Every ^disabled^ Child Matters

"If I could change one thing…"

Parents' views

What parents of disabled children and young people have told us would make the biggest difference in their lives…

Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for every disabled child. We want all disabled children and their families to have the right to the services and support they need to live ordinary lives.

EDCM is a campaign by Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium.

Thank you to all the parents who told us what they want to change.

Get involved

Sign up to support the campaign and find out more at **www.edcm.org.uk** or call us on **020 7843 6318**.

EDCM is hosted by the National Children's Bureau, charity number 258825.

Introduction

EDCM asked parents and carers[1] of disabled children all over the country this question:

"If you could change one thing for disabled children and their families, what would it be?"

Over 500 parents responded, and many of the things they want to change can be summed up in one parent's response:

"That our children are valued, celebrated and included right from the start, and do not become just a funding issue."

The three most common things parents wanted to change were:

1. To **not have to fight** for support
2. To be **included in their communities**
3. To find **educational provision** to meet their child's needs.

This booklet presents parents' responses about the changes that they say would have the biggest impact on their lives. We also include recommendations about the steps that can be taken to bring about those changes, and improve the situation for disabled children and their families.

What comes through clearly and repeatedly in the parents' responses is their anger and exhaustion at fighting an under-resourced system that is not fit for purpose. What is equally apparent is parents' creativity in finding solutions – and their willingness to work with professionals to implement them. Most of all, what shines through is their determination to get the same rights for their children that other children enjoy.

The government has taken positive steps in the right direction, announcing new funding for short breaks and family support in the recent report: ***Aiming High for Disabled Children***[2]**.** The report commits an additional £340 million for services for disabled children, and announces a national indicator to help drive up standards in all local authorities.

But much more needs to be done. Rt Hon Ed Balls MP, the new Secretary of State for Children, Schools and Families, led the ***Aiming High*** review. He has been clear that this funding is a 'down payment'. Families across the country look forward to seeing the full balance delivered and put to good use – and to better lives for their children.

As one parent said:

"If I could change one thing for my child, and all disabled children, it would be to be able to look forward to a bright future."

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[1] Throughout this booklet, we use the term 'parents' to refer to parents and carers.

[2] DfES/HM T(2007), *Aiming High for Disabled Children* – see www.edcm.org.uk/aiminghigh

What parents told us

1. Not having to fight

The one thing most parents told us they want to change is to not have to fight to get the basic, essential support that their children need.

“I would change the fact that my child and my family have to fight for every single service we need – which should be ours by right. For example, school place, speech therapy, occupational therapy, Disability Living Allowance, housing, blue badge, respite care...”

“...to not have to fight for every little thing. To be treated as if we belong in this world, and when I say every little thing, I mean EVERY little thing. ”

“...that we as parents didn’t have to fight for our children to access all the things that other children take for granted in life. Most of all, for them not to be classed as second-class citizens.”

“...to actually get the services and equipment and info that you and your child are entitled to without having to a) find out about it by chance b) fight till you are exhausted c) have to go begging.”

Parents and carers repeatedly presented three practical solutions to the constant problem of having to fight for what they need:

- more **information** for parents
- better **joined-up working** between services
- **key workers** to co-ordinate care for families.

Information

“...to have information at the touch of a button in one place on the internet, about all the service provision for disabled children, teenagers and young adults.”

“Like thousands of carers...I have had to fight tooth and nail for everything that we needed. I believe that any parent who has a child born with a disability should be given a handbook that spells out what their rights are, covering health, social services and education.”

Joined-up working

"It feels like I have been going round in circles since my disabled son was born 17 years ago. I have this vision of the future where the professionals will communicate with each other and help solve some of the issues."

"...if only all the professionals that are involved with my children spoke to each other so that I did not have to repeat their life story every time I saw someone. Doing this takes a lot of time out of an appointment."

"If I could change one thing it would be to establish a multi-agency approach to my gorgeous daughter. As it is I feel like I'm constantly corralling professionals and reminding them she exists."

Key workers

"...I would streamline the dreadful bureaucracy we parents have to deal with. I want to speak to ONE KEY PERSON in one agency who can bring all this stuff together for me, and give me advice that is solid and true. It is really frustrating to be passed from department to department and then referred on to another organisation."

"To get to a position where we don't have to shout to be heard! To have a world where we don't have to chase and re-chase service providers. Where they ring us back, or even ring us first and say 'How can we help?!'"

