

Disabled children's manifesto for change

making
ourselves!
HEARD!

disabled
Every Child Matters

"I will vote for your party if you promise to do your job properly and actually listen and consider what people actually want and feel need to be sorted." Holly

"I will vote for your party if you promise to stop bullying towards people with disabilities." Danika

"I will vote for your party if you promise to listen to everyone as equals." Emma

"I would vote for your party if your promise to listen to disabled people and do things to make our lives easier not harder."

"I would vote for your party if you promise to treat us like equal human beings." James

Contents

Young person's foreword	4
This is our voice	5
Foreword from EDCM	6
We want: Respect	8
We want: Community	12
We want: Commitment	14
We want: Education and training	18
What will you do?	22

Young person's Foreword

"My name is Jade Bracey and I am currently co-vice chair of the Council for Disabled Children (CDC).

At one of our steering group meetings I suggested it would be a good idea to talk about a manifesto. I wanted to do something to make MPs realise how they can improve the lives of disabled young people.

Having our own young person's manifesto would show MPs what we want and hopefully they will make it happen!

Disabled young people often get forgotten or are an afterthought. If MPs can just listen to our messages and understand us, hopefully they will make the changes we want. These changes, no-matter how small, will make a world of difference to the lives of disabled young people.

I hope this manifesto is just the start."

Jade Bracey

Co-vice Chair
Council for Disabled children



This is our voice

Our key messages

- Listen to what we say as we are the experts in our own needs and abilities.
- We should be involved in all decisions about our education and support.
- We are individuals and need different types of support and services to meet our individual needs.
- We need to have meaningful choices.
- Disabled young people moving into mainstream provision need better preparation and support.
- People working with us need to properly acknowledge the barriers and challenges we face, and provide us with the support we need to succeed.
- Everybody needs to understand what it means to be a disabled young person and have respect for us.
- It is not acceptable for disabled young people to be made fun of or face bullying within schools or our local communities.

"Everyone should be treated as an individual, with the same rights of access to leisure, education, health, support, transport, personal development and appropriate housing as everyone else.

Even if that means they need much more support and input to achieve equality. We are not asking for more rights, just the right to equality." Roger

Our challenge to next government

- Make people understand and respect disabled children and young people.
- Support us to take part in our communities, doing the things that all other children and young people do.
- Make sure the services we use can support us to live ordinary lives.
- Help us to get the education, jobs and training we want.

When you are campaigning to be elected we'd like you to listen to us. We want you to understand the issues that are important to us, and tell us what you are going to do to make things better for us.

Foreword from EDCM:



Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for disabled children and young people and their families.

We are delighted to introduce the Disabled Children's Manifesto for Change, which sets out what disabled children and young people want political parties to do to make the UK a better place to live.

Disabled children and young people have the right to participate in every decision that affects them. It is everyone's responsibility to take a proactive approach in identifying solutions and removing barriers, giving disabled children and young people the equal opportunities they deserve.

This manifesto represents the views of disabled children and young people – and sets out what they want parties and MPs to commit to. Based on this, EDCM has the following recommendations:

Party Manifesto Commitments

Every political party should include a commitment in their party manifesto to ensure that services meet the additional needs of disabled children and their families. This should include commitments to sustain investment in services; improve social mobility for disabled children and their families and embed the rights of disabled children in policy and legislation.

Respect

The next government must ensure that health, education, leisure and social care professionals receive training to work with disabled children and young people more effectively. We also want the forthcoming Equality Bill to put pressure on public bodies to address discrimination against disabled children and young people.

Community

The next government has to invest in accessible and inclusive participation structures, so that disabled children and young people can enjoy the same opportunities as their peers. We want forums for disabled children and young people to influence issues around disability.

Education and training

The next government needs to push schools, colleges and apprenticeship schemes to promote opportunities for disabled children and young people. By doing this the disproportionate number of disabled young people who are NEET will be addressed.

This manifesto was written in partnership with Making Ourselves Heard, the project to ensure disabled children's right to be heard becomes a reality.

EDCM Board



Did you know? The number of disabled children and young people is growing, especially children with complex health needs and those diagnosed with autistic spectrum disorders.



Did you know? There are 770,000 disabled children and young people in the UK.

We want: Respect



We want you to make people understand and respect disabled children and young people better.

"I don't want to feel like I'm a nuisance or somebody different. I just want to do everything that everybody else does." Claire

Attitudes

Disabled children and young people should enjoy the same rights and opportunities as other children, and should be fully included in every part of society.¹

Negative attitudes to disabled children and young people are a major barrier. It impacts on every area of their lives and stops them from accessing education, play, sport, health, employment and transport.

