



## Office of the Children's Commissioner

"They still need to listen more"

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A report about disabled children and  
young people's rights in England

November 2014

# Contents

About the Office of the Children’s Commissioner.....	3
Acknowledgments.....	5
Foreword from the Children’s Commissioner.....	6
Executive summary and key findings.....	7
Introduction.....	12
Findings and principle concerns.....	17
Conclusions and recommendations.....	29
References.....	32
Appendix A.....	34



# About the Office of the Children's Commissioner

The Office of the Children's Commissioner (OCC) is a national public sector organisation led by the Children's Commissioner for England, Dr Maggie Atkinson. We promote and protect children's rights in accordance with the United Nations Convention on the Rights of the Child and, as appropriate, other human rights legislation and conventions.

We do this by listening to what children and young people say about things that affect them and encouraging adults making decisions to take their views and interests into account.

We publish evidence, including that which we collect directly from children and young people, bringing matters that affect their rights to the attention of Parliament, the media, children and young people themselves, and society at large. We also provide advice on children's rights to policy-makers, practitioners and others.

The post of Children's Commissioner for England was established by the Children Act 2004. The Act makes us responsible for working on behalf of all children in England and in particular, those whose voices are least likely to be heard. It says we must speak for wider groups of children on the issues that are not-devolved to regional Governments. These include immigration, for the whole of the UK, and youth justice, for England and Wales.

The Children and Families Act 2014 changed the Children's Commissioner's remit and role. It provided the legal mandate for the Commissioner and those who work in support of her remit at the Office of the Children's Commissioner to promote and protect children's rights. In particular, we are expected to focus on the rights of children within the new section 8A of the Children Act 2004, or other groups of children whom we consider are at particular risk of having their rights infringed. This includes those who are in or leaving care or living away from home, and those receiving social care services. The Act also allows us to provide advice and assistance to and to represent these children.

## **Our vision**

A society where children and young people's rights are realised, where their views shape decisions made about their lives and they respect the rights of others.

## **Our mission**

We will promote and protect the rights of children in England. We will do this by involving children and young people in our work and ensuring their voices are heard. We will use our statutory powers to undertake inquiries, and our position to engage, advise and influence those making decisions that affect children and young people.



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## Acknowledgments

We would like to thank the following young researchers who worked with the OCC. They helped us to better understand what is needed to ensure the realisation of disabled children and young people's rights in England.

- Benjamin Giffin
- Marti Hayes
- Rebecca Morris
- Yewande Akintelu-Omoniyi

The contribution they made to this work has been invaluable.

We would also like to thank Zara Todd from the Council for Disabled Children (CDC) and Dr Anita Franklin, from the Centre for Children and Families Applied Research (CCFAR) at Coventry University for working with the OCC and supporting the young researchers to undertake this piece of work.

In addition, we would like to thank the following organisations for working with us and kindly setting up sessions for us with the children and young people they work with.

- Barnardo's: The Flying High Group (North Yorkshire)
- Barnardo's: Include Me 2 (Preston)
- Kids: (Bristol)
- The Alliance for Inclusive Educations (ALLFIE): New Voices Group (National).

Above all, we would like to thank all the disabled children and young people who took part in or were interviewed for this research and spoke openly to us about their lives and the challenges they face.



## Foreword by the Children's Commissioner

For some time, I have been seriously concerned about the inequalities faced by disabled children and young people in England. In a modern western nation, it is unacceptable that we still have to raise the issues in this report. It should not be the case that it is still necessary to tell our readers that these children's lives are affected by the denial of their rights both by those running some services and society at large.

We have legislation to ensure the fair treatment of disabled children and young people (and their families), and high expectations about what they deserve and should receive. As a nation and a society, we commit time and time again, through policies, debates, and public statements to ensuring they receive these entitlements.

The children and young people in this report do accept that in some cases, every effort is indeed being made. But they also tell us, that there remain too many gaps between what is expected and what is promised and what their lives are really like.

We have a choice: to live up to our promises, or continue to fail. It is as simple to say, apparently as easy for us all to promise, and yet as difficult to get right, as that. I commend the findings of this research to you in that sometimes harsh and blinding light. We publish it in the knowledge that when the UN Committee on the Rights of Persons with Disabilities calls the UK State Party to demonstrate how well those rights are realised, this report, and the accounts of real children's lives that it contains, will contribute both soundly and challengingly to the debate.



**Dr Maggie Atkinson**  
**Children's Commissioner for England**



## Executive summary and key findings

This report presents a snapshot of 34 disabled children and young people's views and perceptions about the realisation of their rights as outlined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We also draw on other research, including research carried out by the Office of the Children's Commissioner (OCC), which raises serious issues and presents solid evidence about the fulfilment of disabled children's rights in England.

Four trained young researchers who are disabled undertook the research in collaboration with the OCC. They defined which rights the research should prioritise basing their decisions on their own experiences and on the rights they felt were most important to disabled young people. They also worked with OCC to design and facilitate four focus groups with disabled children and young people. They thematically analysed the data and helped the OCC to think through the issues arising for the organisation, policy and decision makers and practitioners. They also helped to develop the recommendations outlined below.

### Key findings and issues arising for OCC

The key findings are outlined below under each of the rights in the UNCRPD that were examined as part of this research. Many of these rights can only be achieved together – for example the right to work and employment often depends on the realisation of the right to education. Likewise the right to live independently and participate in the community depends on adequate standard of living and access to work and employment. Throughout this report we have noted these links where appropriate.

#### Article 4: General obligations

- The children and young people we spoke to were concerned and anxious about the loss and changes to the benefits and services they and their peers receive.
- As a result of tax and benefit reforms announced in 2010, OCC has highlighted retrogression in the realisation of disabled children's rights (OCC, 2013a).

#### Article 5: Equality and non-discrimination

- The children and young people stated that society in general holds unhelpful, negative stereotypes of disabled people. They thought that people underestimated their ability held limited expectations and aspirations. It was suggested that the media portrays negative images of disabled people and often linked disability with benefit dependency. This is backed-up by research which shows that 67% of the British public feel uncomfortable talking to a disabled person and 36% think disabled people as not as productive as everyone else (Scope 2014).



