Taking a closer look:
Child Poverty and Disability

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INTRODUCTION

A recent research report by the Institute for Public Policy Research (Pillai et al, 2009) warned that if the Government is going to end child poverty by 2020, it will need to do more to help disabled children and parents. The report predicted that, by 2020, up to 58% of people in their 50s will be disabled or self-report long term health problems.

The report also indicated that persistent poverty during childhood significantly limits people's life chances and said that the Disability Living Allowance needs to be available to all disabled children and taken up by more families that experience the extra costs of raising a child with a disability. Families with disabled children are much more likely to be in poverty because of the higher costs associated with bringing up a child with a disability, and, in some cases, the loss of income involved when a parent has given up work to care for the child. With increasing numbers of children surviving infancy due to advances in health care, more children with complex needs are expected to live longer lives.

Official statistics on child poverty from the Household Below Average Income (HBAI) Reports (DWP, 2009) show that children with disabled parents and disabled children are most likely to experience poverty. Research (Monteith and McLaughlin, 2004; McLaughlin and Monteith, 2006) has shown that in Northern Ireland disabled children and children with disabled parents are more likely to be severely poor while recent research carried out by Monteith et al (2008) has shown they are also more at risk of persistent poverty. For families with both a disabled parent and a disabled child, the situation is much worse.

Further, research by McLaughlin and Monteith (2006), indicated that the child poverty rates for children living in families with a disabled adult or child could vary by over 20 percentage points depending on whether an income based measure or a deprivation based measure was used.

The statistics produced from the HBAI series are the government's main method of monitoring child poverty and are based on household income. For some time now, academics, child poverty researchers and disability activists have been concerned whether these figures make accurate comparisons between different household types, and particularly between households with, and Without, the presence of disability (Burchardt, 2005). The conventional method of calculating child poverty rates adjusts income to take into account differences in household size and composition (known as equivalisation). Adjustments are made using an equivalisation scale such as the Modified OECD scale which is currently used in HBAI statistics. These scales adjust household income so that comparisons can be made between different household sizes, such as lone parent households compared to couple families, and also takes into account the number of children or other adults present in the household. However, what is significant is that the equivalisation scale used does not take account of the extra cost of living associated with disability. Estimates of these extra costs have ranged from three times the cost of raising a non-disabled child (Middleton, 1999) to as much as 78% of income for a person with a high-severity disability (Zaidi and Burchardt, 2005). Attempts to quantify the extra costs of bringing up a disabled child have identified additional child care costs (due to lack of availability

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of suitable places), the cost of replacing furniture, bedlinen, clothes and equipment more frequently, and the costs of (non-NHS) therapies which parents find valuable for their child.

Benefits such as the Disability Living Allowance (DLA) are available to assist with the extra cost of disability, whether this is a disabled child or a disabled parent. In the calculation of income in the HBAI reports DLA is included as an income, while there is no recognition of the additional costs associated with disability in the equivalence scales. Therefore, households with a disabled person, adult or child, who receive DLA to meet the additional costs of disability, have that benefit included as income with no allowance made for their extra expenditure. The Department of Work and Pensions (DWP) have resisted calls for adjustments to be made for disability in income analysis and poverty estimates.

This research aims to recalculate the child poverty rates as reported in HBAI reports, removing DLA and Attendance Allowance (AA) from the household income. This will allow examination of a truer sense of child poverty in Northern Ireland, particularly for children who live with a disabled parent or have a disability. In addition, the research uses 12 case studies to illustrate the experiences of parents living on a low income and bringing up a disabled child, and some of the key issues for them. This paper is therefore presented in two parts: firstly, the quantitative data providing a comparison of conventional child poverty rates with revised methods of calculating rates without DLA and AA in household income; and secondly, the insight into the experience of living on a low income based on the stories of families with children with relatively severe disabilities selected randomly from the Family Fund database.

CHILD POVERTY RECALCULATED

Using the Family Resources Survey 2006/7 on which the HBAI reports are based, DLA and AA were removed from household income, and the equivalent analysis re-run to produce revised child poverty rates. This analysis is focused at the level of the child and so the analysis refers to children in poverty, not households with children as per previous research (Evason, 2009).

