination of understanding** that currently exists. Schools and, to a lesser extent, LEAs need guidance on appropriate interventions. In some areas there are good methodologies in existence for improving educational provision (e.g. for children with dyslexia), but the lack of dissemination to schools creates a need for the voluntary sector to promote best practice.

Creation of understanding

Given the need for academic research to advance understanding of the nature of **conditions**, this role is often shared by academics and members of the voluntary sector working in partnership. The dissemination of findings may fall to the voluntary sector as part of their awareness-raising activities. Many academics are partially funded by the voluntary sector and spend a portion of their time working for charities. For example:

Dr John Rack of York University is also the Research Director of the **Dyslexia Institute** and has been involved in the study of early reading development for over twenty years. The academic approach to research in this field has been translated into helpful practice for those involved in dyslexia education as a result.

Professor Sue Buckley, Emeritus Professor of Developmental Disability, University of Portsmouth, is the Director of Research and Training at the **Down Syndrome Educational Trust**. Her lengthy involvement with Down Syndrome research and contact with all other researchers in this field mean that the understanding of the condition is shared and developed efficiently. In common with all academic research, the sharing and publishing of findings is important and this activity is complemented by the charity's network of children and teachers in the field.

The accumulated case-work experience of charities working with emotional and behavioural difficulties increases the understanding of working with this growing group of pupils. The charity **Antidote** has been involved in reporting to the DfES on the effective development of children's emotional and social competence.

Increased understanding of **interventions** is primarily achieved in the voluntary sector by special interest organisations based around individual conditions. This is time-consuming and resource intensive, requiring in the main the funding of research studies. Voluntary sector involvement in this research may include the monitoring of educational activities such as those of the Down Syndrome Educational Trust and the National Autistic Society.

Increased understanding of interventions is achieved in the voluntary sector by special interest organisations based around individual conditions.

The work of the **National Autistic Society** (NAS) in autism provides a useful example. The NAS is one of the largest and most powerful special interest organisations in special educational needs. The NAS was set up in 1962 in response to the lack of state educational provision, with the aim of encouraging a better understanding of autism, and established the first special school for autistic children in the world. Little academic research has attempted to identify best practice and so the NAS has employed a full time researcher with the sole purpose of reviewing literature in the various interventions being practised and identifying successful interventions. It has taken the NAS's existence over a very significant period of time to get this close to understanding the range of appropriate educational interventions.

Down Syndrome Educational Trust is a leading researcher of Down's education in its own right, as well as in a secondary capacity. The methodology and practice of teaching children with Down's has been developing since the late 1970s when Professor Sue Buckley started researching reading development. The charity is now central to the worldwide understanding and sharing of current research from many academics and longer-term experience of those working with generations of children with Down Syndrome.

Innovation is vital to the understanding of the most appropriate interventions and is typically found in voluntary sector independent schools, such as schools belonging to **TreeHouse Trust, Prior's Court, Scope, NCH** and **NAS**. These are reviewed in more detail below in their capacity as providers of education, but their role in innovating to advance understanding should not be forgotten.

The academic research that must eventually underpin this need is always carried out by a charity in the end, since educational institutions are themselves charities. This research is sometimes funded by the government (through grants from the DfES or the Department of Health), but there are examples of charities funding such research, like the Esmée Fairbairn Foundation, and the Gatsby Foundation funding Professor Julie Dockrell of the Institute of Education for work on speech and language interventions. The current focus of much research is on early intervention, especially pre-school. It needs to be remembered that ongoing intervention may be needed for children with special educational needs throughout their schooling, and that there are few studies that provide conclusive evidence of what works. These institutions are voluntary sector bodies and must raise funding in their own right and so should be considered by donors alongside more traditional voluntary sector organisations.

There are many education research institutions in the UK with a strong reputation for work in special educational needs, including:

The **Institute of Education** (part of the University of London), which houses a team of researchers specialising in research into special educational needs, including Professor Julie Dockrell, Editor of the British Journal of Educational Psychology. The Institute also houses Special Educational Needs Joint Initiative for Training (SENJIT), a partnership between the Institute of Education and local education authorities which provides short courses, support groups, local training and consultancy for teachers and other professionals working on inclusion and special educational needs. SENJIT was formed after the Inner London Education Authority (ILEA) was disbanded in order to preserve the core of expertise that had developed.

The **National Foundation for Educational Research** (NFER) is a significant academic research house with a team specialising in special educational needs, including Felicity Fletcher-Campbell who is also national co-ordinator of the European Agency for Development in Special Needs Education. NFER has over 100 research projects running at any one time and is unique in that it raises all of its funds on a per-project basis. Membership includes LEAs, teachers' associations and other organisations with educational and training interests.

Dissemination of understanding

Voluntary sector provision of services to schools covers a large number of types of service, each with very different impacts. The common theme is that services are being provided either where the state is not providing them or where the state does not have the expertise to provide them effectively. Schools and charities work together to enable the school to gain

Usually voluntary sector organisations providing services recover their costs from schools.

maximum benefit and to be left in a sustainably improved position. Usually voluntary sector organisations providing these services recover their costs from individual schools, LEAs or from the DfES. Some, however, may have a funding need arising from core organisational planning or development work that is not recoverable.

First **staff training**. For the state identification system to operate smoothly, schools and LEA staff must have the knowledge necessary to identify children's needs and to match them with appropriate interventions. We showed earlier that these skills were lacking and this is a key area for the voluntary sector to step in and give teachers, co-ordinators and other school support staff those skills.

Disability Equality in Education (DEE) aims to remove barriers in education professionals' views of disability that mean that they find inclusion difficult to understand and implement. DEE trains teachers in disability education (using disabled trainers), publishes materials for schools on inclusive practices for disabled children and provides consultancy advice to schools on inclusive education. 92% of those trained rated the training as good or excellent and 60% said it had changed both their attitudes and practices.

The **National Association for Special Educational Needs** (NASEN) has produced reports on inclusion, curriculum access, partnership with parents, exclusion from school, post-16, early years, professional development, funding, learning support assistants (2001), and the role of the SEN co-ordinator (2001). These reports are designed to give help to schools, LEAs and central government.

The **Social, Emotional and Behavioural Difficulties Association** (SEBDA) supports and informs professional staff as a route to indirectly help children with social, emotional and behavioural difficulties. Membership is around 900 mainly educational staff but includes other professions interacting with children. Additionally around 900 people benefit from training courses, outside of the core membership base.

Within teacher training, the voluntary sector also **trains professionals** who are then placed into and funded by the state system and who are therefore able to work more effectively with children. The continuing professional development (CPD) requirements for teachers are highly complex and there are few funds available for those who wish to develop their skills in the special education field.

The **Dyslexia Institute** trains teachers who then go on to use their new literacy teaching skills in their work as teachers or classroom assistants. Children with dyslexia and related learning difficulties need to learn reading in different ways which are not part of the mainstream training for teachers. Frequently funded by teachers out of their personal resources, this professional development of the workforce has also been funded occasionally by schools and LEAs when they deem it appropriate.

