

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

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.¹ 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

¹ 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 1.²

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

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).³

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

³ 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 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 terms⁴ 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)

⁴ 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.⁵

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

⁵ 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 [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.⁶

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 impairments⁷)
- 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 2.⁸

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.⁹

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

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.

9 The matrix of rights is also available separately at 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.

Table 2.1a: Cross-cutting principles			
Cross-cutting principles	UNCRC Articles	ICESCR Articles	UNCRPD Articles
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.

Table 2.1b: Rights themes			
Rights themes	UNCRC Articles	ICESCR Articles	UNCRPD Articles
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>					
A	Survival and Development	Non-Discrimination Equality of Opportunity and Reasonable Accommodation Discrimination	Best Interests	Respect, Personhood and Evolving Capacity, Independence	Training
	<ul style="list-style-type: none"> - You have the right to life, survival and development. 	<ul style="list-style-type: none"> - You have the right to be treated fairly. 	<ul style="list-style-type: none"> - All actions should be taken by thinking about what is best for your wellbeing and by taking account of your wishes. - To feel safe, not distressed and understood. 	<ul style="list-style-type: none"> - You have the right to be treated with respect and dignity. - You have the right to be encouraged to develop independence. - To have praise and encouragement. - To have privacy and your own space. 	
	<p>Participate, be informed and influence decision making</p> <ul style="list-style-type: none"> - You have the right to have a say in decisions that affect you and for your opinions to be taken seriously. - Your preferences should be treated seriously. - To enjoy yourself, be happy and express emotions (even if this is quite noisy.) 	<p>Inclusion in community and society</p> <ul style="list-style-type: none"> - 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. 	<p>Personal Assistance and support</p> <ul style="list-style-type: none"> - You have the right to access resources to support specific needs. 	<p>Adequacy, Availability Accessibility</p> <ul style="list-style-type: none"> - You have the right to be communicated with in appropriate different ways. 	

Intersecting Principles and Rights Themes – Care and Assistance for Disabled Children					
B	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"> - You have the right to life. - <i>You have the right to express your identity.</i> 	<ul style="list-style-type: none"> - You should not be treated unfairly because of your disability. - <i>You have the right to reasonable changes, to make sure you can enjoy your rights.</i> 	<ul style="list-style-type: none"> - 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. 	<ul style="list-style-type: none"> - You have the right to be supported to achieve your full potential. - <i>Support to achieve your potential should be given whenever opportunities arise, rather than seeing potential as a distant future concept.</i> - <i>To direct as much of life as possible, even if this is only at a very basic level.</i> 	
	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"> - <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> - You have the right to support so that you can communicate what you want. 	<ul style="list-style-type: none"> - <i>You should be included in your community and wider society.</i> 	<ul style="list-style-type: none"> - <i>You have the right to the support that you need to develop.</i> - <i>Support should be from people that you know and can develop a relationship with.</i> 	<ul style="list-style-type: none"> - <i>The care and assistance you need should be free, as far as possible.</i> - You should be able to access services, like education and health. - You should be able to participate in activities alongside children who are not disabled. - <i>To have people supporting you who are able to communicate with you effectively.</i> 	<ul style="list-style-type: none"> - <i>People should be trained to understand the rights and needs of disabled children.</i> - You have the right to information so that you can understand your disability.

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"> – 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. 	<ul style="list-style-type: none"> – You have the right to benefits or social support, to reduce your chance of living in poverty. 	<ul style="list-style-type: none"> – Your parents/carers have the right to enough <u>money, benefits and social support</u> to keep you safe. – What <u>money, benefits and social support</u> your parents/ carers get should be decided by thinking about what is best for you. 	<ul style="list-style-type: none"> – <i>You have the right to more control over money as you become more capable and experienced.</i> 	
	<p>Participate, be informed and influence decision making</p>	<p>Inclusion in community and society</p>	<p>Personal Assistance and support</p>	<p>Adequacy, Availability Accessibility</p>	<p>Training</p>
	<ul style="list-style-type: none"> – <i>You have the right to have a say about changes in how benefits and social support is provided.</i> 	<ul style="list-style-type: none"> – 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. 	<ul style="list-style-type: none"> – 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. 	<ul style="list-style-type: none"> – Your parents have the right to enough money, benefits and social support. – 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. – Your parents should get money (benefits) on time. This money should not be stopped without good reason. 	<ul style="list-style-type: none"> – <i>Social workers, youth workers, support workers and benefit workers should be trained to understand your needs and respect your rights.</i>

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"> - You have the right to live with your family. 	<ul style="list-style-type: none"> - <i>You should not be made to live apart from your family because of your impairment.</i> 	<ul style="list-style-type: none"> - If you are not safe at home, you have the right to live somewhere else where you can be properly looked after. - Where you live should be decided by thinking about what is best for you. 	<ul style="list-style-type: none"> - <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> - <i>If you are away from home overnight, staff should pay you attention and actively engage when working with you.</i> 	
	<p>Participate, be informed and influence decision making</p>	<p>Inclusion in community and society</p>	<p>Personal Assistance and support</p>	<p>Adequacy, Availability Accessibility</p>	<p>Training</p>
	<ul style="list-style-type: none"> - Parents and guardians should listen to your opinions and should encourage you to have your ideas taken seriously by everyone in society. - You have the right to help make decisions in your family about this. - <i>If you live away from home, or spend time away from home, you should help decide about this.</i> 	<ul style="list-style-type: none"> - <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> 	<ul style="list-style-type: none"> - <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> 	<ul style="list-style-type: none"> - You have the right to be cared for and treated kindly by your family. - You have the right to travel to see your family, if you do not live with them. - 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). 	<ul style="list-style-type: none"> - Your family have the right to information and training for family, so that they understand your disability. - <i>Short-break workers should be properly trained.</i>

Intersecting Principles and Rights Themes – Education					
F	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"> - You have the right to receive help with education to help you reach your full potential. 	<ul style="list-style-type: none"> - You have the right to support with school, and to reasonable changes in the way school is organised to suit how you learn. - You have the right learning that suits your religion and family traditions. 	<ul style="list-style-type: none"> - Schools should help protect you from bullying. 	<ul style="list-style-type: none"> - Your education should respect you and encourage your independence. - You have the right to education that suits you as an individual. - You have the right to be treated with respect at school. 	
	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"> - You have the right to input into decisions about what learning you do. - Your ideas should be taken into account when deciding what your school teaches and about education policy more generally. 	<ul style="list-style-type: none"> - All schools and colleges should be accessible. - Education should be inclusive. 	<ul style="list-style-type: none"> - You have the right to personal support from people like Teaching Assistants so that you can learn in ways that suit you. 	<ul style="list-style-type: none"> - You have the right to education that helps you learn and suits your interests. - You have the right to enough opportunities to learn about the different things that interest you. - You have the right to training to help you get the kind of work you want. 	<ul style="list-style-type: none"> - Teachers should be trained to understand disabilities and make sure you achieve your potential.

Intersecting Principles and Rights Themes – Work					
G	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"> - You have the right to work, when you are old enough. This work must not be harmful. 	<ul style="list-style-type: none"> - You have the right to not be discriminated against when looking for work, when seeking promotion or when trying to keep your job. - Any reasonable changes you need at work should be made. 	<ul style="list-style-type: none"> - You have the right to be safe when you are working. - You should be protected from work when you are too young. 	<ul style="list-style-type: none"> - To try to follow a career path that interests you. 	
	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"> - You have the right to make decisions about what work you do. 		<ul style="list-style-type: none"> - You should get personal support to find and keep a job. 	<ul style="list-style-type: none"> - You have the right to be paid for the work that you do. 	<ul style="list-style-type: none"> - You have the right to training to help you get the kind of work you want.

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 be safe when you 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 equal opportunities and 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>	
	Participate, be informed and influence decision making	Inclusion in community and society	Personal Assistance and support	Adequacy, Availability Accessibility	Training
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>	– <i>To meet with other people in your local area.</i> – <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>	– <i>You have the right to take part in activities at school and after school.</i> – <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>	– <i>You have the right to personal support to take part in leisure activities.</i>	– <i>Places you visit should be made easy for everyone to use, whatever your disability.</i> – <i>You have the right to take part in sports with disabled children and with non-disabled children.</i> – <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	
	– You have the right to support and care to help you be as healthy as possible.	– You have the right to health care to suit your needs and your culture and to <i>reasonable changes</i> .	– What health care you have should be decided by thinking about what is best for you and asking your opinion. – <i>People who give you health care should be friendly and help you feel safe.</i>	– You have the right to be respected by medical professionals – people like doctors, nurses and dentists.	
	Participate, be informed and influence decision making	Inclusion in community and society	Personal Assistance and support	Adequacy, Availability Accessibility	Training
	– You have the right to help make decisions about your health care and about health services. – You have the right to information about health care and services.	– Health Services should be near the people and places you know.	– 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).	– You have the right to the best possible health care. – Support and care should be accessible (simple to get and free of cost where possible). – Teenagers should have information about relationship and sexual relationships.	– Health workers should be trained to understand your needs and respect your rights.

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	
	– You have the right to support to get around.	– Transport providers have a duty to make any reasonable changes you need, such as giving you help getting on and off trains.	– You have the right to get around safely, including on the street and when using public transport.	– <i>You have the right to support that enables you to move around as freely as possible.</i> – You should not be forcibly moved without reason.	
	Participate, be informed and influence decision making	Inclusion in community and society	Personal Assistance and support	Adequacy, Availability Accessibility	Training
	– <i>You have the right to make choices about your personal mobility.</i>		– <i>You have the right to personal support, specialist services appropriate vehicles and other supports to enable your mobility.</i>	– You have the right to free public transport, whenever this is possible. – Public Transport should be easy to use. – You have the right to affordable aids and support with mobility. – <i>The environment should be accessible to you.</i>	– <i>You have the right to training and advice to support your mobility from specialist staff.</i>

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.¹⁰

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

¹⁰ 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.

Table 3.1: Infringement of right to basic things you need for living			
The Principle	The Right	The Problem	Suggested Causes
Best interests	<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.
Personhood, evolving capacity and independence	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.
Participate	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.
Inclusion	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.
Personal assistance and support	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.

Adequacy and availability	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.¹¹

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.

¹¹ 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

	The Right	The Problem	Suggested Causes
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."¹⁵

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.

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.

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

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

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
Survival and development	You have the right to support and care to help you be as healthy as possible.	Seizure warning alarm not classed as essential. Only resources classed as essential are provided.	Rigid eligibility criteria. Low income.
Best Interests	What health care you have should be decided by thinking about what is best for you and asking your opinion.	Insufficient quality and quantity of incontinence pads.	Budgetary concerns appeared to come before quality of service provision. Low income.
Personhood, evolving capacity and independence	<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.
Participate	You have the right to help make decisions about your healthcare.	Occasional professional inability and unwillingness to communicate with child.	Lack of skills, knowledge or understanding of disability and children's rights.
	You have the right to information about health care and services.	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.

Inclusion	Health services should be near to people and places you know.	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.
Personal assistance and support	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).	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.
Adequacy and availability	Teenagers should have information about sexual health and relationships.	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.
Training	Health workers should be trained to understand your needs and respect you and your rights.	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

The Principle	The Right	The Problem	Suggested Causes
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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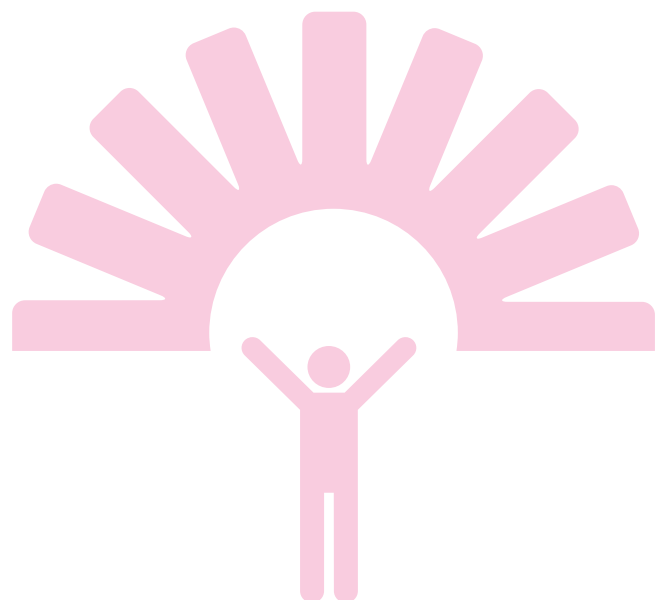
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Office of the Children's Commissioner

Appendix 1: Creating a rights-based framework – a methodology to support “We want to help people to see things our way”

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1 Introduction

This methodology supports the Office of the Children’s Commissioner’s report “*We want to help people see things our way*”: *A rights-based approach to exploring the impact of low income in disabled children’s rights*. It is a reflection of the process of involving children and young people in research which explores the impact of low income on the rights of disabled children.

The Centre for Children and Young People Participation is committed to maximising the opportunities for children and young people to participate in research by directing it, doing it, interpreting it, and reinventing it. This is always constrained by one factor or another, often time, money and the limits of our knowledge. Therefore our commitment to maximising participation is always accompanied by reflection on what is going to be possible in a particular set of circumstances.

This Appendix provides an accessible guide to how we did the research. It is not a model to replicate, as no two research projects are ever the same, but provides a methodology that can be adapted for exploring the impact of poverty on children’s rights.

The Appendix includes the following stages:

- where do we start?
- how do we plan to do it?
- an overview of research plans and reality
- details of participants
- details of activities
- what would we do differently next time?

For further details and examples of the tools used in this research, please contact the authors.

2 Where do we start?

2.1 Aims

This was not a child initiated research project, rather the aims and objectives were set by the OCC. These were:

- To explore the impact of income on disabled children and young people's rights
- To develop a methodology for looking at the relationship between rights and poverty.

The third objective, suggested to the OCC by the researchers, was:

- To pursue child-directed research, inclusive of children with a range of different impairments.

2.2 Limits and resources

We were limited by the need to complete the research within four months, stay within budget and comply with University regulations.

Our key resources were the existing staff team, our networks of connections with young people's organisations and service providers (which were particularly strong in the North West) and a budget big enough to pay for 101 days of staff time plus around £10,000 for things like travel, rewards, accommodation and transcription.

We thought students at UCLan may like to be involved, and that their one-to-one support could potentially facilitate the participation of more children.

2.3 Opportunities for inclusion

Before getting the contract, we issued an open invitation to our contacts to gauge interest in the project amongst people who work with disabled children. From this meeting we were relatively confident that, in a short space of time, we would be able to make contact with a wide range of disabled children and their families on a low income.

In the timescale it was not feasible to support disabled children who had had no prior experience of research to take on roles that included directly conducting research fieldwork in different parts of England.

We wanted to offer opportunities to disabled children who were amongst the most excluded, i.e. children with significant impairments. We also wanted to offer disabled children opportunities to direct the research, as far as possible within our limits.

2.4 Impact

Our goals for impact are inherent in the rights-based approach we adopted and were

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as follows:

- enjoyment, fulfilment and development for children and young people and staff
- change in government policy, furthering achievement of disabled children's rights
- greater capacity and awareness of disabled children's rights amongst children and young people, policy makers and practitioners engaged in the study or reading the research.

3 How did we plan to do it?

3.1 How can we produce this kind of knowledge?

Robust knowledge that can get through different layers of experience to uncover root causes takes time. It is built on communicative exchanges between people and involves thinking about people's everyday lives and the social systems they live in.

Our approach to this research was based on the following ideas about how to produce this kind of knowledge.

- Friere (1973) suggests working with groups of disadvantaged people over time, starting from ideas related to their own experience, then moving through processes of description, explanation, synthesis and action to become aware of more distant issues that may influence their experience, like economic conditions.
- Labonté (2011) suggests working with stories as a way of engaging young people in reflection.
- Lundy and McEvoy (2012) promote a CRBAs to research involving building capacity in children and young people by providing them with 'a wide range of views on the issues from other children'.
- Habashi (2012) indicates the importance of children setting the agenda for research.
- Alderson (2013) suggests looking for the mechanisms that are causing the situations being studied in children's lives.

3.2 How can we maximise influence and inclusion?

We planned to work with two different groups of children and young people to ensure wider inclusion and to maximise children's influence in different parts of the research. We therefore planned to recruit:

The expert group: disabled children who were socially excluded or with significant impairments could direct the focus of our research by guiding us on the important areas to study and informing us about what methods would work for engaging disabled children in discussions of their rights.

The steering groups: disabled children who had done some participatory activities already and would be able to take a greater lead in the research in a faster timescale. However, even experienced young people (like adults) need information from which to develop their understanding of issues like rights and government policy on welfare benefits.

The adult advisory group: To advise the research design and methodology and to respond to and advise the young people's steering group, OCC recruited adults with knowledge of rights, disability and low income.

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3.3 How and why did we plan a rights based approach?

The United Nations' definition of a 'human rights-based approach' is given in its Statement of Common Understanding (2003). The statement outlines three core principles:

- ensuring the activity leads to the realisation of human rights
- ensuring human rights should guide all phases of the work
- ensuring the activity contributes to the capacity of 'duty-bearers' to meet their obligations and 'right-holders' to claim their rights.

We planned five stages in our rights-based approach, each to be led by disabled children.

1. Identifying key rights to study in relation to the impact of low income on disabled children.
2. Understanding how these rights are experienced and the extent to which low income was a barrier.
3. Exploring what changes would enable the achievement of these rights.
4. Naming who has a duty to respect, protect and fulfil these rights and how they might remove the barriers children and families experience.
5. Supporting duty bearers to understand the necessary next steps, and monitoring whether they bring about change.

The research reported here covers the first four of these. The steering group will also participate in a fifth stage which is not reported here.

In each stage we aimed to increase children and young people's capacity to claim their rights, by giving them opportunities to learn about rights and to develop their confidence in and knowledge of claiming rights.

4 An Overview of the research process

Figure 1 outlines the research process we planned and the differences that arose in reality.

