

## EDCM Supporter Survey Briefing

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.

During December 2007 and January 2008 EDCM asked our adult supporters to take part in an online survey to assess the impact of the campaign since our launch in September 2006. 468 supporters took part in the survey.

Our supporters play a vital role in the success of the campaign and the survey gave an opportunity for all supporters to tell us their experiences of engaging with the campaign, to inform the next stages of EDCM, and to help us communicate more effectively with them.

Overall, we are pleased to hear that our supporters are happy with the work of EDCM and how we communicate information. However, our supporters made clear the scale of the challenge faced in improving disabled children's services.

**Over 30% think services for disabled children have got worse in the past two years while 22% think they have improved.**

Supporters were clear that where improvements have been made, this has generally been brought about through constructive pressure applied by parents and families.

### What supporters think has improved:

*"I think that the situation is starting to improve due to the new funding which is being allocated, but the effect has not yet been felt by individuals"*

*"I think things have improved because of the pressure of local parents and the EDCM campaign, but there is still so much that needs to be done especially in terms of transition from children's to adult services"*

*"(It has) greatly improved I believe due to us working as a group of parents with the council in a constructive and positive way... thanks to joining up due to the campaign"*

*"Attitudes and awareness have improved but not services"*

*"For the first time that I know of there was a play-scheme for children with disabilities during the summer holidays"*

However, many comments from supporters also showed the extent of the difficulties families continue to face in accessing the services and support they need – particularly before the funding from the Aiming High for Disabled Children programme has come on-stream.

*disabled*  
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**What supporters think has got worse:**

*"You still have to fight for support and find things out for yourself. We are now accessing more direct support from the voluntary sector"*

*"I have a disabled child who is 16 this year & I have to fight harder now for her to receive appropriate care & education as I ever did. I have asked for very little help... but there is little support when you do ask. They seem to want you to carry on in silence"*

*"Thresholds are becoming too high to receive any help or support - even classing some children as not disabled in their eligibility criteria"*

*"Going through the system feels just as tough as 14 years ago. The problems change and there seems to be new 'rules and hoops' to leap through"*

*"More people seem to be using direct payments to acquire flexible support for their children but families have not been adequately supported in becoming employers of their own support staff"*

*"(Things are) much worse, cutting budgets and services, respite is such a low priority and there's not enough childcare"*

As one supporter observed this is not a simple question and several supporters commented that while some areas have improved, others have not.

**Some things have improved, some things have got worse...**

*"There is still no money, no short breaks, no support, schools closing, but I have noticed a change in attitudes to people with special needs. They are involved more, spoken to, involved in decisions and so on. That has improved, but the end result is still the same"*

*"Improved for the most severely disabled individuals but still a battle to get services. There is a real shortfall of services for children who have moderate learning difficulties"*

*"I'm not sure if it has improved in mainstream"*

*"In all aspects apart from education, which I think may have got worse"*

EDCM also asked our supporters if overall they were optimistic or pessimistic that support for disabled children and families from mainstream and specialist services in their local areas will improve over the next two years (2008/09)?

**The results were evenly split between optimism and pessimism – 40% for each.**

**Supporters who are optimistic:**

*"Optimistic. If bodies such as EDCM continue to lobby the government and enlist as much help as possible from parents and families"*

*"Implementation of a charter of principles will help"*

*"I am hoping that the extent of campaigning and hard work will pay off and make the public and authorities aware of a very neglected sector of the community"*

*"Very optimistic. Actively involved in EDCM Charter and AHDC"*

*"I'm sure your campaign will make a difference"*

*"Optimistic about the PLAN yet pessimistic about it being implemented adequately in real time to support the disabled children and families in local areas if left to the public services alone"*

**Supporters who are pessimistic:**

*"It is very difficult to be anything other than pessimistic, as I have had to fight for the past 15 years for most everything that my son has needed. I still feel that profoundly disabled children are not considered as equals in the vast majority of situations"*

*"My fight for recognition and appropriate support is still on going and I struggle to see a light at the end of the tunnel at the moment"*

*"I'm pessimistic because I don't think that disability is high enough on the agenda but I do think this campaign is making a difference nationally"*

*"Things are supposed to be getting better if you read the papers but the criteria to access children's social care is getting higher. Our daughter has moderate learning disabilities we cannot access services in our local children's centre but do not qualify for help from children's social care. We are in no man's land"*

*"...working within transitions from children's services to adult I see that the holes are so huge I cannot see how they can be bridged and how young people can be given the same understanding and level of service which adult services are a long way to accepting"*

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**Finally, we asked our supporters to tell us what impact EDCM has made since our launch in September 2006. Over 80% of our supporters were happy with progress.**

*"I am very happy, even if your hard work impacts and betters just one person it would be a success"*

*"A very successful campaign, shows what can be done if a) charities work together b) a high level sponsor such as Ed Balls is on board c) campaigning has positive targets rather than complaining"*

*"Great source of info about the national picture, which helps us to lobby with more than just our local concerns on lack of provision and unfair treatment"*

*"In such a short time it seems that EDCM has made a big difference"*

*"Participating in EDCM campaigns has energised our parent group and provided a useful focus. We value being part of something bigger than our own local struggle. EDCM campaigns are a brilliant antidote to feeling depressed and discouraged"*

*"Thank you for campaigning so effectively and productively"*

*"EDCM has certainly been trying but I think there is such a long way to go yet"*

## **Conclusion and recommendations**

Feedback from EDCM supporters demonstrates both the continuing variability of service provision for our families, and the challenge of delivering the transformation in services that *Aiming High for Disabled Children* envisions.

EDCM's supporters want government to remain focussed on delivering *Aiming High for Disabled Children*, and in particular to expand hugely the range and quality of the short breaks they can access. However, they also want disabled children to be a priority for all mainstream children's policy, and for this priority to be translated into increased access for disabled children to children's centres and extended schools.

EDCM will continue to campaign for this to happen in every local area.

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For further information, please contact:

Pamela Shaw  
EDCM Campaign Assistant

T: 020 7843 6318

[Pamela@edcm.org.uk](mailto:Pamela@edcm.org.uk)