The current situation

The government review, ***Aiming High for Disabled Children***, sets out plans for a 'core offer' for families, which has the potential to help parents access the support they need without a fight. The core offer will include:

- **information** for families at every stage of their child's life
- **transparency**, so that families know what services they are entitled to
- **integrated assessments** across agencies.

Aiming High also announced the roll out of the existing Early Support programme, and a new Transition Support programme. These programmes will provide co-ordinated support and access to key workers for children aged 0-5 and for young people aged 14 and over.

However, while these programmes are vital, no funding has been made available to provide key workers for children between the ages of 5 and 14. EDCM is concerned that families of school-aged children may miss out on key worker support.

EDCM priority recommendations

- Delivery of the 'core offer' proposed in *Aiming High* should be measured by the new national indicator on disabled children. This would motivate local authorities to ensure that parents have clear information about the support they are entitled to, and how to access it.
- The Department for Children, Schools and Families (DCSF) should identify resources to support the roll out of Early Support.
- Local agencies, in particular health agencies, should collaborate to provide key workers for families who are in touch with more than one service, regardless of the age of their son or daughter.

2. Being included

The second most common response from parents was that they wanted to be **included in their communities**. They told us they want more places to go and things to do, and access to the activities that other families take for granted.

"I would change the feeling of isolation. I want to see more facilities for children everywhere. Better changing rooms at shopping centres, rides at amusement parks, and lifts at train and bus stations. We love our children and want to enjoy life with them."

"I want my daughter to attend social and leisure activities without lengthy planning, and feeling like she is a problem. We have to take 'the crumbs which are thrown at us' and be glad of them. Don't we deserve better than that?"

"I am the father of an autistic boy aged 15 and if I could change one thing it would be for my son to have a friend of the same age. Everyone would just accept that it was normal for my son to be included in all mainstream activities; he would be seen as a child first by all."

Parents told us what needs to happen for them and their families to be included. Their solutions were **planning**, **resources** and **training** so that disabled children and young people can access the same opportunities as non-disabled children.

"If only we had centres where young people could access the things that interest them, their lives would be much more meaningful. As it is, my son spends 90% of his free time either on the computer or 'attached to his parents' hips' as we trawl round garden centres and the like. It's not good for him and it's not good for us."

"To be able to access the same leisure facilities that non-disabled children use all I need is a trained helper with me."

"...more resources and funding to enable disabled children to access after school clubs, sport, recreation, and play schemes. They have as much right to take part in extra curricular activities as other children."

Parents also pointed out the **barriers** that prevent their families taking part in ordinary activities.

"If I could change one thing it would be to make public transport, notably train and tube stations, wheelchair accessible."

"The one thing that would make life a little easier is changing facilities in toilets that are age and size appropriate for a young person who wears pads. In many situations the only option is the dirty floor...This would make accessing public places much easier and inclusive."

The current situation

The government's proposals in *Aiming High* focus on specialist support for families. Families also want, and have a right, to be included in their communities.

At a local level, EDCM research[3] has shown that local authority Children and Young People's Plans are not addressing the needs of disabled children. Similarly, despite the powerful new duties in the Disability Discrimination Act 2005, we know that disabled children and their families are still experiencing major barriers to accessing mainstream services.

On the subject of training, *Aiming High* commits the Children's Workforce Network to carrying out research into gaps in knowledge in the children's workforce in relation to disabled children and young people.

EDCM priority recommendations

- Every local authority's Children and Young People's Plan should describe how all facilities for children, including children's centres and extended schools, are being made accessible to disabled children.
- The Children's Workforce Network should develop a disabled children's training strategy, to include disability equality training. This should run alongside the implementation of *Aiming High*.
- Accessible Changing Places toilets should be available in all big public places, as called for by the Changing Places campaign.
  Go to **www.changing-places.org** for more details.

In order to be fully included, many parents thought **attitudes towards disabled children and young people** needed to change.

"If I could change one thing it would be for my lovely son to just be included and really accepted for who he is."

"To educate the public about what it is like to be a child with special needs and what it is like to look after that child, and that not every disabled child is in a wheelchair, or looks any different to their child."

