



Making the Impossible Possible

A PERSONAL PERSPECTIVE

Brendan Mc Keever

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PREFACE

In the account that follows of a remarkable campaign, the reader will notice one major gap, and this is the part that the author of the report is not qualified to write because it concerns himself and the role he played, as perceived by other people. It is for this reason that we have demanded the right to write a preface that will go a little way to filling the gap.

Brendan has described the attributes of others (ourselves included) in this account because he recognises the unique and important role played by every individual. On this basis, the story of the abolition of the DFG means test for children without something about the qualities of Brendan McKeever would be like Sleeping Beauty without the Prince, or the battle of Trafalgar with no Nelson.

So we want in these few lines to put on record what this shy, soft spoken man brought to the campaign, which we see as follows.

First of all, whilst so gentle in other things, in matters of principle Brendan will never compromise and his principles are so clear they steer him through the rockiest of moral rapids. There was to be no exploitation of families, no treating of the children as victims and no compromise by himself on the objectives, though others must do what they will. This was his first contribution. Then he had the three great

virtues of faith – that something could be achieved; hope – to keep him going in the face of formidable obstacles – and always compassion towards the suffering of other families.

And, mixing the three together, he had a dogged determinism that would simply not give up when older and wiser and more experienced people told him that what he was aiming for was not achievable.

There are two more things to say. One is that what he contributed besides his natural qualities was just sheer, grinding hard work, carried out month in month out year in year out to the bitter end, writing letters, travelling long miles, talking to people and communicating in every way he could find. Some people stop when they reckon they have done enough. Brendan stops when he thinks there is nothing more he can do. And finally, Brendan McKeever is a part of a family, and always saw how, in the provision and funding of adaptations, the needs of children could not be separated from the needs of the family as a whole. Brendan and his wife and three children have lived the campaign described in this book together. We believe it is the way he is embedded in his family that has in the end provided him with the sustenance for this long hard journey, which has had such a joyous ending.

Frances Heywood, Ginnie Shaw & Keith Bowen
Steering Group of Homes Fit For Children

SUMMARY OF KEY DATES/EVENTS

- 1997** Homes Fit For Children founded in England
- 1998** Parental Involvement (through support from Joseph Rowntree Foundation)
- 1999** Steering Group formed – Wales, N.I. and England – “Means Test the Child” main focus
- 2000** MPs begin to be involved Summer – Family Launch in London, Cardiff, Belfast and Derry of Homes Fit For Children
- 2001** Presentation to O.T. Managers Forum Belfast February – Homes Fit For Children Workshop, Derry with Frances Heywood December – Notification that Fundamental Review Steering Group recommended abolition in NI
- 2002** June – “From Issue to Politics” Conference Derry with Frances Heywood and Parent. Book published October “Beyond Words” Conference in Derry December – EDM 309 Eddie Mc Grady MP (First EDM on this issue)
- 2003** October – COTSSIH Annual Conference Abolition on the agenda (London) 4th December – “Where do the children live?” Conference (Derry) with Joseph Rowntree Foundation, announcement of NI abolition

2004 January – House of Lords debate issue
16th February 2004 – NI means test abolished
March – EDM 770 Roger Berry MP (Second EDM on this issue)
May 2004 – Huddersfield, Cardiff & London
Visits through JRF Project
May – EDM 160 Roger Berry (Fourth and final EDM on this issue)
September COTSSIH Annual Conference (Durham)
Abolition again on the agenda
December – EDM 298 Roger Berry MP (Third EDM on this issue)

2005 March – House of Lords debate issue
27th April – Announcement of Welsh abolition

2005 Summer – English Review Group winds up

2005 Summer – Draft Report from Bristol University

2005 30th September 2005 – Abolition in Wales

2005 27th October 2005 – House of Lords announcement of abolition in England

2005 30th December 2005 – Abolition in England

There were many other events that were just as important as these, which significantly helped the Campaign along but they will be highlighted another day. Here is just a short summary for you.

ACKNOWLEDGEMENTS

It would be impossible to thank everyone who contributed to this campaign. There are too many, and I do not know them all. At the beginning then I want to say a big thank you to all those who played a part in this, whether it was a large part or a small part, your contribution was valued and did make a difference. Some people are named, apologies to those who have been left out, this is unintentional. Those that are named, have been identified as a way of saying a special thank you and it is hoped that although time has passed and some may have moved on, that they still feel proud of their involvement and take this as a complement. If not apologies once again.

I have to say particularly thank you to: Frances, Ginnie, Keith, Jackie, Alison and Paraig for all their hard work over the years, as well as for checking and re-checking the drafts of this story. I hope some day you will tell your stories too, in a way that best suits you. Thanks also to Brother Vianney Kerr for his technical assistance with my grammar and spelling.

To my own group, the Family Information Group, for investing so much time, energy and allowing me to become so involved in this campaign and to my management committee for their help and support and for sponsoring this publication. By raising the issues that affect families of disabled children, we

aim to make positive changes to the quality of life of families.

Thanks to all the families, all the parents, researchers, politicians, individuals, voluntary groups, community groups, housing organisations, NIHE, and other statutory agencies and with a specific mention of the occupational therapy profession, particularly COT and COTSSIH – without your help and the assistance of sensitive civil servants, this story would never have happened. Our publishers, Guildhall Press, are acknowledged for their part sponsorship of this publication, for their professionalism and for their support over the years, resulting in three books and four leaflets. Without my own family, Teresa, Donovan, Ruth and Jack and without their support, none of this would be possible for me, they have put up with so much. In the end, however, these are my thoughts and my views and I take full responsibility for all I have written, in a spirit of true partnership.

SETTING THE SCENE

It was like a theatre. The props were in place and all the main characters in position. But this was not a theatre and people were not acting. History was happening. This was the House of Lords on Thursday 27 October 2005, it was Question Time. For some, just another day in Parliament. It is 11:01am.

A change of scene, the focus moves away from the theatrical environment, to the “real” world. A family in Huddersfield, it could be anywhere, but this family lived in Huddersfield, they were working. Throughout England in different towns and cities, parents of disabled children held their breath. Years of campaigning, letter writing, lobbying MP’s, going to the press, raising awareness, all this could come to an end in just a few minutes. It is now 11:02am.

In offices dotted here and there occupational therapists waited, holding their breath and waited. Many of them had gone out on a limb for families, advocating with and on behalf of families, informing and directing them. Of course some of their managers were not happy and did not see this as their role, but today they would see if all the evidence collecting and lobbying were going to work. It is now 11:03am.

Staff in the research section of the Joseph Rowntree Foundation fell silent as the minutes passed. For so long the Foundation had been raising specific issues

around housing and disabled children by commissioning research through experts such as Frances Heywood, Bryony Beresford and Christine Oldman, by supporting conferences and workshops and by pioneering a unique project with parents, to help them find their voices, it was silent in York. It is now 11.04am.

Back in the House of Lords the discussion on Human Rights in Burma was continuing, it was the First Question. The next question would soon follow. It is now 11.05am.

There was uneasiness growing in some of the major and smaller voluntary, disability, housing, and community organisations. So many of them had worked so hard towards this day, now it had arrived. It just seemed too much. Some were hoping, some afraid to hope. It is now 11.06am.

In the statutory agencies they waited. In this sector too, people had given so much time and energy to the campaign, in different walks of life (unknown to most) who just wanted to know. It is now 11.07am.

Dotted all over Northern Ireland, Wales, Scotland and England, politicians at all levels – Councillors, MP's, MEPs and Members of Assemblies (functioning and not functioning) were waiting, wanting to see. It is now 11.08am.

Baroness Andrews takes centre stage to answer Question Two, tabled by Baroness Wilkins in today's business. It is as if the clock has stopped. Her question is quite simple: "What progress has Her Majesty's Government made on the review of the Disabled Facilities Grant?"

There it was, in just a few short words. This was the trigger but what about the response. A sharp intake of breath.

The drama unfolded as Baroness Andrews – the Parliamentary Under Secretary of State, Office of the Deputy Prime Minister moved forward to speak. Tension was mounting, this was it – years of work for nothing, or was the goal achieved. Seconds ticked by. Baroness Andrews referred to the commissioned research, carried out by Bristol University. The research team was led by Frances Heywood and they had made a number of recommendations, some of which would go out to consultation.

"Oh No," I sighed, how much consultation do we need on the means test. But wait, what has she just said:

"the report recommends that the DFG Means Test should be removed for families with a disabled child and the Government have agreed to implement this change in England from December this year".

All those waiting, anticipating, holding their breath. No “ifs” no “buts”, no consultation, just a decision to abolish the means test in England in December. Incredible, disbelief, shock, tension seeped away, there were tears and laughter, common sense had won through, though very few expected this. Things would never be the same,

Baroness Wilkins went on to thank Brendan McKeever and Ginnie Shaw of Homes Fit for Children and Caroline Gordon of Mencap and many others. (there were many others, all over the countries who had contributed so much).

Somewhere in England, Ruth sits at home in her wheelchair. She knows nothing of lobbying, means test or accessible homes. But up until now she could not get around her home, her dad had to carry her up the stairs to the bedroom and bathroom. Mum and dad smile, they know their child has a right to a better quality of life, the means test prevented this, after December 2005 things will be different.

In Wales David sits in his wheelchair at home. He too knows nothing about lobbying, means test or accessible homes. He just wants to get around his house. His mum smiles their application is in and, as it is after 30 September 2005 (when abolition became effective in Wales), the means test will now no longer be a barrier.

In Northern Ireland, Jack makes his way through the wider door into his extension. Jack also knows nothing about lobbying, means test or accessible homes. His parents smile, they were unaware of a lobbying campaign, the means test had been abolished in NI since February 2004. They just thought an accessible home was a right, as it should be. They smile because access in their homes gives them a real good quality of life.

The abolition of the means test on parents of disabled children, who go through the Disabled Facilities Grants Process (Private Housing Sector), in NI, in Wales and in England is the focus of this story.

The following is a personal viewpoint. It is understood that there are other viewpoints and other stories about this campaign, maybe some even to be told in different ways. It is hoped that some day these also will be told. Of course there are stories that never will be told, as we do not know what everyone did to further this campaign, although all the work is valued and appreciated. Then due to confidentiality and sensitivities there are things that never can be spoken about. Also memory plays tricks and some things just cannot be recalled. For all those, whether they are mentioned or not, a sincere thanks.

On a personal level, I have many memories, different places, strange faces, despair and hope. Ginnie standing near Millennium Bridge proclaiming our

rights, it seemed funny then (apologies Ginnie) but now it is an embedded moment of pride as it took me some time to learn about rights, mainly from Ginnie.