Table 1 compares the conventional method of calculating child poverty, as indicated in the HBAI reports, with this adjusted method with DLA/AA removed from household income. As illustrated in this table, the new method has not affected overall child poverty rates at the UK level to a great extent – with no change in Before Housing Cost figures, and the adjusted method showing a 1% increase on the conventional method after housing costs have been taken out. However, at the Northern Ireland level, differences are more stark. Removal of DLA and AA from household income indicates a 2% increase in child poverty rates before housing costs are removed, and a 3% increase on the conventional method after housing costs are removed.

Taking the analysis of the NI data one step further, Table 2 compares the changes using poverty thresholds of less than 50%, 60% and 70% of the median net equivalised household

Table 1: Comparing the conventional method of calculating child poverty rates to method removing DLA/AA from income, UK and NI

Percentage of children below 60% of median net equivalised household income	Before Housing Costs			After Housing Costs		
	HBAI	new	% change	HBAI	new	% change
UK	23	23	=	31	32	+1
NI	22	24	+2	23	26	+3

Note: HBAI refers to conventional method, new refers to adapted method removing DLA/AA from income
Source: Family Resources Survey 2006/7

Table 2: Comparing poverty thresholds in NI using both methods

Percentage of children below the poverty threshold using net equivalised household income	Before Housing Costs			After Housing Costs		
	HBAI	new	% change	HBAI	new	% change
Below 50% of median	10	11	+1	12	14	+2
Below 60% of median	22	24	+2	23	26	+3
Below 70% of median	33	35	+2	34	36	+2

Source: Family Resources Survey 2006/7

income. Similar levels of increase using the adjusted method are shown after housing costs have been removed, and a slightly lower increase of 1% at the 50% threshold before housing costs.

Both Tables 1 and 2 illustrate the differences to the overall child poverty figures, but what difference does this method of calculation make to the child poverty rates for specific groups of children? The research examined two groups – firstly, children in NI who were living in families with a disabled adult, and secondly, disabled children. Table 3 indicates that the impact of the new method has even greater implications for this particular group. The table shows Before Housing Cost poverty rates as an illustration, to avoid confusion between lots of different sets of data, but the degree of change was similar for both before and after housing costs. At the 50% poverty threshold child poverty rates increased 4 percentage points using the new method, while at the 60% and 70% threshold the degree of change increased by twice that of the 50% threshold (9 and 8 percentage points respectively).

The revised child poverty figures indicated that, if DLA and AA are taken out of income, almost half of children living with a disabled adult are in poverty and almost two thirds are living below 70% of the median net equivalised income. One in five are living below 50% of the median income, indicating serious concerns about child poverty in relation to families with a disabled adult. At the UK level, the adjusted method also indicated an increase in child poverty over the conventional method but not to the same degree as in NI. One in three children living with a disabled adult (32%) in the UK is living in poverty when DLA and AA are included in income, compared to 36% when DLA and AA are excluded from household income calculations (a 4% increase in UK compared to a 9% increase in NI). This difference between UK and NI figures is to be expected given the higher rates of disability and limiting long-term illness reported in NI.

Table 3: Comparing poverty rates for children living in families with disabled adults in NI

Percentage of children living in families below the poverty threshold using net equivalised household income	Before Housing Costs		
	HBAI	new	% change
Below 50% of median	18	22	+4
Below 60% of median	39	48	+9
Below 70% of median	57	65	+8

Source: Family Resources Survey 2006/7

The research also examined the impact of this revised method of calculating household income on child poverty rates for disabled children. While these statistics should be treated with caution, due to smaller sample sizes, they do show a 4% increase in both the UK and NI when compared to the conventional method.

Table 4: Comparing poverty rates for disabled children with both methods in NI and UK

Percentage of children below 60% of median net equivalised household income	**Before Housing Costs**		
	HBAI	new	% change
UK	23	27	+4
NI	26	30	+4

Source: Family Resources Survey2006/7

This analysis has illustrates the extent to which child poverty is underestimated in both NI and the UK. As NI has higher rates of disability it was to be expected that the impact is greater here, with child poverty rates increasing between 2 and 3 percent overall. This revised method of calculating household income results in almost one-third of disabled children, and half of all children living with a disabled adult in the household, living in poverty. The true extent of child poverty in relation to disability has serious implications for policy aimed at tackling child poverty and unless measures address the needs of families with either a disabled adult or a disabled child, child poverty rates will continue to be unaffected. However, measures that could help these families could have a major impact on the achievement of child poverty targets.