I CAN trains speech and language therapists as part of their required professional development training. Its programme of courses is part of the Joint Professional Development Framework that is approved by the National College of Speech and Language Therapists. The courses are also aimed at teachers and learning support assistants who wish to improve their effectiveness with children in school.

TreeHouse Trust School for autistic children in North London is looking to build a national training centre for a methodology called applied behavioural analysis (ABA), which they believe to be the most appropriate intervention for autism. The centre will provide training for teachers from all over the country in ABA to allow a national pool of ABA teachers to be created. No comparable pool of expertise exists in any other autism teaching methodology.

Dissemination of understanding through the distribution of **publications** is one of the easiest and most common methods employed by the voluntary sector. In terms of outcomes, it is one of the most difficult to assess. Almost all organisations we met use publications to spread their messages, but two of the key organisations are:

RNID (formerly the Royal National Institute for the Deaf) produces a series of publications aimed at mainstream teachers, each dealing with a different aspect of the education of children with hearing loss. There are a number of publications in the series

and they are well received. RNID is also involved in research into successful interventions and in the joint drafting of guidelines with the Government.

The **Down Syndrome Education Trust** publishes regular reviews of the literature on Down Syndrome, project briefings and reports. It has developed an electronic publishing approach that enables updated publications to be produced at lower cost.

Provision of services to children

Direct **provision of education** to children by the voluntary sector is relatively small in size when compared with the state's education system. Historically, the care of severely disabled children was shared by the charities and the health services. When their right to education was recognised, and their inclusion in the mainstream started to be advocated, the role of direct service provision began to diminish. There remains a need for direct services, either in addition to the state, or as a showcase of a new service that the state may then roll out nationally.

The state provides the vast majority of schools in the UK and funds most children's places at other schools. Within the provision of education, the voluntary sector, primarily through special interest organisations, has provided some **physical schools**, i.e. special schools, where provision would otherwise not be available. For example **TreeHouse School** was created by parents of children with autism in response to a lack of provision for their children in their LEAs and **Scope** operate a number of schools for children with cerebral palsy in response to a similar lack of provision. While many of these children can and should be educated in the mainstream (as recognised by some of these organisations), there remains a role for the voluntary sector to initiate such provision, the only caveat being that children are not segregated from mainstream provision where they need not be. It should be remembered that in all cases, the full cost of education provision should be paid by the State.

The **TreeHouse Trust** is a charity, based in north London and founded in 1997 by a group of parents whose children had recently been diagnosed with severe autism. TreeHouse was established in response to an unmet need for specialist education for children with autism, to provide a school for 35 children with autism and related communication disorders.

Prior's Court School for children with autism was founded by Dame Stephanie Shirley in response to a similar unmet need. The school is currently registered for ages 5-19 and has 59 pupils, but will eventually have around 70 pupils ranging in age from 3 to 19 years. The school has developed the 'Prior Methodology' (based on the best of Daily Life Therapy and other autism therapies) to meet the very special educational, care and medical needs of its pupils.

The voluntary sector provides a range of **services to children** whose core education is provided for by the state. In many cases the voluntary sector provides evidence from their projects that should inform the larger scale provision of the public sector. Unfortunately, the reality of scarce resources means that many voluntary sector projects that indicate good results cannot be scaled up and introduced universally.

LIFT's (Learning for Life through Technology) 'Digi Smart' initiative for children with specific learning difficulties has demonstrated that their reading ability can accelerate through the use of a web-based series of activities after school. Children were selected because they were slow in learning to read and also displaying a number of behavioural and emotional difficulties. By the end of the project, reading ages had increased by more than their peers in school, and ICT skills had jumped by two or three National Curriculum levels. Parents can become highly engaged in their child's education with the right training and their contribution is particularly valuable to those with additional needs.

The **Dyslexia Institute**'s SPELL-IT evaluation of children with reading difficulty showed that children's reading improved using their Home Support Programme, and this was also the group that showed the greatest increase in their self-esteem and confidence as a valuable secondary benefit of the programme. Changed wording

In all cases the full cost of education provision should be paid by the state.

Scarce resources mean that projects cannot be scaled up and introduced universally.

Within some schools, a **School-Home Support** worker has been provided who can work with pupils and their families to understand the situation and improve matters. This may be simple practical advice on nutrition or homework as well as emotional support for the child that is suffering trauma or exposed to abuse. Although not a direct educational intervention, this type of work supports the child's ability to learn and attend school, enhancing their access to education in all forms.

The **Children's Society** runs a number of projects in specific areas aimed at children with special educational needs. The Society's provision for special educational needs is largely project-based. The projects are founded on an ethic of improving confidence, self-esteem and friendships of disadvantaged children.

The **Royal Mencap Society** (Mencap) works with people with learning disabilities and their families and carers on activities based around three themes: care, advocacy and awareness-raising. For children with special educational needs, Mencap's work focuses on supporting and informing parents, primarily through a helpline, and advocating improvements in provision by government. Mencap also run a college for 16-25 year olds.

The voluntary sector may **provide resources** or funding directly to schools. Resources may be provided to schools where they would not otherwise be provided or where the mainstream equipment is not appropriate. Schools frequently purchase these resources and there are many providers of special educational needs equipment that are in the business for profit. Excellent ICT programs, talking books and sensory equipment are all provided by both voluntary sector and private sector companies. This activity is frequently performed by charities acting as a trading company. In addition, there may be better equipment available for children than the basic provision of the State – this additional equipment may be funded by voluntary contributions. For example, with sufficient funding, the **RNID** provides digital hearing aids and **Whizz-Kidz** provide top of the range wheelchairs.

Funding schools directly is a legitimate option for a donor. Some out-of-school activities incur significant additional costs for children with disabilities and so they are in effect excluded from that activity because schools simply don't have the financial resources to allow them to take part. These activities are frequently 'extra-curricular' but schools should be including all their students, not least because they are now required to according to the disability discrimination legislation introduced in 2002. The reality of budget constraints on most schools means that parents are frequently asked to contribute to the cost of outings making these activities somewhat selective on the basis of means. The additional cost of taking carers and having special transport for disabled children does mean that schools have to leave some children out. There are also concerns from some teachers that they will not be able to cope with the children who have severe special educational needs, making it more difficult to create fully inclusive activities without specialist support. Extra time for those with special needs is a valuable intervention, and this may be provided by after-school clubs and activities that are specifically targeted at those with special needs (for example, Pyramid Clubs where those with behavioural difficulties enjoy activities that are in smaller groups and designed to help them engage with school).

Reduction of exclusions

Reduction of exclusions deserves a separate discussion, since the impact on excluded children is so severe. NPC intends to produce a separate report looking at school truancy and exclusions but since the impact is so great on children with special educational needs, we detail some voluntary sector interventions here:

INaura was established in 2000 to eliminate the use of permanent exclusion as a school management tool. This is achieved by developing and rolling out a process by which LEAs can reduce the need for exclusions through better management of conflicts and reduce the impact of exclusion by using temporary transfers instead of permanent exclusions, therefore ensuring the children concerned receive continuous educational provision.