- Government spending decisions made in 2010 have a disproportionate impact on disabled children and their families (OCC, 2013a).
- OCC's own research on these issues shows a disproportionately high prevalence of disability including neurodevelopmental disorder and unmet mental health needs in young people within the secure estate (OCC, 2012a).

#### **Article 7: Situation of children with disabilities**

- Disabled children and young people report that too often they find it hard to get their views heard and taken seriously. Equally often, they have little autonomy over decisions that affect their lives.
- Disabled children and young people face barriers to communicating with others including professionals and service providers due to lack of training and awareness about how to communicate with disabled children and young people.
- Disabled children are less likely than their peers to be involved in mainstream participation opportunities.
- Concerns have been raised about the lack of advocacy services for disabled children and young people.

#### **Article 8: Awareness – raising of disability rights and disabled people in society**

- The children we spoke to believe that society still holds negative views about disabled children and young people.
- Concerns were raised by those we spoke to, and others in research elsewhere, about the continuing lack of professional support and specialist training for professionals who are at any time likely to work with disabled children.
- The children and young people in this research study considered there should be better representation of disabled children and young people in books, on television and in the media, as a means of encouraging a more inclusive mindset across society.
- To date there has been no government led awareness-raising campaign focused on the general public's awareness of the rights and needs of disabled children. These children consider there should be such a campaign if they are to be treated as the equals they wish to be.
- Those we spoke to wanted more information about their rights, which they consider should be taught throughout their lives in school and college.





### **Article 9: Accessibility and independence**

- The children and young people talked about accessibility of services and the support needed in order to live independently and not being involved in decisions about their independence. These included: lack of accessible transport in the areas where they lived; the accessibility of the school environment; not being able to use certain airlines due to wheelchair weight restrictions; the lack of advocacy services for disabled children and young people.
- Children and young people raised issues of accessible schools (raised under article 24: Education), youth services (raised under Article 30: Access to sport and culture) and work placements (raised under article 27: Work and employment).

### **Article 16: Freedom from exploitation, violence and abuse**

- The children and young people who took part in this research reported distressing accounts of bullying happening to them and their disabled peers.
- The children and young people also reported accounts of not being listened to or taken seriously when reporting bullying to either the police when out of school, or teachers when in school (OCC, 2013c).
- OCC's research shows there are widespread assumptions across society, including in organisations that should be far better attuned to these issues, that disabled children and young people are – and indeed can be – victims or perpetrators of sexual exploitation and/or abuse (OCC, 2014a).
- Although disabled children are just over three times more likely to be victims of child sexual abuse (CSA) than non-disabled children, they are less likely to have child protection plans.
- There is a lack of robust evidence to demonstrate the true levels of violence and abuse faced by disabled children and young people.
- This work calls into question the adequacy of child protection services for disabled children and young people. The OCC will explore this issue further through its inquiry into child sexual abuse in the family environment.<sup>1</sup>

### **Article 19: Living independently and being included in the community**

- The children and young people wanted Personal Assistants (PAs) that are well trained and understand the specific needs of the child or young person they work with. They must involve them in decisions that affect their lives.

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<sup>1</sup> For more details on the inquiry, visit:  
[http://www.childrenscommissioner.gov.uk/info/child\\_sexual\\_abuse\\_within\\_the\\_family\\_environment](http://www.childrenscommissioner.gov.uk/info/child_sexual_abuse_within_the_family_environment)



- Those involved in this research consider there is no serious, and certainly no comprehensive, plan for the real and meaningful inclusion of disabled children in all aspects of the society in which they are growing up.
- Young people placed importance on transition planning from children's to adults' services across health, education and social care, but were not always sure if they had a transition plan in place. Certainly they were not always fully or consistently involved in making vital decisions about their future.
- It is difficult for disabled young people to identify accommodation that is accessible in their local areas. Concerns were raised about residential schools and not wanting to 'disappear' from family and local community.

#### **Article 20: Personal mobility**

- It is not always easy for disabled children and young people to access communication aids which meet their needs and helps to equalise their involvement in discussion, decision making and social activities and engagement with friends.
- Young people also reported wanting, but all too often not being provided with, outdoor power chairs; a circumstance which further limits their mobility and their chance of independent living.

#### **Article 21: Family life**

- Concerns were raised about out of area residential placements impacting on a child's right to family life.
- Concerns were also raised about disabled children being moved around the care system and about the stability of placements and placement breakdown.

#### **Article 24: Education**

- Children and young people told us about feeling unsupported to achieve and pursue academic qualifications and often having little autonomy of over subject choice when reaching GCSEs or A-levels.
- Children and young people told us about how important it was to have good teaching assistants that were properly trained, understood their needs and empowered them.
- Children and young people wanted more support to reach their full potential in education as this is linked to ability to access meaningful employment.
- Young people thought that schools and colleges did not give them enough support to access employment.
- OCC has raised concerns around schools using loopholes in the



admissions system to reduce the number of children with a Special Educational Need (SEN) (OCC, 2014b).

- Children or young people with a disability or SEN are eight times more likely to be excluded both informally and formally than their non-disabled peers (OCC, 2012b).

#### **Article 27: Work and employment**

- Disabled children and young people reported that they faced significant difficulties in accessing paid employment and suitable meaningful unpaid work experience, leaving them to feel isolated and concerned about their futures.
- They wanted more education for employers so they can recognise the potential of disabled young people.

#### **Article 28: Adequate standard of living and social protection**

- Disabled children in England experience higher levels of poverty and personal and social disadvantaged than their peers.
- Some families with disabled children are struggling to afford to heat their homes properly.
- Some disabled young people living independently did not have resources for food and clothing due to not having enough money (Larkins et al, 2013).

#### **Article 30: Access to sport and culture**

- Disabled children and young people often feel excluded from mainstream play and leisure provision and wanted more opportunities.
- There are not enough short breaks to meet families' needs and over the past three years there has been a reduction in short break provision for disabled children and young people.

### **Recommendations**

Many important child rights issues were raised during this work. Through working with the young researchers to analyse the key themes we identified a number of issues which were raised consistently through the focused groups. These issues have been used as the basis for our recommendations.

1. More needs to be done to tackle disability-related hate crime, victimisation and abuse. The current hate-crime strategy is not sufficient in breadth and depth to tackle the specific issues relating to disabled children and young people. We suggest that a specific national strategy led by the Minister for disabilities be produced which address issues related to understanding and provided information about hate crime and ensuring adequate reporting mechanisms and victim support is in place.