The warmth of Keith, always in control, diplomatic and knowledgeable, manoeuvring his way around the Welsh structures with ease. Jackie turning up and being there, even if I had not seen her for years, always loyal and committed as if we just met yesterday. Alison, meeting over a lunchtime meal, one minute in deep serious conversation, the next discussing the merits of punk rock and trying to imagine her with a safety pin through her nose. Paraig burning the midnight oil, always one step ahead, always cautious, working at several different angles but remaining focused. We never did get that celebratory meal.

Frances, always the mother figure to me, ready to step in and calm my anger and frustration, and always there to lend support and to give encouragement, a real friend. Between us we must have dramatically increased BT's profits. So many memories. But it is time to tell the story. However there is one lasting memory for me. Anne coming to me at the conference in Derry, almost in tears. As a parent, she had been through so much in her life. She just could not access the DFG because of the means test. What she said that day still remains, it is what many parents have said since:

“Brendan, it is too late for us, but it is not too late for other parents”. It is not too late for other parents Anne, because of what you and so many others have done. We raised our voices and at last someone listened. This is how I see the story.

Of course some it will be about lobbying, political change and policy into practice. There will be people who will scrutinise this for theories in relation to user involvement. However for those most involved, it is about trust, faith, overcoming adversity and building relationships and friendships. It is about seeing the person behind the issue (any issue), it is about facing the impossible and believing that it just might be possible. It is about real partnership working. This story is about how people made things happen, against all the odds, believed things could change for the better. It's our story, it could be yours too. (Brendan Mc Keever)

WHAT IS IT ALL ABOUT?

It is quite simple. For years disabled children have been living in conditions, which did not suit their needs, through no fault of their own. The grant that was supposed to help parents adapt their homes, the Disabled Facilities Grant – became inaccessible to some parents because of the Test of Resources (means test) associated with it.

There was a number of examples where occupational therapists assessed the need for adaptations for the disabled child but these adaptations could not be carried out because parent/s could not afford the assessed contribution calculated through the means test process.

Disabled children had no voice, very few parents had a voice and the wider community were duped into thinking that disabled children get everything anyway. It was researchers, housing and voluntary groups, as well as occupational therapists that first showed their concern.

So what was wrong with the Test of Resources? The problem was that it was not a test of resources, rather an income based assessment, measured against government allowances for living on. Actual out-goings were not measured and there was no recognition of the full additional costs associated with disability (additional costs that have been verified by

a wide range of researchers) as well as the realistic mortgage and housing costs (allowances came nowhere near these in reality).

But the fundamental truth that was missed was that every child has a right to a safe, accessible home, the rights of these disabled children were being thwarted because of an inaccurate means test and a disregard of an occupational therapist's assessment. As a result some parents did not even enter the DFG process, some pulled out completely, some went into debt but in all cases, disabled children suffered. That is what it was all about.

THE BEGINNING

In reality it did not begin with the campaign. It began, as pointed out in the last section, with the disabled child and his/her family. Disabled children, their siblings, their wider family, all were suffering. But no one was speaking out, there were no voices.

I wonder now where Nicky Wilkins is, formerly Director of Care and Repair England. Nicky with a few others founded Homes Fit for Children in 1997. She used her skills and contacts to bring together about thirty volunteer groups and individuals under the banner of the campaign.

A core group was founded that included RADAR (John Keep and later, Marie Pye), The Disability Group of the Association of Directors of Social Services (Roy Taylor) The National Children's Bureau (Philippa Russell) the Family Fund Trust (Roger Mattingly) Later, Roger Mattingly used resources accumulated from an adaptations course in 1998, to help finance the campaign in its earlier days.

In those days, expectations of success were not very high so although the abolition of the means test was a goal, it became a long term goal. Immediately concerns were to get the means test changed, this test was referred to as "The Test That Fails".

This is how it all began, committed individuals and

organisations desperately seeking change. And some of those organisations so supportive in the late 90's have remained on board the campaign, through thick and thin.

Although Nicky moved on, Ginnie Shaw, Frances Heywood and Jackie Hughes remained with the campaign from its very early days, supported also by Alison Jarvis of the Joseph Rowntree Foundation.

Keith Bowen of Contact a Family (Wales) who was to have a pivotal role in Wales, first met Jackie and Frances at a research launch in London where Jackie, as a parent, was giving a presentation. Although Ginnie was at that event, her first face to face meeting with Keith was in his office in Cardiff, while conducting a radio interview on the campaign for Radio Cleveland. This was during the famous three country launch in July 2000, just before Ginnie rushed from Cardiff to London to meet myself, Roger Mattingly, representatives from Contact a Family and some parents and children.

Over a period of time, those tasked to bring this campaign forward were meeting regularly, building up trust and also growing in confidence as well as continuing to network with concerned individuals, groups and researchers.

Adaptations, as already stated, must be recommended by an occupational therapist. It is not

the parent who wakens up some day and desires an extension. Also adaptations are linked primarily to the quality of life of the disabled child. Such items as outside ramps, lower electrical switches, wider doors, downstairs extension, adapted toilet/shower are usually what are meant by adaptations. They are not luxuries but basics for a disabled child. This was what the campaign was about.

In the beginning, 1997 and moving into 1998 we therefore had people genuinely concerned about the living conditions of disabled children and young people. This was eight years ago, a long long time for a campaign. Concerned individuals and voluntary organisations forged links to highlight the issue to advance it and lobby for change. In the words of the campaign:

“we would like to see the Test of Resources abolished for all adaptations for children and the full cost met by central and local government. We recognise however that this aim, whilst totally justifiable, is ambitious, and have set ourselves some more modest objectives to be achieved in the short term”.

The modest objectives referred to related to the inclusion of actual expenditure in the means test and the replacement of fixed allowances. At that time this may have seemed very ambitious but with the passing of time, the resolve for more fundamental changes grew and these modest objectives fell by the

wayside. The seeds were set however and grounded in the experience of disabled children and their families, always the cornerstone of the campaign.

From that experience, concerned individuals and organisations – very much aware of the situation – collectively agreed to try and do something, by raising awareness and by political lobbying. It was time to move on.

MOVING ON

The first phase of grounding the campaign was now complete, Nicky and her founding fathers/mothers had done their work. As in any campaign personalities come to the fore. As Nicky moved on, the campaign was well steered with Ginnie Shaw (HoDis), Frances Heywood (researcher) and Jackie Hughes (parent) playing key roles in keeping this issue alive. The input of SCOPE (Diane Esmond and Peter Ashworth) was immensely valuable. There were other parents Ian Hartnell (an early co-chair) and Anis Shamsan and Asma Hassan who travelled to meetings and helped to keep the struggle going.

Behind these personalities were individuals and organisations offering support, help and advice. To conduct the campaign we had to have evidence of the impact of the means test, and every time the regulations changed we needed new up to date examples. For this, occupational therapists from around the country helped again and again, and in particular the cases that came from the Muscular Dystrophy OT, Yvonne Masset, and the parents who then talked to us and told us their stories were so important. No-one will ever know how many hours of their own time these OTs put into collecting the information that was needed, and doing it again and again.

One of the key features of the campaign has been the ability to engage individuals and organisations over a long period of time while still retaining the care ethos of the campaign. Over the eight years since its foundation, the Homes Fit for Children Campaign has seen many people come and go. Yet those steering the campaign have never allowed personal interests or indeed personalities to take precedence over the main issue.

If we look back at the infancy of the campaign, we can begin to see the oil that kept all the parts working. This campaign has been built on trust and mutual respect, valuing each other and aware that everyone has something to contribute. These values have always been more important than strategies and plans of action, without them, the campaign would have gone to the wall years ago.

In hindsight, a number of people have looked at this campaign as a model of good practice in relation to “user involvement”. If we look back to those formative years we can see how these elements that were important then, still are. Some people pursue “user involvement” as a goal in itself whereas often good models of practice emerge as a result of “user involvement” as a process towards a different goal. As a concept, during the many years I have been involved in this campaign, I have seldom heard anyone within the campaign refer to the term “user involvement” as a theory.

To put it more simply, the developing of relationships and trust, the recognition that each person had something to bring to this, the valuing of people, respecting difference while still being able to challenge – these were what was important. It was these that built the core ethos, which kept us going in those dark days when there seemed no hope, no outcomes.

This is the ethos that allowed the primary goal to remain the same but which facilitated the change in the objectives, without any major fall out. Again this was the ethos that ensured key people could “do their own thing” as long as this was within the remit of the campaign, there was no looking over shoulders.

But also, and this is very important, this atmosphere facilitated the equal valuing of someone who licked a stamp on a letter to an MP alongside someone who made a presentation. The person/organisation there from the beginning had no priority over someone coming late to the campaign.

This ethos of mutual respect ensured that as far as possible information was accessible, because that is what most people wanted, and always any business was grounded on sensitivity to parents and disabled children.

To some this may seem so far away from political strategy and perhaps it is. This campaign was based

not on a political philosophy but on trying to right a wrong. There was full awareness that we could not right all the wrongs but we were going to try and right a major one.

Early advice was to focus on the one issue, not to diversify or we would be torn apart, we did focus and we now see the results.

THE NEXT PHASE

In those first two years, those leading the campaign, raising awareness of the issue felt that something was missing. They stopped and looked at what they were doing – they had researchers, disability groups, housing organisations, occupational therapists, individuals and a few parents. As they reflected, they also planned on where they wanted to go. In essence they took a reality check.

From all of this, it emerged that if the campaign was to make any headway, there needed to be a deliberate attempt to engage more parents. Jackie Hughes on her own, with some other parents coming and going was not enough. This was not a token attempt at ‘user involvement’ but rather a real attempt to engage people, people whose experience was valued, who could tell it as it is.

Already the foundations had been laid by those that came before, the issue was known but now it was about to be felt, and this was to change things dramatically. Researchers, representative from voluntary, disability, housing and community groups acknowledged that they were not living this issue, day and daily, even though they worked with those who did. The expertise that had previously existed did not need to be replaced, rather additional experts were required and these were the parents of disabled children. To support parents in this, funds were made

available through a private donor, Joseph Rowntree Foundation and some accumulated resources, to pay for travel and childcare costs. I got an invitation to become involved as did some other parents and we all joined in.

NOT AN ISSUE

For many parents the means test was not an issue, they just lived with the impact of it. The culture of that time for a lot of people was not to question the way things were done. For instance if you were told that a means test was the fairest way to administer a grant, then you believed this. If you were told that the actual Test of Resources was based on similar tests in relation to other benefits, you believed that. If you were told that you had to make a contribution, this was personal to you.