BRINGING UP A DISABLED CHILD ON A LOW INCOME

The qualitative research involved 12 case studies which explored in-depth with parents their family situation and circumstances, how they managed on their income, and any particular barriers or difficulties they faced. They were identified randomly from the Family Fund database of children with severe disabilities living in low-income families in Northern Ireland. Interviews were carried out with parents of the children only.

Social Isolation

One of the most striking findings of the qualitative research was the extent of social isolation not only for the children, but for their parents as well. Some of the children travelled long distances to a special school, with journeys of almost two hours in some cases, resulting in very little time for anything outside of school. Other children found it difficult to fit in and had no friends locally, and for some the nature of their disability made it difficult for them to socialise with other children. Most of the parents interviewed reported very poor social lives themselves mainly due to their caring roles, and in particular couples rarely were able to go out together as they shared the caring role and one parent always had to look after their disabled child. Some parents had a family member who helped and were able to give them a break occasionally, but several parents had little support and depended on each other with no break from their caring role. Where children had complex needs, parents found it hard to have anyone to help with their child to enable them to participate socially, and any socialising involved the whole family. In some cases this was very difficult and the family became more isolated. The extent of a child's disability had an impact on siblings as well, who often felt that they were not able to bring their friends home, or worried about their brother's/sister's health.

Lack of services/support

Only a few parents indicated that they had a visit from a social worker, and those that did have experience of a social work visit stated that this was a one-off and not a regular occurrence, despite some parents having sought help when they were feeling extremely desperate and under great pressure. None of the children had a social work assessment of their needs, and none of the parents had a carers' assessment carried out. One parent reported that, when at extreme crisis point, she asked for help from social services but she

Case Study 1

Margaret lives with her partner and her 13 year old son John who is diagnosed with Asperger's Syndrome, Tourette's Syndrome and ADHD.

John has complex behavioural problems, has extreme difficulty fitting in with other children, experiencing bouts of temper and aggravation. Being outside can be very difficult for him as he does not mingle well with other children and his mother feels he needs constant care. Until recently he had attended a mainstream school but after several difficulties in second year of secondary school he now attends a special school. His mother is concerned about his mental health as John worries a lot about school and any incidents during the school day and as his mother describes it, school for John is just *"pressure, pressure, pressure"*. His mother is worried about how he will cope with adolescence and the impact of the teen-age years on his confidence and self-esteem.

Margaret has had little support bar a few organisations providing some leisure activities and Family Fund providing grants to help with key purchases such as driving lessons which have helped her get out more with John, and a laptop for John as computer games are one of the things that keep him stimulated. Margaret has only one experience of a social worker who made an initial visit after she sought help for John. At first Margaret thought this experience was positive as the social worker listened to her worries and situation but was very disappointed to find that the main concern of the social worker was whether John was safe with no help forthcoming. Margaret has had a very difficult time throughout John's schooling with schools not being able to cope and resulting in phone-calls asking for her to take John home. His main support is a psychologist who checks his medication regularly.

Margaret and her partner struggle on a low income to bring up John and provide for his needs. Margaret has been unable to work due to her caring role for John, although she would "love a wee job". When John was small and both her parents were alive she worked part time for a period, but as John got older he was too much for her elderly parents. Financially, it is difficult, and John has extra costs due to his inability to entertain himself or play freely with other children in basic games such as football. His main entertainment is his computer games which are costly. At present, Margaret feels she cannot take a job due to her caring role. John has just changed to a special school and seems more settled there, but it is too soon for her to start thinking about a part-time job during school hours as in the past he had to be collected during the school day with regularity when teachers could not cope. Margaret hopes that John will continue to be settled in this new school and that she can then think about part time work. This would allow her to have a little extra so she could afford some of the leisure activities that might help him outside of the home. In the past, she had tried a few leisure activities which were provided for children, and Margaret said these "were great when they were free, but as soon as they started charging the numbers dwindled away", and then the range of activities were cut due to falling numbers and even more stopped going. John attended activities organised by a church when he was younger, but he is now too old for these and there is very little for him.

