

# “We want to help people see things our way”:

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A rights-based analysis of disabled children’s experience living with low income

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Please note the names of all of the children and young people featured in the report are pseudonyms.

## Foreword from the Children's Commissioner

That some children and young people in England live in poverty is, I hope, not disputed. What we are prepared to do about it, how badly it affects the rights of the children concerned, and whether anybody is listening to them, are subjects on which we agree rather less. But we should be under no illusion: children affected by the challenges of their families living with poverty are acutely aware what that poverty means for them. They have experiences to share, and opinions to express. And they have a right to be heard. It is from that right that our research, and this report, now spring.

The children whose research and recommendations are presented here are particularly affected by the impact of living in low income families and communities. Their families' struggles to make ends meet and yet still live, and provide their children with, a dignified life are compounded by the fact that some children also have a range of disabilities. These can limit what they can do in their lives generally, and basic things such as where they can go to school. Such challenges are considerable, even in families living in comfortable financial and social circumstances. For those living in poverty, they are profound, and can become insurmountable.

Our researchers worked innovatively to make the children working with them into co-researchers of what you will read in this important report. This publication is enhanced by the children whose lives feature in it, who were centrally involved in the research and the production of this report. The university academics who led this work on my behalf, bringing their evidence-based research skills and their background in the wealth of existing literature on poverty and childhood, have ensured the voices of the children sit at the core of the report. Their lives, and their words, ring out from this work, and rightly so.

What you will discover in the following pages is not an easy read. I make no excuses for that fact. I do not accept that for all our claims of civilised sophistication as a country, we still have families who, like that of one mum featured, will be in debt until 2022 or later because they are, quite simply, poor. This is a scandal.

As a nation, we continue to be either unwilling or unable to intervene in this issue in ways that bring such poverty to an end. It is not – it has never been – right that this continues.

This report continues to add my voice, and that of my office, to the urgings of so many organisations that policymakers do not just talk about poor families and wonder how to help them. We need action to end the national shame that is the continued existence of child poverty.

I am proud that the voices of children whose lives are directly and negatively affected by the issues you will find in this report speak so loudly to us all. With me, they present their obvious need, and their equally obvious call: that we act now to make it better and secure both their present, and their future.



**Dr Maggie Atkinson**  
**Children's Commissioner for England**  
**October 2013**

## About the Office of the Children's Commissioner

The Office of the Children's Commissioner (OCC) is a national organisation led by the Children's Commissioner for England, Dr Maggie Atkinson. The post of Children's Commissioner for England was established by the Children Act 2004. The United Nations Convention on the Rights of the Child (UNCRC) underpins and frames all of our work.

The Children's Commissioner has a duty to promote the views and interests of all children in England, in particular those whose voices are least likely to be heard, to the people who make decisions about their lives. She also has a duty to speak on behalf of all children in the UK on non-devolved issues which include immigration, for the whole of the UK, and youth justice, for England and Wales. One of the Children's Commissioner's key functions is encouraging organisations that provide services for children always to operate from the child's perspective.

Under the Children Act 2004 the Children's Commissioner is required both to publish what she finds from talking and listening to children and young people, and to draw national policymakers' and agencies' attention to the particular circumstances of a child or small group of children which should inform both policy and practice.

The Office of the Children's Commissioner has a statutory duty to highlight where we believe vulnerable children are not being treated appropriately in accordance with duties established under international and domestic legislation.

### **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.

# Executive summary

## Background

This research explores the impact that living in low income families has on disabled children and young people's rights, with the aim of:

- gaining a better understanding of disabled children and young people's experiences of living in low income families or neighbourhoods and how their material circumstances affect the realisation of their rights
- developing a framework for understanding the impact that living on low income has on disabled children's rights and the interaction between their rights and poverty
- conducting research in such a way that the participation of disabled children and young people is at the heart of the project's development, methodology and findings.

The report gathers evidence in relation to a number of rights 'themes' that include the basic things children need for living, health, education, work, mobility, family, money and benefits, and access to play, leisure and cultural experiences. In each area there are examples of disabled children not being given the ability or opportunity to enjoy their rights. Sometimes this is the result of a low of income, but not always.

There are also many examples highlighted in this report of disabled children receiving good care and services. These cases demonstrate how low income does not have to be a barrier to the fulfilment of rights. These examples of good services, care and support are the result of the hard work, dedication, commitment and skill of families, communities and professionals that can be found across the country and in every sector.

For each rights 'theme' the research has attempted to distinguish the direct impact low income has on disabled children's rights. This analysis, undertaken by adults and guided by children and young people, shows that while poverty does not have to be a barrier, it is a key explanatory factor in why some disabled children fail to have enough clothes or food, why some families cannot afford to heat their home, why some disabled young people do not have the same educational opportunities available to others, the lack of mobility and independence many disabled young people face and barriers to the healthcare they need. Interestingly, all the disabled young people who took part in the project expressed a strong desire to find work and have a career. While they identified many barriers to achieving this, low income was not considered one of them.

## The context of this report

It is a particularly important time to be undertaking this work given the context of rising levels of child poverty.<sup>1</sup> Disproportionate numbers of disabled children are living in poverty, and the impact of welfare, tax and public service reform has fallen disproportionately on families with disabled children compared to those without.

Recent analysis commissioned by the Office of the Children's Commissioner (OCC) demonstrates how child poverty numbers are likely to rise as a result of tax and welfare reforms by between

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<sup>1</sup> The Child Poverty Act sets out four definitions of child poverty. These are set out in the section 1 of the main report. The most commonly used definition of child poverty draws the poverty line at 60% of median household income before housing costs. For a couple with two children under 14 the poverty line (before housing costs) in 2012 was £384 per week.

300,000 and 700,000 in the five years up to 2015 (OCC, 2013). A disproportionate number of these children will be disabled (four in ten disabled children live in poverty compared to three in ten children in the general population) (Children's Society, 2011). Families with disabled children have also lost more of their household income compared to the average loss experienced by all families with children – a drop of 4.7% and 3.3% respectively of household income as a result of tax and welfare reforms between 2010 and 2015.

Given the current economic conditions, understanding more about the impact low income has on disabled children's rights and the inequalities and barriers disabled children living in poor families face is increasingly important.

## **A child rights based analysis**

OCC's remit states that it is to have particular regard for the UN Convention on the Rights of the Child and legislation currently passing through Parliament will change the Office's primary function to be one that protects and promotes children's rights. It is important, therefore, for the OCC to develop an understanding about disabled children living in low income through a human and child rights-based framework, and to better understand the relationship between rights and poverty.

However, this is not straightforward and this report represents one of the first attempts to do so from the perspective of disabled children. One of the complexities such an approach faces is how to bring together multiple international treaties that are applicable in the case of disabled children.

The United Nations Convention on the Rights of the Child (UNCRC) describes rights that all children under the age of 18 should enjoy, including the right to an adequate standard of living, health, education, safety, privacy, to have decisions made in their best interests, and to have a say in decisions that affect their lives and have these views taken seriously. Disabled children living in low income families or poverty are also protected by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

These treaties are not a set of hypothetical rights. As a signatory to each, the UK Government is obliged under international law to use the maximum extent of its available resources to fulfill all children's rights (Article 4, UNCRC). Subsequent statements and expansions have made it clear that even in the context of an economic crisis States are obliged to make sure that children – and particularly disadvantaged children – are "protected from the adverse effects of economic policies or financial downturns" (UN Committee on the Rights of the Child General Comment 5, 2008). In its last examination of the UK, the UN Committee on the Rights of the Child raised concerns about how disabled children "continue to face barriers in the enjoyment of their rights guaranteed by the Convention, including the right to access to health services, leisure and play" (UNCRC Concluding Observations to the UK Government, paragraph 52). This report examines whether this is still the case for those living in low income families.

## **Poverty and rights**

The issue of low income and poverty relate to disabled children's rights in two ways. First, there is an expectation that, where families or children cannot support themselves, the State will ensure they have an adequate standard of living (Article 27, UNCRC). This will be secured, in part, through the provision of benefits and welfare (Article 26, UNCRC). This means that the Government has a direct responsibility to tackle poverty.

Second, poverty impacts on how children and young people experience other rights such as education, health and personal safety. Less is known about this second aspect of how poverty and rights interact, and this is what this report seeks to explore in more detail. Yet in examining the relationship between low income and disabled children's rights this report also shows that there may be many other reasons why disabled children and young people are denied their rights. Rights may be violated because of discrimination, barriers to agency, poor social networks, a lack of information and advice or poor service provision. Money, or the lack of it, is not the only reason why some rights are breached, and where this is the case, it is clearly identified in text.

There are also many examples in this report where disabled children and young people receive positive support despite financial poverty. Disabled children are, in the majority of cases, well cared and provided for. It is important to note this because it is another demonstration of how poverty does not always lead to all other rights being breached. The report sets out the examples found in the research of families, communities and public services working to overcome the disadvantages that often accompany low income.

## **How we carried out this work**

Article 12 of the UNCRC states that children and young people have the right to have a say and have their views listened to and considered. This is a principle that is very important in the way OCC conducts its work, and is reflected in the way this report has been compiled. The work reflects good participation practice, especially in working with disabled children and young people. For this reason a detailed record of the methodology is recorded separately in Appendix 1.<sup>2</sup>

The team of researchers from the Centre for Children and Young People's Participation in Research at the University of Central Lancashire (UCLan) recruited and supported a steering group of 11 disabled children and young people who led the research. This young people's steering group was advised by an expert group of disabled children and an advisory group of adults. The research was facilitated by a team of adults from UCLan, who also conducted further interviews and focus groups with disabled children, young people and their parents, using research activities developed by the steering group. In total, 78 disabled children and young people and 17 parents participated.

## **Some key definitions**

### **Disabled children**

As this report takes a rights-based approach, we have used the definition of "disabled" used by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that defines disability as:

*"an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."*

This is a broad definition of disability and it is worth noting that the majority of disabled children, young people and young adults who took part in the research would also be considered disabled under the definition set out by the Equality Act 2010 (see details of steering group and expert group members below and in Appendix 1). The Equality Act 2010 states a person is disabled if he or she

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2 Appendix 1 is published separately and accessed at <http://www.childrenscommissioner.gov.uk/content/publications>



has a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities (Equality Act 2010, section 6).<sup>3</sup>

## Low income

This study does not claim that all the disabled children and families in this study live in poverty. It is not possible or appropriate to ask children or families directly about their income levels before inviting them to take part in research. We accessed all the participants for this research through 'gatekeepers' including service providers and parental support groups. These sometimes knew about family circumstances but not always, and almost never knew family income levels.

For interviews we therefore used factors that indicated a family may be likely to experience low-income, as observed in Department for Work and Pensions statistics (2012). These include being in receipt of welfare benefits (especially Job Seeker's Allowance and Housing Benefit); being workless; lone parents; with three or more children; from an ethnic minority (especially Pakistani or Bangladeshi); in social sector rented housing. We also selected local authority areas with the highest levels of child poverty, defined by relative income, and neighbourhoods, within these local authority areas, where low income affected more than 70% of the population and where there was also significant service deprivation (as indicated in Office of National Statistics 2011 neighbourhood statistics).

## How did we decide what we would look at?

The research focused on rights provided in three international human rights conventions:

- The United Nations Convention on the Rights of the Child (UNCRC)
- The International Covenant on Economic, Social and Cultural Rights (ICESCR)
- The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Our steering group of disabled young people discussed aspects of all three documents and the case studies provided by the expert group. From this, the disabled young people identified eight groups of rights that we call 'themes'. These are:

1. Basic things you need for living	2. Money, benefits and social support
3. Family life and alternative care	4. Education
5. Health	6. Mobility
7. Play, association, sport, leisure and cultural activities	8. Work

<sup>3</sup> For further detail see Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability (Office for Disability Issues) [www.odi.gov.uk/equalityact](http://www.odi.gov.uk/equalityact) accessed on 8 July 2013

As well as themes, the steering group (with advice from the adult advisory group) also identified a set of nine cross-cutting principles which should apply to all the themes and treaty documents. These principles are:

Survival and development	Nondiscrimination, equality of opportunity, reasonable adjustments	Best Interests
Respect, personhood, evolving capacity and independence	Participation, information and influence regarding decision-making	Inclusion in community and society
Adequacy, availability, accessibility	Personal assistance and support	Training

**The themes are the rights disabled children should enjoy.**

**The principles guide *how* their rights should be implemented and realised.**

The themes and principles do not cover every right listed in the three treaty documents looked at, but reflect those prioritised by the steering group. The young people on the steering group also prioritised those rights and principles that were likely to be most impacted by a family's income.

The steering group was also clear about the importance of considering both **what** rights their peers should enjoy – regardless of income – and **how** those rights should be implemented (i.e. to look at both themes and principles).

The report sets out a matrix of the eight themes and the nine principles listed above that underpin disabled children's rights. Where themes and principles intersect, the steering group helped the researchers describe what should happen in accessible language. For example, one of the applications of adequacy (principle) to rights concerning the basic things you need for living (theme) is "you have the right to good food that will help you grow and develop". Similarly, the principle of inclusion in community and society applied to the theme of 'money, benefits and social support' is described as "your family should get the money or help they need to give you support so you can live a dignified, self-reliant life and be fully included in your family and community."

The 'intersections' (or relationships) between rights and principles were used by the research team to analyse the experiences described by disabled children and young people, and their families. This approach provides a better understanding of what rights mean to disabled children and young people than simply listing a number of articles from each treaty document in child friendly language. It also exemplifies a more participative approach to research where the young people themselves play a leading role in directing the research.

## **Disabled children and young people's experience of their rights**

In each of the eight themes, we were given examples of good practice. However, in each theme there were also examples of rights not being respected and barriers to their realisation. Even though these barriers included discrimination, limitations on agency and poor service provision, low income also played a part in explaining the problems and challenges experienced by some disabled young people in all but the 'work' theme. Having a low income was not seen as a direct barrier to employment, although being workless or poorly paid could lead to being trapped into a life of low income.

The following is a summary of what the research identified under each theme.

## 1. Rights to the basic things you need for living

*"This house is so damp... when I'm out of here then they'll do it, they'll bulldozer it, condemn it ...I'm losing a hundred pound a week [with gas payments and heating debt being paid off on a pre-payment meter]...that's just to have it on morning and night for a bit of water."*

Parent

The three treaty documents used in this study state that disabled children have the right to the basic things they need for living. In child-friendly terms<sup>4</sup> this means:

- the right to enough food, clothes and heating
- the right to support to live independently
- the right to help make decisions about where they live
- the right to live in the community, near the people and places they know
- the right to the support and services they need to live in the community.

The qualitative research with disabled young people found positive accounts of local authorities meeting requirements to provide housing adaptations. Access to enough space and resources helped to bring about positive changes. For example, one young person created himself a new private space within his own home, to improve his relationship with his disabled sibling and his own emotional wellbeing.

However, there were accounts of some disabled children, young people and their parents not being able to heat their homes properly, afford adequate clothing and/or food. Some were not informed or involved in decisions about changes to where they lived; some experienced delays in adaptations being made to their homes and some did not have enough space nor support for independent living.

There were three accounts of young people not having enough food or regularly missing meals, with one young person not having eaten for two days at the time of being interviewed. There were two accounts of young people not having adequate clothing, although it was unclear from one account as to whether this was because there was a lack of money in the family, or because of problems in his relationship with his carer.

Where there were problems in gaining the basic things needed for living, this was usually the result of low income being compounded by inadequate provision of services, personal support or information.

Therefore, low income did play a part, together with other barriers and problems, in disabled children and young people failing to realise some basic rights. Some of these difficulties are common to other children and young people living in low income families.

From the research with disabled young people it was apparent that, in at least some cases, low income proved a barrier in realising six of the nine cross-cutting principles (a–i) noted above. Therefore disabled children and young people did not have the basic things need for living because of problems with adequacy (of provision); (a lack of their) best interests being prioritised; (lack of)

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<sup>4</sup> These rights are expressed in child friendly language, as directed by the young people's steering group, but they are based in explicit elements of the text of the three conventions and associated general comments. Details of the links between our wording and the provisions of the three conventions can be found in Table 2.1c and Appendix 2. The table is taken from Contact a family (2012) *Counting the Cost 2012: The financial reality for families with disabled children across the UK*.

personal assistance; inclusion (or discrimination); (lack of) participation; and an absence of respect for their personhood and capacity for independent living. This is described in greater detail in the main section of the report.

## 2. Rights to money, benefits and social support

*"I don't get a lot of money, although I do get DLA. Right now I've got no money for food."*

Young man aged 20

*"It's stressful on my mum. I really worry I'm a burden on the family... I'd just like to think maybe one day I could support myself entirely and live on my own."*

Young man, aged 18

Examining the experience of disabled children and young people in relation to children's rights under this theme, it was clear that families with disabled children experience financial disadvantage that is the direct result of their higher living costs. The families and young people interviewed described the additional costs they face because of the extra support or specialist goods and services needed to meet the needs of disabled children and young people. Many of those interviewed suggested that benefit levels are inadequate and do not cover these costs. There were also examples of where the benefit decision making processes was not individualised and failed to show sufficient flexibility to take account of individual circumstance and need. Others commented on benefit workers who do not understand certain impairments and the additional money required to support disabilities such as autism.

Evidence presented under this theme below highlights parents' concerns over the level of tax credits, welfare, and benefits they receive, and how worried they are about changes to the system. Many outlined how precarious some of the children and families' lives would be without benefits. Parents who had previously held good jobs and high status careers noted that giving up their job to care for their child had resulted in a significant loss of income. Other parents noted the stigma attached to claiming benefits, and difficulty re-entering the job market because of a lack of suitable childcare.

Accounting for all those interviewed, there were examples of all nine cross-cutting principles not being met, but again, not all these were the result of low-income. Rather, this theme highlighted: the need for a greater debate about the adequacy of social support and welfare for parents of disabled children and disabled young adults; the need for staff within the benefits system to be well trained and informed; and for young people to be helped to gain experience of exercising choice about money or benefits and opportunities to develop their independence.

## 3. Rights to family life and alternative care

*"He'll always stay with me... I always say to my daughter if anything happens to me and your dad, I says if you ever get married you take in Parviz. It is a worry, I mean you worry, there's no guarantee of life is there? Let's say my husband could get ill and then what? You know, who's going to take care of [my son]?"*

Parent

The experiences collected under this theme were largely positive with most children and young people interviewed feeling supported by their families. What helped was the time families could spend apart from one another, either to gain respite, or simply develop a sense of independence. Services

and support for this kind of provision seems increasingly difficult to access and both parents and children are worried about the possible implication for family life.

Some of the young people who took part in the research had experience of being in care themselves, or seeing a sibling in care. In these cases low income was significant because it affected disabled young people's ability to have contact with siblings who no longer lived with them.

In some cases it was difficult to differentiate from the young people's stories the barriers and challenges that related to low income and what was the result of service poverty. It was certainly the case that the quality of short break provision, and parental access to information about services, varied between different areas, and that this was sometimes related to the area's level of deprivation.

Those families with greater financial resources had the means to overcome some of the issues relating to accessing support services, and so this was the only cross-cutting principle that could be said to be related to low income. The principle of training, Best Interest and personal assistance were also inadequate for many disabled children and young people, but this was not because of low income, but rather inconsistent provision, resourcing, policy and consultation with families.

## 4. Rights to education

*"It clearly states on the statement she should be getting one-to-one support, but I don't see sound nor sight of it basically... she doesn't seem to be getting an awful lot at the moment... I think if, like say the one-to-one support was in place, if somebody spent a couple of hours reading with her, it would make the world of difference."*

Parent

*"Instead of doing a lesson, I go and see this teacher every lesson ... I don't want to get stressed again.... This teacher, she spoke to me in such a way, which I don't know what it is, I just feel that...I can sort of control it and not do it. Putting angry people in the unit wouldn't do a thing... just being told off doesn't do anything because obviously ...but she spoke to me in a way that helped me control it."*

Young person, aged 13

Disabled children, young people and their parents gave accounts of good practice with a number of examples of schools providing specialist support for disabled students. Yet it is also notable that where appropriate education provision was in place, it had often been won through persistent parental pressure.