Perhaps you did not know other people's circumstances, and that others could be in the same situation. As a parent, it was your problem, you felt inadequate because you could not afford to support your child, and it was one more knock. Often those feelings of inadequacy were heightened when those we live with – community, society, make it clear that generally they felt disabled children were well catered for and sometimes often given too much; hurtful perceptions.

Those involved in the campaign had seen all this, from a variety of perspectives, researchers, including Frances Heywood, Bryony Beresford and Christine Oldman had extensively studied the impact of housing on disabled children, and supported by the Joseph Rowntree Foundation, several reports on these issues had been published.

Ginnie Shaw of HoDis, day and daily was dealing with housing matters not only in relation to disabled children but disabled adults too, she was bringing that wealth of experience to the campaign. But as time passed Ginnie was bringing even more. Through her work Ginnie got an insight that much of what we were doing was rights based.

At first, particularly for parents where need and dependency seemed to be the key words, rights was a new and different way of thinking. It took time, but as Ginnie deciphered legislation and interpreted the UN Convention on the right of the child as we progressed, the rights issue was embedded in the ethos of what we were doing, until it slipped off the tongue naturally. Today in a culture of rights this may seem strange but several years ago it was all so new. HoDis invested their limited resources into the campaign at various times, through advertising and facilitating Ginnie's involvement itself, this is often forgotten.

Indeed for parents, so often weighted down by the impact of disability, rights were not even an issue. Frances Heywood, a researcher, lecturer and expert on a number of social issues and like Ginnie, a founder of this campaign, brought so much to moving things forward.

Over the years her research had brought her in contact with so many different situations but also her

network of contacts engaged her with civil servants, housing officials, occupational therapists and many other people. She is and was highly respected in her field. Her gentle, persuasive approach often diffused many tensions that arose as we struggled to bring this campaign out in to the open. One of Frances' greatest attributes is how she values and appreciates people but not just that, how she can let people know this. In both Frances and Ginnie there is integrity and a deep based honesty, but most of all respect for others – a core value in any partnership working.

The original parent – Jackie Hughes – was there, as often as she could. Her presence was a constant reminder of where all this came from and as someone who stuck this out to the end, her perseverance, loyalty and commitment helped ground the campaign as it forged ahead. In attempts to be inclusive, or to try and develop user involvement models, there is often a preoccupation with representation.

What interests are represented, what positions, what balance is there. It was the totality of the parents' experience that influenced this campaign, not whether a disabled child had a physical, learning, sensory or mental health disability. Therefore when the call went out for parents, it was to deepen this holistic approach, to complement what people knew in theory and from practically working with families.

It was recognised that it was difficult for everyone, including parents, to come to meetings. There was much coming and going but the wealth of knowledge and experience that people brought was what was important, not whether they could attend meetings. The parents experience continually informed this campaign, helped to keep its feet on the ground and assisted in developing the ethos that all our work should be sensitive to families, this ruled out any exploitation of families for whatever reason, no matter how much it would move the campaign on.

Shortly after I became involved, Keith Bowen, of Contact a Family (Wales) became engaged, through Ginnie Shaw. Keith is from Wales and had a vast experience of working with families of disabled children. He also had an extensive network of contacts as well as a friendly approach to people which made him very easy to get on with, and often you did not know you were being challenged by him until much later.

Keith has a very sensitive approach to his work and also he is very thorough on everything he does. The core team was taking shape but without the network of contacts, those who regularly came and went and those who supported the campaign, the team would be nothing.

MY STORY

Before the issue, our story begins. A story similar to so many families learning to live with the impact of disability, often their child has been diagnosed with a specific condition/disability. Housing was not an issue; it was simply somewhere to live, to feel comfortable to be at home.

Of course it was an emotive subject. As emotive as the possibility of moving house to accommodate the future needs of our child (who would later go into a wheelchair). It was not something we relished. To us it seemed a very private, individual story – nothing to do with anyone else, certainly not an issue for a political campaign,

We found out that there was a grant, a Disabled Facilities Grant, once an occupational therapist assessed the need for adaptations. It was obvious that we would need adaptations and it became clear that our terraced house was not going to be suitable, unless excessive amounts of money were spent. We moved to a small bungalow, that we could just about afford.

Some mention was made of a means test when the application was made for adaptations to the bungalow but we felt this did not matter as we had no excess income – most of our money went on the mortgage, additional housing costs, endowments,

building insurance, contents insurance, rates) and the additional costs associated with disability needs.

We were devastated when the local housing authority (N.I. Housing Executive) calculated that we could afford to pay just over £2000 contribution towards the grant. we knew we couldn't afford this. It was a complete shock to the system, that we could not afford to adapt our home for our son, even though the occupational therapist had assessed his need for this. We checked locally, questioned how this came about, but it was all down to the means test. We felt we were failures.

The Family Fund, a very supportive organisation for families of disabled children were aware of my interest in housing, several years after this incident. At times my interest was more of an obsession. Alison Cowan of the Fund made me aware that they were producing leaflets on housing through a researcher called Frances Heywood. As they needed Northern Ireland input, she asked if I could ring Frances on this I did and obtained my first ever paid commission work. Funny how things happen, in life.

Critical to the housing campaign were connections, contacts, networks, people knowing other people. In this case now with me the connection was made with Frances, who I had never known or met. We completed our task and life went on, an odd time we kept in touch.

One day some time later a letter arrived from Frances, introducing and outlining the housing campaign, but particularly the need for parents to become involved and asking if I would come to a meeting in London, travel expenses paid.

At first I thought it was a joke, how could I just pick up and go to London, and just for a meeting – that was the role of a business person.

But just as shocking were the details of the campaign. I had thought what we went through was peculiar only to us, as a family. Had I not questioned all this locally and more or less told this is the way it is, it was and ever will be. The letter made an impact.

What was happening now was those personal concerns, those challenges, those barriers were being brought together from individual families and out of this, a campaign was developing to try and change things. I phoned.

Of course she was convincing, I flew to meetings in London and in Birmingham, became a committed member of the campaign team.

THE LAUNCH

The campaign was going for some time before we really had a launch, the time was more than right to bring the campaign out into the open. However, as usual, we did things differently as the launch was totally family focused and involved all the three main regions – England, Wales and Northern Ireland.

A lot of planning went into the launch and through all the planning and preparations, a great sense of co-operation built up. Sometimes we concentrated on events as being the important targets whereas, as in our case, all the work that went into planning and preparing were the most important.

We could not wait for Wednesday 26 July 2000 to come, the day we would come out in the open. Coverage by the local radio, and press in Derry and also in Cardiff was excellent whereas, as expected, in London we ended up almost celebrating the launch ourselves. It was crazy.

The day began early in Derry inside the Guildhall with a local launch hosted by the Mayor Cathal Crumley from Sinn Fein. There was a good turnout of supporters. Around the same time in Cardiff at the Welsh Assembly, there was a launch hosted by supportive Assembly Members and the Welsh Health Secretary Jane Hutt broke off from another

meeting to be present. Once again families were included as they were in Derry.

In each area – Northern Ireland, England and Wales, children had been busy before this making an accessible Lego house, to symbolise what the campaign was about and to show that each of the areas were involved.

The house was built in three parts, one part from each area. On a beautiful July summer day, I carefully picked up the bag which contained the Northern Ireland third of the house, which our son Donovan and daughter Ruth had made and I was on my way from the Guildhall in Derry to the hotel at the airport just outside Belfast. Months of planning were paying off. Cardiff and Derry were launched, now it was Belfast's turn.

Driving to Belfast, I was wondering how this would go and was I really that crazy to be then going on to London? At the Fitzwilliam Hotel at Aldergrove, there was a very poor turn out with only representatives from Contact A Family, Family Fund and ASBAH. But just when I was about to despair, Rev. Martin Smyth (MP) and Paul Clark (UTV) turned up. We had a political representative and regional media coverage. I could not believe the speed at which the media works because just as I was being filmed, another film crew in Derry were on their way to our home to film our son Donovan and the adaptations to our

home – this was only ok'd once both Teresa, my wife, and I gave permission.

The UTV coverage gave us a lot of publicity and the clip was used quite often by us to give people a short summary of what the campaign was about.

However the political side is another story. In reality we were only becoming political aware. In Northern Ireland the Rev Martin Smyth and John Hume were the first two MP's to become interested in the campaign. In England and Wales a few politicians had shown an interest in individual families but at this stage they were not fully engaged in the campaign. But for Rev. Martin Smyth to be at Aldergrove was a magnificent coup and he remained totally committed to the campaign to this day, as did John Hume and his office.

We had another visitor at Aldergrove. Roger Mattingly, Chief Executive of the Family Fund – powerful supporters of the campaign, had flown over that morning to host the Belfast launch. His direct honest answers to the questioning of Paul Clark will always remain with me, he spoke with such sincerity and authority. The links were gelling, he had come from London to Northern Ireland and together we flew back to London to meet some of the people from Cardiff for the final link in the chain – the London launch.

Even though I was in my mid forties then, I could hardly keep up with Roger who was on the brink of retiring. In the warm sunshine we strode through London until we reached the Thames riverbank near the then recently erected Millennium Bridge. The timing was spot on, some had already arrived and soon the others had also gathered. Disabled children, their families, representatives from voluntary groups, they were all there. We handed out leaflets and listened to a statement read out by Ginnie Shaw (HoDis)

Symbolically all three pieces of Lego were put together, we had an accessible home and we had our launch. Time was ticking on, planes and train timetables were beckoning, and each of us said our goodbyes. I flew back to Belfast, drove home to Derry exhausted knowing we had achieved our purpose and that people were beginning to know about the campaign.

It was fun, it was crazy, it was memorable and it had worked, the launch had come and went. However the real hard work, unknown to us, was really just about to begin.

A turning point had been reached, and as we looked over what had happened, we decided to plan for the future. If you like, we developed a strategic plan and as part of that plan it was decided and agreed that we would concentrate on Northern Ireland first, while still continuing campaigning in England and Wales.

All efforts were to be made to put the issue on the agenda firmly in Northern Ireland particularly with the politicians. Northern Ireland was small, it seemed easier to contact politicians and there had been growing support from individuals and groups there. I was asked to lead this up. I decided to try and make a go of it. (This story is more fully told in my own words in “The Impossible Took a Little Longer” – an extract below gives a flavour of the story in Northern Ireland)

NORTHERN IRELAND

The hype was over, we were launched and now we had to try and figure how to go forward. In reality I knew little or nothing about real political lobbying and here was I supposedly leading up a campaign in Northern Ireland, with my fellow campaigners hundreds of miles away.