Figure 1: Research plan and realities

Planned research	Actual research process
<p>1. Train students, recruited from UCLan with some prior experience or knowledge of research and disabled children, to support communication and engagement.</p>	<p>Students were trained as planned and helped collect and develop some of the research activities we proposed to research participants.</p>
<p>2. An expert group, recruited from a short break unit, to get their views on what areas we should focus on and what research techniques would be used.</p>	<p>We met with three different expert groups, and spent one day with each (two at a short break unit and one at a play scheme run by a parental support group).</p> <p>These children and young people had significant learning and communication difficulties or health care needs.</p> <p>They provided information about their lives and the feasibility of different methods, through draw/ write, collage and video tour activities.</p>
<p>3. An advisory group of adults, recruited from key professionals in this field, to have dialogue with the research team and Steering Group about the whole research process and outputs</p>	<p>This group met four times, once with the steering group. They suggested rights to focus on, recruitment strategies, and key definitions within the report and commented on drafts of the Matrix and whole report.</p> <p>The advisory group were very clear that their role was to support the young people in the steering group to make their own final decisions about what to do and how to do it.</p>
<p>4. A steering group, recruited from the youth council, to have dialogue about, design and decide on the research focus, tool, analysis and findings.</p>	<p>We met nine times with a steering group of disabled young people, recruited through Lancashire Youth Council and Barnardo's participation groups in Lancashire.</p> <p>Most of these young people were visually impaired or had Autistic Spectrum disorders.</p> <p>They reflected on the meaning of rights in their own lives using peer video interviewing and explored the</p>

	<p>stories and pictures generated by members of the expert groups. They shared ideas with advisory group members about priority rights to study and they developed and decided the final content and wording of The Matrix of rights to make some of the theoretical concepts more accessible.</p> <p>They wrote the questionnaire and designed a focus group schedule.</p> <p>They analysed the stories from the research interviews and consultation groups</p> <p>They commented on the draft report at three stages, rewriting certain sections.</p> <p>They wrote recommendations for change and made a video about the findings.</p>
<p>5. Two consultation groups of disabled children, recruited in areas experiencing high levels of child poverty, to explore rights and income with using the material developed by the steering group.</p>	<p>Open invitations to participate we sent out through the British Youth Council and local authority youth services in the target areas.</p> <p>Groups volunteered to participate in areas experiencing income and service deprivation.</p> <p>We met twice with two groups and once with a third group of young people.</p> <p>We explored rights and low income as planned.</p>
<p>6. Interview with 20 disabled children and families, recruited from 4 local authorities in the North West. Recruit and conduct two interviews with each of these low income families</p>	<p>We recruited 19 families.</p> <p>In some local authorities we were able to recruit children and families with a range of demographic characteristics related to low income.</p> <p>Due to time pressure, in other areas, we interviewed any parents and young people who met the core criteria – disability and one proxy indicator of low income.</p> <p>Most families only wanted to be interviewed once.</p>

The rights based approach we achieved through this process eventually looked like this.

1. Get together as many resources and people as possible to support young people to lead the research.

2. Develop a matrix of rights from what is important for the expert and steering groups and by matching this with the conventions
3. In interviews and consultation groups, inform other young people and families about these rights.
4. Explore how these rights are experienced and the role of their actions (agency), income and other resources.
5. Analyse the causes of the difficulties and barriers, with a steering group of young people.
6. Write and make videos about what duty bearers should do to make a difference.
7. Continue to take support young people and duty bearers to overcome these difficulties.

4.1 Fluid Consent

Each research activity was underpinned by the principle of Fluid Consent (Larkins, 2013). All parents were sent a letter informing them about the research and offering them the option of not consenting to their child's participation. They were asked to discuss this with their children.

At the time of first meeting, all children and young people were given an explanation of the research and asked to sign their consent if they wished to start participating. Thinking about consent as fluid means ensuring that a) throughout the research activities, participants know they can withdraw consent at any time and b) researchers pay particular attention to verbal and non-verbal cues, to ensure children's wishes were respected and opportunities to opt out and opt back in are provided. This is facilitated by other activities being provided either by members of the research team or host organisations, running alongside the main research activities.

4.2 Creative engagement with children and young people

Engaging children in research as either participants or as co-researchers is a relatively new development and whilst progress has been made in recent years, less attention has been paid to engaging children with disabilities within research (Connors and Stalker, 2003; Morris, 2003; Shakespeare et al, 1998).

Whyte (2006a) notes the historical absence of research with disabled children framed within a rights based approach. Partly this reflects the perceived additional vulnerability of children with disability and the complexity of gaining assent to participate in research (Carter 2009; Carter 2011) and partly it reflects the fact that children with disabilities are a marginalised group whose contributions have, by and large, been overlooked by researchers (Carpenter and McConkey 2012).

Children who have disabilities and who are poor are potentially doubly disadvantaged and very under-represented within research (Stalker, 2012). This appears to be similar to situation regarding the engagement of adults with intellectual disabilities

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where research practice is 'characterised by a lack of consensus, entrenched tensions in value orientations, and gaps in knowledge and practice' (McDonald and Kidney, 2012, p.27).

Whyte (2006a) notes how the values of the researchers can shape the inclusion of children with disabilities. However, engaging children and young people with disability within research can and does help shift to the agenda to one which more appropriately reflects their rights and desire to be core to research that affects them (Badham, 2004).

Eliciting data that genuinely reflects the lives, opinions and perspectives of children takes considerable commitment, preparation and skill by researchers (Carter and Ford, 2012; Turner, 2003). The shift from viewing children as objects to agents has opened up methodological possibilities (Clavering and McLaughlin, 2010). Qualitative research offers a broad platform from which to gain insight into the life-worlds of children and Cocks (2008) proposes that qualitative research is at the forefront of children's disability research. Arts and activities-based, story-based and verbal-based approaches create child-oriented opportunities for children to explore, share, and communicate their own experiences.

Where needed, other communication aids such as Makaton and talking mats can be used to facilitate children's engagement. These approaches also allow children with a wide range of abilities and capacities to contribute in ways which are both possible and meaningful to them (Turner, 2003). However, the focus of research has often been on engaging children using child-centred tools and techniques and within relatively small scale studies whereas Stalker (2012) calls for consideration of longitudinal work, ethnographic work and large scale surveys.

4.3 Strengths and flexibility

The importance of emphasising and engaging with children's strengths rather than focusing on limitations and deficits is fundamental to methodologically robust and ethical research. Drawing on a portfolio of engagement methods is particularly useful when working with children with disabilities as it allows the child to have control over this aspect of the research and also means that the researcher has the ability to engage the child using media most suitable to the child's particular circumstances. In recent years, guidelines have been developed to guide and support researching with children with disabilities (Lewis and Porter, 2004; Martin, 2008; Whyte, 2006b).

Interviews and narrative methods have been used in various studies. Mundhenke et al. (2010) examined the experiences of Swedish children with a variety of disabilities, focusing on their everyday activities and lives. Shikako-Thomas et al (2009) used interviews to examine the quality of life of adolescents with cerebral palsy and interviews were used in a study examining social participation of deaf children following cochlear implant (Punch and Hyde, 2011).

Discussion groups have been used to explore children with disabilities' views about health living (McPherson and Lindsay, 2012). Puppets have been used with pre-school children (Gonzalez-Gil, 2007) and with children with disabilities (Carter, 2005). Photo-elicitation has been used with children (Aldridge, 2012; Carter, 2005) and with adults with learning disabilities (Aldridge, 2007) as a way of facilitating participants to represent their own experiences and needs.

The storybook method offers potential as a means of generating data for young children and those children with cognitive impairment (Anderson and Balandin, 2011). Clarke and Wilkinson (2009) observed and then interpreted the interactions between two ‘non-speaking’ ten-year old boys as a means of capturing non-verbal ‘conversation’.

In different aspects of the research, we used all the techniques detailed below:

- draw and write
- narrative and story telling
- arts based activities
- makaton and flash cards
- photo-voice
- interviews
- group discussions
- play based activities
- video and observation.

5 Details of the research process

This section gives details of the research we did with each group. It looks at the research process outlined in figure 1, and focuses on recruitment strategies, activities and influence over the research process. In sub-section 5.7, we give the demographic characteristics of the research participants.

5.1 Involving students within the research process

An open invitation was issued via course tutors to second and third year and masters students studying social work, social care or children and families.

Rather than a selection process, we asked for students to show commitment to the project by:

- Writing a letter of motivation and application form
- Developing a resource through which they could communicate about themselves to children with communication difficulties
- Attending initial training (one day)
- Contributing to the development of research materials (two x two hour sessions)
- Volunteering time for particular research activities – experts, steering and consultation groups (half day – 10 and a half days)
- Reflecting on and evaluating their experience (1–10 x one hour depending on level of involvement).

The students met with the lead researcher before each session with children and young people, to plan how to support different members of the group to participate in the different activities planned. Throughout the sessions they consciously observed the words and body language of group members and sought to maximise their involvement in the research processes whilst also paying attention to cues that might indicate children and young people did not wish to take part in given activities at given times. They met with the lead researcher after the group session to reflect on what had worked well and where there had been problems, highlighting particular issues that had been communicated and any concerns.

Six students committed a considerable amount of time to this project, supporting repeated meeting with the same young people (in the steering Group activities this amounted to around 50 hours volunteer time from each student). Where students met with young people on repeated occasions, with the lead researcher, they reflected on their observations about the wishes of individual participants in the group activities and they helped develop new strategies to suit the learning styles, emotional responses and strengths of each individual.

5.2 Expert group

Once we received approval for the research from the UCLan PsySoc Ethics Committee, we sent an open invitation to all short break units in the area with a proposal to meet with young people during the half term break.

Three units and one parental-run play scheme then volunteered to ask children and families whether they wished to participate. None of the units worked exclusively with low income children and few children were consistently at the units day after day.

The play scheme was busy with lots of activities and did not want us there every day. We therefore decided to visit three of the four settings, for a day long visit each time. This was in order to maximise the number of children living on a low income who could be involved.

Activities

Each group session started with some informal play activities, provided by the host agency. This enabled children to get to know us and feel a bit more comfortable, with adults they trusted in charge.

We then used the resources we had developed (From the Children's Society About Me model) to introduce ourselves to the young people individually, and to explain the research and to get their signed consent or consent signed by a known and trusted key worker if they could not sign.

We then started the research sessions with activities focused on providing communication tools through which these Experts could tell us about their lives, the things that they liked and didn't like. These included:

- collage
- video tours
- video and audio interviewing.

As the day progressed, we asked those who continued to consent to take part to tell us more about the important things to them, their rights and money. This was through activities like:

- structured games (parachutes, web of wool and words, show and tell)
- choosing rights themes and responding to questions.

We did not use all of the activities we had prepared; rather, we proposed activities that seemed appropriate to the context and the children. For example, with one group, we attended part of their Halloween party and we proposed a game which involved making a giant spider's web with black wool. Every time someone caught the wool they were asked a question. Children then chose which activities to be involved in.

What children told us was important was influenced in part by the pictures we had available for the collage activities. We sought out images on the internet and from their local service providers that would relate to different activities they had engaged in and we used resources that had been prepared in other research with disabled children.

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Analysis

The experts groups influenced our understanding as researchers and that of the steering group members of what rights were important and what activities and approaches might work with disabled children.

We wrote up what certain members of the experts groups had told us about their lives (where these children had given substantial verbal responses). These were presented as stories to members of the steering group. We also photographed everything they had produced and these were also shown to steering group members. Steering group members then thought about what these pictures and stories told them about what rights were important in these children's lives. This guided the steering group in their choice of rights themes for the Matrix, the interviews and the focus group schedule.

The lead researcher and students met for an hour after each session and reflected on what had been communicated to them about rights. The research team also watched the 15 hours of video footage that had been filmed by and with the expert groups and reflected on what rights the expert groups were claiming as important, implied by their actions as well as their visual and verbal communication. Their rights, priorities and claims became part of the Matrix of Rights in the main report, which was the tool used for the analysis of all future research data.

The lead researcher also reflected on what activities had been successful with the expert groups and fed this information into her work with the steering group.

The expert groups influenced:

- which activities they took part in
- the steering group's and research team's understanding of disabled children's lives
- the contents of the Matrix
- the research activities proposed to groups in later stages of the research.

5.3 Advisory group

When we initially planned the research, we recruited two people as advisers, and once we gained the contract, we sought participation from other professionals with key knowledge in this area. We considered inviting young people onto this panel but decided, mostly because of the physical distances involved, to instead facilitate dialogue between the steering group and the advisory group in different ways.

Not all of the advisory group we wanted to recruit were able to participate because of our limitations in funding or because of other demands on their time. We are very grateful to those who did participate.

Activities

Our first meeting with advisors introduced them to the project and to our aims.

We discussed what rights we should focus on and which young people we should recruit. Their ideas on which rights were important were then passed to the steering group.

At our second meeting the advisory group learned about what rights the steering group had prioritised and their proposed interview questions. The advisory group made some suggestions about more rights themes to include and some changes in wording for the Rights Matrix. The steering group had also sent a request for a meeting with the advisory group and there was agreement that members of OCC staff would meet with the steering group and that the next meeting would be joint, if possible.

The next advisory group was a joint meeting with the steering group in Preston. At this meeting the steering group presented their analysis of some of the early stories from the research findings. The advisory group made a commitment to the young people that their research would be used to try to influence the understanding of policy makers and would be publicised more widely.

At their fourth meeting, the advisory group discussed a draft of the report and made further recommendations about definitions and orientation of the analysis. Their suggestions were taken back to the steering group at two further meetings and substantial changes to the report structure were made.

Once the steering group signed off the revised report, the advisory group were given one last chance to comment. Their feedback was integrated with suggestions from the wider OCC team and the final report was presented to the steering group.

The advisory group Influenced:

- the contents of the Matrix
- which participants we tried to recruit for interviews
- the wording of specific definitions and technical terms
- the structure of the report.

5.4 Steering group

An open invitation to participate in the research was given to all disabled young people who had contact with Lancashire Youth Council. Some of the disabled young people participating in this council did not want to participate in the research, so we also asked Barnardo's, who were running groups with disabled young people and who were due to be setting up a further forum, to invite young people they were in contact with.

We took this approach to recruiting young people because it enabled our research to be:

- embedded in other participatory processes
- supported by youth workers who already knew the young people
- directed by young people relatively quickly, as these were experienced young people who were relatively confident in a group setting.

Activities

We met with the steering group in the local council chambers. Their first job was to take ownership of that relatively formal and structured space, by using the resources it provided like microphones, video screens, hammer and gavel.

Each time we met we started with a game or an informal discussion about how everyone was feeling. We provided resources – toys, pens and paper, video kit and audio recorders, and sometimes wigs and hats – which the group members could take ownership of as soon as they arrived. They used these resources to facilitate their engagement in research activities. For example, some could listen better if they could draw, others could take part in a video only if they wore a disguise.

We introduced the plan for each session and then the group members made decisions about what they wanted to do within that. They gradually worked through thinking about their own experiences, the experiences of other disabled children, the important rights to focus on in this instance, and the tools we would use to find out the views and experiences of others. Sometimes we had visits from others, who provided extra specific knowledge.

The activities we used included draw/write, video recording and viewing, story board, group discussions and organised games.

Aims

Our aims for the sessions, which were largely met in practice, are detailed below in Figure 2.

Figure 2: Our main aims for steering group sessions

Session 1 – Intro to each other and to the project

Session 2 – Further understanding of what rights are and how they can be achieved, based on own experiences and existing conventions

Session 3 - Further understanding of what rights are and how they can be achieved, looking at experiences of other disabled children and importance of money

Session 4 – Develop tools 1. Decide what rights we are going to ask other children and young people about and how we are going to do this in interviews/ Christmas Fun

Session 5 – Develop tools 2. Decide how to adapt questions from interviews for consultation event – visit from OCC and LCC Advice Line

Session 6 – Data Analysis 1. Look at what we have found out so far and think about what are the important themes

Session 7 – Data Analysis 2. What else is important in what we have found out?

Session 8 – Review report and make an accompanying child friendly/video version.

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These additional sessions were also held:

Session 4a– a meeting with one young person to start the draft of the questionnaire

Session 6a– joint meeting with the advisory group and included initial analysis of emerging data.

Session 9– further video making and signing off aspects of the report.

Dialogue

Participation is a messy process (Gallagher, 2009) but taking apart the process of participation helps when thinking about how to maximise children’s influence in a research project.

The sessions as described above were supported by a process of dialogue and decision making between the steering group (SG) and different research participants (the expert groups (EG), advisory group (AG), and Research team (RT)). This is detailed in Figure 4 below. Information to support the dialogue was also given to the steering group (via the Research team) from the consultation groups and interviews, but that is not represented here.

Figure 3: Process of dialogue and decision making by steering group, experts and advisors

Dialogue process	Timeline of sessions when each group met			Decisions made
	EG session	SG session	AG sessions	
Info From EG about their lives	Session 1		Session 1	AG decide rights to present to the SG and who to try to interview
Info from RT to SG about the research Info from SG to RT about their life experiences		Session 1 Intro to each other and to the project		SG decide to participate
Info from AG (via RT) to SG about rights		Session 2 Further understanding of rights		
Info From EG to SG about their lives		Session 3 Further understanding of rights and money		SG decide priority rights

Info from RT to SG member on question writing		Session 4a draft interview schedule		
Info to AG from SG and EG			Session 2	AG accepts SG decision on draft interview schedule
Info to SG from one group members		Session 4 Develop tools 1 - interview schedule		SG decide questions for interviews
Info to SG from OCC team		Session 5 Develop tools 2 - consultation groups		SG decide focus group activities
Info to SG from fieldwork, via RT Info to AG from SG		Session 6a Data Analysis 1a and meeting with advisory group	Session 3	AG suggests further revisions to Rights Matrix
Info to SG from fieldwork and AG, via RT		Session 6b – Data Analysis 1b		SG decide key dimensions of change to recommend and wording of Matrix
Draft Report to AG, from RT and SG			Session 4	AG suggests revisions to structure, definitions and Matrix
Draft Report to SG, with suggestions from AG Info to SG on video making		Session 7 – Data Analysis 2		SG decide revisions to structure and additional analysis
Final report to SG from RT Info to SG on video making		Session 8 – finalising report and starting video		SG agree final content of report including Matrix and Some Recommendations
Final Report to AG from RT and SG			Virtual session 5	AG suggest final changes

Final Report plus suggested changes to SG, from RT and AG		Session 9 – finalise video and last words		SG agree absolute final report and video
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The steering group also exercised choice over the research activities they took part in. The plans were prepared by reflecting on what had worked in the previous sessions and focusing on our aims for the next sessions; this might be described as them influencing our plans through our observation.