Every member of our steering group talked about positive experiences and some good teachers. However, even where the general experience in school is good, it does not mean *everything* is good. For example, while one member of the steering group said school was good for 90% of the time, he also said that there were times when he and others felt unsafe.

A number of children and young people said they had experienced bullying and had feelings of anxiety and fear leading to a disrupted education. Evidence from the Anti-Bullying Alliance and work

on child poverty undertaken by the OCC suggest that children experiencing income poverty may be more vulnerable to bullying and less protected from it.<sup>5</sup>

While there were positive stories of local authority and school support, there were also cases of parents experiencing difficulties accessing appropriate and stimulating learning opportunities, families having to travel long distances to receive appropriate education services and insufficient personal assistance and support being provided in some areas.

There were examples where all nine cross-cutting principles were not fully protected and in two (survival and development and personal assistance), low income meant parents could not afford additional support to supplement state provision. While parents not on a low income also faced the same barriers, they could afford alternatives, or supplementary services that overcome these difficulties.

## 5. Rights to health

*“... they only allow you four (incontinence pads) a day anyway so, but like the hospital ones are rubbish like the ones that they give you, so like I buy Tena for Edward, because they are better, they're a better quality so... just to have a next size to change to a pad, you know, it's got to go to a panel meeting... they don't take into consideration the person's going to grow, ... it's just pathetic for some of the things really.”*

Parent

*“People should realise that [the child] is there. People talk down to people with disabilities, if it is mental or physical. It is like you are not there. Like you are invisible.”*

Young person

Disabled children, young people and parents described many instances of good and bad service provision. Many of the difficulties faced are real and have a significant impact on the lives of the disabled children and families interviewed, but it is also apparent that in a small number of cases the concern can be about the potential of what could happen. One such concern is over the transition to adult services, and the potential loss of access to specialist acute support and continuity of care from professionals who are familiar with the children and young people.

Other barriers to realising their right to health care include the distance some families have to travel to receive services. As good and sympathetic dental care is particularly hard to find, families often go to great lengths to find and then keep going to good dentists, or other health services where the professionals are good at understanding their child's needs. For those on low income this means not just lengthy, but sometimes costly journeys.

Others raised concerns about inadequate care, aids and personal support, and limited local service provision. At times this overlapped with difficulties that arise from rigid eligibility criteria or budgetary priorities. For example, in one case a young person prone to seizures was denied a warning alarm because it was not judged as an essential aid. Individual needs may not be identified quickly and as a result personal support, aids and services are not provided when they are needed. While this is not

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<sup>5</sup> The link between poverty and bullying was highlighted by young people during OCC's participation event that contributed to the Children's Commissioner's response to Measuring Poverty [http://www.childrenscommissioner.gov.uk/content/publications/content\\_658](http://www.childrenscommissioner.gov.uk/content/publications/content_658) [accessed on September 2013]. Research on disabled children and young people's experience of bullying and harassment available from the Anti-Bullying Alliance <http://www.anti-bullyingalliance.org.uk/research/sen-disabilities.aspx> [accessed on September 2013]

solely an issue of low income, parents said that they feel as if a lack of money limits their choices and ability to advocate on behalf of their children.

Low income also makes it harder for parents to meet the shortfall left by inadequate service provision. For example, in one case a parent told researchers that incontinence pads for disabled young people provided by the hospital were of poor quality and of insufficient number; consequently she had to either buy others herself or not change her child.

Other issues raised in relation to healthcare were the attitude and behaviour of staff and the impact this has on the information given to parents and children, and the extent to which disabled young people feel they are listened to and included in decision making.

As a result of the concerns raised, there were examples where six cross-cutting principles were not realised: respect; personhood and capacity; participation; inclusion; personal assistance; adequacy; and training. A lack of money played a role in each of these principles as low income significantly restricts the options parents have to overcome problems in these areas.

## 6. Rights to mobility

*"my main problems, most of its transport based."*

Parent

The lack of appropriate transport greatly reduces disabled children and young people's mobility and the range of activities and opportunities they can enjoy. It is not surprising therefore that transport and mobility was an important issue to many, and difficulties with insufficient personal assistance, inadequate equipment, feeling unsafe on public transport or struggling for independence, and inaccessible or unaffordable public transport were all raised by those interviewed.

These difficulties arise when there is insufficient information, advice and support. The experiences shared during the research suggest that there is an under-funding or lack of priority given to maintaining safe public spaces, transport and personal support that would enable disabled children and young people to feel a sense of independence and inclusion.

Low income is seen as a barrier to principles such as adequacy, personal assistance and inclusion.

## 7. Rights to play, association, sport, leisure and cultural activities

*"I mean we, there was a youth club round here, took him because they was saying how good it was but the room was like the size of this and there was like other children and he was in the wheelchair, so there was nowhere for him to move..."*

Parent

Many of the disabled children, young people and their parents felt very strongly about access to play and leisure opportunities. Often seen by others as non-essential, children and families who took part in the research saw play and leisure as very important forms of integration and socialisation that help children develop. There is a debate concerning what support should be given by statutory bodies for things like play opportunities and holidays for disabled children and young people. Nevertheless, there is little doubt from the accounts provided that disabled children and young people face many



more barriers to realising the same experiences and opportunities as other children and young people, and it is one area where low income clearly restricts their opportunities.

There were positive examples of services enabling inclusion in mainstream activities, or specialist activities in which disabled children took the lead in decision making. Yet there were also a number of challenges raised including not being able to afford leisure activities, transport barriers to inclusion in play, the lack of sustainable provision, facilities that were not appropriate or absent of personal support, and exclusion from mainstream provision.

The accounts provided by those interviewed suggested a lack of investment in play spaces and opportunities to meet disabled children's needs and rights. For example, one family noted a lack of physical spaces for changing or a shortage of appropriately trained staff on hand to help in a leisure service. Others noted that reasonable changes to ensure disabled children can play/meet with others/do sport/take part in activities have not been made in their local area.

Low income was a particular barrier to inclusion, personal assistance and adequacy of services in some cases. This was compounded by the cost of leisure activities and transport combined with a shortage of local provision. Principles of training, participation, equality and best interest also failed to be realised, but this was not seen as dependent on a family's or young person's income.

## 8. Rights to work

*"Everyone's equal. I think they should work. Everyone's all equal, so we should get a job."*

Young person

*"I tried so many jobs, like working in cafes or like working in youth clubs... and like people dishonour me... they say 'I know your reference is good... but the thing is we can't let you be here because you've got ADHD', then like, upsetting my disability."*

Young person

When asked their thoughts about working, some disabled young people described difficulty in accessing appropriate work or meaningful activities, feeling pushed into work which felt unsafe, discriminatory attitudes, shortages of training or education, and the need for more reasonable adjustments, supported opportunities and personal assistance to be made available.

It is clear from the interviews conducted that disabled young people are keen to work and have ambitions just like other young people (although some stated that they had never been asked about this before). However, they were concerned about the barriers they faced and the consequences of not being able to find a good job. Disabled young people are worried about living on low incomes and simply want to be given the opportunity to prove themselves in the world of work. This may mean workplaces need to be adapted or that there are opportunities provided for disabled young people to gain training and work experience. Those interviewed were concerned that these opportunities are simply not available.

While low income may play a part in some of the cross cutting principles not being realised, the research did not make this link. The principles of training, survival and development, equality, best interest and respect, personhood and capacity were each flagged as a concern by the evidence, but these barriers were faced by all disabled young people, irrespective of income.



## What the young people's steering would like to see change

Having played a central role in developing and conducting the research the steering group of disabled young people wanted to use the information they had studied to suggest a number changes that they feel could improve the realisation of disabled children's rights, especially those living on low incomes. The OCC feel that it is important to present these in full, and demonstrate that they have played an important role in developing our own final recommendations below.

The steering group proposed:

1. Changes to the benefit, welfare and social support system
  - a. Set budgets that give greater priority to ensuring that disabled children and young people have the basic things they need for living.
  - b. Ensure plans for social security reform and benefit levels are set through listening and giving due weight to the views of disabled children and young people and their families.
  - c. Put on hold the piloting of Personal Independent Payments (PIP) until a thorough review has been undertaken of its potential impact. They should listen to the ideas of more people with different disabilities, to learn from them first about how much they need for living and what would happen if they were in receipt of PIP.
2. Improved provision, appropriateness and timeliness of services
  - a. Enable everyone to have access to specialist education services across the country, to ensure all disabled children are able to reach their full potential.
  - b. Ensure there is enough high-quality, short-break provision to meet the need for disabled children to have a break away from their families.
  - c. Ensure speedy compliance with adaptations to housing. Adopt mechanisms for monitoring and comparing speed and level of provision of adaptations between different local authorities so that standards can be raised in those authorities where there are unreasonable delays.
  - d. Provide more free youth clubs and play, leisure, sport and cultural activities for disabled children.
3. Better support, advice and training for disabled children, young people, their families, and those working with them
  - a. Give children and young people more access to personal assistance to support them to do the things they want to do and help them be more independent. Personal assistance should be free and provided by organisations such as local authorities.
  - b. Ensure enough of the right kind of training is provided to teachers, doctors and youth club staff about the rights of disabled children and young people.
  - c. Ensure young people can access personal assistants to help them realise their rights to independence. Personal assistants should be trained in lifting and handling to enable mobility and the focus of their support must be to enable children and young people's inclusion and independence.

## **Recommendations from the Office of the Children's Commissioner**

### **Recommendations for the Government**

1. Undertake an independent review of the adequacy of support for disabled children and young people. This should include:
  - a. 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 faced by families with disabled children.
  - b. The adequacy of education, health and transport services, in terms of amount of provision; costs of accessing these services/cost at the point of delivery; and quality of service provided.

If the Government accepts the Equality and Human Rights Commission's recommendation to establish a new strategic advisory group on disability, this work could be carried out by this new body.

2. Departments with responsibility for welfare reform and child poverty should ensure that disabled children and young people and their families are directly involved in decisions relating to welfare reform and development of future child poverty strategies. Their views should be listened to and taken into account.
3. Publish clear, accurate and reliable information about rights and service provision for disabled children and young people. Information and advice about benefits, funding for specialist equipment and accessible activities is a priority.
4. Ensure greater awareness of disabled children's rights across government departments and encourage the same awareness in local services and statutory bodies through training and inspection systems that understand the importance of realising disabled children's rights. An awareness of children's rights must include appreciation of their personhood and evolving capacity and ambitions, and necessitates the development of appropriate communication skills.

### **Recommendations for local authorities**

5. Local government should audit existing provision to identify needs and gaps in accessible youth provision including play, leisure, sport and cultural activities for disabled children and young people and publish its plans as to how these services will be provided and sustained. Services used by disabled children and young people must have adequate and respectful facilities to meet their needs (for example toilet and changing facilities), and be run by staff who are well-trained and informed about working with disabled children and young people.
6. Local government should ensure that all disabled young people can access local short-break provision. This provision is key to enabling disabled children's and young people's rights to independence away from the family and access to play and leisure.
7. Local government must provide disabled children and young people living in low income families with the means to access play, sport, leisure and cultural opportunities in their local community. This may include, but is not restricted to, improved transport services (particularly in rural communities).

# 1. Introduction

This research was carried out for the Office of the Children's Commissioner by the Centre for Children and Young People's Participation in Research at the University of Central Lancashire. It presents a picture of the impact of low income on disabled children's and young people's rights.<sup>6</sup>

The study involved 78 children and young people and 17 parents in the following ways:

- an **expert group** (32 disabled children who had relatively severe impairments<sup>7</sup>)
- a **steering group** (11 children and young people who had some experience of participatory group work and most of who had autistic spectrum disorders or who were visually impaired)
- interviews with 19 disabled children and/or their families and three **consultation groups** (in both we particularly sought experiences in a low income).

The study was conducted across seven local authorities and boroughs in the northwest of England, the West Midlands and London.

The expert and steering groups decided on the themes we explored and have contributed substantially to the analysis of the findings. Their ideas were shared with members of an adult advisory group who responded with suggestions and encouragement. The research therefore illustrates a methodology for participatory research which has been co-created through dialogue and action by disabled children and young people. This methodology could, with little additional work, be adapted to explore the impact of low income on the rights of other children and young people. It also shows an approach to designing child-centred co-constructed research inquiries on other subjects. More details about the methodology for this research can be found in Appendix 1.

As international human rights conventions play such a key role in this research, extracts of the relevant aspects of these which we draw on in the main body of the report are detailed in Appendix 2.<sup>8</sup>

In this section we outline:

- why we carried out the research
- definitions, incidence and impact of low income on disabled children
- an overview of the methodology and research participants.

Section two details the framework of our analysis as a matrix of rights.<sup>9</sup>

Section three outlines the findings and is organised into eight themes – or groups – of rights that were our primary focus. These groups or themes are the basic things disabled children and young people

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6 Throughout this report we will use the term "impact of low income on disabled children's rights" to express what the evidence collected from disabled children, young people and their families showed to be the impact of low income on disabled children's rights as defined in relevant UN Conventions that have then been interpreted by the steering group.

7 This included children who were described as having one or more of the following impairments: autistic spectrum disorders, moderate or profound learning disabilities, speech, language and communications needs, severe physical disabilities, significant health care needs, visual or hearing impairments, spina bifida, or Down's Syndrome.

8 Appendix 2 is published separately and is available at [www.childrenscommissioner.gsi.gov.uk/publications](http://www.childrenscommissioner.gsi.gov.uk/publications).

9 The matrix of rights is also available separately at [www.childrenscommissioner.gsi.gov.uk](http://www.childrenscommissioner.gsi.gov.uk).

need for living; money, benefits and social support; family life and alternative care; education; health; mobility; play, association, sport, leisure and cultural activities; and work.

Each of the eight themes contain an illustrative story, evidence of issues disabled children, young people and families identified under that theme (including good practice where this was observed), and an analysis of where key principles in children's rights were breached (that is how the theme was or was not realised) and a summary of what was the result of low income (and what was the result or other factors).

Section four details the steering group's calls for action and our recommendations.

## **1.1 Why we did the research**

This report represents an important project in the overall work of the OCC, and the issues relating to low income, disabled children and their rights are particularly important to examine at this time because:

1. Disabled children are more likely to live in poverty and low income families, and with the predicted increase in the numbers of children living in poverty it is important to understand more about how this may impact their rights.
2. In its last report to the UK in 2008 the UN Committee on the Rights of the Child raised concerns about:
  - a. a lack of comprehensive national strategy for the inclusion of children with disabilities into society
  - b. the barriers children with disabilities continue to face in the enjoyment of their rights, as guaranteed by the convention. The Committee were particularly concerned about the right to access health services, leisure and play facilities.

While there have been some measures put in place aimed at improving the protection of services for disabled children, the UK Commissioner's 2011 mid-term report noted that "co-ordinated progress has been limited" and "serious concerns remain about the implementation of the limited plans that exist".

3. The lack of other in-depth, child-centred qualitative work which shows how low income impacts life for disabled children in real families (Ridge, 2011).
4. It is important to ensure that any policy reforms and change to the provision of public services result in progressive realisation of disabled children's rights, rather than retrogression. It is not clear how recent reforms and funding changes have impacted disabled children and young people.

## **1.2 Definitions, incidence and impact of low income on disabled children**

Three key terms are used in this report – disability, low income and rights. There are many definitions of each, and how these terms are defined can have a significant influence on the conclusion this report draws from the evidence findings noted below. It is therefore important to set out clearly how we define each term. This section also notes the research on the impact

that poverty and low income has on children and young people's lives and outcomes and the additional financial pressures on disabled children and their families.

### 1.2.1 Definitions of disability and low income

#### Disability

As this report takes a rights-based approach, we have used the definition of "disabled" used by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that defines disability as:

*"an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."*

This is a broad definition of disability and it is worth noting that the majority of disabled children, young people and young adults who took part in the research would also be considered disabled under the definition set out by the Equality Act 2010 (see details of steering group and expert group members below and in Appendix 1). The Equality Act 2010 states a person is disabled if he or she has a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities (Equality Act 2010, section 6 (1)).

#### Low income and poverty

This report often refers to 'low income'. Low income includes families living in poverty and indeed the impact of poverty is the main focus of report. However, for methodological reasons set out in section 1.3 below the researchers were not always able to guarantee that participants met the official definition of living in poverty.

The Child Poverty Act 2010 sets out the clearest agreed definitions of poverty, setting out four different ways of measuring the financial welfare of families and individuals. These are set out in Box 1 below.

#### **Child poverty measures as set out in the Child Poverty Act 2010 and Child Poverty Strategy**

**Relative poverty.** Children living in households where income is less than 60 per cent of median household income before housing costs (BHC) for the financial year. Relative poverty after housing costs (AHC) is also monitored.

**Combined low income and material deprivation.** Children who experience material deprivation (judged against a set of measures established by government regulation) and who live in households where income is less than 70 per cent of median household income BHC for the financial year.

**Absolute poverty.** This relates to whether the poorest families are seeing their income rise in real terms.

**Severe low income and material deprivation (as set out in the Government's child poverty strategy).** Children who experience material deprivation and live in households where income is less than 50 per cent of median household income BHC for the financial year. This is also referred to as severe child poverty, however it should be noted that definitions of severe poverty vary according to, for example, what index of material deprivation is being used.

The fact that the Child Poverty Act and Strategy need multiple definitions is an indicator that no one definition alone provides a comprehensive and universally accepted standard. For example, relative low income is an important indicator, but it does not pretend to tell the whole story as it may or may not indicate a family or individual's ability to buy basic goods or access essential services. Conversely absolute measures risk disenfranchising individuals from the communities they live in and the opportunities others can realise.

In the context of this report low income is primarily identified with poverty, first in terms of the relative poverty measure and second in the wider context of the other four measures described in the box above. We do not use the term poverty, but rather use the phrase low income only to ensure accuracy in how we explain the situation of the children, young people and families that took part in this research. Section 1.3 below sets out why some of those who took part may not necessarily meet the requirements of the definitions above, but still remain close to any given poverty line.

## Rights

The definition of disabled children's rights is derived from three UN documents listed and described in section 2.1 below. When the report refers to 'rights' it does not mean every human right applicable to disabled children and young people, but rather the 'key rights' as identified by the project steering group and informed by the advisory group. The rights are set out in detail in section 2 and Appendix 2.

### **1.2.2 Incidence and impact of low income on disabled children**

#### Incidence and prevalence

Prevalence figures for children living with disability are difficult to determine, since they vary depending on the definitions and measures used. Recent research suggests that there may be 800,000 disabled children in the UK; this is over 30,000 more than previously estimated (The Children's Society, 2011). This research also suggests that four in every 10 of these children live in poverty, and around 110,000 may experience severe poverty.

While existing figures published by the Department for Work and Pensions (DWP) in 2013 identify a smaller number than those quoted by the Children's Society (DWP, 2013) they do affirm that disabled children and young people are more likely to be living in poverty (as defined by the four measures in the Child Poverty Act 2010). For example, almost one in three children live in a low income household that has a disabled child (60% of median income after housing costs). This figure is around 20% higher than the equivalent proportion for all children. Similarly the number of children and young people living in households with at least one disabled child and experiencing [low income and material deprivation] is 25% and 33% higher respectively than the average population (DWP, 2013).

The DWP figures are limited in relation to disabled children and their families because they do not account for the additional costs faced by families who have to meet the needs of their disabled children. However, even with these limitations the Government's figures confirm other longitudinal research with young people in England, which shows that disabled children are more likely to experience poverty than their peers (Emerson, 2012). Furthermore latest research suggests that levels of child poverty are set to rise until at least 2020 following decreasing numbers of children living in poverty between 2007 and 2012 (Browne et al, 2013).