Margaret said that the family had not had a holiday for a few years as it is very difficult to organise, since keeping John occupied all of the time they are away is very hard and they cannot afford many activities. She felt John was missing out as other children asked about holidays in September when returning to school. Margaret said that she and her partner do not get out socially as they have no-one to help with John since her parents died.

had no response until a visit from a social worker some two years later.

"I begged, begged social services in tears…for some respite… For me to go down the road of begging I had got to a point that was so low… You know how long it took them to help me… two years! Two years!"

Any services that were accessed by parents tended to be provided by voluntary sector organisations and none of the families had experienced formal respite care, although some felt that, if offered respite, their child would not want it. Some families had informal respite care arrangements with family members, but other families had very little support of any kind. In schools, some parents reported that children who had classroom assistants in mainstream primary schools were not provided with this at mainstream secondary, which had caused problems. This seemed to be a problem in particular with Grammar schools. One parent with a child with Asperger's Syndrome reported that she had moved her child from a grammar school to a high school, as the high school was able to support her child better, and she felt it was *"snobbery"* on behalf of the grammar school that her child was not provided the support of a class room assistant.

Some parents were concerned about their child's or young person's mental health, and while one parent praised their GP for speedy identification of mental health issues, other parents raised concerns and worried about their child as he/she approached adolescence, and the impact of the teenage years on top of existing anxieties and behavioural problems. One parent stated that she felt very much that *"we are left to get on with it"* and were to some extent abandoned by mainstream services.

Lack of social and leisure activities for children

Parents found it hard to access low priced or free activities which suited their child's needs. As one parent indicated:

"when it was free it was full, but once they started charging the numbers dwindled away, then they reduced the range of activities and even more dwindled away."

Some children with complex needs needed a high-level or particular kind of stimulation, and games such as football did not work for them, while some of the activities which suited their child's disability were expensive.

Cost

Parents referred to a *"balancing act"* and *"living on a knife edge"*, when asked about how they coped bringing up their child(ren) on a low income. Several parents referred to the extra costs associated with having a disabled child, such as extra washing due to soiling, replacing clothes and bedlinen more often and higher laundry costs, cost of broken furniture and damage to fixtures and fittings in the home due to behavioural problems, as well as travel expenses to hospital appointments. Most families were unable to take a holiday due to both cost and the difficulties associated with their child's disability. Several parents indicated that the Family Fund grants had helped them cope, whether replacing clothing and bedlinen or being able to afford a rare family holiday.
In some families, one parent worked while the other parent was the major carer, and in one case both parents worked part time. Some parents reported having to give up a job they held prior to having their disabled child, due to caring responsibilities. The father of a child who had become disabled suddenly, as a result of physical and brain injuries caused by a road accident, had to give up his job to be with his child while he was seriously ill in hospital and to help his partner cope with the child's care afterwards. While the child has now made slow but steady progress over several years, it is difficult to find work after leaving a job suddenly and being unemployed for several years.

Case Study 2

Jill and James have two children, Conor aged 17 and Kay aged 7. Conor has cerebral palsy and as a result has both physical and learning disabilities. Conor can walk in his home with the use of a frame but uses a wheelchair when he goes out. Conor has a high level of dependency and needs help getting dressed and with washing. He can manage to eat his food himself if it is cut up for him, but may need a bit of help to finish. Conor loves music, football and fishing. He attends a special school and travels to school by taxi with some other children. He leaves home at 7.15am to get to school around 9.30am and leaves at 3pm arriving home at 4.45pm. He will attend special school until he is 19 years old. Although Conor is 17 he has quite a young learning age and so needs constant supervision as he has no concept of danger. Conor has a limited social life as he spends so much time travelling to and from school.