As the group got to know us and each other more, their active direction of future sessions became clearer so that they took a greater role in setting the plans for future sessions. This was limited, however, by the needs of the research process, which had set aims for every session.

5.5 Consultation groups

Invitations to participate in consultation groups were sent out to the target areas of London and the West Midlands through the British Youth Council and local authority youth work services. These areas were chosen because of their high rates of child poverty.

We received replies from one group in the London target ward and three leads in the West Midlands. We pursued carrying out the work with the group in the West Midlands which was meeting in the most socially deprived area, where there were very high rates of families living on low incomes.¹

Activities

Prior to meeting with the young people the lead researcher (and sometimes the students) met with the group organiser and discussed any particular needs and issues that potential consultation group members might have. We then considered what adaptations to the activities that the steering group had proposed might be necessary. Sometimes this involved us creating more structure and less choice. Other times, this meant we built in more clear opportunities to opt out of the research process at different stages.

The consultation groups started with some information ‘getting to know’ you activities. In the West Midlands, this involved the lead researcher and students joining in with games that young people were already playing, or that were run by the youth club organiser. In London, this involved the researchers organising activities.

We then explained the research and gained consent. The groups were then offered activities from the steering group’s list of activities. This started with discussion lines about rights or question answering games using a parachute, then some people chose to no longer participate.

¹As defined by ONS 2011 and <http://www.neighbourhood.statistics.gov.uk/dissemination/neighbourhood>

We then voted on rights to focus on (Crowley, Aspinwall and Larkins, 2003). Groups then explored these themes through drawing/writing, group discussions and video making.

The consultation group influenced:

- what activities they took part in – by consenting or changing activities proposed
- they informed the steering group’s understanding of how rights are met or not in the lives of disabled children and what needs to change
- they informed the Research team’s understanding of how rights are met or not in the lives of disabled children and what needs to change.

5.6 Interviews

We tried to recruit all of the research participants from the gatekeepers we had already identified in four local authorities.

Service providers sometimes knew about family circumstances but never income levels. For interviews we therefore used factors that indicated a family may be likely to experience low income, as observed in DWP statistics (2012). These included location (as defined by ONS 2011 and <http://www.neighbourhood.statistics.gov.uk> - neighbourhood summaries) plus:

- being in receipt of welfare benefits
- being workless
- lone parents
- three or more children
- from an ethnic minority (especially Pakistani or Bangladeshi)
- some children under three.

We asked gatekeepers to identify families where one or more of these indicators was present as well as there being a disabled member of the family (which itself is another indicator). In two local authorities, our links with gatekeepers enabled us to select interviewees from an anonymised sample of probable low income families to obtain interviews with children with a range of different impairments (and their parents). In two other local authorities, we offered more general invitations to participate to parents of disabled children.

Activities

Children and parents were asked the questions set by the steering group.

Children were shown the pictures first and then asked which right they wanted to talk about. We asked them the questions on the reverse of the picture then, if they were willing, they chose another right and repeated the process.

Adults also followed the same interview schedule with further additions made by the researchers to find out details about their economic situations.

The people interviewed influenced:

Appendix 1: Creating a rights-based framework – a methodology to support “We want to help people to see things our way”

- what activities they took part in – by consenting or changing activities proposed
- they informed the steering group’s understanding of how rights are met or not in the lives of disabled children and what needs to change
- they informed the Research team’s understanding of how rights are met or not in the lives of disabled children and what needs to change.

Parents and carers responded openly to the questions set by the steering group. Interviewers were sensitive to the fact that discussing income and poverty is a delicate issue and were led by participants’ willingness to share details about their financial circumstances. Parents and carers who participated in the study expressed their appreciation that issues around disabled children’s rights were being explored.

6 Overview of the demographic characteristics of the research participants

Figures 4 and 5 below describe the numbers of participants and their ages.

Figure 4: Numbers of children, young people and parents participating in different ways

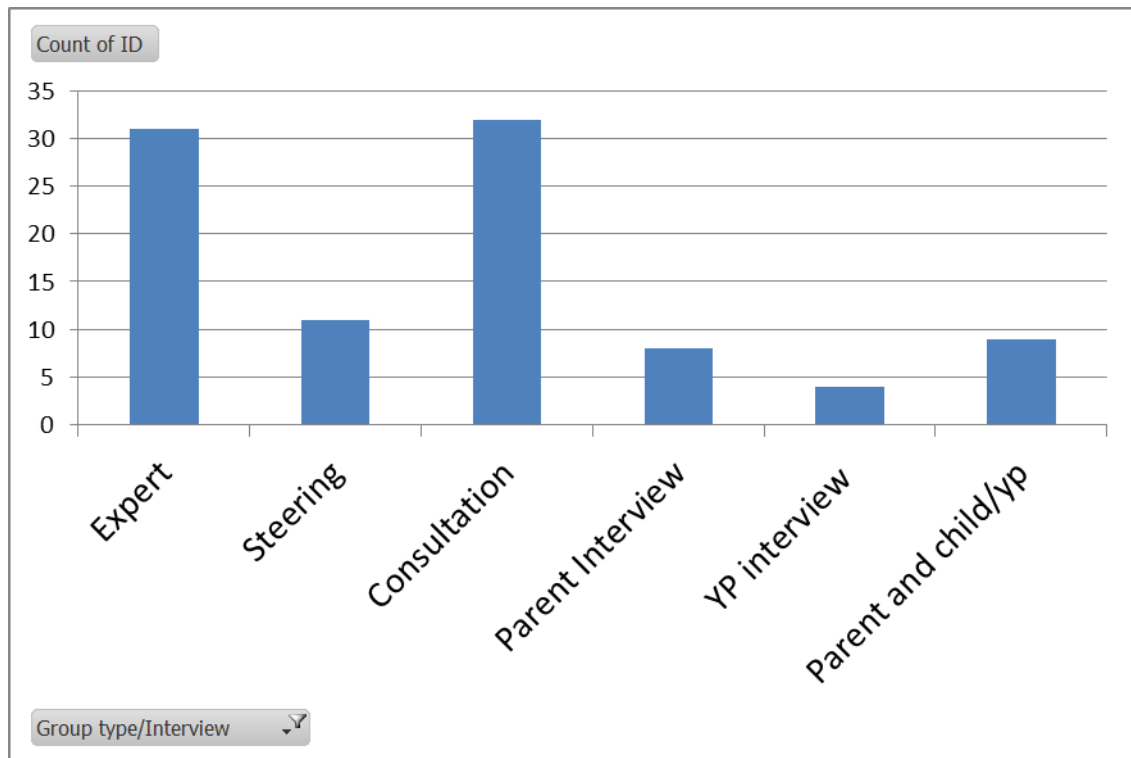
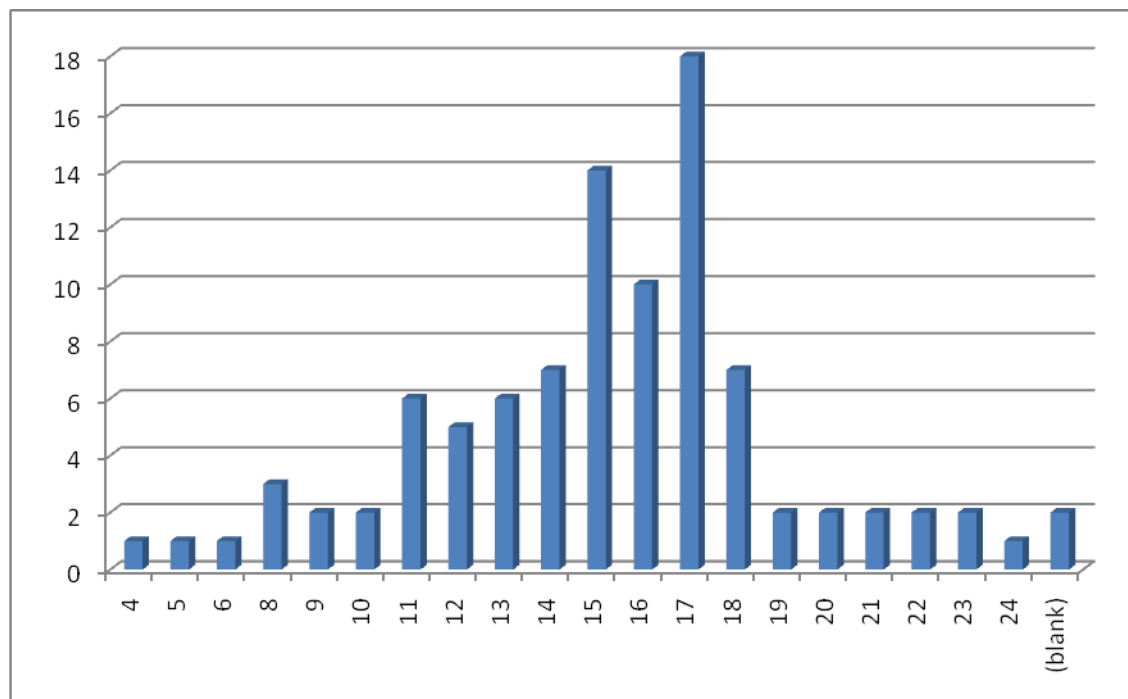


Figure 5: Age distribution of participating children and young people



Figures 6 and 7 below give the details of the indicators of possible low income that were present for the households involved in this research. The relatively high proportion of those from areas of low income and service deprivation reflect the high numbers who engaged in the consultation groups from these areas. The level of low income and service deprivation in one of the places we describe as an 'area of low income and service deprivation' compared to the national average, is indicated graphically on Figure 8 below and further details of these indices can be found at www.neighbourhoodstatistics.gov.uk

Figure 6: Overview of poverty indicators for research participants

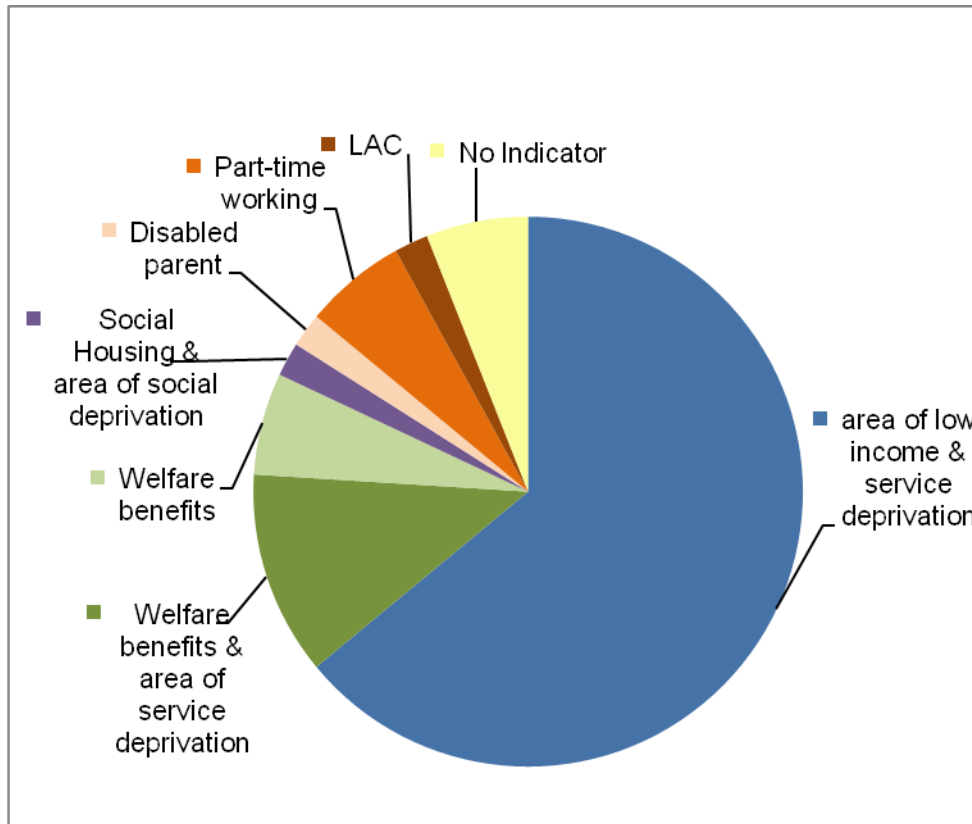
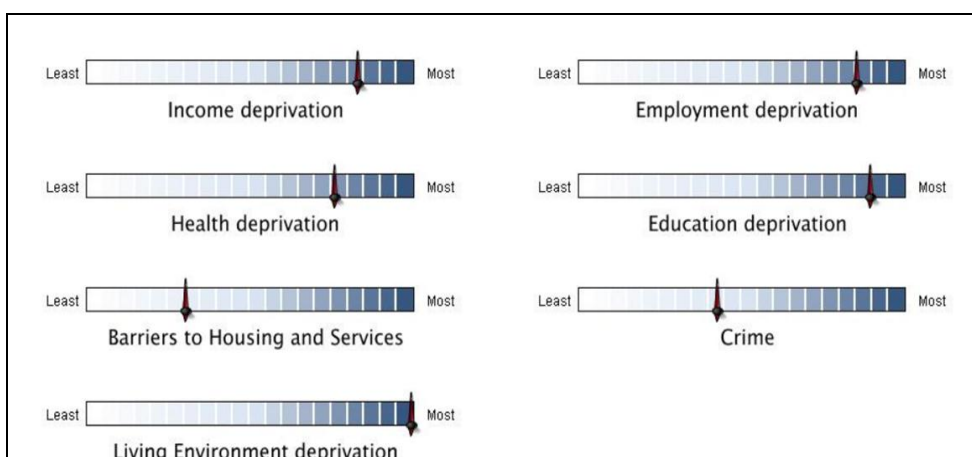


Figure 7: Overview of the service poverty in the neighbourhoods where one consultation group held



7 What would we do differently next time?

Evaluation of working with expert groups

Working with more children for fewer visits may have compromised the amount of depth of understanding we would gain about these children's lives. However, we were very conscious that we were in valuable leisure time settings with these children and that for some, doing other activities was much more interesting than doing the research. In future research it would be worth considering doing this kind of activity in a school setting. We avoided this as we thought a leisure setting may enable greater fluidity in consent. However we felt that as researchers we were very able to pick up cues about consent, and that encroaching on leisure time was more of a concern.

When we used the rights cards as a basis for discussion with the groups we felt like we were pushing them to think about their lives in an abstract way that was beyond the level of understanding that we had managed to support in the short amount of time we had with them. Many children chose to cut this activity short so we dropped this activity after the first group. This demanded that the research team take a greater role in making connections through our interpretation and analysis of what they had told us about their lives.

Student involvement in this facilitated more children's engagement in the research than would otherwise have been possible. However, it would have been more effective if greater staff time had been dedicated to supporting students and if all researchers had worked with the same children for longer.

Evaluation of working with the steering group

Our key aims for the steering group related to the goals for of maximising their influence in the research and for obtaining impact as set out below:

- enjoyment, fulfilment and development for children and young people
- change in government policy, furthering achievement of disabled children's rights
- greater capacity and awareness of disabled children's rights amongst children and young people.

We asked the group members if they enjoyed the research project and whether they had learned anything. The all said they had enjoyed it, and these are some of their comments in response to that question:

We made new friends

Everything was good. The fact that I am able to express myself and issues around people not being treated fairly.

I enjoyed it a lot.

It's something to do. We got to finally talk about our problems and stuff.

Appendix 1: Creating a rights-based framework – a methodology to support “We want to help people to see things our way”

I got to meet new people.

Talking about school and what was wrong was good. We asked the specifically if they had learned anything and if taking part in the group had changed anything for them. These are their responses:

I learned different activities like the bean bag thing and Spike [the Hedgehog].

I got to learn a lot more about what is going on in the world like with other families and other young people and who is getting ripped off and how useless the government are.

Before this I used to get really upset about the way that people with disabilities were treated. And the fact that I can finally help them is invaluable.

We asked if they felt like they made decisions about what we did. They all said yes and that we had met enough times, but there were some things they would have liked to do differently.

Do differently? More teddies.

I decided to do the film project.

Do differently? NO. There wasn't really anything you could have done better.

Different I don't think so 'no'.

Enough times.

I'm happy with you doing the interviews and I would probably freeze on the spot. But if we had met a few more times I could have done it.

Regarding change in government policy, furthering the rights of disabled children, they did not feel the research had made a difference yet, but they had hopes:

Hopefully it will make a difference to other people.

The Government should take other people's experiences on board – those who have gone through the bad things in life.

Evaluation of working with the consultation group

Working with the consultation groups in a youth club setting worked extremely well because this gave a clear message about participation being their choice, and because other activities and spaces were readily available for young people to opt into if they chose to not take part. The venues had many separate rooms and the young people were clearly used to moving between them to engage in different activities as they chose. In the West Midlands in particular there was a real sense that the young people owned the physical space that we were working in.

It was difficult to balance the number of researchers who should be present against appropriate adult-child ratios for different young people. We were a team of three, and this seemed quite big enough as we were their invited guests. But if there had

Appendix 1: Creating a rights-based framework – a methodology to support “We want to help people to see things our way”

been more of us, then some of the young people who needed more one-to-one attention might have been more able to fully participate.

Working with groups twice rather than once gave an opportunity to gain their views about a much wider range of experiences and to find the most effective ways of communicating. For some young people it would have been better for us to get to know them over longer periods. For other young people however, two sessions was long enough to focus on these sorts of issues. Even when we met with one group once some very important findings emerged and the young people reported getting a lot out of the experience.

Young people from London sent us thank you cards saying things like 'we have found out about our rights' and 'thank you that was so cool'.

Young people from the West Midlands said they really enjoyed the activities, they talked about it to their parents, they felt really listened to, they helped each other, and they knew more about their rights

Evaluation of doing the interviews

Access to young people, carers and parents was facilitated via various gatekeepers including schools, short term care units and parent support groups. Identifying children living on low income was most successful through the school and short term care units where our contacts had details about families' financial circumstances. Relying on a third party to negotiate access presented some challenges around timing. Given the limited time available to carry out the interviews, only contacts who responded quickly were followed up. Where children and young people chose to give interviews, two visits were generally carried out and the interview with the young person was usually carried out on the second visit. This provided the young person with the opportunity to get to know the interviewer and also the interviewer to get to know the young person.