## Impact

The incidence and rising numbers of disabled children living in poverty is a concern because of its pervasive impact on their lives (Ridge 2002, 2007, 2009, 2011). Studies show disabled children are at particular risk from many disadvantages associated with poverty, including:

- personal disadvantage and reduced participation in social and educational activities (Houtrow et al, 2012)
- increased risk of poorer health (Emerson et al, 2007)
- lack of leisure, play and holidays (Contact a Family, 2012)
- difficulty in getting to suitable play, leisure and recreational activities, and excessive cost of appropriate facilities (Sharma, 2002: 25)
- rate of renting homes by families with a disabled child (Beresford and Rhodes, 2008)
- more likely than other families to live in overcrowded accommodation (Ibid.)
- living in poor or unsuitable housing can have a negative impact on disabled children in terms of their physical and cognitive development, and opportunities to enjoy everyday childhood activities such as play, physical health and emotional wellbeing
- living in a poor area carries an additional weight of disadvantage. Wheeler et al (2005) have used census data to demonstrate a continuing "inverse care law" (Tudor Hart, 1971) whereby poor communities have the least access to essential life chances and resources.

The impact of poverty on disabled children is thought to be broadly consistent regardless of the specific nature of the disability, as children with intellectual disabilities (Hatton and Emerson, 2009) and children with complex health care needs (Houtrow et al, 2012) being identified as facing similar disadvantages.

This body of research provides a significant rationale for looking at a broad range of rights that every disabled child and young person should enjoy, and demonstrates both how and why the realisation of these rights is fundamental in realising better outcomes.

### **1.2.3 The additional cost of living with a disability**

Research published in 2012 (Contact a Family, 2012) highlighted the additional costs faced by families with disabled children.

For example, a five year old with a physical disability may require pull-up nappies and wipes that cost around £60 per month. A similar child without the same disability does not need these, representing a saving for the child's family. A special adapted child seat for a disabled eight year old cost around £600 compared to £150 or less for a non-adapted seat bought from the high street. Similarly families whose children can use regular keyboards and a computer mouse save over £300 that it costs to buy similar specialist equipment for some disabled children.

As Magadi and Middleton (2007: 20) note, "a different measure of child poverty that took account of the additional costs that are associated with... disability would be likely to show much higher rates of severe child poverty in such households." Yet this project was not able to undertake the work necessary to bring existing poverty measures together with a comprehensive assessment of the additional costs incurred by families with disabled children. Nevertheless the financial pressure these costs place on families can have a significant impact on what rights disabled children can enjoy.



## Case study: Olivia's story

Olivia, aged eight, has a diagnosis of Down Syndrome, dyspraxia and poor muscle tone; she is very active and some of the professionals who are involved with her and her family think she may have ADHD. She lives with her mother, father and one brother. Olivia gets DLA (higher rate) and her family have a Motability vehicle. Her father works but they still have a low income. Olivia wears special boots and has a buggy to help with her mobility. Olivia loves looking at books with people but she can get very cross if she does not have your undivided attention. Olivia likes to have her feet and legs stroked; usually this has a calming effect on her. She likes to go to the local chip shop with her mum to choose her tea – sausage and chips are her favourite. She also likes sensory rooms and going to a voluntary organisation group.

Some of the extra costs Olivia's parents described include:

1. **Lots of hospital and clinic appointments** – these take up a great deal of Olivia's Mum's time meaning she can no longer get paid work. Also because they are not coordinated. The family have to deal with multiple professionals who are located all over the region. This involves a lot of costly travel. Olivia finds being medically examined very difficult so she has to be anaesthetized for things such as tests and investigations and dental appointments. Her parents have to stay with her whenever she is admitted to hospital
2. **Communication aids** – it costs in excess of £75 for a single communication application (such as My IPad Choice), without the add-ons. She uses a similar aid at her special school but cannot bring this home. Olivia communicates using some words but her speech is indistinct and can be hard to understand. She has been taught to use Sign-A-Long but even with this sometimes it is hard for new people to understand her signs as she likes to make them up for herself. She also needs special signing books (£20 each)
3. **Childcare is more expensive** – Olivia wasn't able to go to nursery her brother attends because she could not get the funding for the necessary support and without this no private nurseries in the area were prepared to consider her
4. **Adaptations to housing** – funding for an adapted bathroom helped, but did not cover the full cost
5. **Mobility vehicle and aids** – they had to contribute to cover the cost of a car with sliding doors, special needs car seats, and harnesses. Just one harness is about £80
6. **Personal assistance** – in the school holiday Olivia and her family receive only seven hours direct payments funding to enable her to access a play scheme for disabled children. As Olivia is so active, and because her behaviour can be very unpredictable, her Mum has to employ someone to be with Olivia on a 1 to 1 basis in order to access social activities. The family fund a "babysitter" themselves
7. **Incontinence pads** – Olivia uses pads as she is doubly incontinent. The family are forced buy additional pads. Olivia is only allowed four per day and very often these are used up just at school. They cost £12 a pack
8. **Holiday** – "if we wanted [and could afford to] to go on holiday it would cost us a lot more ... we'd have to look at somewhere more specialist, and somewhere that would cater for her needs... and, you know, somewhere more specific, it does cost a lot more."
9. **Educational Assessment** – Olivia does have speech and language therapy but it was a battle for the family to get it included in her statement. Her family felt forced to commission a private assessment of her communication needs to get this
10. **A bike** – Olivia has a specially adapted three-wheel bike which she likes to use – her Mum and dad bought this for her because they said getting the funding was difficult. This cost is repeated every few years as Olivia grows.



## **1.3 An overview of the methodology and research participants**

The aim of the research is to look at the impact of low income on the realisation of disabled children's rights. Due to the centrality of children's rights we adopt what is known as a rights-based approach to undertaking this research. This approach is outlined in Appendix 2, exploring the impact of low income on disabled children's rights. This appendix is an important document for advocates of children and disabled people's rights.

A child rights based approach (CRBA) starts from a commitment to achieving the rights and guiding principles of the relevant UN conventions; it informs children about their rights; it learns from children about infringements of their rights; it identifies barriers and mechanisms for giving greater effect to rights and it targets action to strengthen and monitor progress towards this.

The research team and an adult advisory group were involved throughout the project, but the young people's steering group made most of the key decisions.

A detailed description of this process can be found in Appendix 1, and is an example of how article 12 of the UNCRC and children's participation rights can be applied to complex research questions and methodology.

### **1.3.1 Participants**

The children and young people involved in the project were all aged between four and 24 years old. Of the 78 young people who took part, 63% were male, 37% were female, 88% were white, 10% were Asian (including Bangladeshi and Indian) and 2% were African. The 11 members of the steering group were aged 12–18 at the start of the research, seven were male and four female. Eight steering group members continue to regularly attend meetings, even though the project lasted for several months longer than initially planned.

It is not possible or appropriate to ask children or families directly about their income levels before inviting them to participate in research. For interviews, we used factors that indicated a family may be likely to experience low income (ONS, 2011; DWP, 2012). These included being in receipt of welfare benefits; being workless; being a lone parent; having three or more children; being an ethnic minority (especially Pakistani or Bangladeshi); having children under three; living in social sector rented housing.

We asked gatekeepers to identify families where one or more of these indicators were present as well as there being a disabled member of the family (which itself is another indicator). For consultation groups, we sought participation from groups in regions where there were the highest levels of child poverty, defined by the relative income measure. Within these regions, we sought groups in neighbourhoods where more than 70% of the population had a low income, and where there was also significant service deprivation.

Therefore, while there is a high correlation between these 'low income' indicators and poverty we are not able to guarantee that all those who took part were 'poor' (as defined by the Child Poverty Act), but can say that they meet DWP's criteria for measuring low income.

To enable the participation of all the children and young people involved in this research, we employed a range of creative, play (Carter and Ford, 2012) and digital media based activities (Haw 2008). Full details of the methods employed are given in Appendix 1.

## 2. The Framework: Key rights and principles for disabled children living in low incomes families

While recognising that all rights are indivisible and interdependent, we could not focus on all rights within the three key conventions applicable to this report (see 2.1 below) within the limited resources of this research project. Therefore, we selected which rights to focus on through a dialogue between the children and young people in the steering and expert groups and the adults on the advisory group. This discussion was informed by two objectives:

- to explore with disabled children the rights important to them
- to focus on social economic and cultural rights, unless children told us otherwise.

Through this process we identified the most relevant rights in relation to the issue in focus – that is the impact of low income on children’s rights, in particular the economic, social and cultural rights (ESCR) of disabled children – and then grouped these rights into ‘themes’. The children and young people also decided to focus on cross-cutting principles that cut across all three conventions and described how their rights should be implemented and achieved.

This chapter describes the process by which those rights themes and principles were identified, and outlines the matrix for exploring the ways in which rights and the cross-cutting principles intersect. The obligations imposed by the different treaties are then summarised, with a particular focus on the duty of State Parties to progressively realise children’s rights to the maximum extent of available resources. This is done so that it is clear what the State’s responsibility is in relation to the individual, family and community.

### 2.1 Key rights and principles

All rights have an economic and social component, as they are dependent on resources and human social environments for their achievement. The rights that we took as a starting point for our research were drawn from three international conventions.

- **United Nations Convention on the Rights of the Child (UNCRC)** – this key instrument under international human rights law on the rights of children was ratified by the UK in 1991 and is the starting point for the work of the Office of the Children’s Commissioner.
- **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** – the key instrument under international human rights law on rights of disabled persons, ratified by the UK in 2009.
- **International Covenant on Economic Social and Cultural Rights (ICESCR)** – the key economic, social and cultural rights (ESCR) instrument under international human rights law, signed by the UK in 1968 then ratified in 1976.

Time was given to the children and young people on the steering group to understand and become familiar with the provisions and intentions contained in each of the three conventions listed above. And the researchers also worked backwards from important concerns that the steering and expert groups identified to explore which rights were relevant to these issues. From this process it was apparent that there are two ways of looking at disabled children’s rights. The first is to group the

articles across the three conventions into themes that describe what kinds of rights children should experience. Another way of looking at the conventions is to recognise that there are cross-cutting principles that describe how rights should be put into effect.

Appendix 2 describes in detail the process of identifying the themes and principles that form the framework for analysing the impact of low income on disabled children's rights in third report. This process drew upon research with the experts group and the advice of the advisory group.

The result of this process was that the steering group identified nine cross-cutting principles from the three conventions named above and the eight rights themes.

### 2.1.1 Rights themes and cross-cutting principles

The nine cross-cutting principles. These are listed in Table 2.1a.

<b>Table 2.1a: Cross-cutting principles</b>			
<b>Cross-cutting principles</b>	<b>UNCRC Articles</b>	<b>ICESCR Articles</b>	<b>UNCRPD Articles</b>
Progressive realisation, to the maximum extent of available resources, avoiding impermissible retrogressive measures	4	2, 4	4.2
Survival and development	6, 23.1		3h, 10
Non-discrimination, equality of opportunity, reasonable adjustments	2	2.2	2, 5, 3b, 3e, 3g,
Best Interests	3, 19, GC 12		7.2, 12, 16
Respect, personhood, evolving capacity and independence	1, 5, GC 12	Preamble	3a, 3d, 3h, 12
Participation, information and influence regarding decision making	12, 13, 14, 17, GC 12		3a, 4.3, 7.3, 21, 29, 33.3
Inclusion in community and society	GC 9		3c, 19, 26.1
Personal assistance and support	23.2, GC 9		12.3, 26 (also in 19, 20, 24)
Adequacy, availability, accessibility	23.3, GC 9		3f, 4, 9
Training	GC9		4(i), 28.2(c)

Each of these principles intertwines with others at any moment. For example, Best Interests cannot be determined without consideration of children's wishes, their rights to survival and inclusion and respect for their personhood and capacity. Nevertheless both steering and advisory groups agreed that these nine principles form a comprehensive means of analysing how disabled children's rights should be implemented.

The steering group also agreed the rights themes we would focus on. They did this by reflecting on what was important to them and what they thought was important to other disabled children in the expert group. From this work the young people identified eight themes – groups of articles that broadly represented the same broad entitlement. These themes describe what rights every disabled child should be able to enjoy and are described in Table 2.1b below.

<b>Table 2.1b: Rights themes</b>			
<b>Rights themes</b>	<b>UNCRC Articles</b>	<b>ICESCR Articles</b>	<b>UNCRPD Articles</b>
Care and assistance for disabled children	23		7.1
Basic things you need for living (adequate standard of living)	27	11	28
Money, benefits and social support (including social security)	26	9, GC 19	28
Family life and alternative care	9, 18, 20	10.1	18.2, 23
Education	28, 29	6.2, 13b	24, 30.2
Health	24	12, GC 14	25
Mobility	GC 9		20
Play, association, sport, leisure and cultural activities	15, 30, 31	15.1a	30
Work	32	6, 7	27

This is not an exhaustive list of rights and provisions (as this would require restating every article and paragraph of the conventions and general comments). Rather, it represents principles and rights themes as identified by members of the expert, steering and advisory groups.

### **2.1.2 Understanding the research matrix**

Using these key themes and cross-cutting principles, the research team reflected on the priorities identified by the experts and steering group, and then drafted a matrix to represent how these related to details of the chosen rights themes and key principles. The steering group then worked on the draft of this matrix to ensure extra rights claims were included if needed and that it was written in child-friendly language (Table 2c). For instance, the words ‘reasonable adjustments’ were change to ‘reasonable changes’. It should be noted however, that some members of the steering group preferred the complete legal texts rather than these summaries and wanted to avoid over simplification.

The advantage of this approach over other ‘child-friendly’ versions of the UNCRC is that rather than simplifying the rights, sometimes to the point of gross inaccuracy, this provides a framework for exploring the complexity of intersecting rights and principles as they are reflected in children and young people’s lives.

The matrix detailed in Table 2.1c is coded as follows:

The text in **bold** has an explicit basis in the three conventions and the associated General Comments.

The text in *italics* represents claims to rights, made by children and young people in the expert and steering groups. These reflect implicit meanings of key principles or how these might be interpreted in the lives of disabled children and young people within the rights themes we focus on.

The text in **bold italics** therefore shows where rights claims by the young people overlapped directly with explicit rights provisions in the conventions or General Comments.

## 2.2 Progressive realisation of the Conventions

It is important to place the matrix set out in Table 2c in the context of the three conventions that it is based on and the duty placed by the UN on States Parties to respect, protect and fulfil the enjoyment of all rights. That means that it is ultimately the Government's responsibility to ensure that the rights outlined in Table 2c are enjoyed by every disabled child and young person regardless of their income.

As our concern is low income, we focus in particular on the obligation of States to progressively realise ESCR, to the maximum extent of available resources. This is expressed for example, in Article 4 of the UNCRC. Article 4 states:

*"States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation."*

The Office of the Children's Commissioner has recently published further advice and analysis of the Government's responsibility in this regard in *An Adequate Standard of Living* (Office of the Children's Commissioner, 2012). This report has also been guided by the work of Aoife Nolan (2011;2013).

Government may not be the initial agent responsible for every right that an individual should enjoy. They are however, accountable for the realisation of an individual's rights. Therefore, while the analysis based on the matrix in Table 2c challenges the actions and barriers that may be the responsibility of families, communities and local services, Government must consider what it can and should do to address these matters.

**Table 2.1c: The matrix: Intersecting principles and rights themes**

<i>Intersecting Principles and Rights Themes – General statement of the principle</i>					
<b>A</b>	<b>Survival and Development</b>	<b>Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination</b>	<b>Best Interests</b>	<b>Respect, Personhood and Evolving Capacity, Independence</b>	<b>Training</b>
	<ul style="list-style-type: none"> <li>- You have the right to life, survival and development.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be treated fairly.</li> </ul>	<ul style="list-style-type: none"> <li>- All actions should be taken by thinking about what is best for your wellbeing and by taking account of your wishes.</li> <li>- To feel safe, not distressed and understood.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be treated with respect and dignity.</li> <li>- You have the right to be encouraged to develop independence.</li> <li>- To have praise and encouragement.</li> <li>- To have privacy and your own space.</li> </ul>	
	<p><b>Participate, be informed and influence decision making</b></p> <ul style="list-style-type: none"> <li>- You have the right to have a say in decisions that affect you and for your opinions to be taken seriously.</li> <li>- Your preferences should be treated seriously.</li> <li>- To enjoy yourself, be happy and express emotions (even if this is quite noisy.)</li> </ul>	<p><b>Inclusion in community and society</b></p> <ul style="list-style-type: none"> <li>- You have the right to a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate active participation in the community.</li> </ul>	<p><b>Personal Assistance and support</b></p> <ul style="list-style-type: none"> <li>- You have the right to access resources to support specific needs.</li> </ul>	<p><b>Adequacy, Availability Accessibility</b></p> <ul style="list-style-type: none"> <li>- You have the right to be communicated with in appropriate different ways.</li> </ul>	

<b>Intersecting Principles and Rights Themes – Care and Assistance for Disabled Children</b>					
<b>B</b>	<b>Survival and Development</b>	<b>Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination</b>	<b>Best Interests</b>	<b>Respect, Personhood and Evolving Capacity, Independence</b>	
	<ul style="list-style-type: none"> <li>- You have the right to life.</li> <li>- <i>You have the right to express your identity.</i></li> </ul>	<ul style="list-style-type: none"> <li>- You should not be treated unfairly because of your disability.</li> <li>- <i>You have the right to reasonable changes, to make sure you can enjoy your rights.</i></li> </ul>	<ul style="list-style-type: none"> <li>- All services for disabled children should be in line with standards of safety and protection, and this should be put before all other considerations, including when deciding on budgets.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be supported to achieve your full potential.</li> <li>- <i>Support to achieve your potential should be given whenever opportunities arise, rather than seeing potential as a distant future concept.</i></li> <li>- <i>To direct as much of life as possible, even if this is only at a very basic level.</i></li> </ul>	
	<b>Participate, be informed and influence decision making</b>	<b>Inclusion in community and society</b>	<b>Personal Assistance and support</b>	<b>Adequacy, Availability Accessibility</b>	<b>Training</b>
	<ul style="list-style-type: none"> <li>- <i>You have a right to information, provided in ways and at a speed that you can understand to help make decisions about things that affect you.</i></li> <li>- You have the right to support so that you can communicate what you want.</li> </ul>	<ul style="list-style-type: none"> <li>- <i>You should be included in your community and wider society.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>You have the right to the support that you need to develop.</i></li> <li>- <i>Support should be from people that you know and can develop a relationship with.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>The care and assistance you need should be free, as far as possible.</i></li> <li>- You should be able to access services, like education and health.</li> <li>- You should be able to participate in activities alongside children who are not disabled.</li> <li>- <i>To have people supporting you who are able to communicate with you effectively.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>People should be trained to understand the rights and needs of disabled children.</i></li> <li>- You have the right to information so that you can understand your disability.</li> </ul>

**Intersecting Principles and Rights Themes – Basic things you need for living**

C	Survival and Development	Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	Training
Food	– You have the right to food and water.	– You have the right to food suited to your culture and needs including dietary requirements.	– Your food and water should be safe.	– You have the right to food in your own right, independent of your family.	
Clothes	– You have the right to clothes.	– You have the right to clothes that suit your culture, religion and needs.	– To have clothes that will protect your privacy.	– To have clothes that help you express your identity.	
Housing	– You have the right to somewhere to live.	– You have the right to somewhere to live that suits your culture and needs.	– You have the right to privacy and safety where ever you live. – Where you live should be decided by thinking about what is best for you.	– You have the right to somewhere to live that respects your dignity. – You have the right to support so that you can grow to live independently.	– If you stay overnight away from home, the staff where you stay should be properly trained.
	Participate, be informed and influence decision making	Inclusion in community and society	Personal Assistance and support	Adequacy, Availability Accessibility	Training
Food	– You have the right to help choose (express preferences about) what food you eat.	– Be able to go out and eat with friends in your community.	– If needed, you should be given help with eating or learning to eat.	– You have the right to enough food. – You have the right to good food that will help you grow and develop. – Suitable food should be easy to get hold of when you need it.	
Clothes	– To help choose what clothes you wear.	– To go shopping for your own clothes.	– If needed, you should be given help with dressing or learning to dress.	– You have the right to enough clothes. – You have the right to clothes that will keep you warm and dry. – To get new clothes when you need them.	
Housing	– You have the right to help make decisions about where you live.	– You have the right to live in the community somewhere near the people and places you know.	– You have the right to the support you need to live in the community in a place where you are not isolated, near to the people and places you know, and the services you need.	– You have the right to live somewhere which has heating, lighting and keeps you protected from the damp. – You have the right to live somewhere that is easily accessible for you and your family and which appropriately accommodates you needs. – You have the right to somewhere big enough to live in.	– If you stay overnight away from home, the staff where you stay should be properly trained.