The Institute of Public Policy Research (IPPR) is working on a project that aims to combine the work of INaura and other groups as well as the needs and concerns of the education system to construct a framework that schools, LEAs and central government can use to drive down the use of exclusions.

Kids Company works with young people who have been excluded from school and have the greatest difficulty in engaging with the education system. They may return to school with the appropriate support or may need to receive their education in a different setting entirely.

Community Links is providing several educational projects in Newham, East London. They have recently started work with a group of primary school children at risk of exclusion from school, to prevent such an outcome .

Chance UK provides mentoring for those at risk of exclusion from school. In each case, the children may have emotional or behavioural needs that are not being met by their family or school and the voluntary sector is stepping in to give the extra support that can enable the child to attend school without disruption.

Helping parents

Helping individual families to progress through the system is a common role that voluntary sector projects take on. This ranges from helping parents in very intangible ways like providing general advice lines on education matters, to training parents in the skills they will need to get appropriate education for their children or representing parents at SENDIST.

Unless a child's education is to be funded privately, his or her needs must be identified by the state, through the process identified on page 19. This system is entirely provided for and resourced by the state, but the significant flaws identified in the system generate a vital role for the voluntary sector in the provision of direct support for parents and children going through the identification process. Interventions aimed at helping parents include phoneline advice, face-to-face case-based support and second opinions as outlined in Table 4.

Table 4: Interventions relating to helping parents

Intervention	Main organisations		
	IPSEA	Network 81	ACE
Publications	✓	✓	✓
Phone support	✓	✓	✓
Face-to-face support	✓	✓	×
Second professional opinion	✓	×	×
SENDIST representation	✓	*	×

The state system relies on schools themselves identifying children's special educational needs and matching them with appropriate interventions until this fails the child, at which point the LEA steps in and a statutory assessment process kicks in, as detailed on page 19. We noted significant variation in schools' ability to identify children who have additional needs in school and this creates the first role for the voluntary sector. In the first instance, many parents are simply not aware of how the process works and so are unable to secure an accurate identification of their child's needs. The voluntary sector can therefore **make parents aware of their rights**. Voluntary organisations like the Independent Panel for Special Education Advice and the Advisory Centre for Education operate phone helplines aimed at parents in this position, which tell parents of their rights and point them in the right direction to find the correct state provision.

The **Independent Panel for Special Education Advice** (IPSEA) provides free independent phone and in-person advice and support to parents on issues relating to the identification of and provision for their children's special educational needs.

The **Advisory Centre for Education** (ACE) provides phone-based advice for parents on any aspect of education. Much of their advice relates to special educational needs

Significant flaws in the system generate a vital role for the voluntary sector in the provision of support for parents.

Many parents are not aware of how the process works and so are unable to secure an accurate identification of their child's needs.

although they do not specialise in the process of identification in the same way as IPSEA and will refer callers to IPSEA if they need specific advice in this regard.

Network 81 provides information, support and training for parents and practitioners who work with children with special educational needs. Network 81 provides advice on the legal rights of children with special education needs and general advice on education provision through a national helpline, to which 3,000 calls are received annually, and the distribution of published material. The organisation also runs a series of training courses for parents and professionals. As a result, Network 81 has built up a national network of around 300 trained 'befrienders' to which parents can be referred for all matters related to special educational needs.

The voluntary sector must **correct biases** such as the fact that schools in some areas are better resourced and better prepared for identifying special educational needs than schools in other areas.

IPSEA targets its advertising exclusively to low-income areas. Around 50% of parents supported with appeals have an annual household income of less than £15,000 and 70% of those represented at hearings come from this category. 5% of families who use SENDIST are from ethnic minorities, indeed 23% of families supported by IPSEA in London are from ethnic minorities.

The Dyslexia Institute provides assessment which may reveal dyslexia and will also improve the understanding of the child's need. In 38% of their assessments, the child is not strictly dyslexic but the detailed findings are helpful in determining the correct course of action to support the child. The hidden difficulties that children have were one of the biases identified by the Audit Commission.

Beyond understanding their rights and requesting an assessment of their child's special educational needs lays a long and complex statutory process outlined from page 19, which we showed is difficult to navigate without significant free time, perseverance, skills and financial resources. These are not available to many parents and so here we see a third vital role for the voluntary sector in **supporting parents through SENDIST**.

IPSEA aims to empower parents wherever possible to push themselves for the rights of their children, through training and support. Where this is not possible, a case-worker will support the family and prepare and deliver their case to SENDIST. In 2002 IPSEA supported 1,000 parents in their tribunal cases, representing one third of all appeals to SENDIST. Additionally IPSEA have a network of volunteer professionals who are able to offer second professional opinions to SENDIST, where the family are unhappy with the LEA's assessment.

The **National Autistic Society** (NAS) provides advice and support to around 900 families per annum; around 120 of these are supported through the SENDIST tribunal, of which 25% were referred to a major legal firm for pro bono representation (the vast majority of these were either upheld or settled before the hearing).

Summary: The voluntary sector delivery opportunity

The diverse range of interventions discussed here presents choices to donors as to how to support children with special educational needs. All interventions covered are vital roles that the voluntary sector must play if children with special educational needs are to receive appropriate educational provision. The specific funding requirements of projects will vary considerably over time, and we recommend careful planning of grants to organisations so that their priorities can be taken into account. Grant-makers will also wish to incorporate their own guidelines and so a matching process is necessary.

Charities face a multitude of difficulties to secure long-term funding for their work, and to fund their general activities when they are not project-based. This is exacerbated by the complexity of the special educational needs area, where a certain amount of expertise is required before the issues can be sensibly analysed. As a result, very few activities identified have reached the scale that they could to adequately satisfy the needs present. There is very good scope for growth in many of the organisations that we met because demand outstrips their ability to supply services. This presents an opportunity for donors and grant-makers significantly to increase delivery for children with special educational needs, over and above the current levels.

Outcomes from all these activities ultimately lead to improved educational provision for children with special educational needs. The historic involvement of many charities over a considerable time has led to their focused expertise in particular categories. This does not need to be replicated by the state but can be harnessed by supporting their work. (For example, teaching methods for those with Down Syndrome or dyslexia can be trained by the relevant groups.) The state system can be enhanced, and provision leveraged, by the involvement of voluntary sector groups. (For example, supporting parents as they navigate the entitlement process.) Giving additional funding to schools, especially in deprived areas where the parental financial involvement may be low, also enables them to deliver more to children and augment the overall educational experience for all.

The exciting range of opportunities is combined with a reported difficulty in fundraising.

Section 4: Outcomes

Although the State largely fulfils its commitment to providing an education for all children, many children with special educational needs are not having their needs met because of significant shortcomings in the provision of their additional, or different, requirements. Most children with special educational needs have their needs identified and receive some level of additional or different provision, but there are significant gaps and, even where provision is happening, a lack of understanding means it is often not possible to articulate what is meant by 'adequate provision' let alone certify that it is being provided.