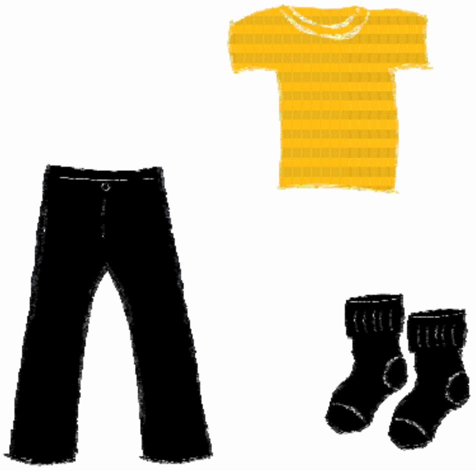
Conor has a social worker but it is only recently that the social worker has become aware that he has significant learning disabilities, and the family feel they have missed out on support as he was noted on records as physically disabled and cerebral palsy. Conor also has respite care with his uncle to give his parents a break occasionally. The family got some financial help from the Housing Executive with adapting the bathroom to suit Conor's needs, but the work has not been satisfactory and there are problems. The family adapted the garage themselves for Conor with a stable snooker table that he can lean on when playing.

Conor has a lot of extra clothes washing due to accidents, meal times and needing help at school with toileting. He also has extra uniforms for school in case of accidents. This year Conor went into senior year and the uniform is different, so Jill has had to buy 3 new sets. The uniform has crests on it and is Expensive, and Jill has tried buying ordinary tee-shirts in the same colour without the crest, but Conor asks where his badge is. The school sweat-shirt with the crest costs £35. In addition, Conor feels the cold and needs the heating on when others in the family could do without it.

Both parents work part-time in term-time with a gross income of under £25,000. They have difficulty getting child care for Conor as child-minders have told them they have to get extra insurance for a disabled child and do not want to take the risk. Jill finds it hard coping with caring responsibilities and her part-time work. Although on a low income they are not eligible for free school meals, so this is an additional expense. The family got some help through Family Fund to pay for bedding and clothing.

Jill says "we're skint" and that they constantly struggle to make ends meet with the cost of clothing, school meals and household bills. Last month was the first time they managed to break-even in a long time and they are up to date on bills. James cited an occasion last year when they got hit by high bank charges after going into the red by £1, which then left them struggling for several months.

Jill and James rarely get out socially together. Even at weekends when Conor is at his uncle's to give them a break, they catch up on sleep as they are so exhausted.



Case Study 3

Matthew is 12 and has complex health care needs, autism, and learning difficulties. He also has Genetic syndrome, skeletal differences, ADHD, behavioural problems, is asthmatic, and experiences bowel and continence problems. Matthew's school attendance is affected due to his ill health, and his mum feels that he is socially isolated due to difficulty in forming relationships. Matthew lives with his parents and older brother Lee, aged 21, who still lives at home. Matthew attends a special unit in a mainstream school and unfortunately has experienced bullying and name-calling in relation to his disability. Matthew has a limited social life. He does not go on school trips as he is not comfortable in this social situation due to his condition. He will not attend after school clubs and has no friends locally. This has all had an impact on his brother as well, as there is little time for him due to caring for Matthew, and he cannot bring friends home.

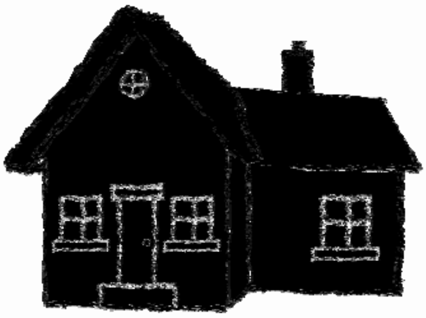
Matthew's mum finds it hard to cope and finds it very difficult looking after Matthew given his complex health needs. At times she feels that it is all too much and has had suicidal thoughts, "sometimes I've thought about just walking into the sea, I would never do it of course". They have had neither social services support nor any written assessment, nor have they received any offer of a carers' assessment. Although Matthew had a social worker there was limited support with no respite care and no regular contact. A clinical psychologist links up with the family to help with behavioural strategies. Matthew's mum feels that they do not have any normal family life, are very isolated, with no support and left to get on with it. They have very little social life as a family and cannot go out as a couple as one parent always has to look after Matthew.