**Intersecting Principles and Rights Themes – Money, benefits and social support**

D	Survival and Development	Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	
	<ul style="list-style-type: none"> <li>– Governments have a duty to make sure you and your parents/ carers have the money, benefits and social support needed to help meet all your rights and needs.</li> </ul>	<ul style="list-style-type: none"> <li>– You have the right to benefits or social support, to reduce your chance of living in poverty.</li> </ul>	<ul style="list-style-type: none"> <li>– Your parents/carers have the right to enough <u>money, benefits and social support</u> to keep you safe.</li> <li>– What <u>money, benefits and social support</u> your parents/ carers get should be decided by thinking about what is best for you.</li> </ul>	<ul style="list-style-type: none"> <li>– <i>You have the right to more control over money as you become more capable and experienced.</i></li> </ul>	
	Participate, be informed and influence decision making	Inclusion in community and society	Personal Assistance and support	Adequacy, Availability Accessibility	Training
	<ul style="list-style-type: none"> <li>– <i>You have the right to have a say about changes in how benefits and social support is provided.</i></li> </ul>	<ul style="list-style-type: none"> <li>– Your family should get the money or help they need to give you support so you can live a dignified, self-reliant life and be fully included in your family and community.</li> </ul>	<ul style="list-style-type: none"> <li>– You and your parents/ carers should get extra money or help, to make sure you get any extra things you need because of your disability.</li> </ul>	<ul style="list-style-type: none"> <li>– Your parents have the right to enough money, benefits and social support.</li> <li>– Governments have a duty to make sure your parents /carers have the money, benefits and social support needed to spend time caring for you (if needed), or to pay for others to care for you while they go to work.</li> <li>– Your parents should get money (benefits) on time. This money should not be stopped without good reason.</li> </ul>	<ul style="list-style-type: none"> <li>– <i>Social workers, youth workers, support workers and benefit workers should be trained to understand your needs and respect your rights.</i></li> </ul>

**Intersecting Principles and Rights Themes – Family Life and alternative care**

E	Survival and Development	Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	
	<ul style="list-style-type: none"> <li>- You have the right to live with your family.</li> </ul>	<ul style="list-style-type: none"> <li>- <i>You should not be made to live apart from your family because of your impairment.</i></li> </ul>	<ul style="list-style-type: none"> <li>- If you are not safe at home, you have the right to live somewhere else where you can be properly looked after.</li> <li>- Where you live should be decided by thinking about what is best for you.</li> </ul>	<ul style="list-style-type: none"> <li>- <i>Staff who support you should respect who you are as an individual and encourage you to do things for yourself (your competence and independence).</i></li> <li>- <i>If you are away from home overnight, staff should pay you attention and actively engage when working with you.</i></li> </ul>	
	<p><b>Participate, be informed and influence decision making</b></p>	<p><b>Inclusion in community and society</b></p>	<p><b>Personal Assistance and support</b></p>	<p><b>Adequacy, Availability Accessibility</b></p>	<p><b>Training</b></p>
	<ul style="list-style-type: none"> <li>- Parents and guardians should listen to your opinions and should encourage you to have your ideas taken seriously by everyone in society.</li> <li>- You have the right to help make decisions in your family about this.</li> <li>- <i>If you live away from home, or spend time away from home, you should help decide about this.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>For you and your family to be part of the community and not trapped at home by difficulties or made to live apart in order to access support.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>You have the right to extra support – from people that you know and can get to know and services – so that you can live at home.</i></li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be cared for and treated kindly by your family.</li> <li>- You have the right to travel to see your family, if you do not live with them.</li> <li>- Support you need to live with your family should be provided at home, in community and as short breaks (where you and your family can have a rest from your each other and do things with other people).</li> </ul>	<ul style="list-style-type: none"> <li>- Your family have the right to information and training for family, so that they understand your disability.</li> <li>- <i>Short-break workers should be properly trained.</i></li> </ul>

<b>Intersecting Principles and Rights Themes – Education</b>					
<b>F</b>	<b>Survival and Development</b>	<b>Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination</b>	<b>Best Interests</b>	<b>Respect, Personhood and Evolving Capacity, Independence</b>	
	<ul style="list-style-type: none"> <li>- You have the right to receive help with education to help you reach your full potential.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to support with school, and to reasonable changes in the way school is organised to suit how you learn.</li> <li>- You have the right learning that suits your religion and family traditions.</li> </ul>	<ul style="list-style-type: none"> <li>- Schools should help protect you from bullying.</li> </ul>	<ul style="list-style-type: none"> <li>- Your education should respect you and encourage your independence.</li> <li>- You have the right to education that suits you as an individual.</li> <li>- You have the right to be treated with respect at school.</li> </ul>	
	<b>Participate, be informed and influence decision making</b>	<b>Inclusion in community and society</b>	<b>Personal Assistance and support</b>	<b>Adequacy, Availability Accessibility</b>	<b>Training</b>
	<ul style="list-style-type: none"> <li>- You have the right to input into decisions about what learning you do.</li> <li>- Your ideas should be taken into account when deciding what your school teaches and about education policy more generally.</li> </ul>	<ul style="list-style-type: none"> <li>- All schools and colleges should be accessible.</li> <li>- Education should be inclusive.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to personal support from people like Teaching Assistants so that you can learn in ways that suit you.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to education that helps you learn and suits your interests.</li> <li>- You have the right to enough opportunities to learn about the different things that interest you.</li> <li>- You have the right to training to help you get the kind of work you want.</li> </ul>	<ul style="list-style-type: none"> <li>- Teachers should be trained to understand disabilities and make sure you achieve your potential.</li> </ul>

<b>Intersecting Principles and Rights Themes – Work</b>					
<b>G</b>	<b>Survival and Development</b>	<b>Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination</b>	<b>Best Interests</b>	<b>Respect, Personhood and Evolving Capacity, Independence</b>	
	<ul style="list-style-type: none"> <li>- You have the right to work, when you are old enough. This work must not be harmful.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to not be discriminated against when looking for work, when seeking promotion or when trying to keep your job.</li> <li>- Any reasonable changes you need at work should be made.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be safe when you are working.</li> <li>- You should be protected from work when you are too young.</li> </ul>	<ul style="list-style-type: none"> <li>- To try to follow a career path that interests you.</li> </ul>	
	<b>Participate, be informed and influence decision making</b>	<b>Inclusion in community and society</b>	<b>Personal Assistance and support</b>	<b>Adequacy, Availability Accessibility</b>	<b>Training</b>
	<ul style="list-style-type: none"> <li>- You have the right to make decisions about what work you do.</li> </ul>		<ul style="list-style-type: none"> <li>- You should get personal support to find and keep a job.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be paid for the work that you do.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to training to help you get the kind of work you want.</li> </ul>

## Intersecting Principles and Rights Themes – Play, Association, Sport, Leisure and Cultural Activities

H	Survival and Development	Non- Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	Training
Play	– You have the right to play.	– You have the right to equal opportunities to play. – Any reasonable changes you need so that you can play should be made.	– You have the right to be safe when you play.	– The play you take part in should be suited to your abilities and interest.	– You have the right to receive training that will help you play, join in leisure and cultural activities and do sport.  – Youth workers/play workers should be trained to understand your needs and respect your rights.
Association	– <i>You have the right to have friends and meet with other children and young people.</i>	– <i>You have the right to take part in activities with other people.</i>	– <i>You have the right to meet with other people.</i>	– <i>The way you take part in activities with other people should be suit your abilities and interest.</i>	
Community/ culture	– <i>You have the right to take part in activities in your community.</i>	– <i>You have the right to go to places in your community and to reasonable changes.</i>	– <i>You have the right to take part in activities in your community.</i>	– <i>The way you take part in activities in your community that you enjoy, should suit your abilities and interests.</i>	
Sport	– <i>You have the right to take part in sport.</i>	– <i>You have the right to take part in sporting activities and to reasonable changes.</i>	– You have the right to be safe when you do sport.	– <i>The way you take part in sport should be suited to your ability and interest.</i>	
	<b>Participate, be informed and influence decision making</b>	<b>Inclusion in community and society</b>	<b>Personal Assistance and support</b>	<b>Adequacy, Availability Accessibility</b>	<b>Training</b>
Play	– You have the right to help make decisions about what and how you play. – Your ideas should be taken into account when deciding what play opportunities are made available to you.	– <i>You have the right to be involved in play activities in your community.</i>	– <i>To have staff who understand the value of play and encourage you to use the equipment that is available.</i> – <i>To have resources specific to your needs (e.g. sensory lights) so that you can play.</i>	– <i>You have the right to take part in art and creative activities.</i> – <i>To play in ways that you like.</i> – <i>To play with imaginative adults to be available to engage you in play activities.</i>	– You have the right to receive training that will help you play, join in leisure and cultural activities and do sport.  – Youth workers/play workers should be trained to understand your needs and respect your rights.
Association	– <i>To make decisions about who you meet up with.</i> – <i>To have information to enable you to make informed decisions about what to take part in.</i>	– <b>To meet with other people in your local area.</b> – <i>To be with people and part of things, as far as possible, so you are not isolated.</i>	– <i>To have personal support to meet with other children and young people.</i>	– <b>You have the right to take part in activities at school and after school.</b> – <i>To meet with other people in ways that you enjoy.</i> – <i>To choose to not join in.</i> – <i>To have a play and leisure environment that is appropriate to your age.</i>	
Community/ culture	– <i>You have the right to help make decisions about what activities you take part in.</i>	– <i>To leave your immediate community area and go on holiday.</i>	– <b>You have the right to personal support to take part in leisure activities.</b>	– <b>Places you visit should be made easy for everyone to use, whatever your disability.</b> – <b>You have the right to take part in sports with disabled children and with non-disabled children.</b> – <i>To have quiet time.</i> – <i>To take part in enough activities in your community.</i>	
Sport	– <i>You have the right to help choose what sports you do.</i>			– <i>To take part in sports that you enjoy.</i>	

Intersecting Principles and Rights Themes – Health					
I	Survival and Development	Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	
	<ul style="list-style-type: none"> <li>- You have the right to support and care to help you be as healthy as possible.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to health care to suit your needs and your culture and to <i>reasonable changes</i>.</li> </ul>	<ul style="list-style-type: none"> <li>- What health care you have should be decided by thinking about what is best for you and asking your opinion.</li> <li>- <i>People who give you health care should be friendly and help you feel safe.</i></li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to be respected by medical professionals – people like doctors, nurses and dentists.</li> </ul>	
	<b>Participate, be informed and influence decision making</b>	<b>Inclusion in community and society</b>	<b>Personal Assistance and support</b>	<b>Adequacy, Availability Accessibility</b>	<b>Training</b>
	<ul style="list-style-type: none"> <li>- You have the right to help make decisions about your health care and about health services.</li> <li>- You have the right to information about health care and services.</li> </ul>	<ul style="list-style-type: none"> <li>- Health Services should be near the people and places you know.</li> </ul>	<ul style="list-style-type: none"> <li>- Your individual needs should be identified quickly and the personal support, aids and services you need, should be free of charge (as far as possible).</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to the best possible health care.</li> <li>- Support and care should be accessible (simple to get and free of cost where possible).</li> <li>- Teenagers should have information about relationship and sexual relationships.</li> </ul>	<ul style="list-style-type: none"> <li>- Health workers should be trained to understand your needs and respect your rights.</li> </ul>

Intersecting Principles and Rights Themes – Mobility					
J	Survival and Development	Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	
	<ul style="list-style-type: none"> <li>- You have the right to support to get around.</li> </ul>	<ul style="list-style-type: none"> <li>- Transport providers have a duty to make any reasonable changes you need, such as giving you help getting on and off trains.</li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to get around safely, including on the street and when using public transport.</li> </ul>	<ul style="list-style-type: none"> <li>- <i>You have the right to support that enables you to move around as freely as possible.</i></li> <li>- You should not be forcibly moved without reason.</li> </ul>	
	<b>Participate, be informed and influence decision making</b>	<b>Inclusion in community and society</b>	<b>Personal Assistance and support</b>	<b>Adequacy, Availability Accessibility</b>	<b>Training</b>
	<ul style="list-style-type: none"> <li>- <i>You have the right to make choices about your personal mobility.</i></li> </ul>		<ul style="list-style-type: none"> <li>- <i>You have the right to personal support, specialist services appropriate vehicles and other supports to enable your mobility.</i></li> </ul>	<ul style="list-style-type: none"> <li>- You have the right to free public transport, whenever this is possible.</li> <li>- Public Transport should be easy to use.</li> <li>- You have the right to affordable aids and support with mobility.</li> <li>- <i>The environment should be accessible to you.</i></li> </ul>	<ul style="list-style-type: none"> <li>- <i>You have the right to training and advice to support your mobility from specialist staff.</i></li> </ul>

### **3. Findings: Disabled children’s and young people’s experiences of rights and the impact of low income and other factors**

Section 1 of this report described what this project was examining and why understanding the impact of low income and poverty on disabled children’s rights is of growing importance. Section 2 noted how this work was carried out and summarised the methodology, and in particular how the matrix of rights themes and cross-cutting principles was developed. This matrix forms the framework for analysing the evidence collected from disabled children, young people and their families.<sup>10</sup>

This section describes those children and young people’s experiences. It is structured along the lines of the eight rights themes that were identified by the steering group. These are:

- 3.1 Basic things you need for living**
- 3.2 Family life and alternative care**
- 3.3 Money, benefits and social support things you need for living**
- 3.4 Education**
- 3.5 Health**
- 3.6 Play, association, sport, leisure and cultural activities**
- 3.7 Mobility**
- 3.8 Right to work**

In each theme the steering group have chosen an illustrative story about one child or young person who took part in the research, and they give comments on what they have learned from this. Each theme then connects the issues identified in these stories with similar and different concerns raised by the other children, young people and families who took part in the research. The second part of each theme then considers how the findings show instances of rights related to this theme (as defined in the matrix) not being respected, protected or fulfilled.

The stories and issues shared with us are not confined to matters affected by low income alone. Therefore, throughout this section, icons are used to flag particular issues as examples of children’s and young people’s agency, good practice, barriers to agency and problems arising directly from low income.

#### **Key to icons**



This sign is used to represent problems arising from low income



Barriers to adequate service provision

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<sup>10</sup> The full description is set out in appendix 1, accessed at <http://www.childrenscommissioner.gov.uk/content/publications>



The positive person is used to represent children and young people's agency



The star icon is used to flag good practice

### 3.1 Basic things you need for living

As the title suggests the issues discussed under this theme involve the provision of basic goods and services including food, clothing and housing. (Table 2b above describes the articles linked to this theme) There were examples of severe deprivation leading to young people being unable to afford to buy food. These examples were thankfully rare but do represent the most basic human right being infringed.

The majority of concerns under this theme were associated with housing, and there were examples of many cross cutting principles that were not being met. The steering group's interpretation of these rights is set out in Table 2c above and represent basic rights that all children and young people should be able to enjoy.

#### Story one: Joe

Joe is 11 years old. He is very small for his age, and has severe learning and physical disabilities and complex health needs, which are life-limiting. He is fed through a tube in his stomach. He lives in a bungalow with his mum and brother.

Joe's mum is single and not working. She receives housing benefit and they live in an area of social deprivation. Joe's mum said:

*"I was living next door to my parents, I'd been brought up around there, so they all knew me, I had support from family and friends, and they helped me with Joe... I had to move to this bungalow up here [so that it could be made accessible for Joe]. I had four days to move right. I got no grant, no decorating materials because they said I didn't fit the criteria right, no help with cleaning, no nothing. It's full of asbestos, it had rats, which is why I've got cats. I had no money to get even any paints."*

*"This house is so damp... when I'm out of here then they'll do it, they'll bulldozer it, condemn it ... The cost of heating is enormous. I'm losing a hundred pound a week [with gas payments and heating debt being paid off on a pre-payment meter]...that's just to have it on morning and night for a bit of water"*

From this and further information provided about Joe's situation steering group members Rosie and Zac commented that:

*"Joe does not get to use parts of his house because his mum cannot afford to heat it. His mum owes the heating company £2000 which she is paying off at £40 a week – it will take her until May 2022".*



### 3.1.1 Not having enough food and clothes



Three young people told us about not having enough food. One young person (aged 20) said they did not have enough money to buy food and again we consider their story in detail in the later theme *Money, Benefits and Social Support*. Another young man (under 18) regularly used a food bank. In addition, two young people described how important parents were in giving them food when they had no money left for this.

In a consultation group in another area young people also talked about the amount of food they received at school being reduced; less meals were provided and portions were smaller and this affected how tired they were and their ability to concentrate.

One young person commented that:

*“The money’s been cut and children go to school and they get some [food]... they [children] get very hungry again and eating junk food, that’s why, that’s why they should have more food. More food at school and then something else at home...”*



One parent also told us about the cost of a high calorie diet, essential to prevent her child’s health from deteriorating, which was another essential component of her family’s weekly expenditure.

Two young people told us about not having enough clothes. One of these was a looked after young person aged 16 who told us that his carers get his allowance but, *“they never give me it, so I have had to ask, like Christmas and birthday...for money to get clothes”*. He said she had no social worker or anyone that he could talk to about this problem.

### 3.1.2 Lack of heating

One of the basic rights noted by the steering group was the right to “live somewhere which has heating, lighting and keeps you protected from the damp” (Table 2c, principle of adequacy, availability and accessibility).

Examples of this right not being met were very rare, but Joe’s was not the only account shared with the research team. One young person (aged over 21) described how her bedroom was so cold that she could not sleep there. She used her Disability Living Allowance (DLA) to help pay household bills as her mother, who was also in receipt of welfare benefits, was paying off debt to prevent their furniture from being repossessed.

### 3.1.3 Adaptation of housing

Other problems encountered related to getting appropriate adaptations. Again the interpretation of what basic provision disabled children and young people should expect is outlined in Table 2c. This includes accessible housing, and space that respects the dignity of a young person and his or her need to be supported by family or friends.

The issue of adapting housing to the needs of a disabled child or young person proved an issue common to a number of young people and parents. One parent described having asked for 13 years for an accessible shower to be installed. Finally, when the borough boundaries changed and she was in a different local authority, she asked again and the shower was installed within two weeks. Another mother described a delay of 18 months in getting the adaptations necessary to ensure her child



could be kept safe. This family felt like their application for help was blocked by someone from the local council. The mother said:

*"He doesn't have any qualifications or anything as an architect, any qualifications in children's development or children with disabilities or anything like that, he appears to oversee the funding aspect of it all, and the process of it all. However, he then attempts to make, or attempts to deny choices or attempts to influence the architect or us on our decisions for our child and ...he very obviously attempts to change every decision that the architects and the OT make or us as parents make for a cheaper alternative, and you have to be very strong as parents to say no."*



In two instances, however, parents told us of prompt adaptations that had made their homes more suitable for their children.

Where adaptations were successfully achieved, parental skills and knowledge of how to get through the system appeared to be crucial, often parents who did get adaptations struggled against bureaucracy and lack of information. This was the case in a number of different local authorities.