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[3] EDCM (2006) *Off the Radar* – available from www.edcm.org.uk/resources

"Young children are taught about race, culture and religion in school and most grow up respecting others' beliefs. No one teaches children about the cultures and difficulties faced by those with special needs or disabilities. I think it is time that this was included in the school curriculum."

The current situation

Under the Disability Discrimination Act 2005, public bodies, including local authorities, have a duty to actively promote equality for disabled people. However, the government's proposals for a new Single Equality Act would dilute this duty before it has had time to make a difference in practice.

EDCM priority recommendations

- The Single Equality Bill should build on current rights rather than weakening them and, in particular, should retain the positive duty to promote disability equality.
- Disability equality should be taught as part of the personal, social and health education (PSHE) and citizenship curricular.

3. Education that meets children's needs

Just under a fifth of the parents who responded to our question wanted to change the education system. They want:

"...fair, correctly supported education for all disabled children."

"I would give every disabled child the right to be educated. It would not be about money, it would be about what the child needs in order to get a place in society and be a person that gives something back."

"I would like my daughter's teacher to see her as the little girl that she is. I would like him to take responsibility for her education, rather than thinking it is the responsibility of a teaching assistant who has no training. I would like him to include her in the classroom, rather than making her spend her whole week in the corridor."

Parents' views were split roughly in half on the issue of 'special schools versus mainstream schools', with strong feelings on both sides of the debate:

"...to not have to fight for the special schools our children need – stop closing them down! They have a right to the education that meets their SEN[4]."

" ...to close ALL special schools and let ALL children go to school together. My son went to special school and learnt nothing. He has no friends. He relies on people paid to be in his life. It may not have been a lot better had he been at his local school, but at least he would be known by people and he would have had the chance to contribute his difference and educate people about difference."

These comments illustrate the need for **a range of provision**. It is crucial that local authorities and schools think creatively about how they can provide the support that disabled children need to reach their full potential, while ensuring that they have access to the full life of their community.

Many parents told us that they want their children to be able to go to their local school, with their siblings and friends. They identified two crucial elements needed for inclusion to work for their children:

- mandatory **training for all education staff** on disability and SEN
- **more resources** to be made available for specialist support services.

"Unless the government increases resources in mainstream education so that it meets the needs of disabled children the whole issue of inclusion becomes meaningless. I would like to see more resources and trained staff if our children are going to cope and improve their educational performance."

" My one change would be for all head teachers, governors, teachers and school staff – including dinner ladies – in mainstream schools to be obliged to participate in a programme of education that gave them an understanding of disability or special needs."

"I could think of many changes, as a parent of a 13 year old just managing to fend off exclusion in a mainstream school (he has autism and ADHD). One would be better training and understanding from staff, and the funding to support this."

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[4] Special educational needs.

The current situation

The government strategy for special education provision, *Removing Barriers to Achievement* has resulted in significant progress. For example, disability and SEN issues are now part of the mandatory training programme for graduate and postgraduate teacher training courses. In addition, the government has increased investment in education significantly in the last 10 years, with most of the new money flowing directly to schools.

Challenges remain because of a lack of accountability and transparency in how the new money has been spent, alongside concerns that the delegation of funding to schools has resulted in a reduction in resources at local authority level. There is also the issue of the time that will pass before a new generation of teachers trained in SEN and disability issues reach the classroom.

In the meantime, the rate of exclusion of disabled pupils and pupils with SEN remains unacceptably high – around 7 to 8 times that for other pupils according to government statistics.

EDCM priority recommendations

- Parent partnership services should be given statutory responsibility, and additional funding, to support parents on disability discrimination and school exclusion issues.
- Schools should be subject to a new legal duty to seek external support for a pupil with recognised SEN before excluding them, or to seek a statutory assessment to bring in support from the local authority.
- All schools should meet their duties to publish disability equality schemes, prepared following consultation with disabled pupils and parents.

Changing one thing – other ideas from parents

Regular breaks from caring

Lots of parents told us they just wanted a **short break** every now and then from their role providing high levels of care 24 hours day for their disabled children. This is sometimes called respite care.

"ONE thing?! There are so many things that need to change, it's very hard to think which would have the most impact. In the end I think it has to be respite. If you have good respite, enough hours and a type appropriate to your individual needs, it makes an incredible difference."

EDCM priority recommendation

- Families with severely disabled children should have a legal minimum entitlement to short breaks.