Matthew's father works part-time, and otherwise they would not be able to cope with the care of Matthew. His job is under threat due to the economic down turn and the family are afraid that they may have to sell their house as they will not be able to afford the mortgage. He earns less than £10,000 a year and they receive the high rate of DLA for care, and the low mobility component for Matthew. The family income also includes Carers Allowance, tax credits and child benefit. As they are not on income support they cannot access a community care grant. The family struggle financially on a low income but have a low mortgage payment which helps.

His mum would love to go out to work and had previously worked as a care assistant, but caring for Matthew means she is unable to work outside of the home. She feels that the support services available are not adequate or not appropriate enough for her situation. His mum feels they are managing financially but that it is a tightrope with no luxuries. They do have a mortgage protection policy and her mother (Matthew's grandmother) helps with informal support and sometimes with money. A recent Family Fund grant meant that they did not have to borrow money on that occasion.

Due to his soiling, Matthew's clothes need constant washing and so the family's laundry costs are higher "as the washing machine is never off", and his clothes and bed linen need replaced more often. The family also have additional costs due to travel for health appointments for Matthew in Belfast.

Matthew's mum said she was very uncertain as to what the future holds at the moment, due to her partner's job being at risk, and the unpredictability of Mark's health and behaviour.



Parents who were working stated that they were not able to get help with school meals or school uniforms for their child(ren) or access community care grants despite a low income, as they were not on income support. One couple stated that they both worked part-time and were £20 better off than on benefits, but in reality they were worse off as they could not access free school meals or uniform grants for their children. Another parent talked at length about the expense of the school uniform for a special school which their child went to, and how the uniform changed moving from junior to senior school. They felt the extra expense was unnecessary as a plain teeshirt or sweatshirt of the same colour was a few pounds, but the school-designated one with the school emblem was very expensive (one parent cited a sweatshirt at over £30). Buying a cheaper version caused problems for their child who wanted the one with "the badge", the same as other children. Parents with children in mainstream schools report similar problems around cost of uniforms.

"*George went through 3 P.E kits in the first year… [uniform]...the shirts were nearly £30 and blazers were nearly £100.*"

The four example case studies included in this paper (from the total of twelve undertaken for this research) further illustrate the struggle some parents with disabled children have on a day to day basis when living on a low income.

Conclusions

This research indicates that while many parents struggle on a low income, for families with a disabled child the struggle is even harder, as they cope with the multiple deprivations of disability and poverty. The quantitative analysis at the beginning of the paper has indicated that overall child poverty rates are underestimated by up to 3% in Northern Ireland due to the lack of recognition of the cost of disability in the current HBAI methodology. The extent of poverty among children living with disabled adults is underestimated by as much as 9%, meaning that half of all these children are living in poverty. The cost of bringing up a disabled child is estimated as being at least 3 times as much as bringing up a non-disabled child, and our qualitative research indicates the major struggle that some parents have when trying to bring up a child with disabilities, and in particular those with complex needs.

References

Department of Works and Pensions, (2009), *Households Below Average Income Report 2005/6-2007/8*, London: DWP.

Dobson, B. and Middleton, S., (1998), *Paying to Care: The Cost of Childhood Disability*, York: Joseph Rowntree Foundation.

McLaughlin, E. and Monteith M., (2006), *Child and Family Poverty in Northern Ireland*, Belfast: OFMDFM.

Monteith, M. and McLaughlin, E., (2004), *The Bottom Line: Severe Child Poverty in Northern Ireland*, Belfast: Save the Children.

Monteith, M., Lloyd, K. and McKee, P. (2008), *Persistent Child Poverty in Northern Ireland*, Belfast: Save the Children.

Zaidi, A. and Burchardt, T., (2005), 'Comparing Incomes When Needs Differ: equivalising for the extra costs of disability in the UK', *Review of Income and Wealth*, 51 (1), pp. 89-114.

Case Study 4

Jack is 6 years old, has autism and behavioural difficulties and attends mainstream school. He has a younger brother Peter aged two, and his relationship with him is good, although difficult at the beginning. Jack has found it difficult to fit in with other children at school. They are friendly but his autism makes it difficult for him to form relationships with other children. His development is delayed in relation to toileting and self help skills and as he has a poor sense of danger he needs constant supervision.