It is clear from these accounts that the issue of consistency of provision across different areas is a source of frustration for some parents who find thresholds or criteria prohibitive or response rates slow. Yet this is not a universal experience and there are many other authorities that meet parents expectations and needs.

### 3.1.3 Privacy and safety



Young people talked about the importance of having their own space as a way of being safe and managing their conditions. One young man (under 16) turned his family junk room into a bedroom, so that he could have space away from his twin brother who had Asperger's. This helped improve their relationship. Parents repeatedly stated concerns about not having enough housing benefit and were worried about the impact of welfare benefit changes.



One young person (aged over 21 years) who did not feel safe at home said she could not afford to move out and did not have any support, such as personal assistance, that would enable her to even try.

The desire expressed by many young people to have their own bedroom may be considered a luxury and not a basic right. However, it was notable how strongly many felt about this issue. As in the case of the young man above children and young people thought there was much benefit in having their own space and access to some private space.

As the research took place before the Government announced safeguards regarding housing benefit for families with disabled children it may not be a surprise that there were strong feelings expressed about this issue, and the results of later research may be different if fears are not realised.

It is also important to note that while some may have experienced delays or disappointments in having their housing adapted some young people got the space they needed by having short breaks away from their families. We return to this in the *Family life and alternative care* theme.

All the examples collected during the research indicate the importance of considering children's Best Interests and safety and their independence when making decisions about what constitutes adequate housing.

### 3.1.4 Analysis: Relationship between low income and the impact on the right to the basic things you need for living

In summary the problems some (but not the majority of) children, young people and families encountered in giving effect to rights to the basic things you need for living were:

- not having enough heat, food or clothes
- not being informed or making choices about where you live
- delays in making adaptations to housing
- not always having enough room and privacy.

Table 3.1 shows how these problems are related to different rights and caused by different factors. Throughout this report evidence has been collected in relation to the rights themes and principles. Not all infringements and violations are caused by low income or poverty.

<b>Table 3.1: Infringement of right to basic things you need for living</b>			
<b>The Principle</b>	<b>The Right</b>	<b>The Problem</b>	<b>Suggested Causes</b>
<b>Best interests</b>	<i>You have the right to privacy and safety wherever you live.</i>	Delays in adaptations needed for child's safety and well-being.	Budget considerations put before best interests.
<b>Personhood, evolving capacity and independence</b>	You have the right to support so that you can grow to live independently.	Insufficient money to move into own accommodation.	Lack of income/benefits for independent living.
<b>Participate</b>	You have the right to help make decisions about where you live.	Having no choice about moving house in order to get adapted accommodation.	Lack of income to pay for private housing in own community area.
<b>Inclusion</b>	You have the right to live in the community, somewhere near the people and places you know.	Having to move house in order to get adapted accommodation.	Lack of income to pay for private housing in own community area.
<b>Personal assistance and support</b>	You have the right to the support you need to live in the community in a place where you are not isolated, near to the people and places you know, and the services you need.	Having to move away from family and friends in order to get suitable accommodation.	Lack of income to pay for own extension.  Lack of adapted social housing in local areas.

<b>Adequacy and availability</b>	You have the right to enough food.	Not enough food in school portions and running out of money to pay for food.	Limited money in benefits or allowance  Reduction in portion sizes.
	You have the right to enough clothes.  To get new clothes when you need them.	Having to pay for clothing using present money.	No access to own clothing allowance money.
	<i>You have the right to somewhere ... which appropriately accommodates your needs.</i>	Delays of over 18 months in obtaining council help with adaptations.  Not having information about how to get adaptations.	Lack of grant money to pay for decorating.  Differences between local borough provision.
	You have the right to live somewhere which has heating, lighting and keeps you protected from the damp.	Cold bedrooms  Cannot afford heat in the adapted sensory room.	Lack of money to pay for heating.
	You have the right to somewhere big enough to live in.	There were fears raised about the impact of the housing benefit reform.	Impending limitation of Housing benefit payments.

### 3.1.5 Analysis of the impact of low income

Not all the problems noted in Table 3.1 are the result of low income, and a lack of service provision, personal support or information were contributory factors to many of the concerns raised.

Yet a lack of money did accentuate many of the problems faced by the families of disabled children and low income was the primary cause of some rights not being fulfilled.

Some of these difficulties (going without food, clothes and everyday necessities and living in poor housing where it is difficult to sleep, study and play) are common to other children and young people living in families on low incomes.<sup>11</sup>

Adequate incomes and good service provision are essential, to enable disabled children to exercise their capacity to take a degree of control over their own lives. For example, the young adult who wants somewhere to live on her own because she does not feel safe at home, but who cannot afford to move out and would also need personal support to make it possible, is an example of someone whose whole life could be much more self-directed if she was properly supported.

<sup>11</sup> See Ridge (2009) for an overview of other research on this.

In contrast, we see examples of young people successfully exercising agency, where services are good or where a family had enough rooms in their house. Children were able to make choices about what they ate, or the young man who moved out of the room he shared, by dint of clearing out a junk room himself, and now got on much better with his brother. Appropriate accommodation was also sometimes achieved through considerable hard work by parents.

## **3.2 Family life and alternative care**

Children and young people talked about the important role of their families. Families and carers helped them to develop new skills and feel safe. Table 2c highlights how families sometimes need help in being kept together, and that children need somewhere where they are safe and properly looked after – whether that is with their parents or, if necessary away from them. That help and support does not always come from social care services as Jez’s story demonstrates.

Jez’s story was selected by the young people’s steering group to illustrate this theme and provides a glimpse of some of the positive experiences described with regard to safety at home and the need for family and supportive services; the role of youth clubs and short breaks in supporting family life; and short break provision.

However other young people and families did not always have the same positive experiences in these areas. They also spoke about difficulties in home based personal support; lack of money to fund contact with families.

## Story two: Jez

Jez is 18 years old and lives in supported accommodation. Jez has a behavioural disorder and development delay. They both talked about the home environment and the sources of help that support independence.

Jez said that it is still hard to stay calm sometimes at home:

*"When I was about three or four my, my mum forget to [make me] take my tablets. ... A social worker took me off my mum and my brothers and sisters just because that I was hyper... I trashed the place, I literally broke everything in my mum's house and literally tear walls down and like I broke my stepdad's car."*

Jez still gets on well with his family and he still has a lot of support from them, but he said he cannot live with them.



Jez also talked about the important role played by the youth club, *"I like to come here [to youth club] to calm myself down"*. Coming to the youth club helped him develop some skills in anger management, *"if anybody winds me up, well I, even I have to walk away or like I shout at them....because inside me I still feel that like [being physically violent]. I still need anger management, because I know, I know how I feel inside but I can't help it because of my ADHD"*.

Jez has 24 hour support in his own flat in a shared building, with a support worker who helps him if he needs any support with practical problems.

On reading this and other stories, the steering group members talked about the importance of disabled children having independence and support. As well as continuing to live together with their family whenever possible, they felt that it was important to recognise that disabled children need space away from their families and that for some children who need 24 hour care, short break centres were the only way in which such independence and space away from their families could be achieved.

### 3.2.1 The role of youth clubs and short breaks in supporting family life

It may be a surprising place to start a section on family life, but young people repeatedly described the value of being able to get away from home by going to youth club. For many youth clubs or similar services were seen as an important means of coping with the stresses of family life, and as such were a form of early intervention or prevention service:

*"You've got family members arguing, you've got other things happening, you've got everything and you ... it feels like you've got nowhere to go, whereas parents can be strict and you're stuck at home and you've got nowhere to get out, they say oh you can't do this or you can't do that, say oh, and you just want to just put your hands in the air and just say I give up, I don't want it anymore, you just feel like you need to get a release,...you feel like you're stuck in four walls."*

Short break provision was also welcomed by parents and children when it enabled children to access new experiences and a welcome change. One parent described the importance of timing:

*“When he started he didn’t settle at all, so we left it for a while and then he started a couple of years later, when he was about nine... it was a learning curve from all of them... but now no issues whatsoever.”*

But the quality of provision was patchy. One child found respite care very stressful because the unit seemed unable to manage his gastric reflux and need to be regularly ‘winded’. His mother commented:

*“they didn’t understand my son.”*

While the provision of these services was not dependent upon a family’s income, poverty could act as a barrier where services were available but required payment or where children and young people had to travel to access them. This was sometimes the case with youth clubs and services and is an issue explored further in the mobility and play, association, sport, leisure and cultural activities themes below.

### **3.2.2 Difficulties in home-based personal support**

Parents usually described their children as having insufficient personal support and assistance from local services. For example, the mother of an 11 year old boy needed an operation which would mean she would need additional help at home. Her son has severe learning and physical disabilities and complex health needs, which are life-limiting. He is fed through a tube in his stomach. He is very nervous of new people. The only support the local authority offered was out of county foster care, on the basis that in-home care would be too expensive. As a result the mother decided not to have her operation, thereby putting her own health at risk.

This was an extreme example but other parents described how an absence of home-based care limited their access to paid employment. Contrastingly parents who were able to access work and employed in relatively well-paid jobs reported being able to pay for additional care and assistance for their children. As children grew older, some parents chose to continue providing support themselves, but this was a source of worry, and parents were concerned about their child’s independence and future.

In transitions to independence, models of service provision were significant, especially for looked after children. At the age of 18, one care leaver experienced carers abruptly being removed and new carers from other agencies being introduced. A second care leaver was able to have his foster parents transformed into paid carers, through direct payments.

### **3.2.3 Lack of money to fund contact with families**

The majority of children and families we spoke to lived together at home for most of the time, but in one instance, a young woman (aged 16) described the circumstances in which her brother, who had autism, had found the transition to secondary education so difficult that his behaviour had deteriorated to the extent that had was taken into a long term residential placement. She said, *“he had to go somewhere else and now he’s far away”*.

This young woman saw her brother once or twice every month, but wanted a bit more money to pay carers or to provide transport to help her see him more often.

### 3.2.4 Analysis: Relationship between low income and infringements of rights to family life and alternative care

Most children and young people felt supported by their family members however some children, young people and parents wanted families to receive more support. Table 3.2 shows how the problems identified in this theme were related to different rights and caused by different factors including short break provision and parental access to information about service provision.

Table 3.2: Infringement of right to family life and alternative care			
The Principle	The Right	The Problem	Suggested Causes
Best Interests  (and Article 23 BI – budget)	If you are not safe at home, you have the right to live somewhere else where you can be properly looked after.	Substitute care is not always provided in the way that children and families want.	Lack of consultation, poor resourcing.
Personal support and assistance	<i>You have the right to extra support – from people that you know and can get to know and services – so that you can live at home.</i>	Lack of appropriate in home personal support.	Lack of consistency in service provision.
	<i>You and your parents should know how care will be provided for you as you grow older (this is a new rights claim to be added to the matrix).</i>	Great uncertainty about what will be available in the future.	Lack of clear transition pathways.
Adequacy	You have the right to travel to see your family if you do not live with them.	Siblings being placed in different settings and not having sufficient contact.	Lack of income.
Training	<i>Short-break workers should be properly trained.</i>	Staff sometimes not able to meet needs of disabled children and young people.	Poor training and recruitment policies.



### **3.2.5 Analysis of the impact of low income in this context**

In relation to rights to family life and alternative care, low income and inadequate or inconsistent service provision challenged the attainment of four out of the nine cross-cutting principles: Best Interests, personal assistance, adequacy and training. Inadequate service provision was the more significant factor in this theme. Low income was a direct causal factor only in relation to one young person who did not have enough money for transport to see her sibling. However as these children were in care, this may too be seen as related to service provision. Service provision was variable between different local authorities in relation to the transitions from child to adult services; quality of short break provision; and, parental access to information about service provision. This confirms the importance of the relationship between geographical location and service poverty and the notion of a 'post code lottery', reflecting the 'inverse care law' (Tudor Hart, 1971 in Read et al 2012).

Ridge's research review (2011) found that low income has an impact on wellbeing and relationships within the home, where parents struggle to sustain family life on inadequate incomes, generating stress and anxiety, and family needs are often in tension with children's own (social and material) needs and desires. Siblings of disabled children also carry a double responsibility in these situations, of caring and coping with low income.

Our research did show that families encountered anxieties about transitions and quality of service provision, and more of these are evident in subsequent themes. But despite the strains, in most instances, parents, grandparents and children supported each other to maintain safe and supportive environments at home. Their success was often linked to personal social capital and the energy to 'take on' the system. It was this challenge of taking on the system rather than the day-to-day care of their children that parents found particularly exhausting.

Disabled children also actively engaged in keeping themselves safe in their home environments. Jez found life impossible when he lived at home with his family, and needed to get away from them in order to calm down and maintain a good relationship with them. The combination of his own independent accommodation, 24 hour support and learning anger management through attending a local youth club enabled him to take more responsibility for himself. Other young people talked about how they kept themselves safe, by using services or equipment, and their own private space, in order to manage stress and to keep themselves feeling safe.

### **3.3 Money, benefits and social support**

The steering group selected Sally's story to illustrate this theme, as it shows the importance of adequate levels of money, benefits and social support and young people's contribution to providing social support to each other. In other themes we have considered how money, benefits and social support enable other rights. In this theme we look at what children, young people and families told us about how the access money and benefits was important in relation to receiving support; adequacy of provision; promotion of independence and the possibility of choice; and accessibility.

### Story 3: Sally aged 20

Sally has an autistic spectrum disorder and has:



*"lots of independence. I live in my own flat. It is hard to manage 'like your shopping, your bills'. I don't get a lot of money [although she did get DLA]. Right now I've got no money for food."*



When asked about this, Sally said she had not eaten for 2 days and that when she has no money for food she just sits in her flat in tears. She said that she is meant to have a key worker, but that the key worker doesn't help her with anything. Her dad cannot help as she has to go to work at 4am, and is tired when he comes home. Her dad wants her to get a job, but she said she feels too frightened to do this and too faint from hunger to try.

During the research she told people in the youth group about her situation. Workers had already been trying to get her some assistance as Sally was in an independent flat without any support but wanted to be somewhere with 24 hour support, like some other people in the group had described.

This was the first time she had talked about not having enough food, and other young people in the group gave her food and also their phone numbers, so that she could ring if she ran out and they would bring food to her flat.

Mark, another young person in the group (aged 16–18), explained that he got vouchers so that he could use the food bank. So Mark told Sally how to use the food bank and he made sure that the workers helped Sally with this.

Commenting on behalf of the steering group, Zac said:

*"There is no reason for people like Sally to not live independently. Young people's independence should be supported by enough personal support and key workers who actually do what they are meant to do."*

#### 3.3.1 Receiving support

Some young people received an income through their work, others were provided with an allowance by parents and carers or through benefits. Similarly, some parents worked whilst others received an income through benefits such as tax credits, carers allowance, Income support and DLA, or a combination of these, and their child's mobility allowance.

Some young people described feeling uncomfortable with their dependence on their parents. One 18 year old young man said:

*"It's stressful on my mum. I really worry I'm a burden on the family...I'd just like to think maybe one day I could support myself entirely and live on my own. Wash my own clothes."*

Parental discomfort with being reliant on state provision of benefits was also a feature. Two families did not claim all of the welfare benefits they thought they were eligible for. One parent said this was as they felt they were not as needy as others. Two families attributed their discomfort to stigmatising attitudes. A parent, who was claiming benefits, put it like this:

*“Parents are proud, proud people... to care for a disabled child in care (she understood) costs a 165,000 pounds a year. What, and we get five hundred quid a month, you know. And then, when the marriage breaks down, the child is taken into care, then the trouble starts, you know. You invest in that parent and that family in those early years, support them, equip them, empower them, give them the opportunity to work, give them child care from the age of b\*\*\*\*y two for crying out loud!”*

Her comments make a clear point about parental contributions to welfare provision. There were significant fears about the prospect of changes in welfare benefit and service provision. The same parent also worried about the stigmatisation of those on welfare:

*“When you have a disabled child you, you become an outcast, you know, a scrounger or whatever we are called.”*

### 3.3.2 Adequacy of provision



The extent to which governments (local and central) were fulfilling their duty to ensure young people and parents had enough financial and social support to meet children's rights and needs was variable. As this report demonstrates some families do not have enough money for basic needs such as heating and low income also impacts on access to health, education, leisure, alternative care, mobility and work.

Many of the parents who were in receipt of DLA stressed how important the existing levels of benefits were to them; they outlined how precarious some of the children's and families' lives would be without the benefits. The mothers in some of these families had previously held quite high status jobs and careers. If they had been able to continue to work they believed that their lives would have been materially much better off. However the opportunity to work was limited by an absence of personal support for their children.

*“If their child was ‘normal’, [parents] not working is highly unlikely, they would be working, they would be at work, there would be sufficient child care to care for that child when that child finishes school at half past three. You try and get after school care for a disabled child, you can't get it. Well, (even if) the school will provide it, then the taxis won't pick them up, so how are you meant to be in two places at once? If you have an able bodied child, that child can walk home from school, not so disabled children... you can't work because we have to stay at home and care for that child, what do we do? The fact of the matter is [parents] won't and they don't [work because] they make it so hard, you know, so there's no flexibility there, there's no freedom, you know, once you have a child with a disability you are automatically expected to become their carer.”*

Parent

The financial pressure on parents was often picked-up by the children and young people we spoke to. Young people who had parents with enough money to provide for them clearly benefited from a level of security that their basic needs would be met, but there were young people who described feeling uncomfortable with this relationship.

### 3.3.3 Personhood, capacity and independence

In other themes we saw that if a child or young person has some level of personal income which they control, either directly or through a revocable proxy, this enables and develops their independence, inclusion and mobility. The children and young people interviewed thought that this was important.

The level of independent resources that children and young people sought varied. Toby, aged 13, said he thought that every child should have about £300 a week; Lucy (aged 24 and living with her parents), described having only a little bit of money of her own a week – about 50 pence a day. All the young people we asked said they wanted to have some money of their own. While £300 per week may be unrealistic, 50 pence a day was thought to be too little by everyone.



The extent to which young people had adequate incomes related to the amount of additional financial support their parents were able to provide. One young person aged 21 said that Income Support was enough because her Mum bought her things she asked for. Zoe (who was soon to turn 16) said in a group discussion that she wanted enough money to live independently but could not afford to as her Mum had had to give up work due to ill health. Ashleigh, aged 15, whose story appears in two other themes, said:

*"I have Christmas money and birthday money, that's it, I don't really get pocket money."*

She thought she should have £10 per week of her own, but her Mum, who receives income support, did not feel she could afford this.

### 3.3.4 Money and independence to exercise choices



Two young people described never having any money of their own, so they could never make any choices. One parent acknowledged that her son could not exercise any choices as she had power of attorney. This was related to his capacity to make decisions. But control over money was not always related to capacity, as two young people aged over 18, who were able to communicate their wishes in a group setting, described having very limited control over their money.



*"[My carer] lets me have a tenner a week. I am 18. I need to do all sorts of stuff and I know what I want. But she won't let me get back control of my benefits. The problem is she has the proxy and I have tried to get it overturned but my key worker, when I still had one that turned up, said that there was nothing he could do."*

Young person

Whilst these cases are unusual, their seriousness does demonstrate the need for attention to young people's control of the benefits they are entitled to, and questions whether some young people's wishes are being respected.



Their experience is in contrast to the families in which parents said that disability benefits enabled them to have enough money to provide their children with more choices. In one family the level of control a young person achieved over his income clearly progressed as he grew older and this was supported by workers, who for example, ensured that he received the right change.