Parents tended to prefer that we interviewed them only once. This was partly due to the difficulty of fitting in two interviews in a relatively short time (4-6 weeks). Research asking parents about low income would benefit from much longer timescales in which parents can develop trust in researchers and then take part in repeat interviews with longer intervals.

Evaluation of working with the students

During the evaluation session with the students they told us that they had enjoyed their time on the project and found it a valuable learning experience. One student said 'a big highlight for me was being able to carry out the research in a fun and interactive way.'

Other students appreciated the opportunity to 'put theory and research into practice', and having the opportunity to 'allow disabled young people to have the space to express themselves.' Students talked about their increased understanding of issues around poverty and disabled children's rights. The students highlighted particularly their increased competence and confidence in communicating with disabled children, and their increased understanding of research processes.

Evaluation against goals for impact

Appendix 1: Creating a rights-based framework – a methodology to support "We want to help people to see things our way"

- Enjoyment, fulfilment and development for children and young people and staff –YES
- Change in Government policy, furthering achievement of disabled children’s rights –We cannot comment on this at this point.
- Greater capacity and awareness of disabled children’s rights amongst children and young people, policy makers and practitioners engaged in the study or reading the research – YES

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Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “*We want to help people see things our way*”

1 Introduction

This Appendix supports the matrix of the Office of the Children’s Commissioner’s report *“We want to help people see things our way”: A rights-based approach to exploring the impact of low income in disabled children’s rights.*

It contains extracts from the three conventions (UNCRC, ICESCR and UNCRPD) and General Comments(GCs) on the interpretation of these from the associated Committees. These extracts represent the rights and principles we focused on in the research.

Full details of the general comments can be found at:

Committee on the Rights of the Child

<http://www2.ohchr.org/english/bodies/crc/comments.htm>

Committee on Economic Social and Cultural rights

<http://www2.ohchr.org/english/bodies/cescr/comments.htm>

The extracts for relevant themes (matrix rows A–J horizontally) and principles (Matrix columns 1–9 vertically) are given in the following subsections, after details of extracts relating to the commitment of resources.

General Comment 9 (2006) (The rights of children with disabilities) is given in full at the end of these subsections as the issues contained in this general comment cut across many of the themes and principles in the matrix.

Section 2: Maximum Extent of available resources

UNCRC Article 4

UN ComRC GC 5 (paras 8 and 9)

ICESCR Article 2.1

ICESCR Article 4

ICESCR GC 19

Letter issued by the Committee on ESCR (CESCR/48th/SP /MAB/SW)

UNCRPD Article 4.2

Vertically down the matrix

Section 3: Survival and development (section 1)

UNCRC Art 6.1

UNCRC Art 23.1

UNCRPD Article 10 (Right to life)

Section 4: Non Discrimination, Equality of Opportunity and Reasonable Accommodation (section 2)

UNCRC Article 2

Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “We want to help people see things our way”

ICESCR Article 2.2
ICESCR GC 20 (paras 1, 28)
UNCRC Article 2
UNCRC Article 3
UNCRC Article 5

Section 5: Best Interests (section 3)

UNCRC Article 3
UNCRC Article 19
UNCRC GC 12 (paras 70–74 on Articles 12 and 3)
UNCRC GC 8 (para 18)
UNCRC GC 13 (paras 47(iii), 48 and 61)
UNCRC Article 7 (Children with disabilities)
UNCRC Article 16 (Freedom from exploitation, violence and abuse)

Section 6: Respect, personhood and evolving capacity, independence (section 4)

UNCRC Article 1
UNCRC Article 5
UNCRC GC 12 (para 20)
ICESCR PREAMBLE
UNCRC Article 3 (General principles)
UNCRC Article 12 (Equal recognition before the law)

Section 7: Participation, information and influence regarding decision making (section 5)

UNCRC Article 12
UNCRC Article 13
UNCRC Article 14
UNCRC Article 17
General Comment 12 (paras 19, 21, 22, 23 13)
UNCRC Article 3
UNCRC Article 4.3.
UNCRC Article 7.3
UNCRC Article 21 (Freedom of expression and opinion, and access to information)
UNCRC Article 29 (Participation in political and public life)

Section 8: Inclusion in community and society (section 6)

UNCRC GC 9
UNCRC Article 3
UNCRC Article 19 (Living independently and being included in the community)
UNCRC Article 26

Section 9: Personal assistance and support (section 7)

UNCRC Article 23(2)
UNCRC General Comment 9 (paras 10–12 and 65)
UNCRC Article 12.3
UNCRC Article 26 (Habilitation and rehabilitation)

Section 10: Adequacy, availability and accessibility (section 8)

UNCRC Article 23 (3)
ICESCR GC3 (paras 1, 2)
ICESCR GC9 (paras 1, 2)
UNCRC (Article General Principles)
Article 4 (General obligations)

Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “We want to help people see things our way”

Article 9 (Accessibility)

Section 11: Training (section 9)

UNCRC GC 9 (paras 20, 27, 32, 49, 60)

UNCRCPD Article 4

UNCRCPD Article 26.2

UNCRCPD Article 28.2

Horizontally across the matrix

Section 12: Care and Assistance for disabled children (section B)

UNCRC Article 23

UNCRCPD Article 7

Section 13: Adequate Standard of Living – basic things you need for living (section C)

UNCRC Article 27

ICESCR Article 11

ICESCR General Comment 19

ICESCR GC 4 Article 11(1) (Housing)

ICESCR G C 12 (Food)

UNCRCPD Article 28

Section 14: Social Security – Money, Benefits and Social Support (section D)

UNCRC Article 26

ICESCR Article 9

ICESCR General Comment 19 (paras 2,6,10,20, 22–27)

UNCRCPD Article 28

Section 15 Family life and alternative care (section E)

UNCRC Article 9

UNCRC Article 18

UNCRC Article 20

UNCRC GC 12

ICESCR Article 10

UNCRCPD Article 18.2

UNCRCPD Article 23

Section 16: Education (section F)

UNCRC Article 28

UNCRC Article 29

ICESCR Article 6.2

ICESCR Article 13

UNCRCPD Article 24

Section 17: Work (section G)

UNCRC Article 32

ICESCR Article 6

ICESCR Article 7

UNCRCPD Article 27 (Work and employment)

Section 18: (Play, association, sport, leisure and cultural activities) (section H)

UNCRC Article 15

UNCRC Article 30

Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “We want to help people see things our way”

UNCRC Article 31
UNCRC GC 12
ICESCR Article 15
UNCRC PD Article 30

Section 19: Health (section I)

UNCRC Article 24
UNCRC GC 12 (para 100)
ICESCR Article 12
ICESCR GC 14
ICESCR GC 19
UNCRC PD Article 25 (Health)

Section 20: Mobility (section J)

UNCRC GC 23 (para 41)
UNCRC PD Article 20 (Personal mobility)

Section 21: CRC/C/GC/9 General Comment 9 (2006) (The rights of children with disabilities) (section A)

Introduction

The key provisions for children with disabilities (Articles 2 and 23)

General measures of implementation (Articles 4, 42, 44 (6))

General principles

Civil rights and freedoms (Articles 7, 8, 13–17, 37a)

Family environment and alternative care (Articles 5, 18 (1–2), 9–11, 19–21, 25, 27 (4), 39)

Basic health and welfare (Articles 6, 18 (3), 23, 24, 26, 27 (1–3))

Education and leisure (Articles 28, 29 and 31)

Special protection measures (Articles. 22, 38, 39, 40, 37 (b–d), 32–36)

2 Maximum Extent of available resources

UNCRC Article 4

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.

UN ComRC GC 5 (paras 8 and 9)

(8) The second sentence of article 4 reflects a realistic acceptance that lack of resources – financial and other resources – can hamper the full implementation of economic, social and cultural rights in some States; this introduces the concept of “progressive realization” of such rights: States need to be able to demonstrate that they have implemented “to the maximum extent of their available resources” and, where necessary, have sought international cooperation. When States ratify the Convention, they take upon themselves obligations not only to implement it within their jurisdiction, but also to contribute, through international cooperation, to global implementation (see paragraph 60 below).

(9) The sentence is similar to the wording used in the International Covenant on Economic, Social and Cultural Rights and the Committee entirely concurs with the Committee on Economic, Social and Cultural Rights in asserting that “even where the available resources are demonstrably inadequate, the obligation remains for a State party to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances ...”. Whatever their economic circumstances, States are required to undertake all possible measures towards the realization of the rights of the child, paying special attention to the most disadvantaged groups.

ICESCR Article 2.1

Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

ICESCR Article 4

The States Parties to the present Covenant recognize that, in the enjoyment of those rights provided by the State in conformity with the present Covenant, the State may subject such rights only to such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.

ICESCR GC 19

(40) While the Covenant provides for progressive realization and acknowledges the constraints owing to the limits of available resources, the Covenant also imposes on States parties various obligations which are of immediate effect. States parties have

immediate obligations in relation to the right to social security, such as the guarantee that the right will be exercised without discrimination of any kind (Article 2, paragraph 2), ensuring the equal rights of men and women (Article 3), and the obligation to take steps (Article 2, paragraph 1) towards the full realization of Articles 11, paragraph 1, and 12. Such steps must be deliberate, concrete and targeted towards the full realization of the right to social security...

(42) There is a strong presumption that retrogressive measures taken in relation to the right to social security are prohibited under the Covenant. If any deliberately retrogressive measures are taken, the State party has the burden of proving that they have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant, in the context of the full use of the maximum available resources of the State party. The Committee will look carefully at whether: (a) there was reasonable justification for the action; (b) alternatives were comprehensively examined; (c) there was genuine participation of affected groups in examining the proposed measures and alternatives; (d) the measures were directly or indirectly discriminatory; (e) the measures will have a sustained impact on the realization of the right to social security, an unreasonable impact on acquired social security rights or whether an individual or group is deprived of access to the minimum essential level of social security; and (f) whether there was an independent review of the measures at the national level.

Letter issued by the Committee on ESCR (CESCR/48th/SP /MAB/SW)

State Parties should not act in breach of the ICESCR, even in times of economic crisis. Any adjustments in policies should meet these requirements: 'first, the policy is a temporary measure covering only the period of crisis; second, the policy is necessary and proportionate, in the sense that the adoption of any other policy, or failure to act, would be more detrimental to economic, social and cultural rights; third, the policy is not discriminatory and comprises all possible measures, including tax measures, to support social transfers to mitigate inequalities that can grow in times of crisis and to ensure that the rights of the disadvantaged and marginalised individuals and groups are not disproportionately affected; fourth, the policy identifies the minimum core content of rights, or a social protection floor...and ensures protection of this core at all times.'

UNCRPD Article 4.2

With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3 Survival and development

UNCRC Article 6 (1)

States Parties recognize that every child has the inherent right to life. 2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

UNCRC Article 23.1

States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

UNCRPD Article 10 (Right to life)

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

4 Non-discrimination, equality of opportunity and reasonable accommodation

UNCRC Article 2

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

ICESCR Article 2.2

The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

ICESCR GC 20 (paras 1, 28)

(1) States parties must therefore adopt measures, which should include legislation, to ensure that individuals and entities in the private sphere do not discriminate on prohibited grounds.

(28) The denial of reasonable accommodation should be included in national legislation as a prohibited form of discrimination on the basis of disability. States parties should address discrimination, such as prohibitions on the right to education, and denial of reasonable accommodation in public places such as public health facilities and the workplace, as well as in private places, e.g. as long as spaces are designed and built in ways that make them inaccessible to wheelchairs, such users will be effectively denied their right to work.

UNCRPD Article 2

“Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms; “Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

UNCRPD Article 3

3(b) Non-discrimination

3(g) Equality between men and women

UNCRPD Article 5 (Equality and non-discrimination)

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

5 Best interests

UNCRC Article 3

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

UNCRC Article 19

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.
2. Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

UNCRC GC 12 (paras 70–74 on Articles 12 and 3)

(70) The purpose of article 3 is to ensure that in all actions undertaken concerning children, by a public or private welfare institution, courts, administrative authorities or legislative bodies, the best interests of the child are a primary consideration. It means that every action taken on behalf of the child has to respect the best interests of the child. The best interests of the child is similar to a procedural right that obliges States parties to introduce steps into the action process to ensure that the best interests of the child are taken into consideration. The Convention obliges States parties to assure that those responsible for these actions hear the child as stipulated in Article 12. This step is mandatory.

(71) The best interests of the child, established in consultation with the child, is not the only factor to be considered in the actions of institutions, authorities and administration. It is, however, of crucial importance, as are the views of the child.

(72) Article 3 is devoted to individual cases, but, explicitly, also requires that the best interests of children as a group are considered in all actions concerning children. States parties are consequently under an obligation to consider not only the individual situation of each child when identifying their best interests, but also the interests of children as a group. Moreover, States parties must examine the actions of private and public institutions, authorities, as well as legislative bodies. The extension of the obligation to “legislative bodies” clearly indicates that every law, regulation or rule that affects children must be guided by the “best interests” criterion.

(73) There is no doubt that the best interests of children as a defined group have to be established in the same way as when weighing individual interests. If the best interests of large numbers of children are at stake, heads of institutions, authorities, or governmental bodies should also provide opportunities to hear the concerned children from such undefined groups and to give their views due weight when they plan actions, including legislative decisions, which directly or indirectly affect children.

(74) There is no tension between Articles 3 and 12, only a complementary role of the two general principles: one establishes the objective of achieving the best interests of the child and the other provides the methodology for reaching the goal of hearing either the child or the children. In fact, there can be no correct application of article 3 if the components of article 12 are not respected. Likewise, Article 3 reinforces the functionality of Article 12, facilitating the essential role of children in all decisions affecting their lives.

UNCRC GC 8 (para 18)

(18) Article 37 of the Convention requires States to ensure that “no child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment”. This is complemented and extended by article 19, which requires States to “take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child”. There is no ambiguity: “all forms of physical or mental violence” does not leave room for any level of legalized violence against children. Corporal punishment and other cruel or degrading forms of punishment are forms of violence and States must take all appropriate legislative, administrative, social and educational measures to eliminate them.

UNCRC GC 13, paras 47(iii)–48 and 61

47 (iii) Preventing violence in care and justice settings by, inter alia, developing and implementing community-based services in order to make use of institutionalization and detention only as a last resort and only if in the best interest of the child.

48. Identification

This includes identifying risk factors for particular individuals or groups of children and caregivers (in order to trigger targeted prevention initiatives) and identifying signs of actual maltreatment (in order to trigger appropriate intervention as early as possible). This requires that all who come in contact with children are aware of risk factors and indicators of all forms of violence, have received guidance on how to interpret such indicators, and have the necessary knowledge, willingness and ability to take appropriate action (including the provision of emergency protection). Children must be provided with as many opportunities as possible to signal emerging problems before they reach a state of crisis, and for adults to recognize and act on such problems even if the child does not explicitly ask for help. Particular vigilance is

needed when it comes to marginalized groups of children who are rendered particularly vulnerable due to their alternative methods of communicating, their immobility and/or the perceived view that they are incompetent, such as children with disabilities. Reasonable accommodation should be provided to ensure that they are able to communicate and signal problems on an equal basis with others.

61. Article 3 (best interests of the child). The Committee emphasizes that the interpretation of a child's best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child's human dignity and right to physical integrity. An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention. In particular, the Committee maintains that the best interests of the child are best served through:

- (a) Prevention of all forms of violence and the promotion of positive child-rearing, emphasizing the need for a focus on primary prevention in national coordinating frameworks
- (b) Adequate investment in human, financial and technical resources dedicated to the implementation of a child rights-based and integrated child protection and support system.

UNCRPD Article 7 (Children with disabilities)

7.2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

UNCRPD Article 16 (Freedom from exploitation, violence and abuse)

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

6 Respect, personhood and evolving capacity, independence

UNCRC Article 1

For the purposes of the present Convention, a child means every human being below the age of 18 years unless, under the law applicable to the child, majority is attained earlier. A child is recognized as a person under 18, unless national laws recognize the age of majority earlier.

UNCRC Article 5

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

UNCRC GC 12 (para 20)

(20)...States parties should presume that a child has the capacity to form her or his own views and recognize that she or he has the right to express them; it is not up to the child to first prove her or his capacity.

ICESCR PREAMBLE

‘These rights derive from the inherent dignity of the human person’

UNCRPD Article 3 (General principles)

The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

UNCRPD Article 12 (Equal recognition before the law)

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “We want to help people see things our way”

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

7 Participation, information and influence regarding decision making

UNCRC Article 12

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

UNCRC Article 13

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.
2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
 - (a) For respect of the rights or reputations of others
 - (b) For the protection of national security or of public order (ordre public), or of public health or morals.

UNCRC Article 14

1. States Parties shall respect the right of the child to freedom of thought, conscience and religion.
2. States Parties shall respect the rights and duties of the parents and, when applicable, legal guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.
3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health or morals, or the fundamental rights and freedoms of others.

UNCRC Article 17

States Parties recognize the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.

To this end, States Parties shall:

- (a) Encourage the mass media to disseminate information and material of social and cultural benefit to the child and in accordance with the spirit of Article 29
- (b) Encourage international co-operation in the production, exchange and dissemination of such information and material from a diversity of cultural, national and international sources
- (c) Encourage the production and dissemination of children's books
- (d) Encourage the mass media to have particular regard to the linguistic needs of the child who belongs to a minority group or who is indigenous
- (e) Encourage the development of appropriate guidelines for the protection of the child from information and material injurious to his or her well-being, bearing in mind the provisions of Articles 13 and 18.

General Comment 12 (paras 19, 21, 22, 23)

(19) Article 12, paragraph 1, provides that States parties “shall assure” the right of the child to freely express her or his views. “Shall assure” is a legal term of special strength, which leaves no leeway for State parties’ discretion. Accordingly, States parties are under strict obligation to undertake appropriate measures to fully implement this right for all children. This obligation contains two elements in order to ensure that mechanisms are in place to solicit the views of the child in all matters affecting her or him and to give due weight to those views.