His mum stated that they had received no social work support, or any help from a learning disability team. They have not received any support services or respite care. Jack's disability has been very stressful for the family with his behaviour causing a lot of relationship problems.

The family's income is under £15,000 a year with one parent working and Jack's mum receiving carers allowance while the family are in receipt of middle rate DLA with no mobility component, working tax credits and child benefit.

Jack sometimes has additional expenses for the family as there are extra doctor's appointments, special classes and the need for activities to be very structured for him. His behaviour causes a lot of damage to the house including, for example, broken bed and other furniture and fixtures in the home. The family find it a struggle to make ends meet and money is generally very tight. Uniforms are very expensive and, as Jack's father works, he does not get a uniform grant despite their low income. School trips are also expensive and these are a struggle but Jack's mum does not like him to miss out.

His mum says she would prefer not to allow a lack of money to affect what he can do but the reality is that some activities are too expensive.

For example, the football group costs £20 and there was a very good play scheme suitable for him over the summer but it was £35 per week. Money is very tight. Jack's mum said

"I feel we are living on a knife edge, not sure which way we will fall."

NOTES

POLICY RECOMMENDATIONS

There are a number of policy recommendations arising from this research:

- DLA/AA should not be included as an income in analysis of poverty if the equivalence scales do not take into account the extra cost of caring for a disabled child or adult in the family.

- Disabled children are still falling under the radar of social work services, with no formal assessment of their needs, and they are missing out on support services. For children with complex needs such as Asperer's Syndrome or other such disabilities that include behavioural problems but do not meet the criteria for Learning Disability team services, this is even more of an issue. All disabled children are entitled to an assessment of their needs, and this must be addressed by social services.

- Carers have a legal right to an assessment of their needs. None of the parents involved in this research had received an assessment. These assessments are essential in order to ensure carers maintain their own health while balancing caring responsibilities with other demands such as work and family commitments. The Department of Health and Social Services needs to put in place steps to ensure that these assessments are carried out and the needs of carers assessed.

- In addition, social services need to consider how they respond quickly in cases of desperate need, where parents of disabled children feel they are at a major crisis point and at risk of no longer coping with their daily caring responsibilities.

- Many parents and their children face social isolation. There is an urgent need for suitable, specialist care for disabled children to enable parents to have short breaks from their caring role. This care could be provided in the home for a few hours or respite care away from the home, depending on the child's particular circumstances and what suits the individual child.

- The social fund and the community care grants system need to be reviewed and extended to those who are working but living on low incomes, in order to provide the necessary support at times of crisis.

- The provision of leisure and social activities is scant for many children growing up in poverty, and children with a disability are even more at risk of being socially excluded. Low cost or free leisure and social activities are needed for disabled children from low-income families to enable them to have a life outside the home and school. Children with some complex needs require particular activities which meet their needs for stimulation.

- Of particular concern is the lack of provision of mental health care for young people. Parents had concerns about social isolation, about behavioural problems, depression and anxiety in their disabled young person, and they in turn worried about them as well as struggling to make ends meet.

- Parents trying to care for a disabled child on a low income were struggling to keep on top of bills and to meet the extra costs incurred in day-to-day care. The extension of free school meals and uniform grants to working parents on a low income would help alleviate some of the stress these parents experience. Several of the families in this research had either one parent working or two parents working part time, and were not eligible for these grants despite low incomes which fall below the poverty threshold.

A joint project between Save the Children and Family Fund.

Save the Children are outraged that millions of children worldwide are still denied proper healthcare, food, education and protection. We work to promote justice for children globally and locally. Here at home we are determined that child poverty is eliminated; that children get a good quality and inclusive education and that child rights are protected and promoted.

For more information on Save the Children in Northern Ireland please contact:

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The Family Fund give grants for things that make life easier and more enjoyable for disabled children and their families. We give grants totalling over £30 million to around 50,000 families across the UK each year.

For more information on the Family Fund in Northern Ireland please contact:

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