2. It is evident that children and young people do not feel they are receiving the right support in education to achieve their full potential. There should be greater training and support (beyond what is currently offered) for teachers in the form of mandatory teacher training which ensures that they have the skills and practical tools to deliver an inclusive education.
3. A statutory requirement for all annual reviews for disabled young people with Education, Health and Care Plans or in receipt of SEN support from Year 9 onwards should have a strong focus on qualifications and the implications for future career aspirations. This should include a requirement for young disabled people to receive appropriate and relevant careers advice/guidance and assistance in brokering work experience placements. There should also be a duty for professionals to put in place the necessary support for young disabled people to access suitable work experience.
4. Disabled young people wanted additional support in accessing work and employment. Therefore the DfE should provide clear and more explicit guidance to schools on the following with a clear direction on how to meet the additional needs of disabled young people:
  - what constitutes a comprehensive careers guidance strategy
  - how to secure independent, external careers guidance
  - how to monitor the impact of this provision effectively.
5. To date there has been no government-led awareness-raising campaign focused specifically on changing general attitudes towards disabled children and young people. Despite numerous disability awareness-raising campaigns are outlined in the *Making it Happen Action Plan* (DWP, 2013) none are specifically intended to benefit disabled children. We would like the Minister for Disabled People to chair a cross-government group to coordinate and develop a strategy dedicated to changing public attitudes and reducing negative stereotypes which are still a barrier to disabled children and young people realising their rights.
6. In *We want to help people see things our way* (Larkins, 2013) we recommended that the Minister for Disabled People to chair a cross-government group to undertake an independent review of the adequacy of support for disabled children and young people. We reiterate this, and note that it should include an analysis of whether the welfare and benefit system is sufficient to provide for disabled children and young people's basic needs and accounts for the higher food, housing, heating, clothing, education, health and transport costs.

The Office of the Children's Commissioner will use the views of the children and young people who took part in this research in a number of different ways. They include:



- to inform and shape any submission we make to the UN Committee on the Rights of Persons with Disabilities (UNCPRD) as well as the UN Committee on the Rights of the Child (UNCRC)
- to inform and shape the Children’s Commissioners strategic priorities for 2015–18 and business plan for 2015–16
- to support current and continued work at the OCC.

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## Introduction

This research was carried out by the OCC in partnership with young disabled researchers. It presents a picture of how 34 disabled children and young people view the realisation of their rights in England in 2014.

The OCC commissioned the Council for Disabled Children and Coventry University to recruit and train four young disabled researchers to work with the OCC to design data collection, deliver focus groups and analyse the evidence obtained from them. The young researchers prioritised specific rights outlined in the UNCRPD which they thought were most relevant to disabled children and young people in England.

Within this report we include evidence of disabled children's rights captured from the focus groups, from other research carried out by the OCC and external research where it supports the issues raised by the children and young people.

The young researchers were involved in:

- developing an ethical and safeguarding framework in which to conduct the research
- developing a sampling framework and identifying potential groups of disabled children and young people to take part
- designing questions and activities for, and delivering, the focus groups
- thematically analysing the data that emerged from the focus groups
- prioritising the key issues that were to be included in the report
- supporting the development of recommendations for improving disabled children and young people's rights in England.

Working with young disabled researchers helped us to ensure that children and young people's views and voices were at the centre of the research process. It allowed the research questions, methodology, and recommendations to be driven by young people.

This research used a methodological approach to participatory research based on previous work undertaken by Franklin and Todd (and others) within the VIPER project (see below). More details about the methodology can be found in the overview of the methodology and research participation section below and in Appendix A.

### **An overview of the methodology and research participation**

The aim of this research was to understand disabled children and young people's perspectives on the realisation of their rights in England in 2014.

The methodology we used included:



- working in partnership with four young disabled researchers to design, deliver and carry out the focus groups and analyse the findings
- undertaking focus groups with disabled children and young people to gather the evidence
- working with young researchers to prioritise findings and develop recommendations.

We wanted to ensure that this work was informed and influenced by the views and experiences of disabled children and young people. We therefore decided to appoint young disabled people as researchers. The aim was to help us to ensure that children and young people’s views and voice were at the centre of the research process. It allowed the research questions, methodology and recommendations to be driven by young people. This research uses a methodology for participatory research, which involves young disabled people as the researchers and participants. The work was also supported by OCC’s Participation team and underpinned by our Participation strategy<sup>2</sup> and Safeguarding policy.<sup>3</sup>

### **Young researchers**

The Council for Disabled Children (CDC) and the Centre for Children and Families Applied Research (CCFAR) at Coventry University were commissioned to recruit and support four disabled young people to work in partnership with the OCC. Todd (CDC) and Franklin (Coventry University) had previously undertaken the VIPER participatory research study with a group of 16 disabled young researchers from across England.<sup>4</sup> These disabled young people had undertaken a three year research study examining disabled young people’s participation in decisions about services. Four of the 16 young researchers applied to take part in this new study and work alongside the OCC. These young people had already undertaken training in research methods (research design, data collection, analysis), ethics, safeguarding and on the rights of children and disabled people. Their extensive experience of undertaking a research project, including developing policy recommendations, meant that they could deliver this project within a tight timeframe and draw upon their knowledge of research to work in equal partnership with the OCC.

The OCC, supported by CDC and CCFAR, worked with young disabled researchers to:

- think through the ethical and safeguarding issues arising from this piece of work
- develop and agree the methods for working with other disabled children and young people

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<sup>2</sup> See details at:  
[http://www.childrenscommissioner.gov.uk/content/publications/content\\_828](http://www.childrenscommissioner.gov.uk/content/publications/content_828)

<sup>3</sup> See details at: OCC Safeguarding Policy Handbook.  
[http://www.childrenscommissioner.gov.uk/content/publications/content\\_828](http://www.childrenscommissioner.gov.uk/content/publications/content_828)

<sup>4</sup> See details at: <http://vipер.councilfordisabledchildren.org.uk/>





- identify a range and diversity of disabled children and young people to take part in the research
- design and carry out the focus groups
- thematically analyse the data that emerged from the focus groups
- develop recommendations
- advise on the final report and children and young people's version.