In other situations, choice might be limited, even when young people had money, as they may lack anywhere to go to spend it. One foster carer described this:



*"[We're] looking at how we [can get] Craig to do more things, and particularly without us. I mean he will have more opportunities to spend, but he doesn't spend a great lot of money, you know. He's stacking it up at the minute, but I think that's probably because there aren't the opportunities..."*

Foster parent

### 3.3.5 Accessible monetary support

Some parents had to overcome misunderstandings and battle to get the levels of income and social support they needed to meet their child's needs. One parent said she had:

*"to fight for stuff, instead of [the services] saying 'Right, we'll get somebody in to assess them'.*



One mum eventually successful because she had a supportive doctor. Other parents also described Social Services or education workers providing help with demonstrating that children met eligibility criteria. But some parents were put off by the forms:

*"it's such a nightmare...it took us so long to fill it in and now they are changing it".*

Parent

There were examples of parents who had lost hope or did not want to appeal a decision as they felt that the risk of losing benefits outweighed the possibility of gaining more. The extent to which families had confidence in battling the system, or networks of support that enabled them to meet the demands of proof of incapacity, were vital. One parent put it like this:

*"It's alright when you have got a big community, a big network or a big circle of friends to help with everything".*

### 3.3.6 Key infringements of rights to money, benefits and social support

The problems some children, young people and families encountered in giving effect to rights to money, benefits and social support were the discomfort and stigma regarding receiving support; inadequate levels of benefits and difficulties in combining caring and paid employment; lack of (control over) money to exercise choices; and barriers to accessing entitlements. Table 3.3 presents the key problems with respect to money, benefits and related social support.

**Table 3.3: Infringement of Right to money, benefits and social support**

	<b>The Right</b>	<b>The Problem</b>	<b>Suggested Causes</b>
Survival and Development	Governments have a duty to make sure you and your parents/carers have the money, benefits and social support needed to help meet all your rights and needs.	As detailed in previous themes, there were reports of levels of income inadequate to meet rights in relation to seven themes and all six cross cutting principles.	Inadequate benefit levels.  Lack of (flexible) employment.

Equality	You have the right to benefits or social support, to reduce your chance of living in poverty.	Some young people were experiencing material deprivation.	Inadequate benefit levels.  Lack of (flexible) employment.
Best Interests	What money, benefits and social support your parents/carers get should be decided by thinking about what is best for you.	Decisions about levels of benefits which children were entitled to were sometimes made without true understanding of individual children and their circumstances, causing families to have to battle to achieve entitlements.	Benefit decision making processes that are not individualised or child-centred.
Respect, Personhood, Evolving Capacity, Independence	You have the right to money, benefits and social support in your own right and you should get more control over money as you get older.	Some young people gained greater control of their income, but others did not.	Lack of (flexible) employment for parents or young people.  Inadequate benefit/ allowance levels.  Lack of personal assistance.
Participate	You have the right to have a say about changes in how benefits and social support is provided.	Changes in benefits are forthcoming and no young people or families had received opportunities to be consulted about these changes.	Very limited Government action in consulting disabled children and their families about benefit changes.
Inclusion	Your family should get the money or help they need to give you support so you can live a dignified, self-reliant life and be fully included in your family and community.	Previous themes demonstrate repeated barriers to inclusion.  The personal support young people needed to be self-reliant was not always available.	Lack of (flexible) employment for parents or young people.  Inadequate benefit/ allowance levels.  Lack of personal assistance.
Personal assistance and support	You and your parents/carers should get extra money or help, to make sure you get any extra things you need because of your disability.	Previous themes (specify) demonstrate low income was a barrier to getting the personal assistance children and young people are entitled to.	Lack of (flexible) employment for parents or young people.  Inadequate benefit levels.  Lack of free provision.



Adequacy and availability	Your parents should get money (benefits) on time. This money should not be stopped without good reason.	Some decisions about DLA, which subsequently were won at appeal, demonstrated a lack of understanding of particular impairments.	Inappropriate decision making processes for disability benefits.  Lack of knowledge in workers.
	Governments have a duty to make sure your parents /carers have the money, benefits and social support needed to spend time caring for you (if needed), or to pay for others to care for you while they go to work.	Some parents chose to not work as they could not combine this with caring for their children – others felt they did not have the option of working as the necessary personal assistance was not available.	Lack of Personal Assistance for children leading to difficulties for some parent in working.
Training	Benefit workers should be trained to understand your needs and respect your rights.	Some decisions about DLA, which subsequently were won at appeal, demonstrated a lack of understanding of particular impairments.	Inappropriate decision making processes for disability benefits.  Lack of knowledge in workers.

### 3.8.7 Analysis of the impact of low income in this context

This rights theme, which considers how money, benefits and social support are distributed and accessed, is obviously very closely linked to issues of low income and poverty. It is not surprising therefore that the research uncovered so many problems and challenges to disabled children being able to attain their rights. Our findings confirm Read et al's (2012) suggestion that living with a disability results in financial disadvantage, related to higher costs of living, reduced paid employment opportunities, inadequate benefits and barriers to accessing benefits. There was also insufficiently flexible provision of the personal assistance that might make parental employment more possible.

The consequences of low income, in relation to the theme of rights to money, benefits and social support, were that some children and young people did not get opportunities to develop independence or to exercise choices regarding money or benefits. As with other research (Roker 1998; Mizen et al 2001), some young people who engaged in this research were concerned about being a burden on their parents and were keen to work, study and contribute to their own (and their household's) income.

Table 3 highlights that this rights theme is centrally about agency, and the extent to which disabled children and young people's agency can be supported by financial benefits and social services of various kinds. We see the example of Sally, who is in an independent flat without support and would like to have 24-hour support. As Zac said on behalf of the steering group, there is no reason for someone like Sally not to live independently. We have also seen that when children and young people have some control over personal income, this can support their independence, choice and mobility. Some families expressly said that disability benefits enabled them to provide their children with more choices, in an appropriately supportive structure.



## 3.4 Education

Edward's story was selected to illustrate this theme because it raises school or education related concerns shared by other young people about bullying and safety; accessing appropriate and stimulating learning opportunities; and problems related to long distances travelled to access educational opportunities.

The previous story of Ashleigh and some of the other accounts also talked about personal assistance and support and the choices and dilemmas about mainstream versus specialist provision. Concerns, barriers and examples of discrimination or poor practice are noted below, but it is also significant that children, young people and families described very positive experiences in mainstream and specialist provision.

### Story four, part one: Edward

Edward (aged 16) lives with his mum. He has an older brother.

He uses an electric wheelchair, is incontinent, has a very unstable medical condition which quickly debilitates him, and is fed via a gastrostomy tube. He has no speech but communicates by eye-pointing and facial expressions. He is dependent on his carers for all of his basic needs. He gets care at home for 14 hours a week, and has short breaks away from home.

Edward now attends a special school for half days only, because of his complex medical needs. His school is located about 15 miles from his home.

One day at his previous school, another child picked him up and threw him on to a paving slab. Edward's mum said there was supposed to be two members of staff either side of him.

After this incident, Edward's mum lost confidence in the school and took him out of education while she looked for another appropriate school for him to attend.

*"I got a letter off Education to say that if I didn't send him back to school they were going to take legal action over me... I would have let them take me to court, I would have fought them all the way over that...[It] was not a safe school for Edward."*

Edward's mum had problems looking for new schools, *"there was two schools that I did like but they were closing within twelve months"*.

Edward's physio suggested a school to his mum and she went to visit:



*"As soon as I got there I had that feel for it and that, and when I spoke to the head teacher at the end of it and he was really sweet. He said he'd take Edward in but when I came back and phoned the Education up they said that there was no way that Edward could go there because it was the same [type of school as where the incident had occurred] ....so I said I tell you what, we'll sue you then over the incidents. And within a day they come back and they said well yeah, he could have a place there."*

She arranged for Edward's part-time attendance at this school, so that his healthcare needs could be properly provided for. But transport was a problem, as there was no provision to bring him back home at lunch time.

Members of the steering group, Will and Reese, thought the right to the best type of education for Edward's needs was the most important priority. Edward, and people like him, need support to help them learn and be safe. Schools, teachers and the Government are a few groups who should try to understand disabilities better. Will and Reese thought better communication, understanding, knowledge, support and funding was needed from the Government to children and the families of children with disabilities.

When Will read this story he said:

*"I felt enraged by the fact that the Government are doing absolutely naff all to help. The most enraging thing was the fact that the mother took him out of school for his own benefit, however, she got told off by some Welfare Officer. People who cannot be at school should have like a card or something, that explains."<sup>15</sup>*

### 3.4.1 Bullying and safety

When children have concerns at school, steering group members stressed that this rarely means that nothing is going well. The steering group discussed their own experiences of bullying at school and this was repeated by several other children through artwork and words.

Young people talked about a lack of understanding from teachers regarding what is needed to ensure safety for children with certain impairments, like Autism. One young person said that getting a diagnosis did not seem to make a sustained difference:

*"They only diagnosed me with dyspraxia when I was 10 and Asperger's when I was 12 and I'm 12 now. Year 6 was OK I had a key worker then, it made me a lot happier. The teachers use to annoy me so much, in Year 5, she got so mad she was swearing at them... [after the diagnosis] certain teachers are nice to you. Certain teachers are even more mean to me."*

There were also some examples of good practice as this young person described:



*"Instead of doing a lesson, I go and see this teacher every lesson ... I don't want to get stressed again... This teacher, she spoke to me in such a way, which I don't know what it is, I just feel that...I can sort of control it and not do it. Putting angry people in the unit wouldn't do a thing... just being told off doesn't do anything because obviously ...but she spoke to me in a way that helped me control it."*

### 3.4.2 Accessing appropriate stimulating learning opportunities

Most of the young people under 16 who we talked to in consultation groups were happy with the learning opportunities they had at school. They named subjects they enjoyed, but there was a sense that these did not always stretch them to meet their potential. Ashleigh said she enjoyed outdoor activities, but:

*"I'd like a bit more maths because I have trouble with that... I'm short on maths".*

Accessing appropriate education or specialist support was sometimes difficult because of a lack of information, as one parent said, *"nobody ever tells you about these things"*. One family had paid for a professional assessment but most families in this study could not afford this.

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12 These are Will's personal views in response to Edward's story.



Three families talked of having to take action in order to get the authorities to respond to their children's needs. In addition to Edward's mother, another parent talked of the battles that she had with the Local Education Authority (LEA) in order to get appropriate autism-specific education for one of her sons and an appropriate mainstream place for the other. She felt that her son's presence at their reviews was very tokenistic, instead of being an opportunity to explore what they really felt about their Individualised Education Programmes (IEP), the lack of curriculums adapted to meet their needs and learning objectives.

### 3.4.3 Personal assistance and support

Where children had Special Education Needs (SEN) statements indicating the need for personal support, this was not always provided, and this limited children's learning. Ashleigh's mum described it like this:



*"It clearly states on the statement she should be getting one-to-one support, but I don't see sound nor sight of it basically... she doesn't seem to be getting an awful lot at the moment... I think if, like say the one-to-one support was in place, if somebody spent a couple of hours reading with her, it would make the world of difference."*

Several families reported that primary schools tended to be better at this than secondary schools.

*"When it comes to his senior years I don't think mainstream will be able to cope with him... in primary there's a lot more support for kids, but in senior school there's not the same support."*

Parent

*"He tried mainstream school here, it was a disaster. They had no support, no understanding, and he just deteriorated really fast, so I took him out of there."*

Parent

### 3.4.4 Choice and dilemmas about mainstream versus specialist provision

Some of the parents had shifted from their original view that mainstream was the "right thing" for their child to accepting the role of special education. One mother told us:

*"It's been really good, she started out in the mainstream class and lasted half a term there, she was statemented for a full-time one-to-one, but what they found was she was becoming very dependent on that one-to-one and it was just her and the adult sat doing her own differentiated curriculum which was pointless really, and we were quite resistant to her going into the special needs class, partly because she is the only girl and we thought she'd stand out like a sore thumb, but actually since she's been in there, because it's six staff with eight children, they sort of circulate a bit more so she's getting more variety of input that's helpful, and she seems to have taken really well to the boys."*

In particular, specialist post-compulsory education was a demand made by the families and carers of many of the children with more complex needs, who felt their children would miss out on mainstream further education. However, accessing specialist provisions could mean children had very long daily journeys to school (up to 25 miles each way). Travel to distant schools was an extra cost at times when school transport was not available.

### 3.4.5 Analysis: Relationship between low income and infringements of rights to education

While there were examples of good practice, some children and young people encountered significant difficulties in relation to education. These are set out in Table 3.4. It shows how the problems identified in this rights theme were caused by different factors and arose in relation to all nine cross-cutting principles.

<b>Table 3.4: Infringements of rights to education</b>			
<b>Principle</b>	<b>The Right</b>	<b>The Problem</b>	<b>Suggested Causes</b>
<b>Survival and development</b>	<b><i>You have the right to receive help with learning and education to help you reach your full potential.</i></b>	Adequate support often lacking.	Lack of sufficient resources in schools – low income families unable to access alternative support.
<b>Equality</b>	<b>You have the right to support with school, and to reasonable changes in the way school is organised to suit how you learn.</b>	School provision is often not appropriate for disabled children.	Lack of flexibility and responsiveness in system.
<b>Best Interests</b>	Schools should help protect you from bullying.	Schools sometimes leave disabled children vulnerable to bullying.	Lack of systematic and responsive anti-bullying strategies.
<b>Respect, personhood, evolving capacity, independence</b>	<b><i>You have the right to education that suits you as an individual.</i></b>	Curriculum may be imposed without regard for individual needs and interests.	Lack of flexibility and respect for disabled children as persons.
<b>Participation</b>	<b><i>You have the right to input into decisions about what learning you do.</i></b>	Children not consulted or listened to.	Belief that adults and professionals know best.
<b>Inclusion</b>	<b>All schools and colleges should be accessible.</b> <b>Education should be inclusive.</b>	Children may have to go to distant special schools simply because of lack of access in mainstream schools.	Under-resourcing of mainstream schools to meet needs of disabled children.

<p><b>Personal support and assistance</b></p>	<p><b><i>You have the right to personal support from people, like teaching assistants, so that you can learn in ways that suit you.</i></b></p>	<p>Personal support not always available.</p>	<p>Under-resourcing of mainstream schools to meet needs of disabled children.</p> <p>Low income families unable to access alternative sources of support.</p>
<p><b>Adequacy</b></p>	<p><b><i>You have the right to training to help you get the kind of work you want.</i></b></p>	<p>Disabled children not always prepared for work.</p>	<p>Policy, system, training and resource issues.</p>
	<p><i>Specialist provision should also be available post compulsory school age</i></p>	<p>Lack of attention to rights to further and higher education.</p>	<p>Policy gaps – insufficient consideration of rights of disabled young people to complete their education.</p>
<p><b>Training</b></p>	<p><b><i>Teachers should be trained to understand disabilities and make sure you achieve your potential.</i></b></p>	<p>Many teachers do not know how to help disabled children.</p>	<p>Not enough training provided for teachers, especially in mainstream schools.</p>

### 3.4.7 Analysis of the impact of low income in this context

In relation to rights to education, all nine cross cutting principles were infringed in different instances. Many of the weaknesses in education provision related to the level of resourcing in schools and local authorities for the education of disabled children – this affects accessibility, provision of support, teacher training and several other areas. In two of nine cross-cutting principles, survival and development and personal assistance, low income was a direct causal factor as low income parents are not able to afford additional sources of support to supplement provision considered inadequate.

Previous research shows low income children experience difficulty in obtaining items that are expected at school, such as course work materials or school uniforms; anxiety, unfairness and vulnerability to bullying; and, barriers to attainment (Roker, 1998; Ridge, 2009). Our research shows these difficulties are compounded for disabled children, who may have additional costs related to school participation and additional activities. They may need extra learning materials or clothing; be unable to use public transport; or, have to travel further.

The steering group observed that schools which are half-way between mainstream and specialist schools and would respond to some of the requests for an understanding environment that many children sought, are very few and far between. Some schools, however also require parents (or local authorities) to contribute towards fees and these are then not available to disabled children on low incomes.

### 3.5 Health

Edward's story, introduced in the education theme above, is continued in this section as his account of the health problems he faces demonstrated issues that others also face concerning from the perspective of his mum misreporting of health diagnosis; the importance of health staff having appropriate attitudes, skills and knowledge, especially communication skills; and the availability of adequate care, aids and personal support. In addition to these issues other children and young people talked to us about the distances they had to travel to receive treatment and worries about the transition to adult services.

#### Story four, part two: Edward's mum

Edward's mum explained how getting appropriate care for Edward is a daily battle.

She felt that Edward was discriminated against because of his learning needs:

*"if you go to the A&E [in local town], when you say 'He's got learning disabilities' ... they've said to us ... 'Well just because he's got them doesn't mean you're going to the top of the queue'. But it's not, it's not you want them to go to the top but, you know when they're screaming ... I found they were quite abrupt and some are quite scared of learning disabilities".*

Edward's mum also described a lack of communication skills in some doctors:

*"one doctor that come ... he said 'Can Edward talk?' And I went well, 'No he can't', and he went 'Well, I can't deal with him... because he can't tell me what's up with him'... So I said, 'Well you're the, you're the paediatric person'. He went well 'I can't see to him' and he went away ... that doctor...who walked away, was quite ignorant. But the other guy he sent he had a full understanding. I think [you need] if you're working in paediatrics... I mean even [anyone] really, you should have an understanding of learning disabilities".*

Edward's mum talked about the importance of age-appropriate and gender-specific provision.

*"There's a male carer [at the school] and Edward likes being with him. So it's like of course! He probably likes being with the boys."*

Getting provision that met personal needs that changed with age was also an issue, particularly concerning incontinence pads:

*"... they only allow you four a day anyway so, but like the hospital ones are rubbish like the ones that they give you, so like I buy Tena for Edward, because they are better, they're a better quality so... just to have a next size to change to a pad, you know, it's got to go to a panel meeting... they don't take into consideration the person's going to grow... it's just pathetic for some of the things really."*

The steering group thought this was ridiculous. They said people should realise that Edward is there. People talk down to people with disabilities, if it is mental or physical. It is like you are not there. Like you are invisible. One of them said, *"people do that to me"*.



### 3.5.1 Appropriate attitudes, skills and knowledge

Although the misreporting described by Edward's mother was an exception, parents were clear that health care professionals need to have good knowledge of their children and this was supported by relationships that developed over time. Sustained relationships also meant that professionals got to know, not just the child, but also the family really well. As one parent explained:



*"[the GP's surgery] adapt to our needs as a whole family extraordinarily well, I have routine communication with the surgery by email because I can't use the phone".*

Families felt comfortable when health care professionals "know exactly what [my child's] like" or they "make sure he's got an appointment on [nurse A's] shift... she's known [child A's] since he was a baby".



In contrast, other children and parents talked of their fears. One child was now so frightened of going to the hospital that he needs medication to calm him down and is sometimes so scared he needs oxygen "to help him breathe". Children and families shared stories of distressing visits to the dentist where their child's needs were not appropriately managed and their children had been traumatised by the experience. Some nurses and doctors in hospitals lacked appropriate attitudes and communication skills for working with children with learning and communication difficulties.

### 3.5.2 Appropriate care, aids and personal support

Healthcare tailored to the child's specific needs was seen as fundamental. In some instances parents were full of praise for the "fantastic support" they got from "school and speech and language therapists and physio" and could find "no faults".

However, some parents felt that decisions were sometimes made without their child's individual context being taken into account. For example, a resource which might be essential for one child could not be allocated as it was not considered essential for the general category or class that the individual child was associated with.

One mother who had concerns about her son dying during his life-threatening seizures was told that an alarm which would alert her at night of her son having a seizure was not "class[ed] as essential". In situations like this it is difficult to see the child's right to be safe or even survive is being supported. Low income families are much more reliant on external sources of support in purchasing devices such as the seizure monitor, than families who have access to disposable income.

The fundamental health and social care issue of managing children's continence was brought to our attention on a number of occasions. Families talked of the inadequacy of supplies both in terms of quality, appropriateness of size and quantity of incontinence pads.