"I don't think it should be like this. You have to work really hard to be included." Jared

Disabled children are first and foremost children. They have the same rights, needs and aspirations as any other child.

"When people think of disabled children they always imagine you're in a wheelchair and sometimes [they] might have Asperger's or ADHD or something."

Adults being over protective or underestimating what disabled children and young people can do also has a negative impact on their confidence.

"They assume that we can't do stuff and then just try to do it before we get the chance to. We just need more time to do it. They rush us." Bex

Disabled children and young people want more respect and understanding, and more positive role models. They should be involved in developing and delivering disability equality training. Disabled adults have an important part to play in supporting disabled young people.

"You know you get the teenagers with the hoodies in the park, hanging round the shops and stuff; they think that every teenager is going to be like that."

We want the next Government to make sure all disabled young people are full members of society and can take part alongside everyone else.

What will you and your party do to make sure services promote equality for disabled children and young people?

What will you and your party do to include disabled children and young people in laws and policies, so they can do the same things as other young people?



We want: Respect

Bullying

Disabled children and young people are more likely to be bullied at school and in their communities.

Bullying is one of the most damaging forms of intimidation and can involve name calling, physical injury, damage to property, rumour spreading and ridicule. It can be manipulative, making the disabled child do something they should not, or deliberately engineering their discomfort or isolation. It can be done in person, or through mobile phones, websites and email (cyberbullying).²

"I can't make friends, they know I go to a special school and they tease me."

The Disability Discrimination Act 1995 requires schools to be proactive in promoting disability equality and eliminating discrimination.

Among its provisions are requirements for schools to promote positive attitudes towards disabled people and to eliminate harassment.

"Ever since I was a child I always got bullied at school, and now we need to do something about it."

Michael



"The kids that bullied me found out how to put my chair onto manual and wheeled me into a bush. The teachers knew and none of them did anything about it. They didn't believe me and said it must have been an accident." Evie

We want the next Government to stop the bullying of disabled children and young people in schools and where we live.

- What will you and your party do to make sure local authorities and children's trusts stop bullying in their area?**
- What will you and your party do to make sure all schools have a disability equality scheme that disabled children and young people helped to write?**

Doing things on my own

Disabled children and young people want to do things without their parents – like all children and young people. A lack of proper support means they often have to rely on their parents or other adults.

"I want to go out and learn how to catch a bus, how to go on holiday, how to go abroad."

"It's hard to ask your parents for things. You want your own space as well as your parents. You don't want to be stuck indoors all day every day doing nothing."

'Buddy schemes' help disabled children and young people access activities independently.



Why should it?!
it's not like you're disabled.. you're not in a wheelchair!



These schemes empower them to build relationships, skills, confidence and independence. Young people want buddies that are a similar age to them and have similar interests.

"You can tell your buddy anywhere you want to go, so you go there with your buddy and not your mum and dad." James

"I never go out with my friends. My mum won't let me."

We want the next Government to make sure we have the right support so that we can do things independently – like other young people.

What will you and your party do to make sure we can live independent lives?

We want: Community

We want you to make sure we can take part in our communities and are able to do the same things that other children and young people do.

"I may not have speech, But I have a voice I can give opinions, I can even argue!"³

Participation

Disabled children and young people have a right to be valued members of their community, and be recognised for what they contribute to that community.⁴

"Children and young people don't seem to be able to get involved in discussions that affect us."

"Give me a choice and don't assume you know what I want."

Disabled children and young people are the best people to ask about how to improve the services that affect them. The reality is they are rarely given the opportunity to have their say.

"We need to be part of what is going on."

We want the next Government to invest in resources so that we can have our say in the services that we use.

- What will you and your party do to make sure there are ways for us to have a say about the issues that affect us?
- What will you and your party do to make sure we are included in all youth services?

"At the age of 19, everything changes. We lose the activities that we loved at school. We miss the friendships and peer groups."

Having things to do outside school

Like everyone their age, disabled children and young people know what they enjoy and what they don't. They want places to go where they can spend time with friends, feel included and safe, and have a laugh. They want a variety of different things to choose from and be involved in decisions from the start.