(21) The Committee emphasizes that article 12 imposes no age limit on the right of the child to express her or his views, and discourages States parties from introducing age limits either in law or in practice which would restrict the child’s right to be heard in all matters affecting her or him. In this respect, the Committee underlines the following:

- First, in its recommendations following the day of general discussion on implementing child rights in early childhood in 2004, the Committee underlined that the concept of the child as rights holder is “... anchored in the child’s daily life from the earliest stage”. Research shows that the child is able to form views from the youngest age, even when she or he may be unable to express them verbally. Consequently, full implementation of article 12 requires recognition of, and respect for, non-verbal forms of communication including play, body language, facial expressions, and drawing and painting, through which very young children demonstrate understanding, choices and preferences.
- Second, it is not necessary that the child has comprehensive knowledge of all aspects of the matter affecting her or him, but that she or he has sufficient understanding to be capable of appropriately forming her or his own views on the matter.
- Third, States parties are also under the obligation to ensure the implementation of this right for children experiencing difficulties in making their views heard. For instance, children with disabilities should be equipped with, and enabled to use, any mode of communication necessary to facilitate the expression of their views. Efforts must also be made to recognize the right to expression of views for minority, indigenous and migrant children and other children who do not speak the majority language “The right to express those views freely”

(22) The child has the right “to express those views freely”. “Freely” means that the child can express her or his views without pressure and can choose whether or not she or he wants to exercise her or his right to be heard. “Freely” also means that the child must not be manipulated or subjected to undue influence or pressure. “Freely” is further intrinsically related to the child’s “own” perspective: the child has the right to express her or his own views and not the views of others.

(23) States parties must ensure conditions for expressing views that account for the child’s individual and social situation and an environment in which the child feels respected and secure when freely expressing her or his opinions.

UNCRPD Article 3

(a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.

UNCRPD Article 4.3

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

UNCRPD Article 7.3

States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

UNCRPD Article 21 (Freedom of expression and opinion and access to information)

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- (a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- (b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions
- (c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- (d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;

UNCRPD Article 29 (Participation in political and public life)

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake...:

(b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including...

(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

(ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

8 Inclusion in community and society

UNCRC GC 9

(Para 11) Paragraph 11 of Article 23 should be considered as the leading principle for the implementation of the Convention with respect to children with disabilities: the enjoyment of a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate active participation in the community. The measures taken by States parties regarding the realization of the rights of children with disabilities should be directed towards this goal. The core message of this paragraph is that children with disabilities should be included in the society. Measures taken for the implementation of the rights contained in the Convention regarding children with disabilities, for example in the areas of education and health, should explicitly aim at the maximum inclusion of those children in society.

UNCRPD Article 3

c) Full and effective participation and inclusion in society

UNCRPD Article 19 (Living independently and being included in the community)

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

UNCRPD Article 26.1

Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

9 Personal assistance and support

UNCRC Article 23(2)

States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

UNCRC General Comment 9 (paras 10–12, 65)

(10) According to paragraph 2 of article 23 States parties to the Convention recognize the right of the child with disability to special care and shall encourage and ensure the extension of assistance to the eligible child and those responsible for his or her care. The assistance has to be appropriate to the child's condition and the circumstances of the parents or others caring for the child. Paragraph 3 of article 23 gives further rules regarding the costs of specific measures and precisions as to what the assistance should try to achieve.

(11) In order to meet the requirements of article 23 it is necessary that States parties develop and effectively implement a comprehensive policy by means of a plan of action which not only aims at the full enjoyment of the rights enshrined in the Convention without discrimination but which also ensures that a child with disability and her or his parents and/or others caring for the child do receive the special care and assistance they are entitled to under the Convention.

(12) Regarding the specifics of paragraphs 2 and 3 of article 23, the Committee makes the following observations:

(a) The provision of special care and assistance is subject to available resources and free of charge whenever possible. The Committee urges States parties to make special care and assistance to children with disabilities a matter of high priority and to invest to the maximum extent of available resources in the elimination of discrimination against children with disabilities and towards their maximum inclusion in society.

(b) Care and assistance shall be designed to ensure that children with disabilities have effective access to and benefit from education, training, health care services, recovery services, preparation for employment and recreation opportunities. The Committee when dealing with specific articles of the Convention will elaborate on the measures necessary to achieve this.

(65) In order to fully exercise their right to education, many children need personal assistance, in particular, teachers trained in methodology and techniques, including appropriate languages, and other forms of communication, for teaching children with a diverse range of abilities capable of using child-centred and individualised teaching strategies, and appropriate and accessible teaching materials, equipment and assistive devices, which States parties should provide to the maximum extent of available resources.

UNCRPD Article 12.3

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

UNCRPD Article 26 (Habilitation and rehabilitation)

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

(a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

(b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas...

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

10 Adequacy, availability and accessibility

UNCRC Article 23 (3)

Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

ICESCR GC3 (paras 1, 2)

(1)...while the Covenant provides for progressive realization and acknowledges the constraints due to the limits of available resources, it also imposes various obligations which are of immediate effect. Of these, two are of particular importance in understanding the precise nature of States parties obligations. One of these, which is dealt with in a separate general comment, and which is to be considered by the Committee at its sixth session, is the "undertaking to guarantee" that relevant rights "will be exercised without discrimination ..."

(2) The other is the undertaking in Article 2 (1) "to take steps", which in itself, is not qualified or limited by other considerations. The full meaning of the phrase can also be gauged by noting some of the different language versions. In English the undertaking is "to take steps", in French it is "to act" ("s'engage à agir") and in Spanish it is "to adopt measures" ("adoptar medidas"). Thus while the full realization of the relevant rights may be achieved progressively, steps towards that goal must be taken within a reasonably short time after the Covenant's entry into force for the States concerned. Such steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the Covenant.

ICESCR GC9 (paras 1, 2)

(1) The central obligation in relation to the Covenant is for States parties to give effect to the rights recognized therein. By requiring Governments to do so "by all appropriate means", the Covenant adopts a broad and flexible approach which enables the particularities of the legal and administrative systems of each State, as well as other relevant considerations, to be taken into account.

(2) But this flexibility coexists with the obligation upon each State party to use all the means at its disposal to give effect to the rights recognized in the Covenant. In this respect, the fundamental requirements of international human rights law must be borne in mind. Thus the Covenant norms must be recognized in appropriate ways within the domestic legal order, appropriate means of redress, or remedies, must be available to any aggrieved individual or group, and appropriate means of ensuring governmental accountability must be put in place.

UNCRPD Article General Principles 3

(f) Accessibility

Article 4 (General obligations)

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- (d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
- (e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
- (f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
- (g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
- (h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

Article 9 (Accessibility)

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- (b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures:

- (a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- (b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- (c) To provide training for stakeholders on accessibility issues facing persons with disabilities;
- (d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
- (e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- (f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- (g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- (h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost

11 Training

(UNCRC GC 9 para 20, 27, 32, 49, 60)

(20) Resources allocated to children with disabilities should be sufficient --and earmarked so that they are not used for other purposes-- to cover all their needs, including programmes established for training professionals working with children with disabilities such as teachers, physiotherapists and policymakers; education campaigns; financial support for families; income maintenance; social security; assistive devices; and related services.

(27) As for professionals working with and for children with disabilities, training programmes must include targeted and focused education on the rights of children with disabilities as a prerequisite for qualification. These professionals include but are not limited to policymakers, judges, lawyers, law enforcement officers, educators, health workers, social workers and media staff among others.

(32) Furthermore, States parties should support the training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives.

(49) In addressing institutionalization, States parties are therefore urged to set up programmes for de-institutionalization of children with disabilities, re-placing them with their families, extended families or foster care system. Parents and other extended family members should be provided with the necessary and systematic support/training for including their child back into their home environment.

(60) The Convention recognizes the need for modification to school practices and for training of regular teachers to prepare them to teach children with diverse abilities and ensure that they achieve positive educational outcomes.

UNCRPD Article 4

(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

UNCRPD Article 26.2

States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

UNCRPD Article 28.2

c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care

12 Care and assistance for disabled children (B)

UNCRC Article 23

(1) States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

(2) States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

(3) Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

(4) States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

See also General Comment 9 below.

UNCRPD Article 7 (Children with disabilities)

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

See also General Comment 9 below.

13 Adequate Standard of Living – Basic things you need for living (C)

UNCRC Article 27

1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.
2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.
3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.
4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

ICESCR Article 11

1. The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international cooperation based on free consent.
2. The States Parties to the present Covenant, recognizing the fundamental right of everyone to be free from hunger, shall take, individually and through international co-operation, the measures, including specific programmes, which are needed:
 - (a) To improve methods of production, conservation and distribution of food by making full use of technical and scientific knowledge, by disseminating knowledge of the principles of nutrition and by developing or reforming agrarian systems in such a way as to achieve the most efficient development and utilization of natural resources;
 - (b) Taking into account the problems of both food-importing and food-exporting countries, to ensure an equitable distribution of world food supplies in relation to need.

ICESCR General Comment 19

(f) Family and child support

(18) Benefits for families are crucial for realizing the rights of children and adult dependents to protection under Articles 9 and 10 of the Covenant. In providing the benefits, the State party should take into account the resources and circumstances of

the child and persons having responsibility for the maintenance of the child or adult dependent, as well as any other consideration relevant to an application for benefits made by or on behalf of the child or adult dependent.¹⁴ Family and child benefits, including cash benefits and social services, should be provided to families, without discrimination on prohibited grounds, and would ordinarily cover food, clothing, housing, water and sanitation, or other rights as appropriate.

ICESCR GC 4 Article 11(1) (Housing)

(7) In the Committee's view, the right to housing should not be interpreted in a narrow or restrictive sense which equates it with, for example, the shelter provided by merely having a roof over one's head or views shelter exclusively as a commodity. Rather it should be seen as the right to live somewhere in security, peace and dignity...

8(b) Availability of services, materials, facilities and infrastructure. An adequate house must contain certain facilities essential for health, security, comfort and nutrition. All beneficiaries of the right to adequate housing should have sustainable access to natural and common resources, safe drinking water, energy for cooking, heating and lighting, sanitation and washing facilities, means of food storage, refuse disposal, site drainage and emergency services...

(d) Habitability. Adequate housing must be habitable, in terms of providing the inhabitants with adequate space and protecting them from cold, damp, heat, rain, wind or other threats to health, structural hazards, and disease vectors. The physical safety of occupants must be guaranteed as well. The Committee encourages States parties to comprehensively apply the Health Principles of Housing 5/ prepared by WHO which view housing as the environmental factor most frequently associated with conditions for disease in epidemiological analyses; i.e. inadequate and deficient housing and living conditions are invariably associated with higher mortality and morbidity rates...

(e) Accessibility. Adequate housing must be accessible to those entitled to it. Disadvantaged groups must be accorded full and sustainable access to adequate housing resources. Thus, such disadvantaged groups as the elderly, children, the physically disabled, the terminally ill, HIV-positive individuals, persons with persistent medical problems, the mentally ill, victims of natural disasters, people living in disaster-prone areas and other groups should be ensured some degree of priority consideration in the housing sphere. Both housing law and policy should take fully into account the special housing needs of these groups. Within many States parties increasing access to land by landless or impoverished segments of the society should constitute a central policy goal. Discernible governmental obligations need to be developed aiming to substantiate the right of all to a secure place to live in peace and dignity, including access to land as an entitlement...

(g) Cultural adequacy. The way housing is constructed, the building materials used and the policies supporting these must appropriately enable the expression of cultural identity and diversity of housing. Activities geared towards development or modernization in the housing sphere should ensure that the cultural dimensions of housing are not sacrificed, and that, inter alia, modern technological facilities, as appropriate are also ensured.

ICESCR GC 12 (Food)

6. The right to adequate food is realized when every man, woman and child, alone or

in community with others, have physical and economic access at all times to adequate food or means for its procurement. The right to adequate food shall therefore not be interpreted in a narrow or restrictive sense which equates it with a minimum package of calories, proteins and other specific nutrients. The right to adequate food will have to be realized progressively.

However, States have a core obligation to take the necessary action to mitigate and alleviate hunger as provided for in paragraph 2 of article 11, even in times of natural or other disasters.

Adequacy and sustainability of food availability and access

7. The concept of adequacy is particularly significant in relation to the right to food since it serves to underline a number of factors which must be taken into account in determining whether particular foods or diets that are accessible can be considered the most appropriate under given circumstances for the purposes of article 11 of the Covenant. The notion of sustainability is intrinsically linked to the notion of adequate food or food security, implying food being accessible for both present and future generations. The precise meaning of “adequacy” is to a large extent determined by prevailing social, economic, cultural, climatic, ecological and other conditions, while “sustainability” incorporates the notion of long-term availability and accessibility...

11. Cultural or consumer acceptability implies the need also to take into account, as far as possible, perceived non nutrient-based values attached to food and food consumption and informed consumer concerns regarding the nature of accessible food supplies.

UNCRPD Article 28 (Adequate standard of living and social protection)

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

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

- (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
- (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
- (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care;
- (d) To ensure access by persons with disabilities to public housing programmes;
- (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

14 Social Security – money, benefits and social support (D)

UNCRC Article 26

1. States Parties shall recognize for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realization of this right in accordance with their national law.
2. The benefits should, where appropriate, be granted, taking into account the resources and the circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child.

ICESCR Article 9

The States Parties to the present Covenant recognize the right of everyone to social security, including social insurance.

ICESCR General Comment 19 (paras 2, 6, 10, 20 and 22–27)

(2) The right to social security encompasses the right to access and maintain benefits, whether in cash or in kind, without discrimination in order to secure protection, inter alia, from (a) lack of work-related income caused by sickness, disability, maternity, employment injury, unemployment, old age, or death of a family member; (b) unaffordable access to health care; (c) insufficient family support, particularly for children and adult dependents...

(6) The right to social security has been strongly affirmed in international law. The human rights dimensions of social security were clearly present in the Declaration of Philadelphia of 1944 which called for the “extension of social security measures to provide a basic income to all in need of such protection and comprehensive medical care”.

(10) While the elements of the right to social security may vary according to different conditions, a number of essential factors apply in all circumstances as set out below. In interpreting these aspects, it should be borne in mind that social security should be treated as a social good, and not primarily as a mere instrument of economic or financial policy....

(h) Disability

(20) In its general comment No. 5 ((1994) on persons with disabilities, the Committee emphasized the importance of providing adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost, or received a reduction in, their income, have been denied employment opportunities or have a permanent disability. Such support should be provided in a dignified manner and reflect the special needs for assistance and other expenses often associated with disability. The support provided should cover family members and other informal carers...

Adequacy

(22) Benefits, whether in cash or in kind, must be adequate in amount and duration in order that everyone may realize his or her rights to family protection and assistance, an adequate standard of living and adequate access to health care, as contained in articles 10, 11 and 12 of the Covenant. States parties must also pay full respect to the principle of human dignity contained in the preamble of the Covenant, and the principle of non-discrimination, so as to avoid any adverse effect on the levels of benefits and the form in which they are provided. Methods applied should ensure the adequacy of benefits. The adequacy criteria should be monitored regularly to ensure that beneficiaries are able to afford the goods and services they require to realize their Covenant rights. When a person makes contributions to a social security scheme that provides benefits to cover lack of income, there should be a reasonable relationship between earnings, paid contributions, and the amount of relevant benefit.

Accessibility

(a) Coverage

(23) All persons should be covered by the social security system, especially individuals belonging to the most disadvantaged and marginalized groups, without discrimination on any of the grounds prohibited under Article 2, paragraph 2, of the Covenant. In order to ensure universal coverage, non-contributory schemes will be necessary.

(b) Eligibility

(24) Qualifying conditions for benefits must be reasonable, proportionate and transparent. The withdrawal, reduction or suspension of benefits should be circumscribed, based on grounds that are reasonable, subject to due process, and provided for in national law.

(c) Affordability

(25) If a social security scheme requires contributions, those contributions should be stipulated in advance. The direct and indirect costs and charges associated with making contributions must be affordable for all, and must not compromise the realization of other Covenant rights.

(d) Participation and information

(26) Beneficiaries of social security schemes must be able to participate in the administration of the social security system. The system should be established under national law and ensure the right of individuals and organizations to seek, receive and impart information on all social security entitlements in a clear and transparent manner.

(e) Physical access

(27) Benefits should be provided in a timely manner and beneficiaries should have physical access to the social security services in order to access benefits and information, and make contributions where relevant. Particular attention should be paid in this regard to persons with The Committee notes that, under ILO Convention No. 168 (1988) on Employment Promotion and Protection against Unemployment, such action can only be taken in certain circumstances: absence from the territory of the State; a competent authority has determined that the person concerned deliberately contributed to their own dismissal or left employment voluntarily without just cause; during the period a person stops work due to a labour dispute; the person has attempted to obtain or has obtained benefits fraudulently; the person has failed without just cause to use the facilities available for placement, vocational guidance, training, retraining or redeployment in suitable work; or the person is in receipt of another income maintenance benefit provided for in the legislation of the relevant

State, except a family benefit, provided that the part of the benefit which is suspended does not exceed that other benefit. Articles 71 and 72 of ILO Convention 102 (1952) on Social Security (Minimum Standards) set out similar requirements.... disabilities, migrants, and persons living in remote or disaster-prone areas, as well as areas experiencing armed conflict, so that they, too, can have access to these services.

See also Para 64 and 65 – violations can occur through commission and omission.

UNCRPD Article 28

Adequate standard of living and social protection

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

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

- (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs
- (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes
- (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care
- (d) To ensure access by persons with disabilities to public housing programmes
- (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

15 Family life (E)

UNCRC Article 9

1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance applicable law and procedures, that such separation is necessary for the best interests of the child.

Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.

2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.

3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests.

UNCRC Article 18

1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.

2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.

3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

UNCRC Article 20

1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.

2. States Parties shall in accordance with their national laws ensure alternative care for such a child.

3. Such care could include, inter alia, foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic

background.

UNCRC GC 12

90. A family where children can freely express views and be taken seriously from the earliest ages provides an important model, and is a preparation for the child to exercise the right to be heard in the wider society. Such an approach to parenting serves to promote individual development, enhance family relations and support children's socialization and plays a preventive role against all forms of violence in the home and family.

91. The Convention recognizes the rights and responsibilities of parents, or other legal guardians, to provide appropriate direction and guidance to their children (see para. 84 above), but underlines that this is to enable the child to exercise his or her rights and requires that direction and guidance are undertaken in a manner consistent with the evolving capacities of the child.