These ambiguities complicate the analysis of outcomes – the actual achievements of charitable activity – and the subject of this section. The aim is to articulate to prospective funders the likely outcomes from supporting the activities of charities. Where possible such outcomes are measured but the issue of measurement in this area is fraught with difficulties. For instance, in the advocacy work of charities it can be impossible to determine whether any changes in policy can be attributed to the lobbying work of individual or collective charities. There is little debate however that they have played an important role.

Introduction to outcomes analysis

All charitable activity is aimed at achieving outcomes. Outcomes are distinct from the outputs of charities. An output is the activity of the charity itself, say the distribution of a leaflet explaining aspects of special educational needs or the phone call with the parents of a child with dyslexia. The outcomes are the changes brought about by these outputs, such as increased understanding of special educational needs among school teachers and improved delivery of appropriate education or parents better able to articulate and secure the needs of their child.

Different charitable interventions produce different outcomes even if working within the same broad area of special educational needs. The purpose of considering outcomes is to explain to funders the potential returns from their funding, i.e. what will be achieved through their support for individual charities. The purpose is not to consider the benefits from meeting the special educational needs of children except insofar as these are only met thanks to the influence brought to bear by charities. Therefore, it is the outcomes from charitable activities and not the aggregate benefits from government policy on special educational needs that are the focus of this section.

The outcomes available from the different charitable interventions fall into four main categories. Some interventions will have outcomes fitting a number of these categories, some will fit just one. The categories are:

- Increasing commitment of the state to special educational needs, in central Government, LEAs or in schools.
- Improving understanding of conditions, successful interventions and inclusive practices, again in central Government, LEAs or in schools.
- Providing services to children in state schools, non-state schools or outside of school which improve their attainment of, for example, reading, writing, language and comprehension.
- Helping parents to get their children's needs identified or to identify and secure appropriate education.

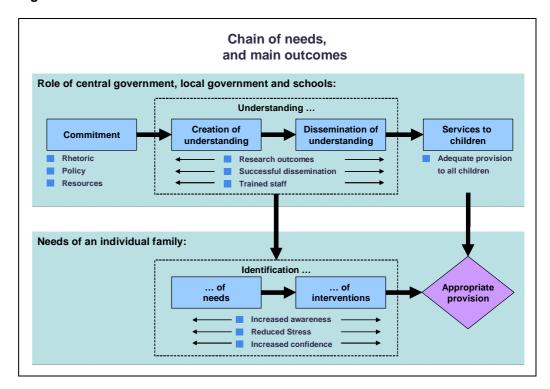
When assessing outcomes it is often useful to distinguish between the cost per user and the cost per successful user. All charitable activities are targeted towards achieving positive outcomes, but some are more successful than others. For example a publication to schools that changes behaviour in only 10% of interventions has a cost per successful user ten times higher than its cost per user. Training in special educational needs for teachers will be effective only for some teachers, reflecting both the teachers and the quality of the training.

Increased commitment should lead to increased provision.

As intervention methods vary in their success rates, these two measures of unit cost are often considerably different and both are of interest to donors. An added complication concerns the term 'effectiveness'. This is sometimes not a binary yes/no measure of success but it may be difficult to produce more precise or tangible measures.

Additionally, outcomes at each stage 'trickle down' to increase all of the outcomes downstream of it (as illustrated in the chain of needs). The most obvious example being that increasing commitment at a national, regional or local level should lead to increased understanding of conditions and of appropriate interventions and therefore lead to increased provision.

Figure 5: Chain of needs and main outcomes



The effectiveness of each intervention can be assessed on three levels:

- Raw output e.g. the number of teachers trained in teaching children with special educational needs.
- Direct outcomes e.g. appropriate education for children.
- Quantified impact e.g. the number of children whose education has improved as a result of better educational provision.

The **raw output** is the easiest of these to measure, and is therefore the level of assessment most frequently quoted by charities, but is not very useful in making comparisons. Considerable information gathering is needed to measure the **direct outcomes** reliably, but these figures are much more useful in assessing the effectiveness of interventions and allocating resources. Comparable data on the **quantified impact** is the most useful measure of effectiveness and enables funders to make clearly informed choices between different kinds of intervention. Unfortunately, complex studies of educational effectiveness are needed to move from the direct outcome data to a good estimate of impact.

Ideally, good quantified impact information would be available for all the different interventions. This could then be compared to the cost of each intervention to estimate cost-effectiveness. This would enable a comparison of the cost of funding one sort of intervention versus another. Where possible this section quotes quantified impact cost-effectiveness data, though this is invariably the exception rather than the rule. This data often comes from individual voluntary sector organisations and so actual costs may vary considerably. Unfortunately the information available is not as broad or reliable as one might hope.

However, using data from individual organisations has the attraction that it represents funding options that are actually available to donors and to grant-makers.

Measuring outcomes is a problematic activity for special educational needs, particularly in long-term projects. There is the problem of longevity of success in projects trying to achieve long-term changes in understanding of disability and in teaching behaviour for example, which are not measurable within a short timescale.

Despite this, grappling with this area is a useful exercise, because some understanding of what constitutes success in special educational needs and the cost-effectiveness of the interventions is better than none. Because of the difficulties, the discussion which follows should not be regarded as conclusive but is aimed at helping donors interested in directing funding to special educational needs.

Increasing state commitment

It is vital that central Government, LEAs and schools recognise the need to improve educational provision for children with special educational needs and commits to improving educational provision. The voluntary sector has strong previous involvement in building commitment through raising awareness of unmet needs and through helping the state to formulate policies and procedures to address those needs.

The outcome of increased commitment is particularly difficult to measure. It is both binary and qualitative. Commitment can either exist or not but, if it does exist, there may be more or less commitment. If commitment does exist there is no clear or reliable way to measure the scale of the commitment. Nonetheless, it is important that the different arms of government show such commitment, otherwise special educational needs are unlikely to receive the necessary attention. A further complication arises when considering the question of attribution. Can one confidently attribute shifts in government commitment to the lobbying work of charities or would such changes have taken place anyway? This question dogs all discussions of the advocacy work of charities and there is no way to answer it adequately.

We will review outcomes in two areas: increasing national commitment, and increasing regional commitment – at LEAs and in individual schools.

Increasing national commitment

The most measurable indicator of national commitment to special educational needs is the formulation of policies, whether they are legislative, regulatory or more informal guidance and advice to LEAs and schools. Typically the key policy issues have related to the process for identification and provision for special educational needs and the move towards favouring inclusive education. In all of these regards the voluntary sector as a whole claims significant successes. These bode well for future efforts to increase government commitment. The voluntary sector was instrumental in calling for the reform of statementing, which was also called for by the Audit Commission and was outlined in the recent Green Paper 'Every Child Matters.' It is likely that this is one area where the voluntary sector will participate very significantly in the formulation of new policy.