Like Edward's mother, other families had to use up a substantial amount of their limited incomes on purchasing extra pads, making this a further necessary component in the family's budget. Joe's mother pointed out that he might use three pads in ten minutes and yet is only provided with three per day. She went on to explain:

*"And...like they said his disability money's for all that and seven nappies. For £14 or summat, you know? And you're thinking, 'Oh God!'"*

Some families also reported lack of access to services, especially at weekends and nights.



### 3.5.3 Distances travelled



Care close to the child's home was seen as beneficial and instances where specialists came out to do clinics in rural settings meant that families did not have to undertake long, tiring and expensive journeys. Families identified that travel to and from hospital and other appointments was an additional and significant drain on their limited finances. However, because the families valued sustaining relationships with professionals they knew and trusted, the physical and financial costs and sacrifices associated with travelling to appointments was seen to be worthwhile.

#### Story five: Azeem

Azeem is a 19 year old young man. He has hydrocephalus, severe learning disabilities, and has a syndrome that causes high blood pressure. His brother is also disabled. Neither of their parents work.

Azeem's mum talked about the problems of getting help from health services now that Azeem has become a young adult. Until he was 18 he always had direct access to staff in the hospital if he needed help. That meant his parents could phone the children's ward and get advice, or he could be admitted without having to go through the GP or Accident and Emergency (A&E) department. Now they have to go through A&E, where health staff do not understand his needs and it takes longer.

David, who was a member of the steering group, commented that *"although Azeem has lots of other concerns about getting his other rights, such as to take part in leisure opportunities that suit his culture, the most important issue for him is getting the healthcare he needs. He has high blood pressure. He needs good help from doctors"*.

Children's needs changed as they got older: they not only got bigger and needed new equipment (wheelchairs, pads), but also puberty created additional issues and costs for the families to accommodate. Parents talked of having to deal with issues related to older children acting in a way that was seen as improper (for example, exposing themselves).

*"He can just blurt out this word, a really horrible word that nobody's meant to say, and you can actually get cautioned for. He needs to know what it means and why can't say it."*

Parent

For one family, sex education was something that school did not seem to pick up with this child, and other professionals had not attempted to deal with it.

### 3.5.4 Analysis: Relationship between low income and infringements of rights to health

While there were examples of good practice, some children and young people encountered difficulties in relation to health services. Table 3.5 shows how the problems identified led to problems realising eight of the cross-cutting principles. This was due to rigid eligibility criteria, budgetary priorities, absence or discontinuity of service provision and staff, lack of skills or understanding, underestimation of children's capacity, lack of local provision, lack of health promotion and service cut backs. In relation to three principles (survival and development, Best Interests and personal assistance and support), low income made it harder for parents to meet the shortfall left by inadequate service provision. A particularly vulnerable time in relation to health was the transition to adult services and the perceived inflexibility of adult services when compared with some of the best children's services.

Table 3.5: Infringements of right to health			
The Principle	The Right	The Problem	Suggested Causes
<b>Survival and development</b>	<b>You have the right to support and care to help you be as healthy as possible.</b>	Seizure warning alarm not classed as essential.  Only resources classed as essential are provided.	Rigid eligibility criteria.  Low income.
<b>Best Interests</b>	<b>What health care you have should be decided by thinking about what is best for you and asking your opinion.</b>	Insufficient quality and quantity of incontinence pads.	Budgetary concerns appeared to come before quality of service provision. Low income.
<b>Personhood, evolving capacity and independence</b>	<i>The right to a smooth transition to adult services.</i>	Move from children's services to adult services with no provision for direct access to ward in an emergency.	Absence of young people's transition services.  Discontinuity of service between child and adult services.
<b>Participate</b>	<b>You have the right to help make decisions about your healthcare.</b>	Occasional professional inability and unwillingness to communicate with child.	Lack of skills, knowledge or understanding of disability and children's rights.
	<b>You have the right to information about health care and services.</b>	Children and young people not actively engaged in health care encounters.	HCPs and other adults under-estimating capacity of and importance to children and young people in decision making.

<b>Inclusion</b>	<b>Health services should be near to people and places you know.</b>	Difficulty in accessing services due to geographical distance.	Specialist services are located in tertiary centres creating access problems.
	<i>You should, wherever possible, be cared for by professionals who you know.</i>	Challenge for child and family when care is provided by HCPs who are not knowledgeable about child's clinical and other history.	Changeover of staff, referrals to new services and transition to adult services.
<b>Personal assistance and support</b>	<b>Your individual needs should be identified quickly and the personal support, aids and services you need, should be free of charge (as far as possible).</b>	Clear and generalised agreement about what can be defined as being essential.  Inflexibility in the supply of incontinence pads to meet young people's evolving needs.	Absence of free provision.  Parental low income.
<b>Adequacy and availability</b>	<b>Teenagers should have information about sexual health and relationships.</b>	Disabled children, especially learning difficulties, not identified as requiring sexual health and relationship education.	This element of a disabled child's growth and well-being not seen as an issue by HCPs.
	<i>The care you receive should not only support acute needs but should promote your health and well-being as well.</i>	Care is sometimes reactive to presentation of acute problems, physiotherapy and other services which could promote well-being not perceived as essential.	Care provided primarily responding to problems and issues rather than also encompassing health promoting interventions and actions. Cut backs evident in services designated as non-essential.
<b>Training</b>	<b>Health workers should be trained to understand your needs and respect you and your rights.</b>	Health workers not necessarily confident in communicating with children with disabilities and their families.	Health workers communication skills generally focus on verbal modes of communication.
	<i>Health workers should be trained to communicate with you and your family.</i>	Health workers not adequately prepared to communicate effectively with children with disabilities.	Health workers either not accessing or not being provided with adequate training opportunities.

### **3.5.5 Analysis of the impact of low income in this context**

Some of the difficulties encountered by the children, young people and families we spoke to mirrored findings from other research with low income which has indicated the difficulties that low income families can encounter in accessing healthcare services (Green, 2007). This difficulty in accessing support compounds the stress and inadequate food and housing which other families have also observed contributing to their poor health (Ridge, 2009).

The difficulties parents described in our study are consistent with various studies which have documented the difficulties that disabled children, young people and adults experience when using NHS resources (EDCM,2009; Michael Report, 2008, Kennedy Report, 2010 and MENCAP, 2012).

One of the recurring concerns this report highlights is the lack of support for children and young people's agency. This theme does not offer specific examples of children's agency being supported. However, it does offer examples of it being undermined, where a child is so frightened of going to hospital that he needs medication to calm him down, or where a doctor walks away from a child because of the child's inability to talk. Where professionals make the effort to bridge the communication gap themselves (rather than expect a disabled child to come to meet them), and offer the time and patience to engage sensitively with each young person as an individual, then young people can feel much more in control of what is going on, and more able to express their wishes and feelings with some confidence. Again it is important to note that supporting agency is not dependent upon income.

### **3.6 Play, association, sport, leisure and cultural activities**

Ashleigh's story was selected by the young people's steering group to illustrate this theme. Although her story is not the most dramatic it raises key issues that are relevant for many children, including not being able to afford leisure activities; transport barriers to inclusion in play; and constraints on children's decision making. Other children and parents, like Joe in the basic needs theme, raised further concerns about the lack of sustainable provision; facilities that were not appropriate or absence of personal support; and exclusion from the mainstream services.

Significantly there are also some positive examples of service provision, that enabled inclusion in both mainstream and specialist activities. These included activities in which disabled children took the lead in decision making.

## Story six: Ashleigh



Ashleigh is 15 years old. She has a visual impairment and a learning disability. She goes to a special school and lives with her mum in a rented house. Her mum does not work. Ashleigh loves clothes, make up, animals, and spending time with friends.

Ashleigh enjoys going to a youth club run for disabled children around the corner from where she lives. She gets to spend time with her friends there.

When Ellie, from the Steering Group, read about Ashleigh she drew this picture to analyse the situation.



Ashleigh does not get pocket money – she says she would like to. She gets bored during the school holidays. Her mum does not drive – the organisation that runs the youth club puts activities and trips on during the holidays, but they are expensive, they used to be cheaper. Ashleigh's mum said:

*"You have everything else [costs like bills and the next set of new glasses to pay for] and you think... "can I afford the next trip?" ... and you have to turn around and, you're not being horrible but you're being realistic and say, "I'd like to but sorry, I can't [pay for it]".*

Her mum also said that the local council puts on some free activities, but because she can't drive, transport is an issue. Taxis are too expensive, and Ashleigh cannot travel by herself.

Ellie said she felt nervous reading Ashleigh's story because, *"she is living in poor condition."*

When Ellie told this story to the steering group, David commented:

*"Many of these stories are the most bad. So, why don't the Government read these stories about someone disabled? It would encourage them to do better."*

### 3.6.1 The importance of association with friends

Parents and young people explained the importance of leisure activities as a means of ensuring young people's inclusion in the community. Young people said, *"staying at home all the time, it's like your life's in hell"*.

A parent explained, *"it's the isolation I think is the worst for somebody like [child's name], you know, not being known in your local community"*.



There were many examples of children and young people attending youth clubs, short breaks with activities, going swimming and horse riding and joining clubs like sports, dance and scouts. However there continue to be barriers to disabled children's involvement in these activities for the reasons set out below.

### 3.6.2 Sustainable provision

Most families described the need for more local activities. One parent explained the relationship between the decreasing availability of services experienced by children with different impairments:

*"there's holiday clubs for children with disabilities obviously, [though] not as much as what there is for children with normal development. But children with mobile disabilities [have some services]... there's nowhere for a child in a wheelchair to go on a holiday club"*.

Where there were youth club or holiday provisions accessible to all, families had concerns about sustainability and lacked information about what was happening, as this parent described:



*"I don't really know the reason they closed it, they didn't really say but they've closed"*.

There were frequent descriptions of services which the children had enjoyed but which closed down due to funding being withdrawn. In any one area demand outstripped resources, for example, as services that were ideal for young people with autism would not necessarily be appropriate for young people with other impairments.

### 3.6.3 Not being able to afford leisure activities

For the remaining services, most required payment which put additional pressure on family budgets, and involved decisions about priorities. Leisure activities were expensive and parents could not go for cheap options. One parent explained:

*"all of your DLA would go for a month on a weeks, a week at [playscheme 1] ... [playscheme 2] is five pound a day, which isn't so bad, but again it's segregated, it's not, it's not getting out and about with the rest of your pals is it?"*



A mother of a young person with complex medical needs shared how she had to choose between providing her son with a high calorie diet or going to a holiday caravan with a hoist.

Holidays were seen as an important part of children's and families' lives. However, not all families could afford to take holidays and sometimes children only got a holiday if they were lucky enough to be selected to have a holiday. One young person explained:

*"I'm really hoping I can get to go... I'm praying hard I can get to go on it. If there's spaces ...they let us go, if there's no spaces you can't go... It's a list thing".*

Another parent receiving income support explained that the cost of the sort of specialist holiday offered by a charity was beyond her means.

*"You look and think, you know, sixty pounds a lot when you're having to pay bills and everything else, you look and you think ooh that's out of my price range. If it's twenty pounds or ten pounds, you don't mind, you think that's not an awful lot but sixty!"*

### **3.6.4 Transport and geographical barriers to inclusion in play**

Families had to use private transport because of children's particular needs. Parents felt that this was expensive and sometimes meant children could not attend activities.

One mother felt her son was missing out socially as it was not easy to have his *"friends round from school... because [his friends] all on transport, they've all got different needs"*.



Families in rural areas faced an absence of local facilities. When one entrepreneurial parent tried to take action on this herself, to set up a local ball pool, she had to 'scrap' the idea as the insurance cover was too expensive. Stigma and lack of respect could also limit access to leisure facilities in the community.

One family explained that other people's reactions to her son's behaviour meant that they *"can't really take him out that often because you get funny looks on the bus"*.

### **3.6.5 Exclusion from the mainstream**

The choice between specialist and mainstream provision was not always available, as shown in these comments from parents:

*"There's still a lot of stigma, there's a lot of discrimination and these mainstream groups do not take on kids with disabilities."*

*"I'd rather him go to a mainstream group, but is he going to get looked after or is he going to get his head kicked in?"*

When trying to access mainstream dancing classes a mother was told that they had "nothing suitable" for her daughter.

One young person described what happened when she went to mainstream activities:

*"Some parents [aren't very friendly]. The parents, it's like, it's just the parents. The kids are alright".*

A lack of changing facilities presented a further barrier. Parents reported being asked to *"pick them [children] up and fetch them home...if their nappy needed changing"*.



As children got older and larger, finding appropriate changing facilities in the community became more difficult. A London Tourist Information Office responded to a request for information about assisted bathrooms with the advice:



*"Take a travel rug and change him [her son] on the toilet floor."*

Some confident parents overcame the stigma. One mother described how her son went to mainstream swimming lesson although *"they [the coaches] would rather he didn't."* Her rationale for challenging this discrimination was that:

*"the system would special him to death if they had half a chance, special everything, special, special after school clubs, special out of school clubs, special activities, special absolutely bloody everything and I won't have it, and it's actually quite hard to defeat the system in this respect and to get out of it, because, you know, the system is anything but inclusive."*



Conversely, there were some good examples of children gaining access to mainstream activities. One child was a member of his local Cubs pack and his participation was supported by having *"a young leader that helps him and old Explorers – sort of take him under their wing"*. Another mother described setting up a dancing club with the support of her friend and her local church.



Where specialist provision was particularly successful, disabled young people had their own organising committee which made decisions about activities organised. They lobbied for councils for funding and developed their skills and confidence.

### **3.6.6 Analysis: Relationship between low income and infringements of rights to play, association, sport, leisure and cultural activities**

Table 3.6 shows how the problems identified in this theme were related to different rights and caused by different factors. Low income, inadequate service provision and discriminatory attitudes led to breaches of this right related to seven key principles: equality, best interests, participation, inclusion, personal assistance, adequacy and training.

Low income was a particular barrier to inclusion, because of the cost of leisure activities and transport. Insufficient prioritisation of funding for disabled children's activities and the personal support to facilitate this was also a factor. There were examples of a lack of physical resources and spaces (e.g. changing facilities) and a shortage of appropriately trained staff.

**Table 3.6: Infringements of rights to play, association, sport, leisure and cultural activities**

<b>The Principle</b>	<b>The Right</b>	<b>The Problem</b>	<b>Suggested Causes</b>
Equality	You have the right to equal opportunities ... any reasonable changes should be made so that you can play/meet with others/do sport/take part in activities.	Inadequate availability of provision that meets the needs of children with disabilities.	Budget considerations mean no/minimal investment in spaces/ places for play.
	<i>You have the right not to be discriminated against when you take part in mainstream activities.</i>	Mainstream activities inappropriately assess risks and are unwelcoming.	Lack of understanding about integration of children with disabilities.
Best Interests	<i>You have the right to be safe when you play/meet with other people/take part in activities in your community/local area.</i>	Physical spaces in which activities take place not safe and/or resourced for needs of some disabled children.	Lack of funding and lack of prioritisation of need to provide local places to play safely.
Participation	<i>To have information to enable you to make informed decisions about what to take part in.</i>	Children not involved in decisions about them and not give choices about what they want to do.	Lack of insight that children should be given opportunity to direct their own play.
Inclusion	<i>You have the right to meet with other people/ play/do sport/take part in activities in your local area.</i>	Children having to travel well outside of their own community to be able to engage in activities.	Lack of income to pay for transport to out of area facilities.  Differences between local borough provision.
	<i>You have the right to be with people and part of things, as far as possible, so you are not isolated.</i>	Children trapped in their own homes and denied opportunity to be with other people.	Lack of income and/ benefits to support travel.  Lack of income and/or lack of benefits or allowance to support carer's travel costs to accompany child.

Personal assistance and support	<i>To meet with other people in ways that you enjoy.</i>	Not enough opportunities for children to be able to participate in things they are interested in.	Budgetary constraints mean lack of local activities.  Lack of income to be able to join in activities of their choice outside of local area.
	<i>You have the right to personal support to take part in leisure activities.</i>	Insufficient personal support means that children are totally reliant on their family.	Budget considerations do not deem play/leisure/sport as essential.
Adequacy and availability	<i>To have activities in your community that meet your basic needs that you can afford to attend.</i>	Not enough local and affordable opportunities that are appropriate to individual children's needs.	Lack of income means that getting to/joining in activities is beyond their financial reach.
	<i>To have enough opportunities to take part in play and activities in your own community.</i>	Not becoming a member of the local community.	Lack of local funding results in lack of good quality, appropriate services.
Training	You have the right to be supported to play/meet with others/do sport/take part in activities by youth and play. workers who are trained to understand your needs and respect your rights.	Inexperienced and untrained staff unable to communicate effectively with child so rights are infringed.  Potential over-estimation of risks in undertaking routine care such as nappy/pad changes.  Mainstream services framing inclusion as problematic.	Lack of training and under-resourcing of staffing for activities, sports and leisure.  Lack of funding and investment in staff results in exclusion of children with disabilities.  Budget considerations side-line and/or override inclusion and mainstreaming.

### 3.6.9 Analysis of the impact of low income in this context

Some of the key challenges that parents, children and young people face in trying to give effect to the right to play are common to children who live in on low incomes. Other studies have found that, for low-income children, opportunities to use and enjoy public space and street play are an essential compensation for the restrictions and lack of space in many homes (Ridge, 2011), but it is precisely this sort of informal play that is denied to many disabled children through lack of personal support, or the impact of specialist education provision meaning their friends are spread over a wide geographical area.

Taking part in organised leisure opportunities is also difficult for non-disabled low income children, with barriers arising due to limited provision, location, attitudes towards young people, cost of participation, and inadequate transport. Disabled children from low income families face additional

difficulties where limited mainstream provision may not make the necessary adjustments to be accessible and where specialist inclusive services are more costly.

The experiences shared with us here demonstrate that disabled children's and young people's agency is being limited by constraints which in many cases could be removed by quite small additions to the available resources. Ashleigh's lack of pocket money may be the result of low family income, as is her inability to afford the taxis that would enable her to travel independently. Lack of transport combined at times with exclusion arising from staff lack confidence and knowledge and in some cases the disappearance of specialist play schemes. On the other hand, we also find positive examples of children, young people and their parents setting up or directing services and children's inclusion being supported by appropriate personal assistance. These examples show how agency is not always linked to low income, but how low income can compound barriers to effective independence and choice.

### 3.7 Mobility

The steering group selected Joe's story because it raises the issues of personal assistance to enable inclusion and independence through mobility. As has been seen in the repeated mentions of issues related to transport or distance, mobility is integral to others themes. In this theme young people and their families highlight the importance of equipment and public transport; dilemmas balancing safety with independence; and a lack of accessibility.

#### Story seven: Joe

Joe was introduced in the theme on basic needs and we learned a bit more about the activities he likes to do in the last section. Joe's mum is frightened of going out. She described her fear:

*"oh it's awful... because I suffer from that agoraphobia. Going out... it's awful."*

Joe's mum said he goes out with carers but there is a bit of a problem:



*"they don't like take him anywhere... in the summer, yeah, it's alright, he can go out but he'll just walk, they'll just walk round the park. In the winter it's like [if it's raining]... they couldn't lift him [into the car]. So I'd have to lift him obviously in the car, but then they wouldn't be able to lift him out of the car to go somewhere."*

When the steering group discussed Joe's story, Dan thought it was unfair that Joe may not get the freedom to go out, *"If that child wants to go outside he should be allowed to do so"*. Reese said, *"they need a special vehicle"*.

Zac said, *"Joe's mum perhaps needs a befriending or mentoring arrangement to get her out of the house and give her reassurance that nothing's going to go wrong. It just might get her confidence up so that she can feel free to go outside and take her son out and basically socialise"*.

They also noted the need for more training for the staff to obviously help them with lifting or provide them with a car with a wheelchair access and a lift.

