



Summary of what disabled children, young people and their parents told us

Every Disabled Child Matters (EDCM) is the UK 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.

During summer 2007, EDCM asked disabled children and young people, and their parents and carers: **“If you could change one thing for disabled children, young people, and their families, what would it be?”**

We had hundreds of responses from all over the country, and published some of them in two booklets. One contains **children and young people's** views, and one **parents'** views. We are sending these booklets to Ministers, MPs, and other key decision makers so that they hear about what needs to change directly from families. This is a summary of the main points from both booklets.

The top three things **disabled children and young people** wanted to change were:

1. to have more **fun things to do**
2. to change negative **attitudes to disability**
3. to make it everyone's right to get a **good education**.

The top three things that **parents** wanted to change were:

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

The current situation

The government has already started to improve things for disabled children and their families with their review: **Aiming High for Disabled Children**. The review 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, as is clear from the wide range of issues identified by children, young people and their parents in this booklet.

Rt Hon Ed Balls MP, the Secretary of State for Children, Schools and Families, has described his new department as 'the Every Disabled Child Matters department'. He has been clear that the funding announced in **Aiming High** is a 'down payment'. Children and families across the country look forward to seeing the full balance delivered and put to good use to improve their lives.

What children and young people said they would change

'The time and chance to be understood for being like I am.'

Gary

'More activities available, with inclusion of everyone.'

Hannah

'I want to be able to do more fun things in life.'

Matthew, 13

'I want disabled kids to have good friends and people who don't pick on them.'

Khaqan, 17

'It should be easier to get help at school, without going through lots of fights, and before it's too late and you have lots of catching up to do.'

Hannah, 16

'I would make people listen to us!'

'More respect for disabled people.'



What parents said they would change

'Our children should be valued, celebrated and included right from the start, and not become just a funding issue.'

'To actually get the services, 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.'

'I could think of many changes, as a parent of a 13 year old just managing to fend off exclusion in a mainstream school. One would be better training and understanding from staff.'

'For my lovely son to just be included and really accepted for who he is.'

'It has to be respite. If you have good respite, enough hours and a type appropriate to your needs, it makes an incredible difference...'

'It would simply be more money; especially for the poorest families with a disabled child.'

'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.'



What needs to change?



EDCM priority recommendations

1. 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 and young people.
2. Families with severely disabled children should have a statutory minimum entitlement to short breaks.
3. Government should invest in a major advertising campaign to promote take-up of Disability Living Allowance.
4. All professionals working with children and young people should have disability equality training, and this should be reinforced by a positive duty to promote disability equality in the new Single Equality Act.
5. Parent partnership services should be resourced to support families on disability discrimination and exclusion issues, and schools should not be able to exclude pupils without making sure their special educational needs have been met.

Copies of the booklets about children's and parents' views, and the accessible summary, can be downloaded from our website, where you can also view a clip from our DVD: **www.edcm.org.uk/onething**

For hard copies of the booklets and the accessible summary, please email **info@edcm.org.uk** or call **020 7843 6318**.

If you would like this summary in a different format or language please contact us and we will try to meet your needs.

Find out more and sign up as a supporter at **www.edcm.org.uk** or call us on **020 7843 6318**.