The clearest example of ongoing advocacy work is when the voluntary sector groups together around times of formulation of legislation and regulation to speak with a single voice where possible (and to clearly articulate divisions where not possible). This voice is provided by the Special Education Consortium. Although attribution of success is difficult, the Consortium and its members had significant behind the scenes influence before publication and can claim significant successes with regard to changes to policy introduced with their support after initial publication:

- Increased rights. Two conditions were removed from the SEN and Disability Act (2001) which limited access to a mainstream school place for children with special educational needs.
- Improved oversight. Ofsted was given the responsibility to monitor the framework for inclusion and LEAs were required to monitor admissions of children with special educational needs and set out their policies clearly.

Attribution of success is difficult, but the Special Education Consortium can claim significant successes with regard to changes to policy.

- Improved Code of Practice. The Code was improved in several ways, including an improved process for identification of children with special educational needs, the strengthening of the voice of the child in decision-making and improved guidance on working with parents.
- Increased rights. Two amendments were put forward by the Government (along with several other commitments) as a result of lobbying by the Consortium increasing children's rights.

Convening this consortium around times of legislation typically cost around £30,000 per annum (50% of which was funded by Consortium members). Establishing the consortium with a permanent presence to pursue policy formulation proactively would cost an additional £30,000 per annum (again around half of which would be recovered from consortium members). The outcomes from such activity are necessarily difficult to define or measure, but the aim would be to ensure that all aspects of education policy gave due consideration to special educational needs.

Additionally, and of increasing importance, is ensuring that special educational needs are considered in related areas of policy, such as wider education initiatives (e.g. league tables) and other areas of government service delivery such as health and social services. Previous successful policy outcomes are not as clear as the purely educational outcomes but include:

- Special educational needs issues are better embedded in other educational frameworks as a result of lobbying concerning the contents of the Code of Practice.
- The SEN and Disability Act (2001) included a commitment to take special educational needs into account in the review of initial teacher training as a result of voluntary sector pressure.

An indirect product of this work by the voluntary sector is increased government spending on special educational needs. Although this cannot be immediately seen from published data, the Audit Commission estimated it for 2000 – 2002 during which total government spend on special educational needs grew at 5% per annum.¹¹¹ It is possible that the voluntary sector can claim some responsibility for ensuring that special educational needs receives a greater attention and share of resources in this way, but definite attribution is impossible. Similarly, the ongoing trend towards inclusion is very likely partly a result of sustained advocacy by the voluntary sector over many years but proving this to be the case is impossible.

Increasing regional and local commitment

Voluntary sector outcomes at a regional level (LEA) or local level (schools) are usually focussed in certain localities because of the fragmented nature of the education system, with over 200 LEAs and over 23,000 schools in England alone. 112

One approach which is particularly difficult to assess the outcomes of is to **work with schools and LEAs** to encourage policies and practices that are appropriate for special educational needs. Such an approach necessarily requires co-operation with schools and LEAs, implying that these bodies are amenable to change. Once again there are clear problems of measurement and attribution even where commitment can be identified.

Where commitment is initially lacking, a more confrontational approach can produce positive outcomes. A number of groups successfully **challenge bad practice**. For example groups have identified failings by LEAs to provide required information on their websites or blanket policies that ban or revoke statements for children. This activity has a much lower cost since the production of a simple report or the threat of a court case can swiftly improve commitment (and so provision) across many LEAs or schools simultaneously.

Funders interested in supporting advocacy to boost public sector commitment to special educational needs must bear in mind the complexities of measurement and attribution. This is not to belittle or demean the role of advocacy. It surely plays a vital role in ensuring that special educational needs are given due prominence in the thinking of policymakers. Rather, it is to highlight that funders will not necessarily know exactly what outcomes they are funding nor, after the event, whether the activities they fund are truly responsible for these outcomes. However, without funding for such activities it is likely that the area of special educational needs would be far less developed than is the case.

Of increasing importance, is ensuring that special educational needs are considered in related areas of policy.

Increasing understanding

The situation is a little less ambiguous when considering the outcomes of increased understanding, primarily through undertaking research and disseminating understanding through publications, conferences, training and the media.

Creating understanding

The voluntary sector is working to fill a need for increased understanding of special educational needs and appropriate interventions. This research is based on a history of creating knowledge that has contributed significantly to the understanding of, and so provision for, children with special educational needs.

The challenge for donors wishing to support the need for increased understanding is to identify organisations with the ability both to create knowledge from well-constructed research and with the credibility to ensure that education providers take note of the findings and translate them into improved educational provision. As with work to increase government commitment, measurement is difficult in this field. However, attribution, while imperfect, is clearer as one can trace shifts in thinking to original research aimed at improving understanding.

Much research is funded by the DfES, but it is widely claimed that the research budget is not sufficiently adequate to resolve the need for understanding and so donors must identify research projects that are additional to government priorities. Typically one might expect a well-constructed and influential piece of research into interventions to cost anything between £30,000 and £100,000. For example one proposed project into successful interventions for children with a particular special educational need is given in Box 7.

Box 7: Example of research project into interventions

The aim of this project is to improve educational delivery to children with a particular special educational need by using the experiences of children who have been able to realise their potential.

Research will focus on identifying the factors facilitating and inhibiting access to the curriculum, highlighting helpful strategies used by teachers to support pupils with this special educational need in classroom settings and investigating how pupils are involved in discussing and planning their own support needs.

It is estimated that around 50 children will be surveyed and the project will take 6 months. Costs total £55,000 and include a launch event / dissemination conference and postal drop of free copies of the final report to ensure maximum dissemination.

Dissemination of understanding

Dissemination of understanding to LEAs and to individual schools is vital. This is done through a number of different methods, including the production of targeted publications and through training professionals in certain aspects of special educational needs.

For example one well-respected voluntary sector **publication** is distributed to every school in the UK and used by a large number to help them to move towards more inclusive education. This costs less than £10 per year per school and less than £35 per year per successful outcome — that is per school that actually uses it to become more inclusive. Typically LEAs and schools cover some of this cost, but there is insufficient will or money to cover the majority of this cost and so there is a role for the voluntary sector to find the difference. A successful outcome here is a more informed school using this publication to improve teaching practices to become more inclusive and offer a better education to children with special educational needs. Inevitably some schools are less progressive than others and will make less use of the publication. Therefore there is a distinction between the cost per user and some estimate of cost per 'success.'

A large number of other publications where outcomes are less well defined are produced by the voluntary sector and distributed to LEAs and schools, disseminating knowledge on how

The challenge is to identify organisations with the ability to create knowledge combined with the credibility to ensure that findings translate into improved provision.

A training programme using disabled trainers to train teachers in disability awareness costs less than £15 per teacher and less than £30 per successful outcome.

better to understand and provide for children with special educational needs. Partly because of the large number that are produced, and partly because of the lack of monitoring by many voluntary sector organisations, it is incredibly difficult to assess the impact of these. A 30 page publication distributed to a targeted selection of around a thousand schools in the UK (plus made available to all schools via the internet) on a particular aspect of special educational needs such as inclusion or on a particular condition typically costs around £20,000. Given that there are more than 20,000 schools, if only small proportions of these make positive use of the publication, the cost per successful outcome is incredibly modest. These costs are sometimes borne by the voluntary sector and sometimes by schools or LEAs themselves depending on the nature of the publication.