92. States parties should encourage, through legislation and policy, parents, guardians and childminders to listen to children and give due weight to their views in matters that concern them. Parents should also be advised to support children in realizing the right to express their views freely and to have children's views duly taken into account at all levels of society.

ICESCR Article 10

The States Parties to the present Covenant recognize that:

1. The widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children. Marriage must be entered into with the free consent of the intending spouses.
2. Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.
3. Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions.

UNCRPD Article 18.2

Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

UNCRPD Article 23

Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “We want to help people see things our way”

- (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized
- (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided
- (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

16 Education (F)

UNCRC Article 28

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:

- (a) Make primary education compulsory and available free to all;
- (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need
- (c) Make higher education accessible to all on the basis of capacity by every appropriate means
- (d) Make educational and vocational information and guidance available and accessible to all children
- (e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.

3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

UNCRC Article 29

1. States Parties agree that the education of the child shall be directed to:

- (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential
- (b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations
- (c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own
- (d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin
- (e) The development of respect for the natural environment.

2. No part of the present article or article 28 shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principle set forth in paragraph 1 of the

present article and to the requirements that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

ICESCR Article 6.2

The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

ICESCR Article 13

1. The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.

2. The States Parties to the present Covenant recognize that, with a view to achieving the full realization of this right:

- (a) Primary education shall be compulsory and available free to all
- (b) Secondary education in its different forms, including technical and vocational secondary education, shall be made generally available and accessible to all by every appropriate means, and in particular by the progressive introduction of free education
- (c) Higher education shall be made equally accessible to all, on the basis of capacity, by every appropriate means, and in particular by the progressive introduction of free education
- (d) Fundamental education shall be encouraged or intensified as far as possible for those persons who have not received or completed the whole period of their primary education.

3. The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to choose for their children schools, other than those established by the public authorities, which conform to such minimum educational standards as may be laid down or approved by the State and to ensure the religious and moral education of their children in conformity with their own convictions.

UNCRPD Article 24

Education

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

- (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity

- (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential
- (c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

- (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability
- (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live
- (c) Reasonable accommodation of the individual's requirements is provided;
- (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education
- (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

- (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community
- (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

17 Work (G)

UNCRC Article 32

1. States Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.

2. States Parties shall take legislative, administrative, social and educational measures to ensure the implementation of the present article. To this end, and having regard to the relevant provisions of other international instruments, States Parties shall in particular:

- (a) Provide for a minimum age or minimum ages for admission to employment
- (b) Provide for appropriate regulation of the hours and conditions of employment

ICESCR Article 6

1. The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.
2. The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

ICESCR Article 7

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of just and favourable conditions of work which ensure, in particular:

- (a) Remuneration which provides all workers, as a minimum, with:
 - (i) Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work;
 - (ii) A decent living for themselves and their families in accordance with the provisions of the present Covenant;
- (b) Safe and healthy working conditions
- (c) Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than those of seniority and competence
- (d) Rest, leisure and reasonable limitation of working hours and periodic holidays with pay, as well as remuneration for public holidays.

UNCRPD Article 27 (Work and employment)

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open,

inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

- (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions
- (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances
- (c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others
- (d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training
- (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment
- (f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business
- (g) Employ persons with disabilities in the public sector
- (h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures
- (i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace
- (j) Promote the acquisition by persons with disabilities of work experience in the open labour market
- (k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour

18 Play, association, sport, leisure and cultural activities (H)

UNCRC Article 15

1. States Parties recognize the rights of the child to freedom of association and to freedom of peaceful assembly.
2. No restrictions may be placed on the exercise of these rights other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.

UNCRC Article 30

In those States in which ethnic, religious or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practise his or her own religion, or to use his or her own language.

UNCRC Article 31

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

UNCRC GC 12

115. Children require play, recreation, physical and cultural activities for their development and socialization. These should be designed taking into account children's preferences and capacities. Children who are able to express their views should be consulted regarding the accessibility and appropriateness of play and recreation facilities. Very young children and some children with disabilities, who are unable to participate in formal consultative processes, should be provided with particular opportunities to express their wishes.

ICESCR Article 15

1. The States Parties to the present Covenant recognize the right of everyone:
 - (a) To take part in cultural life;
 - (b) To enjoy the benefits of scientific progress and its applications
 - (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

UNCRPD Article 30

Participation in cultural life, recreation, leisure and sport

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

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

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

- (a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
- (b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
- (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- (e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

19 Health (I)

UNCRC Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
 - (a) To diminish infant and child mortality;
 - (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
 - (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
 - (d) To ensure appropriate pre-natal and post-natal health care for mothers;
 - (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
 - (f) To develop preventive health care, guidance for parents and family planning education and services.
3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.
4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

UNCRC GC 12 (para 100)

100. Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities. They should be provided with information about proposed treatments and their effects and outcomes, including in formats appropriate and accessible to children with disabilities.

ICESCR Article 12

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
 - (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

- (b) The improvement of all aspects of environmental and industrial hygiene;
- (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

ICESCR GC 14

11. The Committee interprets the right to health, as defined in article 12.1, as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health. A further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels...

Availability

Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party's developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs:

(b) Accessibility. Health facilities, goods and services⁶ have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions:

(i) Non-discrimination: health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.⁷

(ii) Physical accessibility: health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.

(iii) Economic accessibility (affordability): health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.

(iv) Information accessibility: accessibility includes the right to seek, receive and impart information and ideas concerning health issues.

However, accessibility of information should not impair the right to have personal health data treated with confidentiality.

(c) Acceptability. All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

(d) Quality. As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, inter alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.

ICESCR GC 19

(a) Health care

13. States parties have an obligation to guarantee that health systems are established to provide adequate access to health services for all. In cases in which the health system foresees private or mixed plans, such plans should be affordable, in conformity with the essential elements enunciated in the present general comment. The Committee notes the particular importance of the right to social security in the context of endemic diseases such as HIV/AIDS, tuberculosis and malaria, and the need to provide access to preventive and curative measures.

UNCRPD Article 25 (Health)

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

20 Mobility (J)

UNCRC GC 23 (para 41)

...material support in the form of special allowances as well as consumable supplies and necessary equipment, such as special furniture and mobility devices that is deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community.

UNCRPD Article 20 (Personal mobility)

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- (b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- (c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- (d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

21 CRC/C/GC/9 General Comment No. 9 (2006) The rights of children with disabilities (A)

I. Introduction

A. Why a General Comment on children with disabilities?

It is estimated that there are 500-650 million persons with disabilities in the world, approximately 10 % of the world population, 150 million of whom are children. More than 80 % live in developing countries with little or no access to services. The majority of children with disabilities in developing countries remain out of school and are completely illiterate. It is recognized that most of the causes of disabilities, such as war, illness and poverty, are preventable which also prevent and/or reduce the secondary impacts of disabilities, often caused by the lack of early/timely intervention. Therefore, more should be done to create the necessary political will and real commitment to investigate and put into practice the most effective actions to prevent disabilities with the participation of all levels of society.

The past few decades have witnessed positive focus on persons with disabilities in general and children in particular. The reason for this new focus is explained partly by the fact that the voice of persons with disabilities and of their advocates from national and international non-governmental organizations (NGO) is being increasingly heard and partly by the growing attention paid to persons with disabilities within the framework of the human rights treaties and the United Nations human rights treaty bodies. These treaty bodies have considerable potential in advancing the rights of persons with disabilities but they have generally been underused. When adopted in November 1989 the Convention on the Rights of the Child (hereafter “the Convention”) was the first human rights treaty that contained a specific reference to disability (Article 2 on non-discrimination) and a separate article 23 exclusively dedicated to the rights and needs of children with disabilities. Since the Convention has entered into force (2 September 1990), the Committee on the Rights of the Child (thereafter “the Committee”) has paid sustained and particular attention to disability-based discrimination¹ while other human rights treaty bodies have paid attention to disability-based discrimination under “other status” in the context of articles on non-discrimination of their relevant Convention. In 1994 the Committee on Economic, Social and Cultural Rights issued its general comment No. 5 on persons with disabilities and stated in paragraph 15 that “The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.” The Special Rapporteur on disability of the United Nations Commission for Social Development was first appointed in 1994 and mandated to monitor of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly at its forty-eighth session in 1993 (A/RES/48/96, Annex), and to advance the status of persons with disabilities throughout the world. On 6 October

¹ See WouterVandenhoele, Non-Discrimination and Equality in the View of the UN Human Rights Treaty Bodies, p.170-172, Antwerpen/Oxford, Intersentia 2005.

1997 the Committee devoted its day of general discussion to children with disabilities and adopted a set of recommendations (CRC/C/66, paragraphs 310-339), in which it considered the possibility of drafting a general comment on children with disabilities. The Committee notes with appreciation the work of the Ad-Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, and that it adopted at its eighth session, held in New York on 25 August 2006, a draft convention on the rights of persons with disabilities to be submitted to the General Assembly at its sixty-first session (A/AC.265/2006/4, Annex II).

The Committee, in reviewing State party reports, has accumulated a wealth of information on the status of children with disabilities worldwide and found that in the overwhelming majority of countries some recommendations had to be made specifically to address the situation of children with disabilities. The problems identified and addressed have varied from exclusion from decision-making processes to severe discrimination and actual killing of children with disabilities. Poverty being both a cause and a consequence of disability, the Committee has repeatedly stressed that children with disabilities and their families have the right to an adequate standard of living, including adequate food, clothing and housing, and to the continuous improvement of their living conditions. The question of children with disabilities living in poverty should be addressed by allocating adequate budgetary resources as well as by ensuring that children with disabilities have access to social protection and poverty reduction programmes.

The Committee has noted that no reservations or declarations have been entered specifically to article 23 of the Convention by any State party.

The Committee also notes that children with disabilities are still experiencing serious difficulties and facing barriers to the full enjoyment of the rights enshrined in the Convention. The Committee emphasizes that the barrier is not the disability itself but rather a combination of social, cultural, attitudinal and physical obstacles which children with disabilities encounter in their daily lives. The strategy for promoting their rights is therefore to take the necessary action to remove those barriers. Acknowledging the importance of articles 2 and 23 of the Convention, the Committee states from the outset that the implementation of the Convention with regards to children with disabilities should not be limited to these articles.

The present general comment is meant to provide guidance and assistance to States parties in their efforts to implement the rights of children with disabilities, in a comprehensive manner which covers all the provisions of the Convention. Thus, the Committee will first make some observations related directly to articles 2 and 23, then it will elaborate on the necessity of paying particular attention to and including explicitly children with disabilities within the framework of general measures for the implementation of the Convention. Those observations will be followed by comments on the meaning and the implementation of the various articles of the Convention (clustered in accordance with the Committee's practice) for children with disabilities.

B. Definition

According to Article 1, paragraph 2, of the draft convention on the rights of persons with disabilities, “Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (A/AC.265/2006/4, Annex II)

II. The key provisions for children with disabilities (Articles 2 and 23)

A. Article 2

Article 2 requires States parties to ensure that all children within their jurisdiction enjoy all the rights enshrined in the Convention without discrimination of any kind. This obligation requires States parties to take appropriate measures to prevent all forms of discrimination, including on the ground of disability. This explicit mention of disability as a prohibited ground for discrimination in article 2 is unique and can be explained by the fact that children with disabilities belong to one of the most vulnerable groups of children. In many cases forms of multiple discrimination - based on a combination of factors, i.e. indigenous girls with disabilities, children with disabilities living in rural areas and so on - increase the vulnerability of certain groups. It has been therefore felt necessary to mention disability explicitly in the non-discrimination article. Discrimination takes place – often de facto – in various aspects of the life and development of children with disabilities. As an example, social discrimination and stigmatization leads to their marginalization and exclusion, and may even threaten their survival and development if it goes as far as physical or mental violence against children with disabilities. Discrimination in service provision excludes them from education and denies them access to quality health and social services. The lack of appropriate education and vocational training discriminates against them by denying them job opportunities in the future. Social stigma, fears, overprotection, negative attitudes, misbeliefs and prevailing prejudices against children with disabilities remain strong in many communities and lead to the marginalization and alienation of children with disabilities. The Committee shall elaborate on these aspects in the paragraphs below.

In general, States parties in their efforts to prevent and eliminate all forms of discrimination against children with disabilities should take the following measures.

- (a) Include explicitly disability as a forbidden ground for discrimination in constitutional provisions on non-discrimination and/or include specific prohibition of discrimination on the ground of disability in specific anti-discrimination laws or legal provisions.
- (b) Provide for effective remedies in case of violations of the rights of children with disabilities, and ensure that those remedies are easily accessible to children with disabilities and their parents and/or others caring for the child.
- (c) Conduct awareness-raising and educational campaigns targeting the public at large and specific groups of professionals with a view to preventing and eliminating de facto discrimination against children with disabilities.

- (d) Girls with disabilities are often even more vulnerable to discrimination due to gender discrimination. In this context, States parties are requested to pay particular attention to girls with disabilities by taking the necessary measures, and when needed extra measures, in order to ensure that they are well protected, have access to all services and are fully included in society.

B. Article 23

Paragraph 1 of article 23 should be considered as the leading principle for the implementation of the Convention with respect to children with disabilities: the enjoyment of a full and decent life in conditions that ensure dignity, promote self – reliance (Matrix A4) and facilitate active participation in the community. The measures taken by States parties regarding the realization of the rights of children with disabilities should be directed towards this goal. The core message of this paragraph is that children with disabilities should be included in the society. Measures taken for the implementation of the rights contained in the Convention regarding children with disabilities, for example in the areas of education and health, should explicitly aim at the maximum inclusion of those children in society (Matrix B6).

According to paragraph 2 of article 23 States parties to the Convention recognize the right of the child with disability to special care and shall encourage and ensure the extension of assistance to the eligible child and those responsible for his or her care. The assistance has to be appropriate to the child's condition and the circumstances of the parents or others caring for the child. Paragraph 3 of article 23 gives further rules regarding the costs of specific measures and precisions as to what the assistance should try to achieve.

In order to meet the requirements of article 23 it is necessary that States parties develop and effectively implement a comprehensive policy by means of a plan of action which not only aims at the full enjoyment of the rights enshrined in the Convention without discrimination but which also ensures that a child with disability and her or his parents and/or others caring for the child do receive the special care and assistance they are entitled to under the Convention.

Regarding the specifics of paragraphs 2 and 3 of article 23, the Committee makes the following observations:

- (a) The provision of special care and assistance is subject to available resources and free of charge whenever possible. The Committee urges States parties to make special care and assistance to children with disabilities a matter of high priority and to invest to the maximum extent of available resources in the elimination of discrimination against children with disabilities and towards their maximum inclusion in society.
- (b) Care and assistance shall be designed to ensure that children with disabilities have effective access to and benefit from education,

training, health care services, recovery services, preparation for employment and recreation opportunities. The Committee when dealing with specific articles of the Convention will elaborate on the measures necessary to achieve this.

With reference to article 23, paragraph 4, the Committee notes that the international exchange of information between States parties in the areas of prevention and treatment is quite limited. The Committee recommends that States parties take effective, and where appropriate targeted, measures for an active promotion of information as envisaged by article 23, paragraph 4, in order to enable States parties to improve their capabilities and skills in the areas of prevention and treatment of disabilities of children.

It is often not clear how and to which degree the needs of developing countries are taken into account as required by article 23, paragraph 4. The Committee strongly recommends States parties to ensure that, within the framework of bilateral or multilateral development assistance, particular attention be paid to children with disabilities and their survival and development in accordance with the provisions of the Convention, for example, by developing and implementing special programmes aiming at their inclusion in society and allocating earmarked budgets to that effect. States parties are invited to provide information in their reports to the Committee on the activities and results of such international cooperation.

III. General measures of implementation (Articles 4, 42 and 44 (6))²

A. Legislation

In addition to the legislative measures recommended with regard to non-discrimination (see paragraph 9 above), the Committee recommends that States parties undertake a comprehensive review of all domestic laws and related regulations in order to ensure that all provisions of the Convention are applicable to all children, including children with disabilities who should be mentioned explicitly, where appropriate. National laws and regulations should contain clear and explicit provisions for the protection and exercise of the specific rights of children with disabilities, in particular those enshrined in Article 23 of the Convention.

B. National plans of action and policies

The need for a national plan of action that integrates all the provisions of the Convention is a well-recognized fact and has often been a recommendation made by the Committee to States parties. Plans of action must be comprehensive, including plans and strategies for children with disabilities, and should have measurable outcomes. The draft convention on the rights of persons with disabilities, in its article 4, paragraph 1 c, emphasizes the importance of inclusion of this aspect stating that States parties undertake “to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes” (A/AC.265/2006/4, annex II). It is also essential that all programmes be adequately

² In the present general comment the Committee focuses on the need to pay special attention to children with disabilities in the context of the general measures. For a more elaborated explanation of the content and importance of these measures, see the Committee’s general comment No. 5 (2003) on general measures of implementation of the Convention on the Rights of the Child.

supplied with financial and human resources and equipped with built-in monitoring mechanisms, for example, indicators allowing accurate outcome measurements. Another factor that should not be overlooked is the importance of including all children with disabilities in policies and programmes. Some States parties have initiated excellent programmes, but failed to include all children with disabilities.

C. Data and statistics

In order to fulfil their obligations, it is necessary for States parties to set up and develop mechanisms for collecting data which are accurate, standardized and allow disaggregation, and which reflect the actual situation of children with disabilities. The importance of this issue is often overlooked and not viewed as a priority despite the fact that it has an impact not only on the measures that need to be taken in terms of prevention but also on the distribution of very valuable resources needed to fund programmes. One of the main challenges in obtaining accurate statistics is the lack of a widely accepted clear definition for disabilities. States parties are encouraged to establish an appropriate definition that guarantees the inclusion of all children with disabilities so that children with disabilities may benefit from the special protection and programmes developed for them. Extra efforts are often needed to collect data on children with disabilities because they are often hidden by their parents or others caring for the child.