### ***Participants***

The children and young people involved in the focus groups were aged between 5–24 years. Of the 34 children and young people who took part, 19 were female and 15 were male. A full break down of the participants is outlined in Appendix A.

All the children and young people we spoke to were being supported within the community. Those children living within institutional settings were not represented within this research. This was due to the limited time and budget dedicated to this specific piece of work. However, OCC is currently carrying out a specific piece of research looking at the rights of disabled children and young people living within special residential schools.

### ***Focus of the research***

The young researchers went through a process of reviewing the rights outlined in the UNCRPD and systematically prioritising those they felt would have the most impact on disabled children and young people.

After the reviewing process the following rights were identified by the young researchers as the most relevant to disabled children and young people's lives:

- Article 5: Equality and non-discrimination
- Article 7: Situation of children with disabilities
- Article 8: Awareness – raising of disability rights and disabled people in society
- Article 9: Accessibility and independence
- Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Article 16: Freedom from exploitation, violence and abuse
- Article 19: Living independently and being included in the community
- Article 20: Personal mobility
- Article 21: Freedom of expression and opinion, and access to information
- Article 24: Education
- Article 27: Work and employment
- Article 28: Adequate standard of living and social protection
- Article 30: Access to sport and culture.

However, during the data analysis phase we added in Article 4 (general obligations) and Article 21 (family life) as children and young people raised rights issues relating to these Articles.





It is important to note that rights must be viewed as interdependent despite their distinctiveness as particular rights. This means that the enjoyment of any right or group of rights requires the enjoyment of others which may or may not be part of the same category. For example, the right to work or education is dependent on accessibility and independence and personal mobility.



## Findings and principle concerns

### **Article 4: General obligations**

States Parties undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

*If I was Prime Minister I would stop making these cuts and changes to our benefits...'*

The children and young people we spoke to during the focus group sessions were concerned and anxious about loss of and changes to benefits and services. They were particularly concerned about student grants, transport and independent living. They wanted more information about changes to services and benefits.

One young person talked about cuts to Disabled Student Grants and how they are going to affect children and young people, especially if they are not from wealthy backgrounds. The young person said:

*How can I afford to go to university, my family don't have a small fortune...*

The children and young people's concerns about loss or changes to benefits were echoed in the OCC's CRIA on budget decisions announced in 2013 (OCC, 2013a). The analysis found that families with disabled children suffer slightly a bigger loss than families with non-disabled people. The analysis concluded that there is likely to have been retrogression in relation to the realisation of children's rights as a result of government spending decisions.

### **Article 5: Equality and non-discrimination**

States Parties recognise that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

*Society doesn't always treat us equally.*

*It would be good if we could have a disability awareness month like Black History Month.*

The children and young people told us that they felt that in general people still hold unhelpful, negative stereotypes about disabled children and young people. They thought that people, service providers and professionals underestimated their ability and held limited expectations and aspirations for



disabled children and young people.

Some children and young people believed that the media portrayed negative images of people on benefits linking disability to benefit dependency. They thought that all discrimination was wrong but recognised there had been progress with reducing discrimination relating to race and ethnicity. Black History Month, a nationwide celebration of Black history, arts and culture throughout Britain, was provided as an example of an awareness-raising campaign being included in school lessons as a positive action to reducing discrimination relating to ethnicity. They also thought that racism or racist acts were dealt with more seriously within schools and by the local police.

Other issues of equality and discrimination have been highlighted OCC. This includes highlighting the disproportionately high prevalence of disability including neurodevelopmental disorder and unmet mental health needs for young people within the secure estate (OCC, 2012a). Other research carried out by the OCC (2011) found that approximately 60% of children in the youth justice system have significant speech, language and communication needs. It is estimated that around 50% of children in custody have learning difficulties. One in ten boys and one in five girls in Youth Offending Institutions (YOIs) have attention deficit hyperactivity disorder.

The disproportionate numbers of child and young people in the secure estate suggests that there is lack of understanding about the heightened level of risk of offending including several criminogenic factors seen to have a direct impact on the likelihood of offending behaviour as well as the environmental or social processes that may exacerbate difficulties caused by the initial impairment, serving to criminalise young people with neurodevelopmental disorders.

#### **Article 7: Situation of children with disabilities**

States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

*My special school only taught me baking.*

*I want to choose my course.*

The key issue raised by children and young people was that it is hard to get your voice listened to and taken seriously. Some young people told us about feeling forced to take subjects, courses and work experience that they did not choose or want to do. This also has significant implications for the long-term employment outcomes of young disabled people.

Others faced barriers to communicating with others and thought there needed to be more training to understand how to communicate with disabled children and young people. They particularly wanted people and staff that worked with



them to understand their different communication needs. They wanted these communication needs to be met by having access to the right support and for people to take time to listen to them.

One young person said:

*It's hard for disabled children who are non-verbal. They still have an opinion but express it in a different way.*

Children and young people suggested that groups (like the ones they were part of) and 'sessions like this' were important in getting their voices heard.

Research by disabled young people has highlighted that even within formal participation structures (for example local government) disabled children are less likely to be involved in mainstream participation opportunities alongside non-disabled young people (VIPERS, 2012).

In addition, advocacy can help disabled children and young people express their views and interests. However, only a small number of disabled children and young people receive advocacy services (Franklin and Knight, 2013).

Lastly, concerns were raised by the children and young people we spoke to about lack of support and training for professionals working with disabled children. They provided many examples of professionals such as Personal Assistants (PAs), teachers and social workers not fully understanding their needs or involving them in decisions about their lives.

Concerns were also raised in 2013 by the British Medical Association around lack of support and training for certain professionals working with disabled children. They were particularly concerned about early identification falling on nursery staff and lack of focus on child development in the curriculum of teacher training courses (BMA, 2013).

**Article 8: Awareness raising of disability rights and disabled people in society**

States Parties undertake to adopt immediate, effective and appropriate measures:

- a. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities
- b. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life
- c. To promote awareness of the capabilities and contributions of persons with disabilities.



*There needs to be more understanding and awareness of disabled people.*

The children and young people we spoke to thought there was a negative portrayal of disabled people in the media especially when disabled people were linked to benefit dependency. They wanted more general awareness-raising of disabled children's rights and needs. This includes awareness-raising about what disability equipment is needed and used for. One young person said that if they could make one thing better for disabled young people they would:

*...get the Government to make a flyer so people know about disability.*

They also wanted a more positive representation of disabled children and young people in teaching resources used in schools. These should include books, information and other literature and should be included in all education settings from nursery to university.