Training of teachers and LEA staff is another common vehicle for disseminating understanding through the education system. Although core teacher training costs are borne by the State, often special educational needs training is viewed as additional and so at least part of the cost is picked up by the voluntary sector. A training programme using disabled trainers to train teachers in disability awareness costs less than £15 per teacher and less than £30 per successful outcome – that is per teacher who reported that the training had changed their attitudes and practices. Typically LEAs and schools cover most of this cost, but as often seen, there are research and development costs that are not recoverable and which need to be covered by private donations.

Other voluntary sector training programmes which provide training for speech and language therapists typically cost around £120 per person for a one day course, rising to £300-400 for longer courses. The recurring cost of employing practitioners is borne by the state, but in this example the voluntary sector pays for the training development and the course participants may pay for their courses personally. There are instances of LEAs or schools providing a contribution to the cost of such courses. The outcomes will be a better trained or professionally developed cohort of practitioners. The need for ongoing refreshment of such training is widely accepted.

Service provision

Outcomes from service provision are by their very nature the most measurable, but at the same time we have identified few schemes that are wide-reaching among the almost two million children in the UK with special educational needs.

In service provision the voluntary sector provides and runs some **special schools**. While many of the schools we visited appeared to be successfully identifying children with complex needs, few appeared to target their services to those in society who most need their support – for example families on low incomes and those with more than one disabled child. Children will be placed in residential special schools when their needs are particularly severe, and the cost of the placement is covered by their LEA via the statementing process. Ofsted inspects all schools and so individual evaluations are available to assess outcomes achieved with individual children, however standards in special schools are highly variable and Ofsted has reported that many do not consistently provide adequate support to students. Whilst many schools claim that success means educating their children to a point where they could be returned to the mainstream, few are able to demonstrate that they achieve this to any significant extent. School provision typically costs between £30,000 and £50,000 per pupil per annum for a day school and between £120,000 and £160,000 for a residential school, although all of the associated expenses should be recovered from the children's LEAs on a per-pupil basis.

The voluntary sector also provides additional **services to children who are being educated by the state**. Outcomes have been measured in the case of certain projects where the aim was to increase reading age for example, by taking detailed baseline data at the start of the project and ensuring that detailed monitoring of the project was conducted throughout. The cost of providing an after-school reading project that increases their attainment by several national curriculum levels was £1000 per year per pupil. The project included involvement from school staff (paid for their time by the school) and has created lasting value for both the pupils and the staff who are now trained in the technique for future provision.

The proper assessment of a child's needs can be provided by the voluntary sector and should result in the most appropriate educational programme being given. The outcome of correct intervention rather than prolonged misunderstanding is immeasurable and will be tangibly displayed in better attendance at school, better attainment in class and, eventually,

the greater achievement of the child's capability and academic potential. Costs will typically be £300 for such an assessment, however, since the detailed input and evaluation of highly trained professionals is required.

The setting up of centres that can assist children by properly assessing their needs, and developing the best intervention strategy accordingly, has been costed at £60,000-£150,000 per centre. The ongoing running costs of such centres should be shared with, or carried entirely by, the state. The outcomes would be children who were better able to access the education system and centres of expertise where their special needs were understood and supported. Each centre could be expected to assist hundreds of cases per year and to improve the experience and confidence levels of the staff employed.

The voluntary sector gives **direct assistance to state schools**, either through the provision of resources or through supporting individual schools' activities. The regular provision of journals and updated educational resources will generate improved outcomes for the pupils concerned at very low cost. For example, teachers who remain abreast of the latest reading techniques for children with different special needs will be in a position to achieve greater reading attainment from their pupils. These publications will frequently include valuable and useful teaching tools and ideas for the practitioner to use in school. Schools may decide to purchase special equipment or IT programmes for their pupils which cannot be afforded within the normal budget. Additional fund-raising or contributions from parents are then required. For example, dyslexic pupils and slow writers benefit from using a special keyboard (costing £200) with a touch typing programme (costing £1000 per year for a licence for 30 pupils). The outcomes from such additional inputs will include both the educational attainment of the pupils as well as their enhanced confidence at accessing an approach that works. In the case of dyslexia, for example, this can make the difference between passing and failing a GCSE exam.

Outings and school trips are also worth mentioning since their outcomes are widely beneficial to school children but their provision may require involvement from donors. A typical outdoor education trip will involve aspects of the curriculum but will also provide enjoyment, new experiences and social interaction that are all part of the education process for all children. (For example, children in urban schools may never experience the countryside or learn about nature unless they are able to visit it. Many pupils are not able to have holidays with their families due to lack of resources). The children with special educational needs may require help which increases the cost of the trip and, in more severe cases, may lead to their exclusion from the activity altogether. The cost of including all pupils will vary from case to case, but the sum of £225 secures a residential trip for one pupil. Typically, secondary schools in deprived areas would fall short of their budget for trips and visits by around £5000 per year and therefore need to cut back on these activities. (Provision of support for the children with special educational needs is frequently the most expensive portion because they need additional adult supervision).

Helping families

We showed earlier how the system for identifying children's special educational needs and identifying appropriate outcomes was complex and strained because of the necessary funding constraints. We also showed the vital role the voluntary sector plays in satisfying the need. The main methods of intervention and associated costs are outlined in **Table 5**. In this area outcomes are tangible and, also, there is hard evidence of the number of successful interventions. This enables estimates of cost per successful intervention.

The voluntary sector plays a vital role in helping families to secure provision.

Table 5: Interventions and approximate costs of helping parents

Intervention	Cost per intervention	Cost per successful intervention
Publication to all schools (Some print plus internet)	£1	£5 - £10
Phone support	£20	£50 - £100
Face-to-face support	£50	£100-150
Second professional opinion	£50	£100-150
SENDIST representation	£200	£200-300

Whilst each of these interventions is appropriate for specific circumstances, they all lead to broadly the same outcome – improved educational provision for children with special educational needs. Although they do so via other more immediate outcomes:

- Reduced family stress associated with identification of children's needs and identification of appropriate outcomes.
- Increased parental awareness of their rights under the assessment procedures and under education law and regulations more generally.
- Increased parental confidence at dealing with particular problems and all future difficulties associated with their children's special educational needs.

The relatively low costs of the outcomes involved in Table 4 are striking, particularly when compared with the material changes in provision of education which can result from the charitable interventions. Certainly, considered as some form of 'return' on a funder's 'investment,' changing the educational provision for a child for a sum as small as £200 is extremely attractive. Organisations offering the outcomes on which the calculations are based are worth supporting.

Different parents require very different approaches to support and advice. As an illustration we outline three very different types of family and their associated needs – families with low needs (affluent educated), families with medium needs ('average' families) and families with high needs (low income and little educational attainment plus possibly more than one disabled child and English as a second language).

The relatively low costs of the outcomes deriving from helping parents are striking.