I remember saying at a meeting in London some time before this, wouldn't it be great if we got representatives from all the main parties in Northern Ireland behind this issue, including Sinn Fein and the Democratic Unionist Party (DUP), I am not sure if most of the people there knew what I was talking about.

I made a commitment to my colleagues that I would not compromise on this issue – it was abolition of the means test or nothing. This was easy to say, as I never believed, in reality, that we would ever get to a stage where abolition was being considered as a realistic option.

However the true reality that needs to be emphasised was that although I had been asked to lead up this campaign through the Family Information Group with a total workforce of one – this is me, I was not alone. It would be hard to believe that one person, working on their own, could easily create a campaign for change. Later in our campaign when indications were

coming from statutory authorities that this could be a personal type crusade, this was soon refuted by the diversity of voices calling for change.

The reality too is that the media often home in on “the human interest” story and ignore completely the broader issues. I forget now the number of times we were approached by the media to put forward families to be interviewed – we refused unless we identified other agencies or groups who would check with families first – remember one of our core aims was always to remain sensitive to families, and we stuck by this.

In any campaign, I believe whoever is leading it up, needs to constantly remind him/herself that no matter what the media may say and no matter what others interpret, the leader is only representing the views and is tasked to bring people behind the issue. Of course this can be very difficult but it is very important and often you will read or hear your own words, quoted out of context. Unfortunately this is something that has to be lived with when in the public arena.

My own reassurance was that, as mentioned earlier, as I had no real expectations that we would make any significant difference, I could throw myself into this and perhaps pave the way for other issues in the future to come through. Despite these feelings I felt it was only right that I gave it my best shot and effort so I threw myself into building upon the work already

done by Homes Fit For Children and by our own Family Information Group.

As Frances Heywood was coming to Northern Ireland early in 2001, just over six months after the family launch, I asked her to come to Derry for a small meeting.

The day before our meeting in Derry I had been invited to make a presentation on “Homes Fit For Children” at the housing workshop Frances was attending just outside Belfast. Really now the pieces of the jigsaw were being put in place in Northern Ireland.

In the build up to Frances’ visit, hectic work was going on in the background to engage as many people/organisations as possible in this campaign and to sound out politicians at a variety of levels. On Friday 23rd February 2001, twenty-six people turned up at Foyle Disability Resource Centre to see Frances as the issues around the campaign were discussed.

Frances gave her full support to move the issue forward in Northern Ireland, explaining that her visit to Derry was to personally pledge that support. A mixed audience of parents of disabled children, local councillors, representatives from political parties, representatives from the voluntary and statutory sectors including health, social services and housing.

With the support of the Family Information Group's management committee, time and resources were now re-directed into moving the campaign forward. The wide support network that had been built around the group over the years was proving very fruitful as more and more organisations offered advice, help and support. Those who knew us locally and those who worked with us throughout Ireland and the UK knew who we were, what we were doing and what we were trying to achieve. In other words our credibility checked out, as we had spent a number of years raising the issues that affected families of disabled children.

Presentations on this issue were made to several different audiences over the years: Chartered Institute of Housing, Professional Occupational Therapists, Joseph Rowntree Foundation, Western Health and Social Services Council, National Children's Bureau and locally to interested groups. Also through our own workshops/conferences it remained a constant theme that we would come back to.

All this work helped to put the issue on the agenda, people were waking up to the issue – not necessarily agreeing with our solution, but waking up to the fact it was an issue. Also articles were written and submitted to a range of magazines, mostly in the disability field.

However the real change came when in Northern Ireland we got devolved power through the Northern

Ireland Assembly. I personally wasn't sure what this meant until we got letters from the Law Centre and the Children's Law Centre confirming that our Assembly had the power to change things in relation to housing.

You do not need to know everything yourself, if others who have the knowledge share it with you. I carried those two letters around with me for months. The real battle had begun – Politics and I assure you I had a lot to learn and I had to learn very fast.

POLITICS

Think about the complications of putting a jigsaw together. This is what we had to do in the NI political arena to really try and fit the pieces together. Campaigners in the UK with Homes Fit For Children had been advocating for some time that they needed an MP to lead the campaign up. By the time we came to decision day, we had a lot more than one MP.

For many people, including myself, politics seems far away from everyday living. Often we ask ourselves what has politics to do with us and we end up being critical of our politicians for doing nothing in Northern Ireland with the emphasis on religion and allegiances, sometimes we can feel even more alienated.

There were many times during this campaign where I felt I had to bite my tongue when I listened to political statements from MP's, MLAs who supported our campaign but yet were saying things on other subjects that I found hard to listen to. But there seems many angles to politics.

Politics is supposed to be about change, "the art of the possible" I think someone once said of it. When there is a realisation from those involved in any issue, that it is the government who control what is happening, then politics has to enter the arena.

Politics could be at local council level – I once thought local councillors only made decisions on emptying bins or street cleaning, I was rudely awakened, at Assembly (MLA), at Westminster (MP) and at European (MEP) levels.

The interesting part of the Northern Ireland story is that sometimes we have politicians working at a variety of levels for example a local councillor who is also a MLA and an MP. Also local councillors in Northern Ireland can have a very positive impact on their own party, right up to MEP level.

Another very important feature is that those who work in party offices have a great influence on what is a priority for their own particular politician and indeed it is often those who do work in such offices that carry out the research, attend meetings and feedback to the politician in question.

From our experience of lobbying it is vital you get to know the personal assistants of the politicians that you want to work with, that you build up a good working relationship with them. Also value local councillors and the power of the local council, ensure they are invited to your events and keep them informed and updated.

We found the MLAs we met genuine, keen to help and interested once we explained the issue to them, and also they are very accessible – almost on your

doorstep. MPs and MEPs are also very important, try and get an occasional face-to-face meeting with whomever you want to work on your behalf. In Northern Ireland, if you can, it can be beneficial to have cross party support for your issue, with at least one representative from each of the major parties.

In politics however there are many different strands. There will be politicians who take a keen interest, who help to guide you and support you and point you in the right direction. Others will be very keen to follow things through for you. There may be others who will simply write a letter on your behalf. All of these are important but each politician does things differently. Sometimes the writing of the letter – which may seem so trivial – can be one of the most important things to be done in a campaign. Politicians can often change things that we do not have the power to change ourselves.

In Northern Ireland before the Assembly was set up we already had support from Rev. Martin Smyth and John Hume and locally we had councillors such as Helen Quigley, Maeve McLaughlin, Jim Clifford and Cathal Crumley showing a keen interest in our work. In the background we also had politicians such as Rev Ian Paisley asking questions on our behalf and later he would also come on board to fully support the campaign.

The Assembly came at the right time. Mary Nelis

(MLA) was one of the first assembly members to lend her support. Support is the right word as several face to face meetings took place with Mary – who has a special interest in children’s rights – and she was able to give me a lot of guidance and information.

What may seem unusual to most people, was that much of the information and advice was given in a non-partial, and in a non-party political way. Mary attended many of our events and an unfortunate broken arm prevented her from hearing the news of the abolition at first hand at a housing conference in Derry.

Mary was also one of the first MLA’s – there were three in total: Patricia Lewsley, David McClarty and Mary herself who asked questions in the Assembly prior to the setting up of the Review Group by Nigel Dodds.

Also during this period, face to face meetings were taking place with Mark Durkan, Mark had a sound understanding of the issue from the “means test the child” and as it moved into the abolition policy Mark subtly raised the issues with his colleagues at the Assembly, and his role of Deputy First Minister was of great help and influence with Mark taking over John Hume’s role as party leader, he became very influential in ensuring all the SDLP MP’s came in to support the campaign the way he did. Both his assistant Martin, and John Hume’s assistant Paul

Herron were very supportive during this whole period of the campaign.

At this time we needed another champion at Westminster, we already had Rev Martin Smyth and John Hume and Rev Ian Paisley asking questions. Through Mark we got in contact with Eddie McGrady and his assistant Teresa, she was excellent in guiding our campaigning work.

Teresa explained how Early Day Motions (EDM) were a means of attracting political support and although in themselves changed little, could be a good gauge of support. We went for this and after intensive lobbying involving Frances Heywood and her sister, our colleague in Wales and York, eventually seventy five MP's signed up to the Early Day Motion (in effect supporting the campaign) and with the four Sinn Fein MP's who do not sign these motions, we had 79 MP's – a far cry from the one which originally thought we needed.

On other occasions during those months I met MLA's such as Patricia Lewsley, Michelle Gildernew (and I was that naïve that when I met Michelle at the City Hall in Belfast I did not know she was also an MP), Nigel Dodds, John Tierney and several other SDLP party members in passing during their annual convention.

Nigel Dodds was the Minister in the Assembly with responsibility for the Department for Social

Development, the department that would be responsible for seeing through any changes in relation to the means test. As stated earlier, in response to questions from Mary Nelis, Patricia Lewsley and David McClarty he invited a review into the means test. I met him by accident in Derry when he was officially opening a refurbished disability organisation office.

Believe it or not I hated networking. However when to my surprise I saw that he was officially opening the premises, reluctantly I walked up to him and introduced myself. We had a short chat in which he mentioned the review. All I really wanted was for Nigel Dodds to see a face behind the Homes Fit For Children Campaign. I hope he did but I knew that this type of lobbying was really stretching us.

Before moving on to the MLA's and councillors it is worth reiterating how we got so far. We started with two MP's – Rev. Martin Smyth and John Hume, with initially Rev. Ian Paisley asking questions and writing letters in the background, he later came on board. Through Mark Durkan we were able to contact Eddie McGrady's office and at their suggestion an Early Day Motion was put forward at Westminster to gauge support for the campaign. At this stage we had all SDLP MP's signed up, all DUP MP's except one, and all Ulster Unionists except one, but eventually we did get the other DUP and UUP MPs and also through the work of Maeve McLaughlin, Gerry McLaughlin

and especially Mary Nelis and Sue Ramsey, we had all four Sinn Fein MP's supporting and endorsing the campaign, even through they could not sign Early Day Motions in principle.

However I believe one of the secrets of this campaign was that we did not stop at one off letters. All our politicians were regularly asked to write letters to the Minister, ask questions etc. and to keep up the pressure – Rev Ian Paisley, Gerry Adams, Mary Nelis, Gregory Campbell, Eddie McGrady, Mark Durkan and the Rev. Martin Smyth seemed to lead the way in this but it was closely followed by quite a few other politicians both MP's and MLA's. The constant barraging kept the issue alive when it was so nearly dead, it was an excellent ploy that we milked to the end.