The children and young people we spoke to also wanted more information about their rights and entitlements. They thought this would equip them with the skills to challenge prejudices and rights violations. They thought that information about their rights should be taught in schools and colleges and/or provided to them by Personal Assistants and other support staff.

To date there has been no government-led awareness-raising campaign focused specifically on raising the general public's awareness of disabled children and young people's rights or aimed at changing negative, unhelpful and harmful attitudes. Numerous disability awareness-raising campaigns are outlined in the *Making it Happen Action Plan*, though none are specifically intended to benefit disabled children (DWP, 2013).

### **Article 9: Accessibility**

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

*It's difficult getting on and off the ramp when catching the bus, this is because there is not enough space.*

Young people thought that getting some of their travel paid was a good thing. However, they also told us about the limited availability of accessible public transport in their local area. They talked about the difficulties of getting on and off the ramp when catching the bus due to the ramps not being big enough.



When public transport was available, young people told us they often faced a lack of understanding from bus and travel companies about their needs and even reported bus drivers just driving past them.

One young person said that:

*The bus driver just drives past me and other disabled people at the bus stop.*

Another noted that:

*The bus drives off before I have a chance to sit down.*

The young people we spoke to wanted public transport staff to be given training about how to meet the needs of disabled children and young people.

Children and young people talked about how the lack of transport or inaccessibility of public transport leading to loss of independence, feelings of isolation and reliance of other provisions such as taxis which are expensive or family members.

Young person being educated in mainstream, state funded schools talked about access within schools being problematic, with lifts not working and the school building being difficult or impossible to move around. They said:

*The lifts don't work, space in classrooms is too small and I cannot get around the dinner hall or move round the corridors.*

This inability to navigate the school building leads to being excluded and isolated from lessons and other learning or extra circular activities.

One young person also talked about facing some difficulties when travelling by aeroplane, including being unable to take flights with some airlines because they will not carry wheelchairs above a certain weight.

Young people also talked about lack of accessible employment opportunities and access to reasonable adjustments (please see Article 27 work and employment).

**Article 16: Freedom from exploitation, violence and abuse**

States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

*I was severely bullied all my life and nothing was done about it. I didn't know what to do.*

*Bullying is not dealt with or taken seriously... the school turned round and told*



*me to deal with it myself.*

*I can switch off my hearing aid so I don't have to listen to what others are saying about me.*

*They used to prank me and think I'm stupid.*

The children and young people shared startling information about experiences of bullying. They talked about bullying in school, when using public transport and even reported accounts of feeling bullied or victimised during work experience. One young person told us about how he was victimised whilst using buses and the bus driver doing nothing to help. He reported feelings of distress and being scared whilst using the bus to and from school and around his local area. He told us that:

*...the bus companies could do more to keep disabled children and young people safe.*

The children and young people's views are echoed in research carried out by McLaughlin et al (2012) and Naylor et al (2012). This research shows that young people with SEN and/or disabilities who experience a wide spectrum of different difficulties are likely to be affected by bullying.

Additional research carried out by disabled young people with other young disabled people revealed important information of young people's experiences of disability-related hate crime. The report outlined that:

- eight out of ten young disabled people who completed the survey say they have been harassed, humiliated or embarrassed by a person's attitude to them being a disabled person
- two out of three young disabled people who completed this survey have been taunted or verbally abused because they are disabled
- 62% of young disabled people who completed the survey say they have been or may have been the victim of disability hate crime
- only four out of ten young disabled people who completed the survey and have been harassed or abused, or are currently being harassed or abused, have reported the incident to a person in authority
- eight out of ten young disabled people who completed the survey think that the police do not take disability hate crime seriously enough
- 79% of young disabled people who completed the survey think some disabled people may be dissuaded from reporting hate crimes because of the police's negative perceptions surrounding hate crime and disability
- only 40% of young disabled people who completed the survey are aware that harsher penalties are given for crimes motivated or aggravated by a victim's disability (Trailblazers, 2012).





Our Inquiry into Child Sexual Exploitation in Gangs or Groups (CSEGG) and our Rapid Evidence Assessment on intrafamilial child sexual abuse have highlighted widespread assumptions that disabled children and young people are neither victims or perpetrators of sexual exploitation and/or abuse (OCC, 2013c; 2014a). Our Rapid Evidence Assessment on intrafamilial child sexual abuse highlighted that although disabled children are just over three times more likely to be victims of CSA than non-disabled children, they are less likely to have child protection plans (OCC, 2014a).

The inadequacy of safeguards for protecting disabled children and young peoples from abuse is a consequence of unhelpful and harmful assumptions as well as a result of disabled children not recognising abuse or not being about to verbally communicate issues of abuse.

These findings are further supported by research carried out by Jones et al (2012), which confirmed that disabled children are more at risk of violence. A lack of robust evidence means that the true levels of violence are not yet known.

**Article 19: Living independently and being included in the community**  
States Parties to this Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community...

*I want to be able to live independently when the time is right.*

*My PA didn't understand my specific need.*

Children and young people raised many issues relating to their ability live independently and within their community. Key to this was accessing the right levels of support to live independently as part of the transition young disabled people make from school to work. This issue interrelates with other rights within the Convention including Article 24: Education and the issue off support into work.

Young people talked about the importance of PAs in order to support independent living. They wanted PAs that were well-trained and understood their specific needs. However, some reported a lack of staff understanding of their needs. Others wanted access to more personal assistance as this would help disabled children and young to live with increasing levels of independence.

One young person said:

*I want more assistance who would take me to rock gigs and stuff so I don't*





*have to go with my parent, which is lame...no offence.*

However, many young people presented us with distressing accounts of PAs making decisions on their behalf. There were accounts of disabled children and young people not feeling involved in decisions that affect their lives and having limited control and choice.

One young person said:

*I should be allowed to make my own decisions with the freedom others have.*

Some young people talked about the importance of services such as social care, health and housing in supporting them to live independently and to help with transition planning from children's to adult services. However, young people told us that they had limited contact with relevant professionals and some did not know if they had transition plans.