Table 6: Families requiring assistance

Level of need	Aspects of need	Route to approaching charity
Low	Unsure of a specific piece of information	Will seek out publication from charity's website or seek out helpline number and make brief phone call.
Medium	Unsure of SEN statutory framework and needs guidance in approaching LEA / school	May seek out the charity, but will likely respond to an advert or verbal recommendation. Will make use of publication, but at least one in-depth phone call is likely to be needed.
High	Unsure of educational statutory framework and needs extensive guidance through all details of case	Will respond to proactive targeting by the charity and may be uneasy about talking on the phone. Likely to require detailed case support, probably face-to-face, including preparation by the charity of correspondence with LEA / school and possibly personal representation at meetings / SENDIST.

Unfortunately we did not identify many organisations that successfully target families with a high level of need and we suspect this remains an area of concern. Only a few organisations deliberately and successfully target those parents who are likely to have the highest levels of need for support. There is an urgent need, therefore, to support organisations that do target such families successfully as well as to encourage the establishment of new organisations sharing this aim.

Summary

Many charities working in the area of special educational needs play vital roles in producing positive outcomes for the educational system as a whole, augmenting the results that schools can obtain. These organisations support individual children and their families, improve the capacity of teachers and carers to educate children, and communicate the findings of research activities in the field. Recording and measuring these outcomes is frequently extremely difficult, but the outcomes are no less real for this. Funders should consider each case on its merits but the discussion here has highlighted some of the outcomes available in this field as well as the limitations on assessing outcomes. Where successful outcomes have been achieved within well-managed organisations, and often in schools, the potential to replicate good practice and generate a wider spread of benefit is enormous.

We have highlighted those general areas where needs are greatest and funding should be directed - in increasing commitment, understanding and service provision. Given the much larger numbers of children with needs that are in mainstream schools, we also favour those projects that are strategically positioned to support mainstream schools. This may include sharing of expertise from centres of excellence, training teachers and other staff, as well as working in schools and after school to boost the children's education.

Many voluntary sector organisations receive their funding for relatively short-term projects and would benefit from longer-term support in order to effect more sustainable change in the sector. Following careful assessment of the organisation, and with appropriate levels of monitoring, it is generally preferable and more effective to provide strategic funding rather than one-off project finance.

The potential to replicate good practice and generate a wider spread of benefit is enormous.

Conclusion

A large, and growing, number of schoolchildren have special educational needs that mean they require additional support in order for them to attain their individual potential. The necessary constraints in education funding mean that many are not having their needs correctly assessed and are not receiving appropriate extra provision. In many cases understanding falls short, meaning that they do not get specialist help with adequate training.

This situation is leaving families in turmoil and large numbers of children without an appropriate education and the social advantages that come with it. The positive talents and abilities of many children remain undiscovered as a result. The relatively poor levels of literacy among some primary school children could suggest a failure to deliver appropriate education to those with specific learning difficulties. Families are finding themselves in financial and emotional hardship while their children with special educational needs have a high probability of being excluded from school. The eventual social exclusion that results from a poor education is not unique to those with special educational needs but is a major cause of potential increased crime and antisocial behaviour.

The lack of educational provision also costs society financially. Improved educational provision leads to improved employment prospects, economic and fiscal contribution. For example, estimates put the lifetime cost to the public purse of a child with autism at about £3 million, and suggest that even moderate improvements in educational provision could potentially result in major savings in later living costs. It is impossible to quantify the potential creative contribution of many children where their needs have been properly met and their abilities optimised, but the potential is clearly enormous.

There are many interesting voluntary sector organisations making significant impacts on improving the educational prospects for these children. They range from organisations innovating and researching methods of teaching, to organisations helping those most in need to understand their rights and obtain the education that they need. The improved understanding of the conditions, and how best to educate the children in each group, remain key objectives of both the state system and the voluntary sector.

In terms of priorities for grant-makers, we have identified training of expert staff, building the ability of mainstream schools to deliver inclusion, and supporting parents as they navigate the system as the major areas that require support. In addition, more academic research is needed into good practice in teaching methods and interventions that work. The findings then need to be disseminated to the universe of interested practitioners and training given where necessary. In all areas of the teaching of children with special educational needs, there needs to be ongoing training, development and sharing of good practice, in order to bring the highest standards of education to the children that need it. For the children themselves, the earliest possible assessment, and provision of the most appropriate programme of support, would reap savings of both time and money in the long-run. There are opportunities for donors to fund projects researching the validity of interventions or establishing assessment capabilities in schools. Where pilot projects give good results, subsequent governmental funding can leverage that initial capital many times over. The specific projects, and funding needs of the providers, should be the subject of careful analysis and we would be delighted to discuss these aspects in order to create a timely set of recommendations.

Having published these research findings, NPC is in a good position to provide targeted funding recommendations for donors wishing to address the gaps in the system and would welcome further discussions. The purpose of this report has been to analyse a range of interventions and to discuss the qualitative and quantitative outcomes created by these interventions. NPC's analysis should be regarded as a tool to help donors effectively direct their funding into a field where the need is great and the outcomes both positive and immensely valuable.

Selected voluntary organisations

We provide here tables of selected voluntary organisations. Each organisation is represented in the table relating to the need for which their work is most appropriate, although it should be emphasised that many organisations operate across multiple needs. Needs are defined as previously described in Figure 1 (page 12).

Increasing state commitment

Organisation	Description of SEN related work	Expenditure (2002, £k)
Alliance for Inclusive Education	Supports parents in obtaining inclusive education and campaigns for inclusive education. Projects give a voice to disabled children in the special educational needs debate.	96
Council for Disabled Children	Concerned with government policy and practice in the delivery of a variety of services to children with disabilities. Membership comes mainly from the voluntary sector.	Not available
National Children's Bureau	Promotes the interests and well-being of children and young people across their lives. Advocates the participation of children and young people in matters affecting them.	5,986
Parents Autism Campaign for Education	Supports parents in obtaining applied behavioural analysis for their children with autistic spectrum disorder. General helpline support is given to parents with autistic children.	Not Available
Special Educational Consortium	Brings together the voluntary sector and other interested parties in a co-ordinated manner to identify policy concerns and represent them to government.	30