"I get fed up because there aren't enough places to go with suitable activities for young people. If there were places with lots of different things to do, I wouldn't be stuck at home on the computer all the time." Patrick

There are numerous barriers denying access to play and positive activities for disabled children and young people. These include staff and peer attitudes, poor access and a lack of accessible and affordable transport. Additionally, there is a lack of appropriate activities for disabled young people when they reach 18.

"I go to drumming club in school but there's nothing I can join outside school. I'd like to go to a youth club."

We want the next Government to make sure we have better places to go and more things to do, including play and positive activities.

What will you and your party do to make sure we can take part in activities with other young people?

What will you and your party do to make sure the people who work with us understand us properly and help us to do the things we want to?

"I think you should have affordable transport making it accessible, training the drivers so they can appreciate the problems that disabled young people have." Matthew

Transport

Disabled children and young people want to make changes to the public transport system. Barriers include: poor availability and accessibility high costs, feeling intimidated by how busy public transport is, staff attitudes.⁵

"You can't get to places, like if you want to go and meet your friends in town." Kim

Disabled children and young people want to use public transport independently. Travel training supports young people to develop confidence and skills, so they can travel to school independently and access positive activities outside of school safely.

"I would go to the gym with my buddy, I would go on the buses to meet [her] then she stopped 'cos the bus took ages to get her home." Rosie

We want the next Government to make sure we can use public transport safely and easily.

What will you and your party do to make sure we can get travel training so we can travel on our own?

What will you and your party do to make sure all public transport staff understand us and can help us?

We want: Commitment

We want you to make sure the services we use help us to live ordinary lives.

"Doctors don't listen the first time we say something is wrong, then they listen when it's too late. They use really long technical words and they don't always explain what those words mean which is confusing. They get really impatient with us - that's not nice!"
Lavinia

Health

Disabled children and young people use NHS services significantly more than other children and young people, yet they have poor experiences of both specialist and universal health services.⁶

"When I was younger I wasn't involved in decisions about operations. Now I'm older I have been taught more about operations and have more say in decisions. Making these decisions is hard. I would like an advocate just for me." Adam

Disabled children and young people often don't feel confident visiting a doctor without their parents. This is because information is not accessible and health care staff simply don't understand how to communicate with them. Often staff speak to the young person's parent or carer and not directly to them about their own health.

"One time I said to the doctor, 'Excuse me, it's not about my mum, it's about me!'" Kirsty

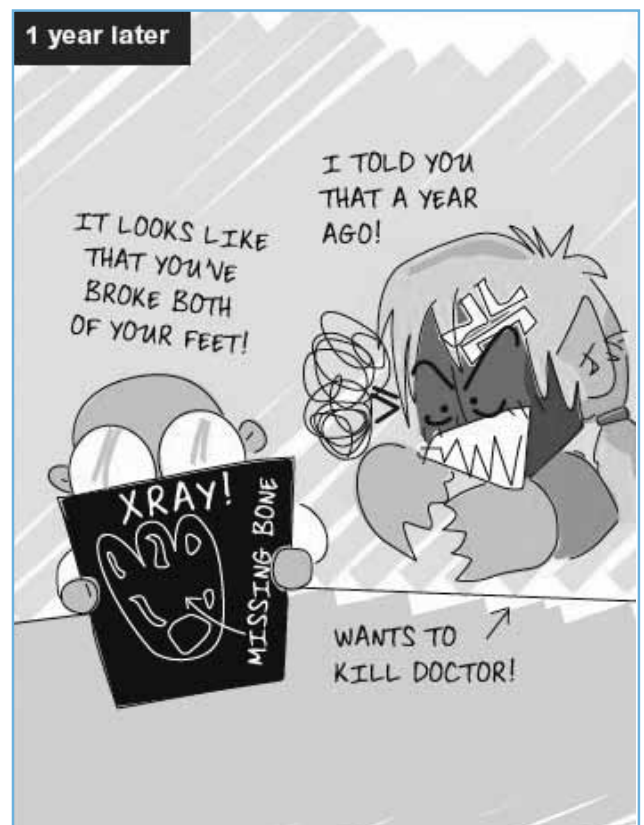
Disabled children and young people want support to access health services independently. They also want more information on how to stay healthy, including better options for healthy eating. Schools, colleges and communities should take the lead in promoting healthy living.

"I get my parents to phone in case they ask complicated questions. Sometimes I've had people that talk fast or make things sound complicated so you don't know what they're saying." Rob

We want the next Government to make sure we have better experiences of health services.

What will you and your party do to make sure health staff can communicate properly with us about our health needs, and involve us in decisions about our health care?