But although Northern Ireland was forging ahead, it is vital to understand that in England and Wales the work was steadily going on at different levels. This steady work in England and Wales was needed to help build the case for all three areas. Before the Early Day Motion we had the support of British MP's Diane Abbot, Nigel Jones, followed by Hugh Bayley, Roger Berry and also we had Ros Wilkins (peer) and from the Welsh Assembly Sue Ryder.

It took a lot of work from Ginnie, Frances and Keith to make this happen. The Early Day Motion however blew it all open, as mentioned earlier – 75 MP's

signed up with the five additional Sinn Fein MP's, it really was on the agenda in England and Wales.

It was unbelievable how, within days over four hundred MP's were made aware of the campaign by an orchestrated logistics exercise involving letters, envelopes and stamps going from Northern Ireland to Frances Heywood, her sister and a small team of friends and within a while nearly every backbench MP had a personal letter and a leaflet on the campaign, crazy.

Politics however works at different levels. We tried to get the 26 councils in Northern Ireland to come out and back us. We got eight, four of whom invited us to make presentations. Also the body representing all the Councils in Northern Ireland came in behind us, so in the end we did not need the 26 individual councils.

I remember our little group of Family Information Members going along to our first council presentation – to Derry City Council.

Prior to the Council meeting, intense lobbying went on to try and make sure councillors understood the rights issue. When we got to council, it was encouraging and heart warming to hear the support from councillor after councillor from each of the parties present. By the time we left council we were assured of their support. This could not be believed by colleagues in England.

The support from the councils, the debates, the questioning – very much kept the issue alive and focused and was yet one more pressure on the government. This also kept us on our toes.

So we had the MP's and now a selection of councils. Alongside of this was our MLA's, not just from the Derry area, but all over Northern Ireland, some of whom were also MP's. Initially we targeted those who sat in the DSD Sub Committee at Stormont and also those who lived locally or had stood locally. Through contact with councillors and other politicians we got most our local MLA's in Derry on board as well as MPs from Derry representing other constituencies, Gregory Campbell and Martin McGuinness.

How did this happen? It didn't just happen, we had to try and make it happen with intense lobbying. At first we would send out some brief information on the campaign and ask politicians to lend their support. This would then be followed up by a phone call, to see if there was any response. If we got responses from one party member, usually we would inform other party members to see if this would encourage them to come on board. We were particularly keen to get party leaders on board, in the end we got all four of the main party leaders on board. This is how we did our lobbying.

Once we had our politicians on board, their job was to keep the issue alive. Many of them did this by

either written or verbal questions to ministers. Others asked specific questions on our behalf and we tried to vary these. Other politicians offered their support and this was our lifeline.

Certain individuals at local level, such as Mary Nelis and Mark Durkan pointed me in the right direction, encouraged me, showed me different angles of approaching the issue and gave the necessary advice and support when needed. This was followed up by support from their offices. Next there was the Early Day Motion, from Eddie McGrady's office. It was indeed Eddie's personal assistant, Theresa, who educated me about EDMs. I knew nothing about them.

There are very few areas of life that politics does not touch, but our whole campaign seemed as if it was going to sink to oblivion when the Assembly in NI was suspended. Just a few weeks prior to this I was in Stormont with Mary Nelis and Sue Ramsey building up our political influence, which now cruelly was pulled away. No assembly and a review that seemed at first to be a delaying tactic, our world was falling apart. Then one NI minister, simply followed by another, direct rule minister – John Spellar and even he seemed steeped in controversy, we thought we were getting nowhere

All this political activity did not happen in a vacuum and there were other significant events happening

which were to impact dramatically on the campaign. The assembly suspension was nevertheless a severe blow to the campaign and we were not even sure at that stage if the review, promised by Nigel Dodds would even go ahead and if it did what kind of authority the findings would have, with a direct rule minister. Confusion and frustration reigned.

In this section I have concentrated on the politics angle but politics also intervened a lot in the other events. Just before intense pressure was built up there was a dramatic development on a joint housing and Department of Health review (“The Fundamental Review” as it is often referred to) and later the review group initiated by Nigel Dodds came up with a major surprise, it is time to have a closer look at these two reviews.

Just before this, I feel it is worth reflecting on all this political activity in NI. There is no doubt that the initial thrust for this campaign came from England. But also the support and work going on in the background in both England and Wales gave NI the backdrop that it needed to help, eventually, Minister John Spellar to make the decision he did.

However the detail of the NI political activity is given to try and demystify politics, to bring it home to the reader, not to give an analysis of political activity in NI at that time. Most of us involved knew nothing of politics whether at council, Assembly or at

Westminster but we learned and we shared this with our friends in England and Wales.

What did we learn? The importance of information sharing and with email (and I was a very reluctant conscript to this form of communication) this was speeded up and accurate information was transferred quickly. This was a key role for all of us involved. Letter writing, particularly to politicians and ministers – the importance of this was acknowledged later by a senior NI civil servant.

Perseverance, commitment, mundane work as part of the bigger picture. Of course, it is no fun sticking hundreds of leaflets into envelopes, no fun at all except when you know that there is a small team is waiting for them somewhere in England. Then you know in a few weeks that maybe that EDM will attract more MPs to sign, and it had something to do with that leaflet. There is a strange sense of satisfaction in this. We learned this.

Also we knew not to take politics too seriously, not politicians or what they said about other issues. In NI we had the support of our politicians on this issue, their views on other issues were not relevant to this. We were focused and so were they. We valued our councillors' support as much as the support of a MLA, MP or indeed a MEP, they were all part of this jigsaw.

Some will look to NI as leading the way in the decision on abolition. It was more than this NI showed how information exchange worked in practice, it showed how information sharing really did empower, it showed that everyone could play a part in this, could contribute and it showed that hard work paid off.

For many, politics is a bad word. We seem to get caught up in our differences, whether they are religious or political. But sometimes something sweeps all this away. We have seen that with the death of Football Legend George Best and his burial in NI in a very dramatic way. In a smaller scale we saw it with the abolition issue. Cross party support was essential, we got it in NI but also in Wales and England. These are the lessons we learned in NI. Now the reviews.

REVIEWS

In December 2001 I finally got written confirmation from the Steering Group of the Joint Fundamental Review of the Housing Adaptation Services of one of its findings.

This Review Group, made up of staff from NI Housing Executive and Department of Health and Social Services & Public Safety had spent some time looking in depth at issues around adaptations both in the public and private sector and made a number of recommendations for improvements.

The appointment of a dedicated worker, for a limited period of time, to work across departments was very far sighted. Paraig O'Brien brought a wealth of experience to this position and worked enthusiastically and meticulously on all the issues coming through this review, which was one of the most comprehensive reviews ever taken on these specific issues in Northern Ireland. Paraig was working closely with Nuala McArdle (DHSSPS), the Community Occupational Therapy Managers Forum (NI) and colleagues from NI Housing Executive and DSD, some of which found their way on to the NI Review. Brid De Ornellas, David Bass, Kathleen Hicks, Sean Cassidy and Michael O'Carroll. There were others that I am not aware of but I know all of them worked hard – not on our issue, but on all the issues.

There were concerns over waiting time for adaptations, the scarcity of occupational therapists, heating problems, as well as generally trying to improve the service, how information was presented and how to get users more involved in the process. The Review Group invited submissions and of course we brought the concerns of Homes Fit For Children to the Review Group.

A letter arrived just before Christmas in 2001 with the words:

“Although we have no legal reason to pursue the issue on equality grounds, the Steering Group is recommending a change in Northern Ireland legislation to exempt adaptations for children from a means test”

I could not believe what I was reading. Here were those who worked most closely with this issue from health, social services and housing recommending exemption – surely this would now happen.

Despite what I said about my total doubt of change ever happening, for a brief few weeks I had some hope. I thought this recommendation would be put to the DSD Committee as the assembly, through our political lobbying all of the members of that committee would be aware of the issue and we had support from some of its members. Because of where the recommendation was coming from –

those with direct experience – I thought it would pass through the committee positively, be endorsed by the minister and then go on to the full assembly for ratification.

What seemed a high turned quickly to a low when instead, when another review was set up. At that time I thought this was a delaying tactic, I could not understand why we needed yet another review and although I was invited on to the Review Group, it took a lot of convincing from colleagues in the campaign before I finally decided to agree to sitting on the new Review Group. I believe we missed a golden opportunity but all was not lost, the Joint Fundamental Review Group's recommendation formed the basis of our Early Day Motion, through Eddie McGrady at Westminster.

After the lack of responses to the Fundamental Review Group's recommendation, I was not very confident going into the next Review Group. Although by this time the assembly was suspended, the review was allowed to continue. I set down strict guidelines around my entry into the Review Group and they were acknowledged.

I therefore, after some time, found myself on the Review Group that was looking into the means test in relation to parents of disabled children. If I am being honest I really thought this was a tokenistic exercise, to be seen to be doing something and I was very

apprehensive of being a part of all that but this is what I had signed up to.

The majority of the review group was made up of people, at a senior level from the NI Housing Executive and the Department of Social Development. However the group also included Paraig O'Brien, a researcher from Queens University, Brid De Ornellas an occupational therapy manager from Belfast, a representative from Disability Action and myself. The first meeting took place in Belfast on Monday 2nd March 2003, chaired by David Crothers, Director of Housing at the DSD.

As outlined earlier, at this early stage, only two voices – myself and that of the Disability Actions' representative indicated that abolition of the means test was the only option.

That first meeting was a frightening experience even though everyone around the table seemed to have a great respect for each other and David Crothers ensured that everyone had an opportunity both to speak and to be listened to. I was reassured that abolition was not being ruled out but privately I thought it would be very difficult to get it firmly on everyone else's agenda.

It was a very matter of fact meeting. There was clearly a problem with the existing process which was adversely affecting some parents. All the lobbying by

parents, by community and voluntary groups and all the pressure coming from our politicians in Northern Ireland was paying off.

In any campaign it is vital that people are not only aware of the issue, but also how that issue affects people. Those most affected know but often those outside the situation do not. This is why the lobbying of MP's may simply mean, someone going in and informing him/her of how the issue impacts them. Sometimes we can get so caught up in situations that we think lobbying is all about letter writing, street protest, "going public" but it could be as simple as walking into a politicians office and telling the story.

It is not unique to this campaign, but those most affected knew the issue inside out, the issue that affected their daily lives. They lived with the impact and they felt the injustice of the process. Whatever else goes on, the crux of campaigning for me is that those most involved should know the issue. In most cases they do and by linking with others they can obtain the additional information that is often needed.