Young people recognise the importance of adaptations in homes to enable independence and being able to access relevant training and financial support. They also wanted choice about where to live and who to live with and more information about independent living and the support that they were entitled to.

A similar view was highlighted by young disabled people who reported that they find it difficult to identify accommodation that is accessible to them because local authorities and estate agents have poor knowledge of adapted properties in their area (Trailblazers, 2012).

One young person raised the issue of not wanting to attend a special residential school, as he had concerns about such placements including impact on his right to family life and being included in his local community. This issue is raised in more detail under Article 24 (education).

**Article 20: Personal mobility**

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities...

*Wheelchairs are given by the NHS but communication aids are not. Things need to be paid for privately.*

The young people told us about the importance of being able to communicate and socialise with others from 'outside their family'. They thought it was important to have equipment that suited their individual needs whatever the cost and to be able to choose the equipment that they felt best met their needs. They also wanted others to understand the purpose of their equipment. One young person said that it was not easy to get communication aids and they ended up going through a tribunal to get what they needed.



One young person felt forced to learn sign language and resisted because he thought it would limit his speech and language development support and because of the limited number of people using sign language.

Another issue raised was access to outdoor power chairs. These we seen as essential to support greater access to outdoor spaces and activities enabling greater mobility and independent living. One young person said:

*I can't go to music festivals or camping without an outdoor power chair.*

**Article 23: Right to family life**

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.

*Everyone deserves a family.*

There was a concern that some disabled children and young people were being 'moved around' the care system and that this was impacting on their right to a family life. However, one young person told us how important her foster mums had been.

One young person raised concerns about the use of residential special education and was concerned about the impact of living away from family and realising a right to a family life.

**Article 24: Education**

States Parties recognise the right of persons with disabilities to education. With a view to realising this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning...

*Teachers understand disabled young people more but they still need to listen more and get better training to support our needs.*

Children and young people raised a number of issues relating to their right to an education. These included:

- lack of subject choice
- accessing the right support to attend and achieve in mainstream education
- limited aspirations and expectations from teachers and children and young feel that they were not supported to achieve their potential
- accessibility of the school environment
- not being able to access life skills
- low expectations from teaching staff



- being taught separately in separate class
- paying for Personal Assistants and for additional support (not covered in disability allowances) so that young people can attend mainstream education.

Lack of choice and support were reoccurring themes raised throughout the session relating to education. They often felt unsupported to achieve and pursue academic qualifications and often had little autonomy of over subject choice when reaching GCSEs or A-levels. Achieving academically and being supported to reach full potential was also linked to ability to pursue further education and access meaningful employment.

This is backed up by data which shows that amongst working-age adults with a Level 3 qualification (equivalent to two A-levels) or higher, 14% of disabled people lack employment but want to work, while 6% of non-disabled people want work but lack work. The disparity between disabled and non-disabled people is more striking for those without a Level 3 qualification, with 26% of disabled people wanting but lacking work compared to 12% for non-disabled people. Achieving academically is one way of reducing the employment gap (Joseph Rowntree Foundation, 2014).

Children and young people told us about how important it was to have good teaching assistants that were properly trained and understood their needs. Some young people expressed that they had good support at college or university so that they could achieve academically and prepare for independent living.

One young person told us that he couldn't participate in science experiments during lesson time because it was considered too dangerous. However, the teacher let him stay after class to do experiments. He told us:

*I was grateful but still felt different to others and not included in the class.*

Other young people expressed concerns about what would happen after school or college. They felt they were moved from course to course with little thought of planning for the future. There was a particular concern around employment opportunities post-education. They thought that college did not give them enough support to access employment with one young person saying:

*It's hard to leave college because you don't know what to do.*

Other research shows that nearly one in four young people say that they have not had enough information to make choices for their future. However, this rises to just under a quarter of disabled young people (EHRC, 2011).

One young person told us she had good support with the academic side of university but no support with the social side. She wanted to join clubs but felt that the support to do so was not in place. One young person said that he had resisted going to a residential school as he didn't want to be taken away



from home and wanted to be included within his local school. He said he had met many young people growing up who just ‘disappeared’ when they got to a certain age and he didn’t want this to be him as well. The same young person said that his family funded his PA so he could attend mainstream education.

In addition, OCC’s own research found that children with a disability or SEN are eight times more likely to be excluded both informally and formally than their non-disabled peers (OCC, 2012). In addition, headteachers, advocacy groups and other stakeholders repeatedly told us about unlawful schools admissions activity. They claimed that a minority of schools used loopholes in the admissions system to ‘improve’ their intake, and reduce the number of children who had needs which it would be difficult and/or expensive for the school to accommodate (for example those with SEN, particularly at School Action or School Action Plus levels).

**Article 27: Work and Employment:** States Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

*There is not enough [paid employment] for disabled young people in my area. We want to work but can’t find a job.*

Some young people reported having good work experience opportunities and expressed how important and valuable these were. It was clear that the young people wanted to work and that they have ambitions. However, they were concerned about the barriers and consequences of not being able to work.

The majority of young people told us about the lack of accessible work experience opportunities and the lack of choice when it came to accessing work experience. Others described difficulties on accessing appropriate work. They thought that lack of employment opportunities generally made it harder for disabled young people as they face significant amount of competition.

They also thought that employers held negative attitudes and that they were often overlooked for positions they were qualified for. One young person said that if you could change one thing to make life better for disabled young people they would:

*...educate employers so they see our potential and understand that we are asset.*

Other young people talked about not receiving enough support from their college or school to access work or work experience. Young people reported feeling that their lives were not going anywhere and that their potential is being wasted.



These findings were echoed in a piece of research carried out in 2013 where young people reported difficulties accessing appropriate work, feeling pushed into work which felt unsafe, discriminatory attitudes, a shortage of training for staff and young people, and the need for more reasonable adjustments (Larkins et al, 2013).

**Article 28: Adequate standard of living and social protection**

States Parties recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.

OCC's work looking at child poverty and disability found accounts of families with disabled children who could not afford to heat their homes properly. In addition we found that some disabled young people living independently did not have enough food or were regularly missing meals, and there were accounts of a young person not having adequate clothing (Larkins et al 2013).

Children and young people also experienced financial disadvantage as a direct result of their higher living costs. This is because of the specialist support services and goods needed to meet the needs of the young people. Many suggested that benefit levels are inadequate and do not cover these costs (Ibid.).

