

Parent's Survey
New standards for Disabled Children
RESULTS

In order to improve health services in England a series of 'National Service Frameworks' (NSFs) are setting standards against which care should be judged and improvement measured. It is hoped that a major benefit of this process will be an end to the kind of inequalities in service people experience depending on where they happen to live – sometimes called the 'service post-code lottery'.

Contact a Family is playing a key part in the work of the Disabled Children's External Working Group charged with drawing up the CHILDREN'S NATIONAL SERVICE FRAMEWORK. Central to that role is our ability to act as a magnet for opinion and recommendations about the ways in which disabled children and their families should be cared for, supported and enabled so that they can live full and fulfilled lives

"The Children's National Service Framework will be about putting children and young people at the centre of care, building services around their needs."

Important words and ones that the Disabled Children's External Working Group hopes to see translated into real action and improvements for all children in England.

During May and June 2003, we asked disabled young people and people who care for a disabled child for their views. We received 243 responses to our detailed 12 page questionnaire. Many thanks to those people - the results are as follows:

Key Messages

The following is a list of the key messages that the External Working Group on Disabled Children has boiled down from the longer wish lists received from disabled children and their families. They reflect what families tell us they want from the support and services they need - services that could feature in the National Service Framework for Children.

Key Message	Final Position	Average Score
Disabled children should get the support they need to participate in everyday life. Services should enable them to have the same opportunities and experiences as non-disabled children.	1	3.05
Disabled children and their families should be encouraged and supported so that they can make informed choices about their own assessments, treatment and care, and in the planning and development of services that affect them.	2	3.53
All families with high levels of need should have access to a key worker/care manager – someone with responsibility to speak and argue on their behalf and who has a commitment to families receiving co-ordinated services and care.	3=	3.85
Agencies should work together properly so that children get their needs identified as early as possible.	3=	3.85
Families of disabled children should receive effective early care/support including timely therapy services and provision of equipment.	5	3.91
Service providers should work effectively together so that families receive co-ordinated support from the agencies they deal with.	6	4.18
If a child is 14 or older the agencies that currently provide them with services should be carrying out effective planning to ensure the shift to adult services takes place as smoothly as possible.	7	5.43
All services are culturally sensitive to and responsive to the needs of black and minority ethnic families.	8	6.79

Promoting Inclusion

The National Service Framework hopes to set standards requiring that disabled children and their families from all communities receive the support they need to participate fully in society – enjoying access to the experiences, opportunities and services that other children and families enjoy.

Key changes encouraging inclusion	Final Position	Average Score
Health, care and education services should work together.	1	2.64
Disabled children should have access to GPs, dentists and others providing 'primary care' within 24 hours. This access should include a booking system that is sensitive to the particular difficulties certain children have with long waiting periods before appointments. It also covers the need when redesigning or refurbishing surgeries and care centres that the extra needs of disabled children are taken into account.	2	3.77
Local Authorities should ensure existing laws such as the Disability Discrimination Act and the Special Educational Needs and Disability Act are applied to all their services.	3	3.78
The duty that housing, transport and leisure services should work together to promote inclusion as a core part of disabled children's assessment and action plans.	4	4.09
Hospital department booking systems should be sensitive to the particular difficulties certain children have with long waiting periods before appointments.	5	4.11
Schools should start to become places in which children with disabilities and their families can get access to other health and social services – developing into what is known as 'extended schools'.	6	4.32
Providers of children's services should receive disability equality training.	7	4.35

Partnership and Participation

The National Service Framework hopes to set standards requiring that disabled children and their parents be involved as active partners in decisions about their treatment, care and services

Key changes encouraging participation	Final Position	Average Score
Children and parents should be automatically consulted and helped when it comes to decision-making about current treatment and care.	1	2.58
Timely, appropriate, accessible and accurate information should be provided by all relevant agencies so that children and families can take part in decision-making about current and future treatment and care.	2	2.79
Children and parents should be automatically consulted and helped to participate both: <ul style="list-style-type: none"> when it comes to planning their child's specific future treatment and care; and when new planning of services for disabled children and their families takes place. 	3	2.88
Facilities/equipment/skilled workers should be available to assist children who find 'engagement and interaction' difficult so that they can be helped to contribute to assessment and decision-making about their health or social care.	4	4.30
Those working with disabled children and their families should receive appropriate communications training.	5	4.72
'Patient Advice and Liaison Services (PALS) and Independent Complaints and Advocacy Services (ICAS) should ensure that they are known to, accessible to and can easily be used by disabled children and their families	6	5.71
Interpreting and advocacy services should be available in all service settings.	7	5.73
Additional support should be available to ensure 'hard-to-reach' groups such as families from some minority ethnic backgrounds or in rural areas are properly consulted about issues relating to treatment and care.	8	5.92

Should all organisations involved in the treatment or care of disabled children have a staff member with the specific duty of ensuring children's (and families') participation?