For me at this first meeting the important factors were once again that abolition of the means test was not being ruled out and that there was a recognition that the current process did cause problems for at least some families.

For some time the Homes Fit For Children campaign had claimed that the cost of actually abolishing the means test would not be excessive. The Family Fund, who are very supportive of the campaign, had made rough estimates of this cost in the past but were never listened to. In addition when the savings of administering the Test of Resources process and all the bureaucracy involved in it are taken into consideration then the overall cost would be diminished further.

Unfortunately it proved impossible to actually calculate the real costs as comparable figures just were not available. Rev. Martin Smyth had asked questions about this at Westminster and we had asked similar questions of NIHE. There was some general information available.

Information on costings were needed to enable the Minister to make some kind of decision. Paraig O'Brien along with David Bass, (NIHE and part of the Review Group) were asked by David Crothers to pull a team together including Sean Cassidy and Kathleen Hicks (both of NIHE and in the Review Group) to carry out a sample research in Derry and Belfast grants offices. This was to be a critical exercise. The fact that my home town of Derry was to play a vital role in this research project was important to me, and I had a lot of faith in our local NIHE Grants Department as we had worked closely with the Derry office on several occasions. I was confident that if

accurate information could be found that the original findings of the Family Fund previously, would prove to be very similar in Northern Ireland.

When you look at this, clearly it can be seen in any campaign situation evidence and information are very crucial elements. If this can be gathered in advance, it can be more useful – in this situation we had no choice. So we have the issue itself, the impact of that issue and now the evidence that shows how that issue affects others. It would be important too if further information relating to the issue could also be gathered. Most of these factors can be addressed by anyone with an interest in the subject, it does not require specialist training or guidance. Again we have to remember that the strengths of many campaigns is that the issues are actually felt by those involved.

At the end of that first meeting in Belfast I wasn't sure whether I was coming or going. Even if all the evidence proved to be positive towards change, the fact was that the Minister still had to make the decision, we could only make a recommendation. I know many occupational therapists and the staff at the NIHE grants offices in Derry and Belfast worked very hard to get accurate information, I knew the team of researchers were dedicated to the task of collecting objective information, but what I was not sure of, what I did not know was what would happen after all this information was brought forward. Two

voices calling for abolition, to me, did not seem to be enough. We had an impossible hill to climb

Weeks passed, our campaigning in Northern Ireland, England and Wales continued. Letters still kept flying back and forward, questions asked but only standard answers given. Those of us involved in the campaign had to keep encouraging each other but this was difficult, nothing seemed to be happening. Months passed.

Just before the summer of 2003, a meeting (the second and final one) was called for Tuesday 1st July. This was it. I did not know what would happen but I had few expectations that we could have a positive outcome. Despite being in the holiday period, all but one of the Review Group turned up. As the meeting began David Crothers summarised the evidence coming from the sample researching. As expected, the cost of implementing abolition was very small, even when allowances were made for additional circumstances. The possibility of abolition was mentioned but I could not believe my ears. I asked David could he repeat what he was saying.

A debate followed, it seemed to me a very legalistic debate. Fortunately we already had addressed the equality issue (and the Equality Commission was excellent with providing information on this which were concerns around section 75 in Northern Ireland. Now we were at the crux. Again I asked for

clarification. David Crothers again said that the main recommendation on the table was the abolition of the means test for parents of disabled children. He went around the room, not one voice, not two voices, no a unanimous vote and endorsement of the main recommendation – abolition of the means test.

I wanted out of that room, in case anyone changed their mind. I could not believe it. Of course I still knew that the Minister – a British Minister (John Spellar), not a local Northern Ireland one had to respond and that was another obstacle. But for now I phoned home, phoned Frances and just tried to take all this in – from two voices to a unanimous endorsement and this all happened over two meetings.

No one can under-estimate the importance of the work carried out by Paraig O'Brien, David Bass, Kathleen Hicks, Sean Cassidy and the staff at the Grants Offices throughout NI including Derry and Belfast. Nor can anyone deny the skills of chairing that David Crothers brought to this very difficult review and his own confidence in dealing with the issue. The other members of this Group contributed positively to a process that was inclusive and no matter what the outcome would have been, I believe every member felt that they were involved and had something valuable to say.

Of course our core value: the right of every child to an accessible home was possibly of no significance but

that was our value and it is important but also what was important that if this recommendation was acted upon, then it would result in more children having accessible homes.

The realisation that there was a problem, where previously people may not have been aware of this, the very very strong political and community lobby for change and then the low cost estimate for change all helped change the two voices into one unanimous voice. We had to wait on the official recommendation and the news of it going to the Minister. This was not allowed to be in the public domain. Weeks passed, months passed, frustration set in.

CATCHING OUR BREATH

We had reached a critical point in the campaign. I received a copy of the Review Group's recommendations, including the main priority one – believe it or not – the abolition of the means test for parents of disabled children was the main recommendation.

I still had not been sure that by the time the recommendation reached the printed paper that it would still be a priority. It was.

As this is a personal view, from Northern Ireland, the emphasis has been on what was happening here. However, as pointed out earlier, pressure, lobbying and awareness raising was continuing in England and Wales. At times it may not have seemed as intense or concentrated, but it was happening and it needed to happen to ensure that the climate was as positive as possible for a decision to be made in Northern Ireland.

In England and Wales the lobbying of MP's continued, with parents encouraged to bring their issue to their own MP. Although this is a slow process, the number of MP's interested in the issue was growing. Key members of the Homes Fit For Children Campaign were involved at different levels in general reviews on housing issues, meeting and discussing the issues with senior civil servants, and

of course evidence of the impact of the current process was being gathered and followed up on. This, on the ground, detailed work – which never hit the headlines – was the life blood that has kept the campaign going in England and Wales.

Frances, Ginnie and Keith, supported by a growing number of volunteers and community groups, by parents such as Jackie, and by those who had shown an interest in the campaign.

It has to be remembered that leading in Northern Ireland was part of the overall plan, a plan that of course included England and Wales. As the weeks turned to months once again, the information was that John Spellar(MP) was consulting with his colleagues in England, Scotland and Wales. Of course this did not mean that his colleagues would approve of the recommendation but at least they now were aware of it.

This consultation was frustrating and delayed a response from John Spellar, but now in hindsight it means that all the regions were involved, in some way, in the decision and at least it is on the agenda more so than it would have been in other circumstances.

Although we tried to catch our breath during the time of waiting, the delay in the response from the Minister thrust us all again to step up the campaign. Again

MP's and MLA's were asked to write to John Spellar, simply to ask him what the recommendation was from the Review Group and what was his response to this. Letters were landing on his desk from all over. where our political pressure was brought to bear and these in turn were landing on David Crothers desk. We really needed the recommendation out in the public domain but just could not do it and we definitely did not want to leak it to the press – there was too much respect for the Review Group members. It was a very, very frustrating time but we were used to this by now, but it wasn't any easier to deal with.

Our MLA's and MP's in Northern Ireland were very tolerant of us and very supportive during this period when standard letters were emerging from John Spellar's office in replies on a regular basis simply stating that John Spellar was working on the Review Group's recommendations.

As we move towards the conclusion of this story, let's catch our breath again and have a quick look over the recent years. Between the two reviews, we brought out a publication "From Issues To Politics" at a launch in Derry at the end of June 2002. At a launch attended by Frances Heywood (her second visit to Derry) and hosted by Deputy Mayor – Mary Hamilton, we again put the issue firmly on the agenda.

A local parent, speaking for the first time, stole the show as she explained her anger at leaving her home

(which she did not want to do) to build a new home as this was more affordable than having to make the contribution towards the Disability Facilities Grant. This parent, who for reasons of confidentiality, we cannot name had a powerful influence on the campaign, more so than she will ever know, ably supported by her husband.

At the launch Clionagh Boyle of Derry Children's Commission challenged my pessimism about the action of the campaign. Even at that stage I had no real hopes that we would succeed. I replied I was being realistic. Derry Children's Commission was an inspiration to us, always there, offering support and help and yet still challenging. Along with organisations such as Contact A Family and Carers NI as well as the multitude of other groups, from a variety of backgrounds, were now making their influence tell us they wrote to ministers. Helen Ferguson of Carers NI and Nuala Norris with Fildelma of Contact A Family publicised the campaign, advised on difficult situations and continued to support our activities. We very much appreciated their valued support.

In the background we also had the Joseph Rowntree Foundation, the jigsaw was nearing completion. At an event in London, during this time, I was very critical of Rowntree for sitting on the fence on this issue, of researching but then not acting, I began to realise that they had their boundaries.

Over sausages and mash in a London pub, the year previous Alison Jarvis (Joseph Rowntree Foundation) and I discussed the possibility of a housing conference in Northern Ireland, probably in Belfast. It is a long story but eventually we agreed on a regional conference in Derry for December 2003 – “Where Do The Children Live?” Alison and her research colleagues – Bryony Beresford would attend.

THE ANNOUNCEMENT

The organising of the conference was, as they say, doing my head in. This was a Joseph Rowntree Foundation funded conference, and unlike all the other conferences we ran, I felt that we had to have everything totally perfect. As I insisted I could run a regional conference in Derry, rather than in Belfast, this was another headache.

As I wanted David Crothers (Director of Housing at the DSD) to speak, I felt we needed to keep issues around the housing campaign out of the agenda and also we wanted to attract a wide audience.

It was hectic, on the day I picked Alison and Bryony up at a hotel, went to Radio Foyle for an interview and then on to the City Hotel for the conference itself, our Group members had everything ready at the hotel as the audience numbers between seventy or eighty began arriving. By this stage John Spellar's decision was more or less forgotten, although I had written to him (as I always did when we had events) to say wouldn't this be an opportune moment to make a decision – fat chance!

I was helping out at reception when Paraig, who was one of the speakers, came out and said David Crothers wants you in the room when he speaks, by this time the Mayor, Shaun Gallagher had already left as had the two newspapers. At this point I said I was

busy. A few minutes later Paraig came out again to say it was important that I was in the room, reluctantly I went in and sat down.

I had only sat down when I heard David Crothers mention me by name. This was a bit unusual for a senior civil servant and I always believed that David was a straight talker but to personalise my involvement in housing issues and then to mention the Homes Fit For Children Campaign – incredible! I couldn't figure out what was going on, I had spent a lot of time and effort trying to keep the issue out of this day, which was to look generally at housing issues for disabled children and their families.