The detrimental impact of exposure to poverty on the health and wellbeing of disabled children has recently been highlighted in the Annual Report of the Chief Medical Officer, *Our Children Deserve Better: Prevention Pays* (Department of Health, 2013).

**Article 30: Access to sport and culture**

States Parties recognise the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

- a. Enjoy access to cultural materials in accessible formats
- b. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats
- c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

*Youth clubs for disabled young people are limited and we don't have as many options as non-disabled young people.*



Children and young people thought that there should be more opportunities for disabled children and young people to access play and leisure facilities. They see it as important for integration and socialisation. Some young people talked about feeling excluded from mainstream play and leisure services. Another young person said:

*I want more clubs for disabled and non-disabled young people so we can play together.*

A survey published by the OCC (2013d) found that disabled children and young people rated access to sport and going on holiday more highly than non-disabled children and young people. This indicates that they face greater challenges in their access to recreation.

A report published by Ofsted (2013) echoed similar views to that of children and young people, who suggested that more needs to be done to ensure disabled young people can access youth work provision available in their locality.

Additional barriers to accessing play provision were raised by children and young people in another research project carried out by OCC. These included affordability, lack of transport and facilities that were inappropriate due to lack of changing facilities or trained staff (Larkins et al, 2013).

A recent study found that eight out of ten family carers said they do not have enough short breaks; four out of ten had never had a short break; and four out of ten felt their short breaks service had got worse in the last three years. Despite recent government investment of over £1.2 billion in short breaks provision, three out of ten councils closed the service in the last three years and over half have cut spending (Mencap, 2013).



## Conclusion and recommendations

This research highlights disabled children and young people's perspectives of the enjoyment of their rights. It highlights major obstacles and barriers which prevent disabled children and young people realising their rights as outlined in the UNCRPD. In order to understand these challenges the Government needs to increase its research with disabled children and young people to understand rights violations and what needs to change from the perspective of disabled children and young people.

Many important child rights issues were raised during this work. Through working with the young researchers to analyse the key themes we identified a number of issues which were raised consistently through the focused groups. These issues have been used as the basis for our recommendations.

### Recommendations

Many important child rights issues were raised during this work. Through working with the young researchers to analyse the key themes we identified a number of issues which were raised consistently through the focused groups. These issues have been used as the basis for our recommendations.

1. More needs to be done to tackle disability-related hate crime, victimisation and abuse. The current hate-crime strategy is not sufficient in breadth and depth to tackle the specific issues relating to disabled children and young people. We suggest that a specific national strategy led by the Minister for disabilities be produced which address issues related to understanding and provided information about hate crime and ensuring adequate reporting mechanisms and victim support is in place.
2. It is evident that children and young people do not feel they are receiving the right support in education to achieve their full potential. There should be greater training and support (beyond what is currently offered) for teachers in the form of mandatory teacher training which ensures that they have the skills and practical tools to deliver an incisive education.
3. A statutory requirement for all annual reviews for disabled young people with Education, Health and Care Plans or in receipt of SEN support from Year 9 onwards should have a strong focus on qualifications and the implications for future career aspirations. This should include a requirement for young disabled people to receive appropriate and relevant careers advice/guidance and assistance in brokering work experience placements. There should also be a duty for professionals to put in place the necessary support for young disabled people to access suitable work experience.





4. Disabled young people wanted additional support in accessing work and employment. Therefore the DfE should provide clear and more explicit guidance to schools on the following with a clear direction on how to meet the additional needs of disabled young people:
  - what constitutes a comprehensive careers guidance strategy
  - how to secure independent, external careers guidance
  - how to monitor the impact of this provision effectively.
5. To date there has been no government-led awareness-raising campaign focused specifically on changing general attitudes towards disabled children and young people. Despite numerous disability awareness-raising campaigns are outlined in the *Making it Happen Action Plan* (DWP, 2013) none are specifically intended to benefit disabled children. We would like the Minister for Disabled People to chair a cross-government group to coordinate and develop a strategy dedicated to changing public attitudes and reducing negative stereotypes which are still a barrier to disabled children and young people realising their rights.
6. In *We want to help people see things our way* (Larkins, 2013) we recommended that the Minister for Disabled People to chair a cross-government group to undertake an independent review of the adequacy of support for disabled children and young people. We reiterate this, and note that it should include an analysis of whether the welfare and benefit system is sufficient to provide for disabled children and young people's basic needs and accounts for the higher food, housing, heating, clothing, education, health and transport costs.

The Office of the Children's Commissioner will use the views of the children and young people who took part in this research in a number of different ways. They include:

- to inform and shape any submission we make to the UN Committee on the Rights of Persons with Disabilities (UNCPRD) as well as the UN Committee on the Rights of the Child (UNCRC)
- to inform and shape the Children's Commissioner's strategic priorities for 2015–18 and business plan for 2015–16
- to support current and continued work at the OCC.

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- to support current and continued work at the OCC.



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## Appendix A: Methodology

The aim of this research was to understand disabled children and young people's perspectives on the realisation of their rights in England in 2014.

Originally the research was intended to assist the pre-sessional working group of the UN Committee on the Rights of Persons with Disabilities (UNComRPD) in its forthcoming consideration of issues on which to examine the UK on its initial report to the UNComRPD. However, the date for this examination was postponed by over 12 months so we decided to present the findings in a report looking at the state of disabled children's rights in England in 2014.

### Our approach

We wanted to ensure that this work was informed and influenced by views and experiences of disabled children and young people. We therefore decided to appoint young disabled people as researchers. The aim was to help us to ensure that children and young people's views and voices were at the centre of the research process. It allowed the research questions, methodology, and recommendations to be driven by disabled young people.

This research therefore uses a methodology for participatory research, which involves young disabled people as the researchers and participants. The work was also supported by OCC's Participation team and underpinned by our Participation strategy and Safeguarding Policy.

Young disabled researchersThe Council for Disabled Children (CDC) and the Centre for Children and Families Applied Research (CCFAR) at Coventry University were commissioned to recruit and support four disabled young people to work in partnership with the OCC. Todd (CDC) and Franklin (Coventry University) had previously undertaken the VIPER participatory research study with a group of 16 disabled young researchers from across England.