D. Budget

Allocation of budget: in the light of article 4 "...States parties shall undertake such measures to the maximum extent of their available resources...". Although the Convention does not make a specific recommendation regarding the most appropriate percentage of the State budget that should be dedicated to services and programmes for children, it does insist that children should be a priority. The implementation of this right has been a concern to the Committee since many States parties not only do not allocate sufficient resources but have also reduced the budget allocated to children over the years. This trend has many serious implications especially for children with disabilities who often rank quite low, or even not at all, on priority lists. For example, if a State party is failing to allocate sufficient funds to ensure compulsory and free quality education for all children, it will be unlikely to allocate funds to train teachers for children with disabilities or to provide for the necessary teaching aids and transportation for children with disabilities. Decentralization and privatization of services are now means of economic reform. However, it should not be forgotten that it is the State Party's ultimate responsibility to oversee that adequate funds are allocated to children with disabilities along with strict guidelines for service delivery. Resources allocated to children with disabilities should be sufficient --and earmarked so that they are not used for other purposes-- to cover all their needs, including programmes established for training professionals working with children with disabilities such as teachers, physiotherapists and policymakers; education campaigns; financial support for families; income maintenance; social security; assistive devices; and related services. Furthermore, funding must also be ensured for other programmes aimed at including children with disabilities into mainstream education, inter alia by renovating schools to render them physically accessible to children with disabilities.

E. Coordination body: "Focal point for disabilities"

Services for children with disabilities are often delivered by various governmental and non-governmental institutions, and more often than not, these services are fragmented and not coordinated which result in overlapping of functions and gaps in provisions. Therefore, the setting up of an appropriate coordinating mechanism

becomes essential. This body should be multi-sectorial, including all organizations public or private. It must be empowered and supported from the highest possible levels of Government to allow it to function at its full potential. A coordination body for children with disabilities, as part of a broader coordination system for the rights of the child or a national coordination system for persons with disabilities, would have the advantage of working within an already established system, provided this system is functioning adequately and capable of devoting the adequate financial and human resources necessary. On the other hand, a separate coordination system may help to focus attention on children with disabilities.

F. International cooperation and technical assistance

In order to make information among States parties freely accessible and to cultivate an atmosphere of knowledge-sharing concerning, inter alia, the management and rehabilitation of children with disabilities, States parties should recognize the importance of international cooperation and technical assistance. Particular attention should be paid to developing countries that need assistance in setting up and/or funding programmes that protect and promote the rights of children with disabilities. These countries are experiencing increasing difficulties in mobilizing the adequate resources to meet the pressing needs of persons with disabilities and would urgently need assistance in the prevention of disability, the provision of services and rehabilitation, and in the equalization of opportunities. However, in order to respond to these growing needs, the international community should explore new ways and means of raising funds, including substantial increase of resources, and take the necessary follow-up measures for mobilizing resources. Therefore, voluntary contributions from Governments, increased regional and bilateral assistance as well as contributions from private sources should also be encouraged. UNICEF and the World Health Organization (WHO) have been instrumental in helping developing countries set up and implement specific programmes for children with disabilities. The process of knowledge exchange is also valuable in sharing updated medical knowledge and good practices, such as early identification and community-based approaches to early intervention and support to families, and addressing common challenges.

Countries that have endured, or continue to endure, internal or foreign conflict, during which land mines were laid, face a particular challenge. States parties are often not privy to plans of the sites where the land mines and unexploded ordnance were planted and the cost of mine clearance is very high. The Committee emphasizes the importance of international cooperation in accordance with the 1997 Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on their Destruction, in order to prevent injuries and deaths caused by landmines and unexploded ordnance that remain in place. In this regard the Committee recommends that States parties closely cooperate with a view to completely removing all landmines and unexploded ordnance in areas of armed conflict and/or previous armed conflict.

G. Independent monitoring

Both the Convention and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities recognize the importance of the establishment of an

appropriate monitoring system³. The Committee has very often referred to “the Paris Principles” (A/RES/48/134) as the guidelines which national human rights institutions should follow (see the Committee’s general comment No. 2 (2002) on the role of independent national human rights institutions in the promotion and protection of the rights of the child). National human rights institutions can take many shapes or forms such as an Ombudsman or a Commissioner and may be broad-based or specific. Whatever mechanism is chosen, it must be:

- (a) Independent and provided with adequate human and financial resources
- (b) Well known to children with disabilities and their caregivers;
- (c) Accessible not only in the physical sense but also in a way that allows children with disabilities to send in their complaints or issues easily and confidentially
- (d) It must have the appropriate legal authority to receive, investigate and address the complaints of children with disabilities in a manner sensitive to both their childhood and to their disabilities.

H. Civil society

Although caring for children with disabilities is an obligation of the State, NGOs often carry out these responsibilities without the appropriate support, funding or recognition from Governments. States parties are therefore encouraged to support and cooperate with NGOs enabling them to participate in the provision of services for children with disabilities and to ensure that they operate in full compliance with the provisions and principles of the Convention. In this regard the Committee draws the attention of States parties to the recommendations adopted on its day of general discussion on the private sector as a service provider, held on 20 September 2002 (CRC/C/121, paras. 630-653).

I. Dissemination of knowledge and training of professionals

Knowledge of the Convention and its specific provisions devoted to children with disabilities is a necessary and powerful tool to ensure the realization of these rights. States parties are encouraged to disseminate knowledge by, inter alia, conducting systematic awareness-raising campaigns, producing appropriate material, such as a child friendly version of the Convention in print and Braille, and using the mass media to foster positive attitudes towards children with disabilities.

As for professionals working with and for children with disabilities, training programmes must include targeted and focused education on the rights of children with disabilities as a prerequisite for qualification. These professionals include but are not limited to policymakers, judges, lawyers, law enforcement officers, educators, health workers, social workers and media staff among others.

³ See also the general comment No. 5 (1994) of the Committee on Economic, Social and Cultural Rights regarding persons with disabilities.

Article 3 (Best interests of the child)

“In all actions concerning children...the best interests of the child shall be a primary consideration”. The broad nature of this article aims at covering all aspects of care and protection for children in all settings. It addresses legislators who are entrusted with setting the legal framework for protecting the rights of children with disabilities as well as the decisions-making processes concerning children with disabilities. Article 3 should be the basis on which programmes and policies are set and it should be duly taken into account in every service provided for children with disabilities and any other action affecting them.

The best interests of the child is of particular relevance in institutions and other facilities that provide services for children with disabilities as they are expected to conform to standards and regulations and should have the safety, protection and care of children as their primary consideration, and this consideration should outweigh any other and under all circumstances, for example, when allocating budgets (Matrix B3).

Article 6 (Right to life, survival and development)

The inherent right to life, survival and development is a right that warrants particular attention where children with disabilities are concerned. In many countries of the world children with disabilities are subject to a variety of practices that completely or partially compromise this right. In addition to being more vulnerable to infanticide, some cultures view a child with any form of disability as a bad omen that may “tarnish the family pedigree” and, accordingly, a certain designated individual from the community systematically kills children with disabilities. These crimes often go unpunished or perpetrators receive reduced sentences. States parties are urged to undertake all the necessary measures required to put an end to these practices, including raising public awareness, setting up appropriate legislation and enforcing laws that ensure appropriate punishment to all those who directly or indirectly violate the right to life, survival and development of children with disabilities.

Article 12 (Respect for the views of the child)

More often than not, adults with and without disabilities make policies and decisions related to children with disabilities while the children themselves are left out of the process. It is essential that children with disabilities be heard in all procedures affecting them and that their views be respected in accordance with their evolving capacities. In order for this principle to be respected, children should be represented in various bodies such as parliament, committees and other forums where they may voice views and participate in the making of decisions that affect them as children in general and as children with disabilities specifically. Engaging children in such a process not only ensures that the policies are targeted to their needs and desires, but also functions as a valuable tool for inclusion since it ensures that the decision-making process is a participatory one. Children should be provided with whatever mode of communication they need to facilitate expressing their views. Furthermore, States parties should support the training for families and professionals on promoting

and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives.

Children with disabilities often require special services in health and education to allow them to achieve their fullest potential and these are further discussed in the relevant paragraphs below. However it should be noted that spiritual, emotional and cultural development and well-being of children with disabilities are very often overlooked. Their participation in events and activities catering to these essential aspects of any child's life is either totally lacking or minimal. Furthermore, when their participation is invited, it is often limited to activities specifically designed for and targeted at children with disabilities. This practice only leads to further marginalization of children with disabilities and increases their feelings of isolation. Programmes and activities designed for the child's cultural development and spiritual well-being should involve and cater to both children with and without disabilities in an integrated and participatory fashion.

V. Civil rights and freedoms (Articles 7, 8, 13–17, and 37a)

The right to name and nationality, preservation of identity, freedom of expression, freedom of thought, conscience and religion, freedom of association and peaceful assembly, the right to privacy and the right not to be subjected to torture or other cruel inhuman or degrading treatment or punishment and not to be unlawfully deprived of liberty are all universal civil rights and freedoms which must be respected, protected and promoted for all, including children with disabilities. Particular attention should be paid here on areas where the rights of children with disabilities are more likely to be violated or where special programmes are needed for their protection.

A. Birth registration

Children with disabilities are disproportionately vulnerable to non-registration at birth. Without birth registration they are not recognized by law and become invisible in government statistics. Non-registration has profound consequences for the enjoyment of their human rights, including the lack of citizenship and access to social and health services and to education. Children with disabilities who are not registered at birth are at greater risk of neglect, institutionalization, and even death.

In the light of article 7 of the Convention, the Committee recommends that States parties adopt all appropriate measures to ensure the registration of children with disabilities at birth. Such measures should include developing and implementing an effective system of birth registration, waiving registration fees, introducing mobile registration offices and, for children who are not yet registered, providing registration units in schools. In this context, States parties should ensure that the provisions of article 7 are fully enforced in conformity with the principles of non-discrimination (art. 2) and of the best interests of the child (art. 3).

B Access to appropriate information and mass media

Access to information and means of communication, including information and communication technologies and systems, enables children with disabilities to live

independently and participate fully in all aspects of life. Children with disabilities and their caregivers should have access to information concerning their disabilities so that they can be adequately educated on the disability, including its causes, management and prognosis. This knowledge is extremely valuable as it does not only enable them to adjust and live better with their disabilities, but also allows them to be more involved in and to make informed decisions about their own care. Children with disabilities should also be provided with the appropriate technology and other services and/or languages, e.g. Braille and sign language, which would enable them to have access to all forms of media, including television, radio and printed material as well as new information and communication technologies and systems, such as the Internet.

On the other hand, States parties are required to protect all children, including children with disabilities from harmful information, especially pornographic material and material that promotes xenophobia or any other form of discrimination and could potentially reinforce prejudices.

C Accessibility to public transportation and facilities

The physical inaccessibility of public transportation and other facilities, including governmental buildings, shopping areas, recreational facilities among others, is a major factor in the marginalization and exclusion of children with disabilities and markedly compromises their access to services, including health and education. Although this provision may be mostly realized in developed countries, it remains largely un-addressed in the developing world. All States parties are urged to set out appropriate policies and procedures to make public transportation safe, easily accessible to children with disabilities (Matrix J3) and free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child (Matrix J8).

All new public buildings should comply with international specifications for access of persons with disabilities and existing public buildings, including schools, health facilities, governmental buildings, shopping areas, undergo necessary alterations that make them as accessible as possible.

VI Family environment and alternative care (Articles 5, 18 (1–2), 9–11, 19–21, 25, 27 (4), and 39)

A. Family support and parental responsibilities

Children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects. Such support to families includes education of parent/s and siblings, not only on the disability and its causes but also on each child's unique physical and mental requirements; psychological support that is sensitive to the stress and difficulties imposed on families of children with disabilities; education on the family's common language, for example sign language, so that parents and siblings can communicate with family members with disabilities (Matrix E9) material support in the form of special allowances as well as consumable supplies and necessary equipment, such as special furniture and mobility devices that is deemed necessary for the child with a

disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community (Matrix D6). In this context, support should also be extended to children who are affected by the disabilities of their caregivers. For example, a child living with a parent or other caregiver with disabilities should receive the support that would protect fully his or her rights and allow him or her to continue to live with this parent whenever it is in his or her best interests. Support services should also include different forms of respite care, such as care assistance in the home and day-care facilities directly accessible at community level (Matrix E8). Such services enable parents to work, as well as relieve stress and maintain healthy family environments (Matrix D8).

B. Violence, abuse and neglect

Children with disabilities are more vulnerable to all forms of abuse be it mental, physical or sexual in all settings, including the family, schools, private and public institutions, inter alia alternative care, work environment and community at large. It is often quoted that children with disabilities are five times more likely to be victims of abuse. In the home and in institutions, children with disabilities are often subjected to mental and physical violence and sexual abuse, and they are also particularly vulnerable to neglect and negligent treatment since they often present an extra physical and financial burden on the family. In addition, the lack of access to a functional complaint receiving and monitoring mechanism is conducive to systematic and continuing abuse. School bullying is a particular form of violence that children are exposed to and more often than not, this form of abuse targets children with disabilities. Their particular vulnerability may be explained inter alia by the following main reasons:

- (a) Their inability to hear, move, and dress, toilet, and bath independently increases their vulnerability to intrusive personal care or abuse;
- (b) Living in isolation from parents, siblings, extended family and friends increases the likelihood of abuse;
- (c) Should they have communication or intellectual impairments, they may be ignored, disbelieved or misunderstood should they complain about abuse;
- (d) Parents or others taking care of the child may be under considerable pressure or stress because of physical, financial and emotional issues in caring for their child. Studies indicate that those under stress may be more likely to commit abuse;
- (e) Children with disabilities are often wrongly perceived as being non-sexual and not having an understanding of their own bodies and, therefore, they can be targets of abusive people, particularly those who base abuse on sexuality.

In addressing the issue of violence and abuse, States parties are urged to take all necessary measures for the prevention of abuse of and violence against children with disabilities, such as:

- (a) Train and educate parents or others caring for the child to understand the risks and detect the signs of abuse of the child;
- (b) Ensure that parents are vigilant about choosing caregivers and facilities for their children and improve their ability to detect abuse;
- (c) Provide and encourage support groups for parents, siblings and others taking care of the child to assist them in caring for their children and coping with their disabilities;
- (d) Ensure that children and caregivers know that the child is entitled as a matter of right to be treated with dignity and respect and they have the right to complain to appropriate authorities if those rights are breached;
- (e) Ensure that schools take all measures to combat school bullying and pay particular attention to children with disabilities providing them with the necessary protection while maintaining their inclusion into the mainstream education system(Matrix F3)
- (f) Ensure that institutions providing care for children with disabilities are staffed with specially trained personnel, subject to appropriate standards, regularly monitored and evaluated, and have accessible and sensitive complaint mechanisms (Matrix C9)
- (g) Establish an accessible, child-sensitive complaint mechanism and a functioning monitoring system based on the Paris Principles (see paragraph 24 above);
- (h) Take all necessary legislative measures required to punish and remove perpetrators from the home ensuring that the child is not deprived of his or her family and continue to live in a safe and healthy environment;
- (i) Ensure the treatment and re-integration of victims of abuse and violence with a special focus on their overall recovery programmes.

In this context the Committee would also like to draw States parties' attention to the report of the independent expert for the United Nations study on violence against children (A/61/299) which refers to children with disabilities as a group of children especially vulnerable to violence. The Committee encourages States parties to take all appropriate measures to implement the overarching recommendations and setting-specific recommendations contained in this report.

C. Family-type alternative care

The role of the extended family, which is still a main pillar of childcare in many communities and is considered one of the best alternatives for childcare, should be strengthened and empowered to support the child and his or her parents or others taking care of the child.

Recognizing that the foster family is an accepted and practiced form of alternative care in many States parties, it is nevertheless a fact that many foster families are

reluctant to take on the care of a child with disability as children with disabilities often pose a challenge in the extra care they may need and the special requirements in their physical, psychological and mental upbringing. Organizations that are responsible for foster placement of children must, therefore, conduct the necessary training and encouragement of suitable families and provide the support that will allow the foster family to appropriately take care of the child with disability.

D. Institutions

The Committee has often expressed its concern at the high number of children with disabilities placed in institutions and that institutionalization is the preferred placement option in many countries. The quality of care provided, whether educational, medical or rehabilitative, is often much inferior to the standards necessary for the care of children with disabilities either because of lack of identified standards or lack of implementation and monitoring of these standards. Institutions are also a particular setting where children with disabilities are more vulnerable to mental, physical, sexual and other forms of abuse as well as neglect and negligent treatment (see paragraphs 42-44 above). The Committee therefore urges States parties to use the placement in institution only as a measure of last resort, when it is absolutely necessary and in the best interests of the child. It recommends that the States parties prevent the use of placement in institution merely with the goal of limiting the child's liberty or freedom of movement. In addition, attention should be paid to transforming existing institutions, with a focus on small residential care facilities organized around the rights and needs of the child, to developing national standards for care in institutions, and to establishing rigorous screening and monitoring procedures to ensure effective implementation of these standards (Matrix E2).

The Committee is concerned at the fact that children with disabilities are not often heard in separation and placement processes. In general, decision-making processes do not attach enough weight to children as partners even though these decisions have a far-reaching impact on the child's life and future. Therefore, the Committee recommends that States parties continue and strengthen their efforts to take into consideration the views of children with disabilities and facilitate their participation in all matters affecting them within the evaluation, separation and placement process in out-of-home care, and during the transition process. The Committee also emphasizes that children should be heard throughout the protection measure process, before making the decision as well as during and after its implementation. In this context, the Committee draws the attention of the States parties to the Committee's recommendations adopted on its day of general discussion on children without parental care, held on 16 September 2005 (CRC/C/153, paragraphs 636-689)(Matrix E5).

In addressing institutionalization, States parties are therefore urged to set up programmes for de-institutionalization of children with disabilities, re-placing them with their families, extended families or foster care system. Parents and other extended family members should be provided with the necessary and systematic support/training for including their child back into their home environment.

E. Periodic review of placement

Whatever form of placement chosen for children with disabilities by the competent authorities, it is essential that a periodic review of the treatment provided to the child, and all other circumstances relevant to his or her placement, is carried out to monitor his or her wellbeing.