As if this was not enough, he refereed to me as a 'pain in the backside' because of my letter writing campaign to MP's, MLA's and other politicians. Then I found out what it was about, he said to acknowledge this, he had a certificate for me. So I thought I was to get a 'Pain in the Backside' certificate. I was invited on to the stage.

We opened the beautiful framed certificate. David asked me to read the first few lines. I glanced over the words, my eyes filled up and in total shock I stood there. I stood there in front of seventy or eighty people, unable to speak. This was not a 'pain in the backside certificate' as I had thought. Instead it was a press release, embargoed until 10.30am (to coincide with the start of our conference) from John

Spellar announcing the abolition of the means test on parents of disabled children from early 2004 in Northern Ireland. Incredible news, sensitively delivered. Speechless I walked off the stage, out to my wife in reception, shared the news and was fit for nothing the rest of the day, nor fit up to two weeks later. We all had done the impossible, what we were told we couldn't do, we did.

The applause faded, the congratulations offered, I got through the day, I got through the weeks. The limited press coverage was by now exhausted, yet the significance had not sunk in, not really. Our colleagues in England could not believe it. I could not believe it, months on from the last review group meeting, in a political climate where we had no assembly, a political decision was made. England and Wales had to follow.

All the extremely hard work of the politicians paid off, as did the work of the parents, the voluntary and community groups, the researchers, campaigners, occupational therapists, NIHE staff and everyone involved. Groups like Contact a Family, the Family Fund, Disability Action, Carers Northern Ireland and so many more, sticking with us. It was a victory for common sense, a victory for "partnership". The last piece had been put into the jigsaw. We hadn't compromised, we didn't lose focus. We persevered, committed to change and change we did.

Radio Foyle (Susan Mc Reynolds) and the Derry Journal were very encouraging and covered the story, Belfast Telegraph had John Spellar's press statement and later the Newsletter gave it coverage. At the conference one parent came up to me and said (it is to late for us, but it is not to late for others". It is not. The impossible did take a little longer but it was achieved. Whether it is housing, or any other issue, our story will hopefully show that you can attain the impossible when you work closely with others. We knew we were right, we just had to convince others and we did. Thank you to **everyone** who gave support, it was a hard battle but now we have an end. Nothing is impossible.

THE FALL OUT

Immediately after the announcement of abolition in Northern Ireland (December 2003), preparations were put in place to ensure that information on this got out in time for the actual date of abolition – 16 February 2004. At this time, besides the press release, there seemed to be no other publicity around abolition. For the third time, we produced a leaflet and followed this up with phone calls and press releases. At one photo call in Derry's Guildhall, campaigners stood alongside N.I. Housing Executive staff to announce abolition – a tangible sign of partnership working.

However if some people expected that the fall out would be that England and Wales would immediately follow the example of N.I., no one within the campaign had these expectations. We knew it was going to be hard work in Wales and even harder work in England, where traditional mindsets just did not seem to be moving on. Although delighted with the decision in Northern Ireland, we all knew we had some unfinished business in England and Wales.

Although this campaign started in England and virtually all of the preparation work took place there, the decision to lead up in Northern Ireland which resulted in abolition there, had other repercussions. As a result of the N I decision, major housing reviews were initiated both in England and Wales.

These reviews different from the review of the means test in NI in that they were more comprehensive in nature. Also the process differed between England and Wales, England set up a review group, the Welsh Review was led by a senior civil servant. We took stock.

TAKING STOCK

One of the strengths of the Homes Fit for Children campaign was the ability to act on your own initiative but at the same time work in a co-ordinated way as part of a team. Also the campaign was always dependent on contacts doing the work. It would have been impossible for the small group of key individuals to do all the work. Over and over again our network of contacts walked the extra mile. Furthermore. As stated before, Northern Ireland did not happen on its own, the support from England and Wales, including the political support through Early Day Motions, were crucial in putting pressure on Northern Ireland.

We revisited Northern Ireland, to try and figure out what worked well there. Immediately we realised that we needed more support from parents of disabled children, occupational therapists, and more involvement from the community/voluntary sector as well as individuals from the statutory sector. In addition to this we knew we needed to bring back some of the larger voluntary groups into the heart of the campaign. Evidence was also a key area that needed to be explored more, and if possible down the line, evidence of the positive impact in Northern Ireland.

Paraig O'Brien, chair of one of the most influential (in housing) specialist sections in occupational therapy COTSSIH, continued the process of gathering evidence from parents and he encouraged other

occupational therapists e.g. NAPOT to do the same. Paraig had been one of the key figures in the Northern Ireland Housing Review Group and his professional expertise and understanding are beyond question.

Although in the early stages many professional bodies did not connect themselves to abolition, their evidence gathering, proactive awareness rallying, advocacy role and commitment to quality of life became a strong influence towards change.

Although Paraig took a very professional approach to this issue he always remained sensitive and conscientious, he never lost this throughout. As chair of COTSSIH (College of Occupational Therapists Special Section in Housing) he was meticulous in engaging other occupational therapists in this process.

To put it another way, the evidence had to show what was actually happening. It was very much a “bottom up approach”. But that was not all.

Just as parents were learning that change would not be possible without political influence, a serious debate was now going on within the occupational therapy field on the same theme. This was not party political manoeuvring, rather it was the interpretation of politics as a force for change, crossing party political lines, often called politics with a small “p” but the “p” can also be quite powerful.

Therefore it was not enough that occupational therapists throughout England and Wales were gathering evidence of the impact of Disabled Facilities Grants on parents of disabled children.

It was not even enough that they were identifying and recording unmet need. Their concerns over parents not going into the DFG process, pulling out of the process, going into debt because of the process and particularly the means test, those concerns were not enough.

Occupational therapists had to influence the Review in England and Wales in a very positive and concentrated way. In England they secured a place for an occupational therapist on the Review Group this was shared by Kate Sheehan and Julia Skelton, both of whom regularly fed into this review. Pieces of the jigsaw were fitting together.

THE JIGSAW

Experience in Northern Ireland had shown, that no one element, no one group or organisation on its own, could change the regulations around this policy of means testing. It was often repeated, and it is true, that those playing the smallest part, those coming on board at the later stages had as much to offer as those in for the long haul, as well as those perceived to be doing too much.

One of the strengths of this campaign was that it was able to accommodate this, able to be inclusive of those who came and went, of those who appeared to come on board late as well as those who just wanted a background role or could only do a little. They all made up the jigsaw, they were all vital pieces that made up the full picture, if any piece had been missing, there would be no full picture.

However although the campaign was being co-ordinated by the key contacts, those linked to the campaign often “did their own thing”, as long as it was within the ethos of the campaign and sensitive to families. Others associated with the campaign often linked with us, shared information but as individual organisations and/or groups pursued the issue with their own agenda.

This is why the campaign did not get directly involved with the coalition that emerged in England after

abolition in NI. Each allowed the other space to go forward on the issue while still co operating and sharing experiences. Also Homes Fit For Children campaign was pursuing a total abolitionist policy, we had no room for compromise, we were aware that other groups might want to compromise at some stage. It was a totally professional and amicable approach.

We can now see the picture emerging in what was going to be a very tough battle. It was following the game plan of Northern Ireland but on a much larger scale. Let us look at this again, before we move forward.

Parents of disabled children knew the need, they felt the impact of this means test on their daily lives, and they knew that they, their disabled children and siblings were missing out on a quality of life, not just that they deserved but had a right to a safe accessible home.

Occupational therapists were aware that there was a problem, they were not sure of its extent or indeed the full impact of the DFG means test. They were gathering evidence, beginning to advocate on behalf of and with parents and help support parents.

The resource issue linked to the DFG, the exclusion (because of the means test) of families who had been assessed as needing adaptations was actually

undermining the profession and individual occupational therapists. It was creating tension and frustrations within the profession. But the promotion of the advocacy role of occupational therapists, and the engagement of the profession in the English and Welsh Review process, as it had been involved in Northern Ireland were at least positive signs of progress.

In the voluntary/community sectors, there was a drive to engage more groups, and in a more meaningful way some of those groups who in previous times had shown no interest but through time, and also it must be said through lack of information and updates from us, were not now engaged. We always knew we needed the resources but more importantly the expertise of these groups, particularly in the political field, if this was going to work.

Caroline Gordon, Policy Officer of Mencap responded and emerged as another key figure. Through her commitment and energy a consortium of characters were brought together, led up by Caroline and Mencap. As pointed out earlier, the campaign worked closely with organisations but did not become part of consortiums for the reasons outlined, and also we worked individually with some groups within this consortium with which we had built strong ties.

Some may find this strange but in essence it meant that we were not interfering with each other. The consortium did not need to pass things through us to

proceed, and vice versa. But there was a strong positive working relationship and we recognise fully the impact that both Caroline and the consortium members made, progress would probably not have been possible without them. They had contacts, networks, websites, political clout, expertise in lobbying, families, publicity and they used all of this to the full.

Caroline did a lot of work on the Early Day Motions and in securing cross party support for these. Just as the campaign was concluding Caroline moved on, but by that stage both she and the consortium had had their influences, they were a major part in the jigsaw. Caroline was the first person to phone me after the announcement in the House of Lords, although I never met her, her influence is written all over this campaign in its later days.

Of course where the consortium and other organisations came to the fore was in their political expertise and lobbying, other vital parts of the jigsaw. In Northern Ireland we had visibly seen the power of politics work through councils, the Assembly (before it fell) and at Westminster. To have all eighteen NI MP's at Westminster, supporting abolition – not just in NI, but also in Wales and England, at one stage was phenomenal. This had as much to do with the politicians on the ground as the campaign itself. But for NI to work it took all the elements, including the Westminster one, particularly as the Assembly had shut down during the campaigning.

WALES

This is where Keith Bowen in Wales came to the fore in that country. Keith knew the Welsh Assembly well, he had contacts and was well respected. Contact A Family, for whom he works, have a positive reputation wherever you go for supporting families.

Keith, his colleagues in Contact A Family and other organisations in Wales such as SNAP, diligently went about their business, collecting evidence, advocating with families, engaging politicians, publicising the issue, researching its impact, engaging others right across the board, feeding into and influencing the Welsh Review, all to bring this issue to the fore. At the same time, as in NI, Keith was ensuring that in the Welsh Assembly there was recognition of support for abolition at Westminster and he was very involved in lobbying on this.

The lead civil servant and his team in Wales consulted widely, and Keith regularly kept in touch. The team also visited Northern Ireland to gauge what impact abolition had there.

Although a Review, not a Review Group, there seemed to be an openness in the Welsh Review, which really tried to gauge the broader picture. The civil servants involved must be congratulated for going out of their way, not just to engage parents through Contact A Family and other groups but many other stakeholders too.