These disabled young people had undertaken a three year research study examining disabled young people's participation in decisions about services. Four of the 16 young researchers applied to take part in this new study and work alongside the OCC. These young people had already undertaken training in research methods (research design, data collection, analysis), ethics, safeguarding and on the rights of children and disabled people. Their extensive experience of undertaking a research project, including developing policy recommendations, meant that they could deliver this project within a tight timeframe and draw upon their knowledge of research to work in equal partnership with the OCC.

Utilising and building upon the VIPER model of disabled children and young people's participation as co-researchers and partners in the research process (Franklin and Todd, 2014a) The Office of the Children's Commissioner, supported by CDC and CCFAR held two one-day workshops with the young



researchers to develop:

- an ethical and safeguarding framework for this work
- develop and agree the methods for working with other disabled children and young people
- identify the disabled children and young people who took part in this research

The young researchers also had session where they considered and examined the UNCRPD and the reporting process.

### **Recruitment of the research participants**

We worked with the young researchers to explore the demographics of the children and young people they thought should be included as research participants. They specifically requested that we should try and recruit:

- a wide age range (5-25 years)
- disabled children and young people from different ethnic backgrounds
- a good geographical spread including a mix of children and young people living in urban and rural areas
- children and young people with a range of disabilities and specifically communications needs.

All the children and young people we spoke to were being supported within the community. Those children living within institutional settings were not represented within this research due to the limited time and budget dedicated to this specific piece of work. However, OCC is carrying at a specific piece of research looking at the rights of disabled children and young people living within special residential schools

### **Designing and developing the resources and session plans for the focus groups**

During one of the workshops the young people explored the approach they would like to take with regards to the focus groups. The young researchers drew on their experience of undertaking focus groups from their previous VIPER research to consider the importance of ensuring the focus groups were accessible and engaging to all children and young people and highlighted that you would need to tailor each session to meet the needs of specific individuals. With this in mind they went on to suggest activities and that could be carried out with the different groups, and developed a flexible focus group framework which examined the rights prioritised but which could be adapted to meet the access needs of the groups they were consulting. They included ice breaker games, comfort breaks and a variety of activities to facilitate discussion.

Information about the project was also developed to send to the children and young people who might be interested in taking part in the research and who met the criteria for inclusion. The young researchers helped the OCC think



through the content of this and ensure it was presented in an accessible format. The young researchers had previously designed information sheets and consent forms and adapted these to meet the new research project.

The research focuses on exploring with the children and young people the realisation of rights outlined within the UNCRPD. The CRPD focuses on a broad set of rights relating to all disabled people. The young researchers decided they wanted to focus on certain rights outlined in the CRPDs that they felt were most relevant to disabled children and young people. The young researchers went through a process of reviewing the rights outlined in the CRPD and systematically prioritising the rights that they felt would have the most impact on disabled children and young people.

The young researchers were also conscious that they did not limit discussion by the choice of rights that they had made and so included a very open question to enable young people to raise issues pertinent to them.

After the reviewing process the following rights were identified as the most relevant to disabled children and young people's lives:

- Article 5: Equality and non-discrimination
- Article 7: Situation of children with disabilities
- Article 8: Awareness – raising of disability rights and disabled people in society
- Article 9: Accessibility and independence
- Article 16: Freedom from exploitation, violence and abuse
- Article 19: Living independently and being included in the community
- Article 20: Personal mobility
- Article 21: Freedom of expression and opinion, and access to information
- Article 24: Education
- Article 27: Work and employment
- Article 28: Adequate standard of living and social protection
- Article 30: Access to sport and culture.

However, during the analysis process Article 4 (general obligations) and Article 21 (family life) were added as children and young people raised rights issues relating to these articles.

We agreed that the sessions would be co-facilitated by a young researcher and Lisa Davis, Senior Policy Adviser for Rights and Equalities, from the Office of the Children's Commissioner. Therefore, each young researcher co-facilitated one focus group session each. The young researchers were supported by either Zara Todd from the Council for Disabled Children (CDC) or Anita Franklin from the Centre for Children and Families Applied Research (CCFAR). The OCC Participation team also supported the development and delivery of the sessions and capturing the data.

## **The research participants**



The focus groups took place with the four groups of young people outlined in the table below.

<b>Group</b>	<b>Location</b>	<b>Number of participants</b>	<b>Description of the group</b>
<b>Barnardo's: The Flying High Group</b>	North Yorkshire	6	A group of disabled young people, aged 16–25. They come from different areas across North Yorkshire.
<b>Barnardo's: Include me 2</b>	Preston	20	A group of children aged 5–11 from across Central Lancashire (West Lancashire, Preston, Chorley and South Ribble areas).
<b>Kids</b>	Bristol	6	The Kids group are young disabled people aged 16–24 all from the South West.
<b>The Alliance for Inclusive Education (ALLFIE): New Voice Group</b>	National	2	A group of young people aged 11–18 from across England.

The children and young people involved in the focus groups were aged between 5–24 years. Of the 34 children and young people who took part, 19 were female and 15 were male. All the children and young people we spoke to were being supported within the community.

### **Focus groups**

The focus groups were carried out over two to three hours. They generally consisted of time at the beginning for the session for staff and young researcher to meet and greet the research participants. We always started the session with an icebreaker and this was followed by three activities tailored to each group and aimed at examining a specific right. We generally had two breaks with refreshments and snacks to help keep energy and motivation high.

### **Analysing the data and developing recommendations**

The young researchers were then brought together to undertake a thematic analysis of the data using the rights as a framework. Data were reviewed under each right. And key findings identified before the young researchers started to think about specific recommendations for change.



The recommendations within the report are based on the young researcher's views.

### **Writing the report**

Lisa Davis, Senior Policy Adviser at the OCC took responsibility for writing the report based on how the young researchers had themed the data and their views on the recommendations. Lisa used information from other research carried out by OCC where it identified issues relating to disabled children and young people's rights. In addition, this was supplemented by external research where it supported issues raised during the focus group sessions.

### **Reviewing the final report and developing the children and young people's version.**

We held a final session with the young researchers to review the final report. This provided them with an opportunity to highlight any gaps in the researchers, ensure the key issues were raised in the executive summary and further shape the final set of recommendations. In addition, they provided clear steer and advice on accessible children and young people's version of the report.







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