What will you and your party do to make sure we can use an advocate when we need to?



Doctors are annoying because they don't listen the first time we say something is wrong and then listen when it's too late

We want: Commitment



Housing

Disabled children and young people are one of the worst housed groups in Britain. Not only that, but many cannot access parts of their home, something that restricts both their independence and safety.

Many disabled children do not have their own bedroom. Some cannot even access functional rooms such as kitchens and bathrooms independently.⁷

"It's difficult for me to get out in my garden because social services say I can only have one ramp and that has already been provided at my front door. To get out into the garden I have to wait for an adult to walk down the street and around into the forest and then we can come in through a back gate."

"I would prefer my mum and dad not to help us in the toilet 'cos I'm getting older - it's nerve wracking and stuff. Even though it's my mum and dad I still don't like it. It's hard getting up the stairs." Laura

Bad housing prevents disabled children and young people from learning skills and developing confidence that can help them to live independently.

"I love my sink, because if it weren't for my sink I wouldn't be able to get myself a drink, I wouldn't be able to do my teeth, and I wouldn't be able to wash my hands or anything like that."

Good housing promotes independence and life skills which disabled children and young people value greatly. It also allows them to enjoy more control in their lives.

"My social worker is trying to get me a place, somebody comes in and helps you if you need it. They help me to do my cooking sometimes and save money for electricity and gas." Jamie



"When they don't talk to you or talk to your parents... it's like I'M HERE!" Danielle

We want the next Government to make housing a priority for us.

What will you and your party do to make sure we can live in decent houses with our families?

What will you and your party do to make sure when we grow up we can live in houses that help us to be independent and safe?

We want: Education and

We want you to help us get the education and job we want, and access training like other young people.

"Although I have a very high IQ, I cannot always write down the alphabet or understand complicated questions, and my handwriting is slow and bad. If I take exams I am not allowed to use a computer or Dictaphone – so I cannot compete equally with others. The only help I am then given is to get me back to being 'average'. I am not average. I should be able to get straight As with simple help." Christopher

Education

Disabled children and young people don't just want a good education, they want to have a say in the education they receive.

Disabled children and young people want to feel welcomed by schools, included in all aspects of school life and supported to learn and make friendships.

"Having school councillors is good. They talk about the school, and they talk to the head teacher about what we said. People get to pick which school councillors

they want. We talk to them about the playground and how things can be improved." Uriels

When decisions are being made about a young person's education the most important thing is to treat them as individuals and listen to them as they know what's best for them.

"You should have easier access to getting 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

In all settings, disabled children and young people want the same opportunities as non-disabled students to achieve qualifications and skills. This will lead to job and training opportunities and help them to gain confidence and control over their own lives.

"We have problems but so what? We are not stupid."

There are many barriers that contribute to bad experiences in mainstream settings. These include inadequate facilities and signage; not making the right adjustments in exams; a lack of inclusion in activities and school trips; and poor attitudes towards disabled students. This has to change.⁸

training

"I would make all those involved in learning environments, such as schools and colleges, go on compulsory courses to give them understanding of disabilities. This would stop the lack of understanding in people and other students, by telling them we are not 'weird', 'retarded', and most definitely not 'lazy'!" Katie-Rose

We want the next Government to make sure we get a good education and have our needs met in school.

What will you and your party do to make sure we get the help that we need in schools automatically, without being excluded?

What will you and your party do to make sure schools and colleges are positive about disability and special educational needs?

"We should be allowed to continue learning for as long as we need to and to do something we really enjoy and want to do. We should not be given menial jobs but be given opportunities just like other people who do not have a disability. We should be treated the same." Holly

Colleges and training

While some colleges are able to provide support for disabled young people, others struggle to offer this. Disabled young people need support to make sure they move forward after college. Although some local areas are starting to invest in this, very few have clear systems for supporting young people.

"There are some qualifications that I'm doing at college that don't lead me to what I want to do in life."

Further education colleges need to make reasonable adjustments for young people to ensure their inclusion and development beyond college. Young people also need more information about courses and options at an earlier age, and support to make decisions

"Interpreter helped me at college - committed - sign not speak." ⁹

We want the next Government to make sure we can go to college and take part in training.

What will you and your party do to make sure we can go to college and take part in training?

We want: Education and



"What annoys me is when you put your health down on job applications. All I get is no reply or applications are all full, but when you walk past the shop they still have vacancies." Rob

Employment

As with all young people, disabled young people want access to good jobs when they leave school and college. They should be able to access the same range of employment and training opportunities as any other young person.