Yes 176 72%

No 67 28%

Co-ordinated Services

The National Service Framework hopes to set standards requiring that families and disabled children have access to a seamless service – one that provides a single point of contact for information and support. (This section is closely linked to Section Ten: Transition)

Key changes encouraging co-ordination	Final Position	Average Score
The Code of Practice for disabled children with Special Educational Needs (SEN) should operate across health and social services. The implications of this are numerous but at its heart the Code encourages support for disabled children that is properly co-ordinated by all those services involved – including regular meetings between professionals to assess current support and plan transition services.	1	2.38
Key workers to support families with high levels of need should be recruited.	2	2.72
Systems that enable information about disabled children to be shared by medical/therapeutic professionals and their departments should be set up with children's and parent's consent.	3	3.16
Local multi-agency groups responsible for driving and monitoring improvements in the services for disabled children should be created.	4	3.28
There should be training for those working in agencies in a range of skills including communication; disability equality; ethnicity and culture; raising expectations of disabled children and family centred assessment and care.	5	3.37

In principle, would you object to confidential information about you and your family being shared in a responsible manner by agencies in order to promote the effective planning and monitoring of services in your area to take place?

Yes 33 14%
No 210 86%

Early Identification, Diagnosis And Assessment

The National Service Framework hopes to set standards requiring prompt identification and sensitive communication of children's additional needs arising from specific or rare health conditions. The provision of speedy and accurate information about services is also crucial.

Key changes encouraging early identification, diagnosis and assessment	Final Position	Average Score
<p>Each area should have a full range of diagnostic, assessment and support services available to families caring for disabled children. To include:</p> <ul style="list-style-type: none"> • Each area having staff with the skills and experience appropriate to supporting children with a range of disabilities including autistic spectrum disorder. • Each area having a paediatrician with training in neuro-disabilities. 	1	2.39
<p>Assessments will result in the drawing up of an agreed 'plan' addressing the child's developmental needs and the family's needs.</p>	2	3.41
<p>Assessments will record children's abilities as well as difficulties – the emphasis should always be on creating plans that aim to maximise a child's developmental progress.</p>	3	3.83
<p>Health and social care professionals should receive the child development training it takes to spot when children's developmental needs are not being met.</p>	4	4.06
<p>Collaboration between agencies leading to better assessment and planning for children showing early signs of emotional/behavioural problems.</p>	5	4.16
<p>Agencies should carry out proper screening measuring the age at which children's disabilities are identified in order to create clear benchmarks</p>	6	4.23
<p>Agencies will use a common language in all their communications about children with disabilities, their services and the needs of families</p>	7	4.84

Early Intervention

The National Service Framework hopes to set standards ensuring children with disabilities receive the best possible start in life. There could be a system of early intervention and support when any unmet need in terms of health or social provision will be identified. The emphasis could be on removing the barriers that prevent disabled children and their families from gaining all they are entitled to.

Key changes encouraging early intervention	Final Position	Average Score
All disabled children should have early access to expert diagnosis and assessment identifying their likely educational requirements.	1	2.38
Each family should quickly receive a Family Support Plan based on early diagnosis and assessment. This should include undertaking for support from housing and leisure services where appropriate.	2	3.09
Mental health and behavioural support services will be available to children with emotional or behavioural difficulties (including autism spectrum disorders)	3	3.92
Families should receive timely therapy and equipment services designed to assist their involvement in the community. (Also see Section 10: Equipment)	4	3.98
Agencies should work in a co-ordinated way to children without a statement but with special educational needs both in early-years settings (e.g. nurseries) and at school. As a part of this professional health and social service support should be available in schools	5	4.03
As soon as children are discharged from hospital they should have access to community paediatric nursing where appropriate.	6	4.59
Local authorities should make direct payments to families of disabled children so they get true choice in the kinds of services/support they need.	7	4.91

Tackling Inequalities And Providing Family Support

The National Service Framework hopes to set standards that ensure children with disabilities have equal access to services whatever their condition, ethnicity, social circumstances or geographical location. As well as having access to high standards of care and support, children should be treated with dignity and respect. Services should cater to the needs of the whole family.

Key changes reducing inequalities and boosting family support	Final Position	Average Score
A range of short-term breaks (respite) should be available to families. Short-term care providers should be governed by strict child-protection systems.	1	2.99
Support for parents/carers should include training to deal with disrupted sleep and coping with their children's behavioural difficulties.	2	3.00
Professionals should listen to and respect parents/carers and their children – particularly those who do not use speech or have limited or no English	3	3.47
There should be childcare services available for parents that wish to return to work.	4	3.92
Families should receive up-to-date benefits information from family support services	5	3.95
There should be a thorough improvement in residential care – its funding and availability. The emphasis should be on giving families far greater access and choice when it comes to the use of residential care for children. Included in this should be agreements regarding family contact with children in long-term residential care and improved links with schools to encourage attempts at reintegration	6	4.65
Standards should be laid down by which the speed, sensitivity and inclusiveness of services may be assessed. Waiting times, cultural awareness, take-up rates by different ethnic groups, etc. should all be measured.	7	4.91

Transitions

The National Service Framework hopes to set standards for high-quality multi-agency support for disabled young people, which gives them choice and control over their lives and maximises their opportunities for education, training, employment and the greatest possible independence.