### 3.7.1 Personal assistance, equipment and public transport



Children's mobility rights rely on their parents' economic resources and social capital, and other appropriate personal assistance, equipment and accessible transport. Some young people were getting support such as training on using local transport and accompaniment, while others were not. A young person who communicated with closed responses talked about this with an interviewer as shown in the conversation below:

*Interviewer:* "Have you got somebody who does that kind of thing with you [being a personal support person] to keep you safe when you are out in your local area?"

*Young person:* "No."

*Interviewer:* "How about going out in the community and going on buses, can you do all of that on your own?"

*Young person:* "No."

One parent talked about the expense of paying for carers' tickets as a barrier to using public transport, which limited her opportunities to go out. Another parent said:



*"my main problems, most of its transport based. If they helped towards taxis and transport you'd have a wider availability of things. I tend to shop local".*

Due to the limited rural bus and train services the time involved in using public transport was a problem for her:

*"sometimes when you drop them off it's time to turn back around and pick them up again".*

### 3.7.2 Safety versus independence

One young woman with a learning disability, who attends a day centre every day, said that her lack of personal assistance made her feel unsafe travelling and in her community. She said that if she had more money this would help her buy the personal support she needed.

Other young people talked about security and safety on public transport. Safety while using buses was a problem that was frequently remarked upon. One young person described feeling uncomfortable because of drunkenness and strangers on buses:

*"it makes you feel awkward. Also, there's where to stand, sit and look on a bus because if you stare at someone dodgy they get upset".*



In contrast, another young person was frustrated at his parent's and teacher's insistence that he should not cross roads by himself, even though he was of secondary school age. Although his mother was keen to explain the issues around teachers' responsibilities for health and safety, the young person did not think it was necessary to help him. He had a strong wish for increased independence.

This desire for independence was echoed by other young people. For example, one young person who had autism said support to learn to use public transport was very important to help him realise his right to be independently mobile.

### 3.7.3 Accessibility

For children who used wheelchairs, buses were often not accessible. Access to cars through the Motability scheme was described as providing crucial support to families with disabled children – it enabled children to be involved in day to day activities in the community and not confined to their homes. Motability vehicles were described as essential for accessing specialist health services. One parent described popular misconceptions about Motability vehicles:



*“you’ve got to put a big deposit down that you lose – there’s a misconception about disabled people having free cars”.*

Motability vehicles were important when family cars were not big enough to hold wheelchairs and every family member. The private transport provided could help ensure the safety of children with autism and severe learning disabilities, who, because some have no sense of danger, regularly run away from parents, or try to get out of the vehicles they are in.



Young people described how money could help in realising their right to mobility, by giving them access to driving lessons. Nathan, aged 20, however, said he’d asked his mum for lessons but she had said “no” as “*money’s a bit tight*” and his fortnightly ‘dole money’ of £110 was not enough to pay for lessons himself.

### 3.7.4 Analysis: Relationship between low income and infringements of rights to mobility

Table 3.7 shows how the problems encountered by some children, young people and parents relate to seven principles within this rights theme. Three of these (personal assistance, inclusion and adequacy) were directly related to low income. Low income could mean that young people could not afford the personal assistance they needed, that parents could not afford to pay the transport fares of personal assistants, or that driving lessons were too costly. In some instances rights were also breached by a lack of affordable or accessible service provision.

Table 3.7: Infringements of right to mobility			
The Principle	The Right	The Problem	Suggested Causes
Equality	Transport providers have a duty to make any changes you need, such as giving you help getting on and off trains.	Inadequate availability of provision that meets the needs of disabled children.	Lack of appropriate information, advice and support.
Best interests	You have the right to be able to get around safely, including on the street and when using public transport.	Public spaces and transport that are not safe and/or resourced for the needs of disabled disabilities.	Under-funding and lack of prioritisation of need to maintain safe public spaces and transport.

Respect, personhood, evolving capacity, independence	<i>You have the right to support that enables you to move around as freely as possible.</i>	Inadequate availability of personal support to assist disabled children to get around as they grow.	Lack of priority and funding to support disabled children's independence.  Low income making driving lessons unaffordable.
Inclusion	<i>The right to assistance with mobility beyond your immediate local area, to enable inclusion in the wider community (this is a new rights claim to be added to the matrix).</i>	Parent who has to 'stop local' and others who related their experience of confinement.	Low income.  Lack of affordable or accessible public transport.  Absence of personal support.
Personal assistance and support	<i>You have the right to personal support, specialist services appropriate vehicles and other supports to enable your mobility.</i>	Inadequate availability of personal support, specialist services and appropriate vehicles to enable mobility.	Under funding and lack of prioritisation to provide personal assistance and support that promotes mobility.
Adequacy and availability	You have the right to free public transport whenever this is possible.	Not enough local and free public transport.	Lack of funding and priority to provide free public transport.
	You have the right to affordable aids and support with mobility.	Not enough affordable aids and mobility support.	Lack of funding to make mobility aids affordable.
	<i>The environment should be accessible to you.</i>	Environments are not accessible or set up to meet the needs of disabled children.	Lack of priority to make public spaces accessible for disabled children.
	Public transport should be easy to use.	Public transport is not always accessible.	Lack of funding and priority to make public transport accessible.
Training	<i>You have the right to training and advice to support your mobility from specialist staff.</i>	Inexperienced and untrained staff unable to communicate effectively with child so rights are infringed.	Lack of training and under-resourcing of staffing for mobility advice and support.



### **3.7.5 Analysis of the impact of low income in this context**

Children who live in on low incomes have recurrently described the lack of affordable transport being a barrier to their participation in activities in the community; “public transport can be expensive, inflexible and inadequate, it can also make them feel unsafe” (Ridge 2011: 79). Our research confirms that the problem is compounded for young people who live rurally where bus services may be poor. Children who are disabled face further difficulties as transport is not always accessible, and personal support is not always available. For some participants in the study, vehicles provided safe means of transport for children and young people who could not use public transport due to their health care needs or behaviour.

If young people cannot get about when and where they need to, their right to live with a degree of autonomy is massively compromised. This applies whether it is a fit and active young person who simply needs good public transport that does not cost more than they can afford, or someone who needs to be lifted and carried. Sometimes the obstacles may not be financial: for instance, the young man who thought his parents and teachers were wrong to insist that he should not cross roads by himself. In many cases, however, the obstacles are directly related to low family income, as we have just seen. Unless these issues are addressed, many young people will continue to be unnecessarily restricted in the lives they can lead for themselves.

### **3.8 Right to work**

A discussion between two of the steering group members was chosen to illustrate the right to work because it demonstrated issues of discrimination; training and education; the need for reasonable adjustments in the workplace; and importance of personal assistance that are shared by many disabled young people.

Other young people spoke about appropriated meaningful work and other activity; and how they dealt with competition for work.

## Story eight: Zac and Azraa

This is a summary of 18 year old Zac and 16 year old Azraa's discussion about work. They are both visually impaired.

Azraa talked about her ambition to be a nurse and Zac, who is currently a youth council member, is hoping to become a youth worker.

Zac and Azraa said that disabled young people *"don't get the right to work because people think you're not capable of doing it."* They believed that some jobs need certain abilities, like sight, whilst other jobs need support such as the availability of braille or adapted equipment.



However, Azraa described getting exactly the kind of support she needed at college to follow her career aims and the effort she put in to realising her ambitions.

Both Zac and Azraa said that *"People want to be independent, treated equally and achieve something in their life"* and *"if people don't get the right to work they feel pushed to the side and not accepted in society"*.

With regards to what needs to change to support disabled young people to achieve the right to work they suggested that:

- employers need to adapt things and find a way that suits them to do things
- we need an educational service that explains what disabled people can do
- we need help and support to work in employment, like you get help and support in education.

### 3.8.1 Discrimination

Both the UN conventions that provide the framework to this research and UK Equality Legislation clearly state that disabled young people should not be discriminated when it comes to opportunities to work. Yet while this right is widely acknowledged there was some discussion amongst the young people about the likelihood of being able to work and gaining paid employment. Two young people said all disabled children *"have the right to work"* but two others said they did not think they would ever work. Another said that, *"everyone's all equal, so we should get a job"*.

However, many young people described discrimination making it difficult to access employment and in training:



*"Yeah. I think that people who are disabled; some people turn them down and say you can't have this choice because you're in a wheelchair. I think that's wrong – they should let them do the job they want, no matter if they're in a wheelchair or not."*

*"I tried so many jobs, like working in cafes or like working in youth clubs... and like people dishonour me... they say I know your reference is good... but the thing is we can't let you be here because you've got ADHD, then like, upsetting my disability."*

*"they make me Hoover all the stairs ... I had to wash everything up, get everything off the shelves... took me all day, one day to wash everything."*

This last quote was in relation to a current childcare work experience placement. The young trainee told us she only spent ten minutes with children during a whole day.

### 3.8.2 Training and education for employment



Despite these difficulties there were examples of successful matches between young people's interests and their employment or training opportunities. A special school had arranged work experience at local stables for a 16 year old girl who loved animals, which boosted her confidence for the future:

*"I don't think I'd need much help with animal work, I think I'd be able to get on with that."*

But some young people lacked education in basic skills, such as maths. One young person said:

*"I haven't seen much training for disabled people."*

Many parents were concerned that their sons and daughters would be left without any day time activities once they left their special schools.

### 3.8.3 Appropriate work and meaningful occupation

Young people and parents were sometimes concerned about whether the work or occupation offered to them was appropriate. A parent suggested that home was the only place that her son felt safe, and emphasised that he:

*"doesn't like touch, which could make going to work quite difficult".*

A 22 year old man with learning disabilities, who was keen to work, described becoming anxious when his job centre suggested that he should become self-employed:

*"Self-employment means me earning my own money, where I'd lose my benefits automatically and I can't afford to do that. Without them benefits I can't feed myself. I can't live."*

Self-employment would be difficult for him as he said he has no idea about money or risk; when on work experience with a gardening company he said he had nearly cut his hand off because he was not aware of some dangers. The suggestion that he should take up self-employment had caused both him and his mother a great deal of worry and uncertainty.

Reflecting on this, steering group members stated:

*"The Government are too insistent in pushing disabled people into jobs. Tests of eligibility for benefits should be changed as the forms are too long and confusing, it feels like they are written to trip you up."*

In the absence of appropriate work opportunities, some young people spoke of the importance of a day centre which they attend every day and where they were learning cooking, English and dancing. Their accompanying worker explained that the centre used to provide employment experience in their own café and now provides young people with support to do courses and training, but that there was very little equivalent suitable provision across the local authority.

### 3.8.4 Competition for work

Young people described a range of jobs they would like to do. These included being a dancer, teacher, musician, working in shops, chef, footballer and working with computers. They were all putting efforts into acquiring the necessary skills to perform these roles. One young person who hoped to get a job in a café talked about practising washing up at home, whilst another was practising his computing skills to improve his job prospects.

They also described the challenges of a competitive job market:

*"You have to have the qualifications and you have to have the right experience for the job, otherwise you won't get in."*



*"There's always someone, there's going to be someone better."*

### 3.8.5 Analysis: Relationship between low income and infringements of rights to work

Table 3.8 shows how the problems identified in this theme related to six cross-cutting principles.

Young people were very keen to work and had ambitions (although in some cases they had never been asked about these before).

Low income did not appear to have a direct impact on realising this right, wider social and community factors were more significant. Lack of work opportunities, lack of training opportunities, workplace discrimination and insufficient funding of support services were the key issues.

**Table 3.8: Infringements of the right to work**

The Principle	The Right	The Problem	Suggested Causes
Survival and development	You have the right to work, when you are old enough. This work should not be harmful.	Inadequate educational, training and few employment opportunities.	Lack of priority and provision in preparing disabled young people for employment, lack of employment vacancies.
Equality	<i>You have the right not be discriminated against when looking for work, when seeking promotion or when trying to keep your job.</i>	Negative attitudes and perceptions towards disabled young people by employers and employees.	Lack of awareness and equality in employment opportunities.
Best interests	<i>You have the right to be protected from compulsory labour.</i>	Young disabled people being forced to take on inappropriate work.	Lack of training and awareness around the needs and abilities of disabled young people in the work place.

Respect personhood, evolving capacity, independence	<i>You have the right to meaningful occupation if you cannot work.</i>	Lack of supported and open employment opportunities.	Lack of priority and appropriate opportunities for young disabled people who wish to work.
Participation	You have the right to make decisions about what work you do.	Young disabled people being forced to take on inappropriate work.	Pressure to take up self-employment even if this is unsuitable.
Training	<i>You have the right to training to help you get the kind of work you want.</i>	Lack of opportunities to gain training and experience.	Lack of training and under-resourcing of staffing.  Insufficient requirement for mainstream services to make reasonable adjustments.

### 3.8.5 Analysis of the impact of low income in this context

Our findings confirm earlier research in which gaining employment and access to an income was seen as important for disabled children (Sloper et al, 2008). Children living in deprived areas, however, have fewer opportunities to gain employment due to a lack of work opportunities (Ridge, 2011). Lack of the social capital (that is, networks of connections with people who can offer job opportunities) is a common factor for disabled and non-disabled children (Beresford 2006). Some of the additional barriers resulting from disability that parents, children and young people face in attaining these rights are: training, specialist advice/guidance around adequate adjustments, meaningful supported employment opportunities (for those unable to obtain a job), and discrimination.

In the matrix we noted the need for benefits workers to be properly trained but, there appears to be a culture of expectation that people on benefits should be working. Not all of the young people who participated in our research felt that they would be able to work, because of their cognitive, emotional or behavioural impairments.

It is surprising that young people outside of the steering group did not mention reasonable adjustments or personal support in relation to work. This reflects perhaps a lack of awareness of their rights in this area.

In this theme there are several positive examples of disabled young people's capacity for exercising individual agency. Zac and Azraa talked about young people's capabilities for different types of work, and of the need for support to enable them to do particular jobs. As they told us, '*[disabled young] people want to be independent, treated equally and achieve something in their life.*' Young people showed determination and perseverance, practising washing up in order to get a job in a café, or practising computing skills to improve their job prospects, identifying gaps in their education (eg maths skills) or demanding the training courses that would improve their prospects.

## 4. Recommendations: Relevant duty bearers and what they should do

It is the Government, as the signatory to the UN conventions used to frame this research, and as the State Party, that has a duty to give effect to disabled children's rights. The UN expects the Government to do so to "the maximum extent of available resources." Children and disabled children in particular, are especially vulnerable and sensitive to reforms that may affect the support they receive.

Together with the rise in children living in poverty this research has considered how income impacts the ability of disabled children and young people to attain the entitlements set out in UN conventions. It clearly demonstrates that income has a profound impact on the lives of the children and families we spoke to. However it is not the only factor that acts as a barrier to rights.

It is also clear from our work that, while the Government may be ultimately responsible for ensuring disabled children's rights, families, communities, and local services play a crucial role in this story. Therefore, having played a central role in developing and conducting the research the steering group of disabled young people wanted to use the information they had studied to suggest a number changes that they feel could improve the realisation of disabled children's rights, especially those living on low incomes.

The OCC feel that it is important to present these in full, and demonstrate that they have played an important role in developing our own final recommendations below.

### **The project steering group proposed:**

1. Changes to the benefit, welfare and social support system
  - a. Set budgets that give greater priority to ensuring that disabled children and young people have the basic things they need for living.
  - b. Ensure plans for social security reform and benefit levels are set through listening and giving due weight to the views of disabled children and young people and their families.
  - c. Put on hold the piloting of Personal Independent Payments (PIP) until a thorough review has been undertaken of its potential impact. They should listen to the ideas of more people with different disabilities, to learn from them first about how much they need for living and what would happen if they were in receipt of PIP.
2. Improved provision, appropriateness and timeliness of services
  - a. Enable everyone to have access to specialist education services across the country, to ensure all disabled children are able to reach their full potential.
  - b. Ensure there is enough high quality, short break provision to meet the need for disabled children to have a break away from their families.
  - c. Ensure speedy compliance with adaptations to housing. Adopt mechanisms for monitoring and comparing speed and level of provision of adaptations between different local authorities so that standards can be raised in those authorities where there are unreasonable delays.

- d. Provide more free youth clubs and play, leisure, sport and cultural activities for disabled children.
3. Better support, advice and training for disabled children, young people, their families, and those working with them
    - a. Give children and young people more access to personal assistance to support them to do the things they want to do and help them be more independent. Personal assistance should be free and provided by organisations such as local authorities.
    - b. Ensure enough of the right kind of training is provided to teachers, doctors and youth club staff about the rights of disabled children and young people.
    - c. Ensure young people can access personal assistants to help them realise their rights to independence. They must be trained in lifting and handling to enable mobility and the focus of their support must be to enable children and young people's inclusion and independence.

## **Recommendations from the Office of the Children's Commissioner**

### **Recommendations for the Government**

1. Undertake an independent review of the adequacy of support for disabled children and young people. This should include:
  - a. 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 faced by families with disabled children.
  - b. The adequacy of education, health and transport services, in terms of amount of provision; costs of accessing these services/ cost at the point of delivery; and quality of service provided.

If the Government accepts the Equality and Human Rights Commission's recommendation to establish a new strategic advisory group on disability, this work could be carried out by this new body.

2. Departments with responsibility for welfare reform and child poverty should ensure that disabled children and young people and their families are directly involved in decisions relating to welfare reform and development of future child poverty strategies. Their views should be listened to and taken into account.
3. Publish clear, accurate and reliable information about rights and service provision for disabled children and young people. Information and advice about benefits, funding for specialist equipment and accessible activities is a priority.
4. Ensure greater awareness of disabled children's rights across Government departments and encourage the same awareness in local services and statutory bodies through training and inspection systems that understand the importance of realising disabled children's rights. An awareness of children's rights must include appreciation of their personhood and evolving capacity and ambitions, and necessitates the development of appropriate communication skills.



## Recommendations for local authorities

5. Local government should audit existing provision to identify needs and gaps in accessible youth provision including play, leisure, sport and cultural activities for disabled children and young people and publish its plans as to how these services will be provided and sustained. Services used by disabled children and young people must have adequate and respectful facilities to meet their needs (for example toilet and changing facilities), and be run by staff who are well-trained and informed about working with disabled children and young people.
6. Local government should ensure that all disabled young people can access local short break provision. This provision is key to enabling disabled children's and young people's rights to independence away from the family and access to play and leisure.
7. Local government must provide disabled children and young people living in low income families with the means to access play, sport, leisure and cultural opportunities in their local community. This may include, but is not restricted to, improved transport services (particularly in rural communities).

## 5. Conclusion

Many of the difficulties these children and young people encountered are similar to those that other children living on low incomes have identified in previous research. This underlines the role of low income as an indirect causal factor in the infringement of rights, even where it was not directly responsible. For example, living in a service-poor area (associated with low income) could compound other difficulties.

Our work did show how low income is a vital component in explaining why some disabled children and young people fail to enjoy their rights. In some cases low income is a direct explanatory factor. In others money enables individuals and families to find alternatives to provision and support that they are denied or unable to access from public services.

Therefore, money – both family income and public funding – can make a difference in all of these areas, but it should not be a barrier to improvement. Yet money, or specifically low income, was not always the main or only reason why some disabled children and young people were not able to attain the rights that should be afforded them.

Disabled children also faced additional barriers to the enjoyment of their rights that arose from a lack of training for the professionals they relied on, inadequacy of provision, insufficient personal assistance, and the principle of best interests being inadequately applied to decisions that affected them. This was symptomatic of a lack of priority being accorded to the obligation to respect, protect and fulfil the rights of disabled children.

This report offers a series of recommendations set out in section 4. These are focused on addressing the main obstacles disabled children and young people face in being able to attain their rights. Low income is a very important factor in explaining the difficulties many disabled children and young people face, and therefore a number of the recommendations to the government concern the need to address this matter.

With the number of children living in poverty likely to rise significantly over the next five years, and the disproportionate numbers who are disabled, the challenges and difficulties revealed in this report make support for the families and young people we worked with all the more urgent.

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