Creating / disseminating understanding of conditions

Organisation	Description of SEN related work	Expenditure (2002, £k)
Down Syndrome Educational Trust	The charity that provides research and understanding of the educational needs of those with Down Syndrome. Supporting schools where a pupil has Down's, working directly with local children and ensuring that good practice is shared throughout the global research community.	207
Dyslexia Institute	The largest UK provider of services for dyslexic people including assessment, education and training for practitioners. Centre-based work is expanding to include partnerships with mainstream schools to ensure that the largest numbers of potential needs are met.	5,969
Emotional Health Alliance	A grouping of organisations that work in the field of emotional and behavioural difficulties. The group's work is highly varied but their interests are common and so the alliance is an efficient vehicle for policy influence and research. Members of the alliance are charities in their own right, including National Pyramid Trust, School-Home Support, Kids Company, Chance UK, Antidote, Mental Health Foundation, Coram Family, Positive Play, Young Minds, Home-School Liaison, Family Links, Total Learning Challenge.	Not Available
I CAN	The charity for those with speech and language difficulties, running two special schools, Early Years Centres, as well as a range of training courses and services to improve the education of children with these difficulties.	7,585
Royal Mencap Society	Works with people with learning disabilities and their families and carers. Supports parents of children with learning difficulties to obtain educational provision.	128,000 ^{XII}
National Autistic Society	Runs six schools and provides support for children with autistic spectrum disorder. Support extends to advice about and representation at SENDIST where necessary.	46,014
RNIB	Works to help people with serious sight problems by providing services to children and adults and influencing or supporting others to improve their policies, services, goods and facilities.	84,474
RNID	Campaigns for rights and provides services for deaf and hard of hearing people in the UK. Supports and advises educators on appropriate teaching for children who are hard of hearing.	44,169
Scope	Disability organisation with focus on cerebral palsy providing educational services and support including support and advice to mainstream schools. Operates six special schools.	89,694
Social, Emotional and Behavioural Difficulties Association	Supports and informs professional staff to help children with social, emotional and behavioural difficulties. Offers local and national training and advice to members and non-members.	82

XII 2003 data

Creating / disseminating understanding of interventions

Organisation	Description of SEN related work	Expenditure (2002, £k)
Centre for Studies on Inclusive Education	Produces reports and studies for schools and government relating to the benefits of inclusive education and methods by which mainstream schools can become more inclusive.	255 ^{XIII}
Disability Equality in Education	Trains teachers in disability awareness and how to identify and work with disabled children as well as publishing a number of documents advising and guiding schools on inclusion.	459
Inaura	Developing a model for LEAs to reduce the need and impact of school exclusions. Works with schools and LEAs to encourage and implement the model.	86
Institute for Public Policy Research	Interfaces between academics, practitioners and policy makers to develop policy recommendations. Has a project relating specifically to the reduction of exclusions.	2,049
National Association for Special Educational Needs	Promotes education and training for those with special educational needs. NASEN has over 11,500 members and reaches a significant readership through its journals: British Journal of Special Education, British Journal of Visual Impairment, Support for Learning, Journal of Research in Special Educational Needs and the magazine Special!	Not available
National Parent Partnership Network	Supports Parent Partnership Officers in LEAs with training / advice (who themselves offer support and advice to parents). Organised through the Council for Disabled Children.	Not available

Providing services to children

Organisation	Description of SEN related work	Expenditure (2002, £k)
Afasic	Works with children with communication impairments, advocating inclusion in society and supporting parents and carers. Also provides training for parents and professionals.	379 ^{XIV}
Bloomfield Learning Centre	The Bloomfield Learning Centre has provided assessment and teaching to children with special educational needs for 10 years. It is based on Guy's Hospital site and is staffed by qualified dyslexia specialists who have the support of psychologists.	Not Available
The Children's Society	Supports children in problems caused by deprivation, disability and injustice with five local / regional projects relating to special educational needs.	43,474
Kids Company	Provides educational services within schools where children have mental health difficulties, as well as working with those who have been excluded from school.	2,119
NCH	Work in the special education field includes residential special schools for those with profound and multiple difficulties, community support projects for those with special needs, general counselling and support for families.	112,796
NPC Extra Curricular Support	The gap in provision of educational activities and visits that cannot be afforded by schools or parents has been identified by NPC as a cause for support. The inclusion of all pupils in these activities requires additional funding.	Not Available
NSPCC	The National Society for the Prevention of Cruelty to Children specialises in child protection and the prevention of cruelty to children. NSPCC has a project relating to disability and education.	90,584
Peach	Parents for the Early Intervention of Autism in Children supports parents in obtaining applied behavioural analysis (ABA) for their autistic children.	Not Available
National Pyramid Trust	Promotes a model approach to the support of children's emotional health at school by setting up clubs in schools that are locally managed. Provides guidance and maintains quality of the model with central co-ordinators.	501 ^{XV}
Springboard for Children	Provides a literacy programme for children with learning difficulties in inner city primary schools. A team of specialist teachers and trained volunteer offers one-to-one literacy teaching, to help children realise their full potential.	Not Available
TreeHouse Trust	Primary school for 35 autistic spectrum disorder children where the ABA technique is employed. Expanding into training and service dissemination as well as secondary school for the founding children.	1,122 ^{XVI}

XIV 1996 data XV 2003 data XVI 2001 data

Helping parents

Organisation	Description of SEN related work	Expenditure (2002, £k)
Advisory Centre for Education	Advice and information for parents on all aspects of education, including parents' entitlement to additional support.	534
Contact a Family	Supports families of disabled children through a helpline in all aspects of their lives, including many queries relating to educational advice. The first point of call for many parents.	2,507 ^{XVII}
IPSEA	Independent Panel for Special Education Advice provides free support to parents in obtaining appropriate education through phone and face-to-face support, including representation at SENDIST where necessary.	227 ⁱ
Network 81	Provides phone and face-to-face information support for parents who work with children with special educational needs, to help them to obtain correct educational provision.	131 ¹
Parents for Inclusion	Run by parents, to help children with special educational needs by empowering their parents. Offers helpline support as well as local groups in some areas.	283

XVII 2003 data

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Further reading

Readers interested in the policy and practice of special educational needs will enjoy two excellent reports Statutory Assessment and Statements of SEN: In need of review? and Special Educational Needs: A Mainstream Issue both by the Audit Commission and available on their website

The Future of Special Schools, Every Child Matters and Removing Barriers to Achievement, The Government's Strategy for SEN, from the DfES provide background on the Government's view of, and plan for, special educational needs.

Detailed further information is available at the following websites:

www.teachernet.gov.uk/wholeschool/sen

www.sendist.gov.uk

Interviews conducted

In the process of completing this report, we were fortunate to be able to have very detailed discussions with over 40 charities and experts in the field of special educational needs. In particular we would like to acknowledge the help and support of:

- Advisory Centre for Education
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- The Children's Society
- Contact a Family
- Council for Disabled Children
- Culloden Primary School, Tower Hamlets
- DfES
- DisabilityEquality inEducation
- Disability Rights Commission
- Down Syndrome Educational Trust

- Dyslexia Institute
- EastleaCommunitySchool, Newham
- Elizabeth Foundation
- Emotional Health Alliance
- Furrowfield Special School, Gateshead
- I CAN
- Inaura
- Independent Panel for Special Education Advice
- Institute of Education
- Institute for Public Policy Research
- LIFT
- Kids Company
- Mencap
- National Autistic Society
- National Children's Bureau

- National Foundation for Education Research
- National Parent Partnership Network
- National Pyramid Trust
- NCH
- Network 81
- Parents for Inclusion
- Razor Edge
- RNID
- St Marylebone School, W1
- Scope
- Social,
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 Behavioural
 Difficulties
 Association
- School-Home Support
- Special Educational Consortium
- TreeHouse Trust
- Who Cares? Trust

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