Key changes encouraging improvement in supporting transitions in the lives of disabled children and young people.	Final Position	Average Score
A co-ordinated needs assessment should be made available covering the young person's likely health, housing, leisure, transport and benefits/welfare needs in adulthood.	1	2.84
Service organisations should work out agreed principles and commitments (protocols) concerning the needs of disabled young people – particularly with regard their independence in adulthood.	2	3.14
Systems should be put in place for identifying disabled children at the age of 13 who are fast approaching transition into adulthood.	3	3.19
There should be specific arrangements for managing the transition of those with life-limiting conditions or particularly high levels of need.	4	3.81
There should be greater use of the Connexions service in planning, co-ordinating and delivering support before, during and after transition.	5	4.35
There should be performance indicators measuring the effectiveness of services in improving disabled young people's transition into adulthood.	6	4.42
Transition plans should meet the needs of black and minority ethnic children and young people.	7	5.63
Local authorities should promote direct payments to disabled young people	8	5.65

Therapies

The National Service Framework hopes to set standards concerning the timely provision of physiotherapy, occupational and speech & language therapy assessments for disabled young people. If recommended, such therapies should be agreed with the child's family and their benefits should be spelled out in terms of stated aims regarding the child's eventual skills and capacities.

Key improvements in the provision of therapies for disabled children and young people.	Final Position	Average Score
There should be no delay between a child's assessment and the start of recommended therapy or therapies.	1	2.40
Therapy should be delivered in places where the child feels most comfortable and which are least disruptive of the family's life.	2	3.09
Families should be 'active partners' when it comes to decision-making about therapies for their children.	3	3.13
In order to cut down the number of therapists dealing with families, the professional bodies governing physiotherapists, occupational therapists and speech therapists should assess their practitioners' unique and common skills. Where skills are common this may allow doubling up of the therapies being offered by individual therapists.	4=	4.39
Proper systems should be set up to measure the outcome of therapies for individual children.	4=	4.39
A national survey should be carried out to highlight regional inequalities in the availability of various therapies.	6	4.51
There should be local monitoring of waiting times for therapies against agreed national targets.	7	4.71

Equipment and Adaptations

The National Service Framework hopes to set standards requiring that disabled children and young people have the equipment and housing they need for their health, well being, development and social inclusion. It is recognised that access to such equipment and housing will also benefit the health and well being of families caring for disabled children.

Key changes encouraging improved access to equipment and suitably adapted housing for disabled children and young people.	Final Position	Average Score
Agencies should be required to review and assess the long-term housing and equipment needs of disabled children. Equipment and housing assessments should be an automatic part of this process and should be family-centred at all times	1	2.69
Agencies should collaborate fully with housing agencies so that the needs of disabled children are properly accounted for in the design and provision of accommodation.	2=	3.42
There should be a significant increase in the numbers of paediatric Occupational therapists with the training to provide housing and equipment advice/support to families.	2=	3.42
Funding should be available to assist families with disabled children when they move, if need be, into more suitable housing.	4	3.51
Eligibility criteria for equipment should be standardised and lower age restrictions will be removed.	5	3.74
Housing adaptation grants should be extended to provide payments to help with the cost associated with re-housing.	6	3.93
National standards should be set to measure whether or not families receive 'essential equipment' within target set times	7	4.73

Children with Complex and Continuous Health Needs or Life-Limiting Conditions

The National Service Framework hopes to set standards requiring that children with complex and continuous health needs and/or a life limiting conditions will receive the help that enables them to live in the family home and to participate in school and community life. It also hopes to establish the requirement that parents'/carers' needs are assessed and that respite care should be made available as required.

Key Reforms catering to the needs of children with complex and continuous health needs or life-limiting disorders.	Final Position	Average Score
Parents should be assessed for their needs as carers. These needs should be met - including the necessity for short breaks both inside and outside the home.	1	3.27
There should be a 24-hour children's community nursing service that families can call on both in emergencies and also in order to maintain 'ordinary' family life.	2	3.50
Schools should have the necessary resources so that they can meet the needs of children with complex health requirements. This should enable them to play as full as possible a part in school life. This care should be based on a detailed Health Care Plan devised and monitored by a named 'Health Contact' and 'Named Teacher'.	3	3.79
Agencies with responsibilities for the care/support of children with disabilities should develop a strategic approach to the special requirements of children with continuous health needs or life-limiting conditions.	4	3.80
Hospital departments and clinics should link their systems so that families are not faced with multiple appointments.	5	3.85
Toilet and other personal care facilities suited to use by children with complex health needs should be available in all locations in hospitals and health care locations.	6	4.83
'Palliative care' services should be available in a form families wish and where they need it.	7	5.16
Drugs and other 'medical consumables' will be classified as appropriate for use in home, community and in hospital settings.	8	6.60
Rules should be established across services concerning the health and safety and child protection issues relating to the lifting, handling and providing of medicine doses requiring invasive action (e.g. administering drugs rectally).	9	6.74