VII. Basic health and welfare (Articles 6, 18 (3), 23, 24, 26, and 27 (1-3))

A. Right to health

Attainment of the highest possible standard of health as well as access and affordability of quality healthcare is an inherent right for all children. Children with disabilities are often left out because of several challenges, including discrimination, inaccessibility due to the lack of information and/or financial resources, transportation, geographic distribution and physical access to health care facilities. Another factor is the absence of targeted health care programmes that address the specific needs of children with disabilities. Health policies should be comprehensive and address early detection of disabilities, early intervention, including psychological and physical treatment, rehabilitation including physical aids, for example limb prosthesis, mobility devices, hearing aids and visual aids.

It is important to emphasize that health services should be provided within the same public health system that provides for children with no disabilities, free of charge, whenever possible, and as updated and modernized as possible. The importance of community-based assistance and rehabilitation strategies should be emphasized when providing health services for children with disabilities (Matrix I6). States parties must ensure that health professionals working with children with disabilities are trained to the highest possible standard and practice based on a child-centred approach. In this respect, many States parties would greatly benefit from international cooperation with international organizations as well as other States parties (Matrix I9)

B. Prevention

Causes of disabilities are multiple and, therefore, the quality and level of prevention vary. Inherited diseases that often cause disabilities can be prevented in some societies that practice consanguineous marriages and under such circumstances public awareness and appropriate pre-conception testing would be recommended. Communicable diseases are still the cause of many disabilities around the world and immunization programmes need to be stepped up aiming to achieve universal immunization against all preventable communicable diseases. Poor nutrition has a long-term impact upon children's development and it can lead to disabilities, such as blindness caused by Vitamin A deficiency. The Committee recommends that States parties introduce and strengthen prenatal care for children and ensure adequate quality of the assistance given during the delivery. It also recommends that States parties provide adequate post-natal health-care services and develop campaigns to inform parents and others caring for the child about basic child healthcare and nutrition. In this regard, the Committee also recommends that the States

parties continue to cooperate and seek technical assistance with, among others, WHO and UNICEF.

Domestic and road traffic accidents are a major cause of disability in some countries and policies of prevention need to be established and implemented such as the laws on seat belts and traffic safety. Lifestyle issues, such as alcohol and drug abuse during pregnancy, are also preventable causes of disabilities and in some countries the fetal alcohol syndrome presents a major cause for concern. Public education, identification and support for pregnant mothers who may be abusing such substances are just some of the measures that may be taken to prevent such causes of disability among children. Hazardous environment toxins also contribute to the causes of many disabilities. Toxins, such as lead, mercury, asbestos, etc., are commonly found in most countries. Countries should establish and implement policies to prevent dumping of hazardous materials and other means of polluting the environment. Furthermore, strict guidelines and safeguards should also be established to prevent radiation accidents.

Armed conflicts and their aftermath, including availability and accessibility of small arms and light weapons, are also major causes of disabilities. States parties are obliged to take all necessary measures to protect children from the detrimental effects of war and armed violence and to ensure that children affected by armed conflict have access to adequate health and social services, including psychosocial recovery and social reintegration. In particular, the Committee stresses the importance of educating children, parents and the public at large about the dangers of landmines and unexploded ordnance in order to prevent injury and death. It is crucial that States parties continue to locate landmines and unexploded ordnance, take measures to keep children away from suspected areas, and strengthen their mine clearance activities and, when appropriate, seek the necessary technical and financial support within a framework of international cooperation, including from United Nations agencies. (See also paragraph 23 above on landmines and unexploded ordnance and paragraph 78 below on armed conflicts under special protection measures).

C. Early identification

Very often, disabilities are detected quite late in the child's life, which deprives him or her of effective treatment and rehabilitation. Early identification requires high awareness among health professionals, parents, teachers as well as other professionals working with children. They should be able to identify the earliest signs of disability and make the appropriate referrals for diagnosis and management. Therefore, the Committee recommends that States parties establish systems of early identification and early intervention as part of their health services, together with birth registration and procedures for following the progress of children identified with disabilities at an early age. Services should be both community- and home-based, and easy to access. Furthermore, links should be established between early intervention services, pre-schools and schools to facilitate the smooth transition of the child.

Following identification, the systems in place must be capable of early intervention including treatment and rehabilitation providing all necessary devices that enable children with disabilities to achieve their full functional capacity in terms of mobility, hearing aids, visual aids, and prosthetics among others. It should also be emphasized that these provisions should be offered free of cost, whenever possible, and the process of acquiring such services should be efficient and simple avoiding long waits and bureaucracies(Matrix I8 top).

D. Multidisciplinary care

Children with disabilities very often have multiple health issues that need to be addressed in a team approach. Very often, many professionals are involved in the care of the child, such as neurologists, psychologists, psychiatrists, orthopaedic surgeons and physiotherapists among others. Ideally these professionals should collectively identify a plan of management for the child with disability that would ensure the most efficient healthcare is provided.

E. Adolescent health and development

The Committee notes that children with disabilities are, particularly during their adolescence, facing multiple challenges and risks in the area of establishing relationships with peers and reproductive health. Therefore, the Committee recommends that States parties provide adolescents with disabilities with adequate, and where appropriate, disability specific information, guidance and counselling and fully take into account the Committee's general comments No. 3 (2003) on HIV/AIDS and the rights of the child and No. 4 (2003) on adolescent health and development in the context of the Convention on the Rights of the Child(Matrix I8 bottom).

The Committee is deeply concerned about the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities. This practice, which still exists, seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects. Therefore, the Committee urges States parties to prohibit by law the forced sterilisation of children on grounds of disability.

F. Research

Causes, prevention and management of disabilities do not receive the much needed attention on national and international research agendas. States parties are encouraged to award this issue priority status ensuring funding and monitoring of disability focused research paying particular attention to ethical implications.

VIII Education and leisure (Articles 28, 29 and 31)

A. Quality education

Children with disabilities have the same right to education as all other children and shall enjoy this right without any discrimination and on the basis of equal opportunity as stipulated in the Convention.⁴ For this purpose, effective access of children with

⁴ In this context the Committee would like to make a reference to the United Nations Millennium Declaration (A/RES/55/2) and in particular to the Millennium Development Goal No. 2 relating to universal primary education according to which Governments are committed to "ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete

disabilities to education has to be ensured to promote “the development of the child’s personality, talents and mental and physical abilities to their fullest potential (see articles 28 and 29 of the Convention and the Committee’s general comment No. 1 (2001) on the aims of education) (Matrix F1 and Matrix F9 top). The Convention recognizes the need for modification to school practices (Matrix F2) and for training of regular teachers (Matrix F9) to prepare them to teach children with diverse abilities and ensure that they achieve positive educational outcomes.

As children with disabilities are very different from each other, parents, teachers and other specialized professionals have to help each individual child to develop his or her ways and skills of communication, language, interaction, orientation and problem-solving which best fit the potential of this child. Everybody, who furthers the child’s skills, abilities and self-development, has to precisely observe the child’s progress and carefully listen to the child’s verbal and emotional communication in order to support education and development in a well-targeted and most appropriate manner (Matrix F4 bottom).

B. Self-esteem and self-reliance

It is crucial that the education of a child with disability includes the strengthening of positive self-awareness, making sure that the child feels he or she is respected by others as a human being without any limitation of dignity. The child must be able to observe that others respect him or her and recognize his or her human rights and freedoms. Inclusion of the child with disability in the groups of children of the classroom can show the child that he or she has recognized identity and belongs to the community of learners, peers, and citizens. Peer support enhancing self-esteem of children with disabilities should be more widely recognized and promoted. Education also has to provide the child with empowering experience of control, achievement, and success to the maximum extent possible for the child (Matrix F4).

C. Education in the school system

Early childhood education is of particular relevance for children with disabilities as often their disabilities and special needs are first recognized in these institutions. Early intervention is of utmost importance to help children to develop their full potential. If a child is identified as having a disability or developmental delay at an early stage, the child has much better opportunities to benefit from early childhood education which should be designed to respond to her or his individual needs. Early childhood education provided by the State, the community or civil society institutions can provide important assistance to the well-being and development of all children with disabilities (see the Committee’s general comment No. 7 (2005) on implementing child rights in early childhood). Primary education, including primary

a full course of primary schooling and that girls and boys will have equal access to all levels of education”. The Committee would also like to refer to other international commitments which endorse the idea of inclusive education, inter alia, the Salamanca Statement and Framework for Action on Special Needs Education adopted by the World Conference on Special Needs Education: Access and Quality, Salamanca, Spain, 7-10 June 1994 (UNESCO and Ministry of Education and Science of Spain) and the Dakar Framework for Action, Education for All: Meeting our Collective Commitments, adopted by the World Education Forum, Dakar, Senegal, 26-28 April 2000.

Appendix 2: Rights explained – a list of human rights Articles and Conventions used in “We want to help people see things our way”

school and, in many States parties, also secondary school, has to be provided for children with disabilities free of costs. All schools should be without communicational barriers as well as physical barriers impeding the access of children with reduced mobility. Also higher education, accessible on the basis of capacities, has to be accessible for qualified adolescents with disabilities. In order to fully exercise their right to education, many children need personal assistance, in particular, teachers trained in methodology and techniques, including appropriate languages, and other forms of communication, for teaching children with a diverse range of abilities capable of using child-centred and individualised teaching strategies, and appropriate and accessible teaching materials, equipment and assistive devices, which States parties should provide to the maximum extent of available resources.

D. Inclusive education

Inclusive education⁵ should be the goal of educating children with disabilities. The manner and form of inclusion must be dictated by the individual educational needs of the child, since the education of some children with disabilities requires a kind of support which may not be readily available in the regular school system. The Committee notes the explicit commitment towards the goal of inclusive education contained in the draft convention on the rights of persons with disabilities and the obligation for States to ensure that persons including children with disabilities are not excluded from the general education system on the basis of disability and that they receive the support required, within the general education system, to facilitate their effective education. It encourages States parties which have not yet begun a programme towards inclusion to introduce the necessary measures to achieve this goal. However, the Committee underlines that the extent of inclusion within the general education system may vary. A continuum of services and programme options must be maintained in circumstances where fully inclusive education is not feasible to achieve in the immediate future (Matrix F6).

The movement towards inclusive education has received much support in recent years. However, the term inclusive may have different meanings. At its core, inclusive education is a set of values, principles and practices that seeks meaningful, effective, and quality education for all students, that does justice to the diversity of learning conditions and requirements not only of children with disabilities, but for all students. This goal can be achieved by different organizational means which respect the diversity of children. Inclusion may range from full-time placement of all students with disabilities into one regular classroom or placement into the regular class room with varying degree of inclusion, including a certain portion of special education. It is important to understand that inclusion should not be understood nor practiced as simply integrating children with disabilities into the regular system regardless of their challenges and needs. Close cooperation among special educators and regular

⁵UNESCO's Guidelines for Inclusion: Ensuring Access to Education for All (UNESCO 2005) provides the following definition "Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children...Inclusion is concerned with the identification and removal of barriers..." (p. 13 and 15)

educators is essential. Schools' curricula must be re-evaluated and developed to meet the needs of children with and without disabilities. Modification in training programmes for teachers and other personnel involved in the educational system must be achieved in order to fully implement the philosophy of inclusive education(Matrix F6).

E. Career education and vocational training

Education for career development and transition is for all persons with disabilities regardless of their age. It is imperative to begin preparation at an early age because career development is seen as a process that begins early and continues throughout life. Developing career awareness and vocational skills as early as possible, beginning in the elementary school, enables children to make better choices later in life in terms of employment. Career education in the elementary school does not mean using young children to perform labour that ultimately opens the door for economic exploitation. It begins with students choosing goals according to their evolving capacities in the early years. It should then be followed by a functional secondary school curriculum that offers adequate skills and access to work experience, under systematic coordination and monitoring between the school and the work place.

Career development and vocational skills should be included in the school curriculum. Career awareness and vocational skills should be incorporated into the years of compulsory education. In countries where compulsory education does not go beyond the elementary school years, vocational training beyond elementary school should be mandatory for children with disabilities. Governments must establish policies and allocate sufficient funds for vocational training(Matrix F9 Top).

F. Recreation and cultural activities

The Convention stipulates in Article 31 the right of the child to recreation and cultural activities appropriate to the age of the child. This article should be interpreted to include mental, psychological as well as the physical ages and capabilities of the child. Play has been recognized as the best source of learning various skills, including social skills. The attainment of full inclusion of children with disabilities in the society is realized when children are given the opportunity, places, and time to play with each other (children with disabilities and no disabilities). Training for recreation, leisure and play should be included for school-aged children with disabilities.

Children with disabilities should be provided with equal opportunities to participate in various cultural and arts activities as well as sports. These activities must be viewed as both medium of expression and medium of realizing self-satisfying, quality of life.

G. Sports

Competitive and non-competitive sports activities must be designed to include children with disabilities in an inclusive manner, whenever possible. That is to say, a child with a disability who is able to compete with children with no disability should be encouraged and supported to do so. But sports are an area where, because of the physical demands of the sport, children with disabilities will often need to have

exclusive games and activities where they can compete fairly and safely. It must be emphasized though that when such exclusive events take place, the media must play its role responsibly by giving the same attention as it does to sports for children with no disabilities(Matrix Hd8).

IX. Special protection measures (Articles 22, 38, 39, 40, 37 b-d, and 32-36)

A. Juvenile justice system

In the light of article 2 States parties have the obligation to ensure that children with disabilities who are in conflict with the law (as described in article 40, paragraph 1) will be protected not only by the provisions of the Convention which specifically relate to juvenile justice (arts. 40, 37 and 39) but by all other relevant provisions and guarantees contained in the Convention, for example in the area of health care and education. In addition, States parties should take where necessary specific measures to ensure that children with disabilities de facto are protected by and do benefit from the rights mentioned above.

With reference to the rights enshrined in article 23 and given the high level of vulnerability of children with disabilities, the Committee recommends – in addition to the general recommendation made in paragraph 73 above – that the following elements of the treatment of children with disabilities (allegedly) in conflict with the law be taken into account:

- a) A child with disability who comes in conflict with the law should be interviewed using appropriate languages and otherwise dealt with by professionals such as police officers, attorneys/advocates/social workers, prosecutors and/or judges, who have received proper training in this regard;
- b) Governments should develop and implement alternative measures with a variety and a flexibility that allow for an adjustment of the measure to the individual capacities and abilities of the child in order to avoid the use of judicial proceedings. Children with disabilities in conflict with the law should be dealt with as much as possible without resorting to formal/legal procedures. Such procedures should only be considered when necessary in the interest of public order. In those cases special efforts have to be made to inform the child about the juvenile justice procedure and his or her rights therein;
- c) Children with disabilities in conflict with the law should not be placed in a regular juvenile detention centre by way of pre-trial detention nor by way of a punishment. Deprivation of liberty should only be applied if necessary with a view to providing the child with adequate treatment for addressing his or her problems which have resulted in the commission of a crime and the child should be placed in an institution that has the specially trained staff and other facilities to provide this specific treatment. In making such decisions the competent authority should make sure that the human rights and legal safeguards are fully respected.

B. Economic exploitation

Children with disabilities are particularly vulnerable to different forms of economic exploitation, including the worst forms of child labour as well as drug trafficking and begging. In this context, the Committee recommends that States parties which have not yet done so ratify the Convention No. 138 of the International Labour Organization (ILO) concerning the minimum age for admission to employment and ILO Convention No. 182 concerning the prohibition of and immediate action for the elimination of the worst forms of child labour. In the implementation of these conventions States parties should pay special attention to the vulnerability and needs of children with disabilities.

C. Street children

Children with disabilities, specifically physical disabilities, often end up on the streets for a variety of reasons, including economic and social factors. Children with disabilities living and/or working on the streets need to be provided with adequate care, including nutrition, clothing, housing, educational opportunities, life-skills training as well as protection from the different dangers including economic and sexual exploitation. In this regard an individualized approach is necessary which takes full account of the special needs and the capacities of the child. The Committee is particularly concerned that children with disabilities are sometimes exploited for the purpose of begging in the streets or elsewhere; sometimes disabilities are inflicted on children for the purpose of begging. States parties are required to take all necessary actions to prevent this form of exploitation and to explicitly criminalize exploitation in such manner and take effective measures to bring the perpetrators to justice.

D. Sexual exploitation

The Committee has often expressed grave concern at the growing number of child victims of child prostitution and child pornography. Children with disabilities are more likely than others to become victims of these serious crimes. Governments are urged to ratify and implement the Optional Protocol on the sale of children, child prostitution and child pornography (OPSC) and, in fulfilling their obligations to the Optional Protocol, States parties should pay particular attention to the protection of children with disabilities recognizing their particular vulnerability.

E. Children in armed conflict

As previously noted above, armed conflicts are a major cause of disabilities whether children are actually involved in the conflict or are victims of combat. In this context, Governments are urged to ratify and implement the Optional Protocol on the involvement of children in armed conflict (OPAC). Special attention should be paid to the recovery and social re-integration of children who suffer disabilities as a result of armed conflicts. Furthermore, the Committee recommends that States parties explicitly exclude children with disabilities from recruitment in armed forces and take the necessary legislative and other measures to fully implement that prohibition.

F. Refugee and internally displaced children, children belonging to minorities and indigenous children

Certain disabilities result directly from the conditions that have led some individuals to become refugees or internally displaced persons, such as human-caused or natural disasters. For example, landmines and unexploded ordnance kill and injure refugee, internally displaced and resident children long after armed conflicts have

ceased. Refugee and internally displaced children with disabilities are vulnerable to multiple forms of discrimination, particularly refugee and internally displaced girls with disabilities, who are more often than boys subject to abuse, including sexual abuse, neglect and exploitation. The Committee strongly emphasizes that refugee and internally displaced children with disabilities should be given high priority for special assistance, including preventative assistance, access to adequate health and social services, including psychosocial recovery and social reintegration. The Office of the United Nations High Commissioner for Refugees (UNHCR) has made children a policy priority and adopted several documents to guide its work in that area, including the Guidelines on Refugee Children in 1988, which are incorporated into UNHCR Policy on Refugee Children. The Committee also recommends that States parties take into account the Committee's general comment No. 6 (2005) on the treatment of unaccompanied and separated children outside of their country of origin.

All appropriate and necessary measures undertaken to protect and promote the rights of children with disabilities must include and pay special attention to the particular vulnerability and needs of children belonging to minorities and indigenous children who are more likely to be already marginalized within their communities. Programmes and policies must always be culturally and ethnically sensitive.

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