Better financial support

A number of parents want to change the dire financial situation in which families with disabled children often find themselves. These financial difficulties are largely due to the **increased costs of bringing up disabled children**, the **lack of accessible childcare**, and the current **shortfalls in the benefits system**.

"My one change would be simply more money; especially for the poorer families with a disabled child, and especially if they have a severely disabled child. I feel carers allowance should be set at minimum wage level."

EDCM has produced a full briefing on Disabled Children and Child Poverty that you can download at **www.edcm.org.uk/childpoverty**

EDCM priority recommendation

- Government should invest in a major advertising campaign, based on that used for tax credits, to promote take-up of Disability Living Allowance. EDCM estimates that this would lift at least 100,000 families living with disabled children out of poverty.

The chance to go back to paid work

Parents pointed out the need for more **affordable**, **accessible childcare places**, and **better training for childcare professionals**. They also told us they need **employers to be more flexible**.

"Provide more support to allow parents of disabled children the chance to work. Provide affordable childcare - and not just affordable childcare, but actual, existing, I-will-look-after-your-child-while-you-earn-a-living childcare."

EDCM priority recommendations

- HM Revenue and Customs should increase the upper limit of eligible childcare costs under Working Tax Credits for families with a disabled child to £300 per week.
- The next spending review should invest significant new resources in supporting childcare providers to increase access for disabled children, particularly children with complex needs and older children and young people.

Better support for young adults

Parents want the right support so their children can access appropriate **opportunities in education**, **work**, **and/or independent living** as they move into adulthood.

"Once our children finish school at either 16 or 18 years old, there is very little available for them. These people deserve to have the same opportunities as their non-disabled counterparts."

EDCM priority recommendation

- The government should re-examine the funding available for adult and community learning in order to ensure that all disabled young people can access courses that meet their needs.

Housing

The government has identified that as many as three-quarters of families with disabled children live in **unsuitable housing**[5].

"I need adequate housing so that my son can be safely involved in his basic needs, and included in more supported independence - washing, preparing meals, etc."

EDCM priority recommendation

- When a family is assessed as requiring significant adaptations to their home, local authorities should have discretion to award Disabled Facilities Grant payments of up to £50,000.

Parents told us about lots of other changes they would make if they could. Here is a selection of some of them. You can see more on our website at www.edcm.org.uk/onething

"If I could change one thing for disabled children and their families, it would be..."

"It would be to ensure that my son got adequate therapy services from the NHS so that he can achieve his full potential and have a better quality of life."

"Equipment should be easier to get. My son has been on the waiting list for a bigger wheelchair for six months. Without his wheelchair we can't leave the house. This affects us all as a family, including siblings."

"More recognition and support for siblings – their education and well-being can really suffer."

One parent told us: "I would ask the children what they want". We completely agree. We have produced another version of this booklet, which contains the views of children and young people. Order or download a copy at **www.edcm.org.uk/onething**

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[5] Prime Minister's Strategy Unit (2005), *Improving the Life Chances of Disabled People*.

Finally, parents were understandably frustrated by being continually assessed for and consulted about services that were then not **delivered**. They have heard enough about reports and proposals; they have told us what needs to be done, and are now demanding **action**.

"If I could change one thing I would stop all the endless consultations going on all over the county. The answers remain the same as 10 years ago, 5 years ago, yesterday. It's time to stop asking and just get on with creating the services we so badly need. Bring on the physios, speech therapists, occupational therapists, counsellors, play scheme workers, respite workers, etc and we will be just fine!!"

Conclusion

Disabled children are currently at the centre of the government agenda in a way that has never been seen before. *Aiming High* will make a real difference to families, but if the government is serious about ensuring that **every** disabled child matters, more action is needed.

Government must act now to ensure that disabled children and young people can be included in their communities, and get high-quality education that meets their needs and allows them to thrive. Finally, they must ensure that parents can put their energy into bringing up their children, and enjoying life with them, rather than into fighting for services.

The last word goes to this parent:

"As parents of a child with special needs we feel that these children are a blessing. They can give as much to the world as non-disabled children can. Just give them the chance."

To see more comments from parents about what they want to change, and to see children and young people's views, please go to **www.edcm.org.uk/onething**

For copies of the accessible summary, or the booklet about children's views, please contact us.

You can:

go to our website: **www.edcm.org.uk**

email us at **info@edcm.org.uk**

call us on **020 7843 6318**

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