"Filling in an application form can be hard. They're very difficult indeed. Because I have tried to do one on my own but couldn't do it so after that I lost the place on the job."

While employment opportunities are starting to get better in many areas, employment rates for disabled young people are very low.

"I think that young disabled people should have more help and support when they are looking at career options and looking for a job. When a disabled person is going for an interview, it doesn't matter how many qualifications they have or how 'good' they look on paper, as soon as they go into the interview room the interviewer is automatically wary by whatever disability they have. This means the person is less likely to get a job just because they're disabled." Jo

training

Many disabled young people find they have endless unpaid work placements that never lead to paid work. Local areas need to make sure young people have advice about the range of opportunities available in their area, and are able to choose what type of employment they want to access.

Disabled young people who either choose not to, or are unable to access education or employment, need access to opportunities that provide them with meaningful activity. These options should be personalised, to ensure that young people have a choice.

"I am feeling worried about getting a job. I need help myself. How can I help others if I need help myself? I want to help children but I have a disability. How can I always be there, how will I work?"

Disabled young people sometimes need extra support with employment and training, including support with interviews, writing CVs and travelling. They also require continued support and good communication in the workplace.

"People at my work need to understand how to communicate with me. They need to treat me as an individual." Tim

We want the next Government to make sure we have good job opportunities.

What will you and your party do to help disabled young people get paid jobs that help us lead an independent life?

What will you and your party do to make sure employers can support disabled young people in the workplace?



Did you know? Pupils with special educational needs are over 9 times more likely to be permanently excluded from school than other pupils.

What will you do?

Thank you for listening to our voice. We want this manifesto to lead to the change we want and deserve.

Now we want you to tell us what you will do to make things better for disabled children and young people.

To find out more and respond to our questions go to www.edcm.org.uk/dcmanifesto

You can also watch our DVD and download copies of this manifesto, EDCM campaign tool and EDCM policy briefing

Contact us

Website: www.edcm.org.uk

Email: info@edcm.org.uk

Phone: 020 7843 6082

A cartoon illustration of a girl with blonde hair in pigtails, wearing a green top. She is holding a speech bubble that contains the text 'CHANGE OR ELSE!' in large blue letters, and 'Thank you for reading!' in smaller black cursive letters below it.

**CHANGE
OR ELSE!**
Thank you for reading!

1. Council for Disabled Children (2008) 'Inclusion Policy'

2. Department for Children, Schools and Families (2008) 'Bullying Involving Children with Special Educational Needs and Disabilities: Safe to Learn: Embedding anti-bullying work in schools'

3. Department for Children, Schools and Families (2008) 'Bullying Involving Children with Special Educational Needs and Disabilities: Safe to Learn: Embedding anti-bullying work in schools'

4. Council for Disabled Children (2008) 'Inclusion Policy'

5. Every Disabled Child Matters (2008) 'Going Places!'

6. Every Disabled Child Matters (2009) 'Disabled Children and Health'

7. Every Disabled Child Matters (2008) 'Disabled Children and Housing'

8. Disability Equality in Education (2008) 'Impact of the Duty to Promote Disability Equality in Schools'

9. National Deaf Children's Society (2008) 'Deaf Children and Young People's views on what makes them feel included and excluded'

"I will vote for your party if you promise to get young disabled people involved in decisions." Gemma

"I would vote for your party if you promise to give more chances for people with hidden disabilities to do the things they want to do and reach the goals they have themselves"

Harriet

"I would vote for your party if you promise to listen to disabled children and young people... if you don't then there's no point in me voting."

"I would vote for your party if you promise to make jobs easier for disabled people to get." Matthew

"I would vote for your party if you had a disabled person in your party." Hannah

This manifesto is endorsed by



Believe in
children
Barnardo's



Leonard
Cheshire
Disability


The Communication Trust
Every child understood


The Children's Trust
Tadworth
For children with multiple disabilities


TreeHouse®




The Children's
Society

Children's Rights Alliance
for England

ndcs
every deaf child

Disabled Children Matter Wales
Plant Anabl yn Cyfri Cymru 


action for
children

Whizz-kidz
move a life forward


family fund
helping disabled children

contact a family
for families with disabled children

Council for
Disabled
Children

mencap
The voice of
learning disability

special
educational
consortium

This manifesto features the real voices of disabled children and young people. Where quotes have no name, the young person wished to remain anonymous. Special thanks to Lavinia Scott for providing illustrations.