When earlier in the year it was announced in the Welsh Assembly that the means test would be abolished in Wales, later in the year, there was shock but a great sigh of relief. Yet another piece of the jigsaw was in place, when on 30 September 2005 the means test in Wales was abolished as had been promised earlier in the year.

Keith has looked back over those years of work on this issue, and in his own words highlighted what he has seen as being the key actions during the campaign in Wales:

1. Giving evidence to the Health and Social Services Committee Review of Services for Children with Special health Needs
2. Informal meetings with the Health and Social Services Committee and Housing committee
3. Ongoing meetings with the Minister Edwina Hart
4. Developing links with the key civil servants
5. Developing links with Assembly Members from all parties
6. Taking part in the DFG bench marking process
7. Taking part in the Welsh Assembly Group for DFG Review

We now had Wales and Northern Ireland. But things were not looking positive when feed back was indicating very strongly that the government, particularly the Office of the Deputy Prime Minister in England was not simply going to follow the example of Wales. It was as if we were just starting over, all over again in England. It was very frustrating, but in reality we were not starting over as much work had already been done, the political spin did not work.

PIECES IN PLACE

But before we go there, an important element missing in this summary of the jigsaw – the parents' role and their engagement with others. Joseph Rowntree Foundation (JRF) in co-operation with the campaign supported a project, which helped parents find their voice – in Wales and England. What follows is a summary of that unique project which happened in the Spring of 2004. and which engaged all the key contacts in the campaign. The project shows the commitment and innovative approach of the Joseph Rowntree Foundation in relation to this particular issue.

What is surprising about this campaign is that a number of organisations did stick with it for the full duration. JRF was one of them. From the early days in helping sponsor activities, particularly the parents involvement in meetings. The comprehensive support given to research into housing and issues affecting families of disabled children.

At one time I was critical of JRF for what I perceived was their stopping short of going so far with research and then not pursuing this in a political way. In hindsight it is now easy to see that the thrust of JRF ensured that in a political sense this issue would get on the agenda, but in a subtler and perhaps meaningful way than just by direct campaigning.

As they supported parents, research, fact finding evidence for families in England, conferences (including the one in Derry where the announcement of abolition was made) and the specific engagement of parents in England and Wales already mentioned, they were able significantly to influence policy without ever having to directly be involved in politics. In another sense everything they did seemed political, but not party political, the pieces were being put in place.

Cascading seems to be the best word to describe what was now happening, after the NI and Welsh decisions, it was not as if each time we were starting over as so much work was going on in parallel. Rather each time we were starting from a different point, and each time this point was further on, no matter what spin was being fed to us.

The complexity of the networks built up ensured this and although at the highest level politically, information could be feedback that the decisions in NI and Wales did not affect England, in reality internal discussions had always gone on before these decisions. Ministers and departments were made aware of these in advance and whether they had to endorse them, we don't know, but they at least had to be knowledgeable about them and their implications.

Therefore the cascading of all this information continued, on ministers, government departments,

the voluntary and community sector, on professionals working with families – particularly occupational therapists, on parents, on researchers and sometimes on the media.

Although it took some time to impact those with direct responsibility for this issue in government, slowly, subtly things began to move and traditional mindsets – even in the voluntary as well as the statutory sector, began to move and shift. Although complex arguments were at times put forward as to why abolition could not happen in England, we had heard and refuted all the arguments before, we did this again.

For us a fundamental truth was emerging (and this was greatly influenced by the ethos of the work of HoDis over the years) and this was the right of every child to have a safe accessible home.

Families in NI and Wales were no different to families in England, so it followed that England would have to follow the example of NI and Wales.

We believed, rightly so, that parents in England would become very angry if this did not happen, and they were becoming angry already. Although support for abolition was growing, what was also growing was the depth of that support.

Parents were getting information, were finding a voice individually and as part of groups, they were

going to their MP's and asking for support, many of their MP's were responding by signing Early Days Motions and/or asking specific questions.

JRF were there with a very strong support mechanism as policy into practice and vice versa were being played out in the real stage of life.

Occupational therapists were coming to the fore in advocating, influencing and gathering evidence.

Researchers again were articulating in their own way, findings for their investigations in a variety of platforms.

But also the community and voluntary sectors were both working together and independently on this issue, as they never had been before. The jigsaw was taking shape, even some of the most difficult pieces were beginning to fit in. Some of us even glimpsed what the whole picture might be.

But would politics respond?

ENGLAND

The real question was, did all this activity, all this work all this energy, did it matter, could it matter, could it impact decision-makers? Of course we had together changed things in Northern Ireland and Wales, but could this be done in England too, we did not know, and certainly we did not realise it would take almost two years after the NI announcement to make it happen. Of course we tried and tested all the methods, already rehearsed elsewhere but we were just not sure.

England was bigger, naturally, and this meant of course that more resources would be needed if abolition was to happen there. But also in England, or at least in certain parts of it – primarily in the mindset of those who had a responsibility for this issue in government, was that the means test was directly linked with the ‘ability to pay’ and was an ideal method of meeting those who were most ‘vulnerable’ and ‘in need’.

Need was being defined in economic terms not social terms and vulnerability seemed to be linked to weakness not social circumstances.

This was the perception and we kept trying to refute this, at all levels, arguing that it was a professional occupational therapist that was identifying the actual need while it was the means test that was often

preventing the need being met. We believed and still believe that this was a very profound argument.

But of course there was the resource issue. In England this kept playing and replaying until it became nauseating. No one seemed to have figures or able to estimate figures of how much the change could cost. In the end research commissioned by the Government (Bristol University) came up with a figure but whatever is the actual figure, it is a small investment in families who already invest so much.

However what needed to be said and was said, was that unless the issues affecting disabled children were prioritised, then we would have no hope of getting this through in England. Unless the government invested in families, saw the bigger picture, supported families who already were supporting themselves, already investing in themselves (and saving the government millions in community social care bills, if they had to rely on local authorities for this care), unless this happened, there was no point.

As in NI and as in Wales, we had to ask could politics work? Could we bring practice, the reality of the families' living situation, into policy, and influence positively the policy makers. The real questions remain unanswered.

We looked in anticipation at the Early Day Motions, motions which we subtly saw as petitions of support

from MP's but which would highlight the issue politically and put pressure on government. Eddie McGrady (MP) for NI lead the first one, Roger Berry the second and with support from Caroline and the coalition two further Early Day Motions appeared, led by Roger Berry. Four EDMs were placed over the period of the campaign (each one lasts just one parliamentary session), with the last EDM 160 attracting the most signatures to date – 160 as I write. Politics was working.

DEVASTATION

In one sense the setting up of the English Review Housing Group, to oversee the issues arising from housing, including the DFG means test in relation to parents was a very positive move. Chaired by Senior Civil Servant, Jeff Hollingworth, it brought together many experts in this field, and with a little pressure from the occupational therapy profession, this included an occupational therapist.

Later the leading government department, Office of the Deputy Prime Minister commissioned research to look in depth at some of these issues, not just the means test. It was anticipated that the findings from this research would greatly influence government thinking on these issues. The research was a major piece of work and the role of the Review Group was going to be very significant. But I soon became devastated.

So why devastation? This was a personal feeling. As the names of those chosen to participate in the Review Group emerged, increasingly I became frustrated and isolated.

Although very happy that what I considered “experts” were being chosen as part of this group, if I had been cynical or paranoid I would have wondered why all the key players in our campaign were being picked, knowing that the remit of the Group would at least put some restrictions on their activities in the campaign.

One by one, the English Review Group plucked our activists, supporters and sympathisers. Ginnie Shaw (HoDis), Alison Jarvis (Joseph Rowntree Foundation), Jackie Hughes (parent) and later Frances Heywood (to lead research team from Bristol University). Only Keith in Wales left and myself, our campaign key team from Homes Fit For Children seemed completely depleted, I was devastated.

On the other hand I was pleased with so many people with a knowledge of the campaign and of housing issues were advising government through this Review Group. Also if anyone should have been picked for the research, and to lead it up, it would have to be Frances. But Frances had to leave behind her campaigning first and foremost she is a researcher, a social researcher who is good at her job.

Her research for government could not be flawed, and any recommendations had to be based on evidence not her own feelings and philosophy. It must have been a very difficult job for her to lead this up and by necessity my communication with all my colleagues, who were now on the Review Group would be limited.

Just when I thought my main task was over, as I prepared to maybe even put my feet up after abolition in NI, I again was thrust into a new role, a role particularly in England where I knew that we would need more support.

During the course of its activities, on behalf of Homes Fit For Children I presented an interim summary report to DFES and a more comprehensive report to the actual Review Group. In addition to this I provided a summary report to Joseph Rowntree Foundation. Extracts from these documents is contained in the Background Section. The English Review Group could collate its evidence through its own Review Group, we were collating ours from families in England with the support of JRF while occupational therapists were gathering their own evidence.

I got over my own devastation and worked this through by throwing myself into the JRF project of collating evidence from families in England impacted by the DFG means test. Although this may be seen as evidence gathering rather than research, it was proving to be quite disturbing. I was fully engaged before I knew it.

Contacts already made in the JRF Parent Participation Project, and further follow up with the Parent Project UK and Duchenne Family Support Group were critical to this exercise. They all helped to gather evidence.

With the information being gathered by the English Housing Review Group, the continued researching carried out by occupational therapists and indeed information carrying from the voluntary/community bodies and charities, there could no longer be an argument for government that they did not know what

was happening, and how families were affected. Alongside all this, parents and MPs were engaged.

Evidence became the key and the focus. Voluntary and community groups were encouraged to identify parents affected, to signpost them in the direction of their MP. Individual parents were also directed in this way. MPs, through a targeted leaflet campaign, were informed of the issues and encouraged to sign the latest EDM by the Campaign.

Parents as well as the voluntary and community groups and of course a growing number of occupational therapists were kept informed, information was flying back and forward, press releases, statements, updates, statistical data, media coverage all helped in this. The process was repeated over and over again and was supplemented by some MPs asking questions in Parliament.

During the year 2005, it became clear that others and we were impacting government, with the Welsh decision on abolition, really putting the issue on the agenda in England. NI could be ignored, I am sure many thought, but not Wales too. The English Review Group was beginning to wind up, and the Bristol research was coming to their own conclusions. It was soon coming to showdown and many of us were exhausted, frustrated and very apprehensive.

THE WAITING

It is like being at an airport and waiting for a delayed aeroplane to take off. What seem to be hours, is only minutes and as each expected time of departure passes, frustrations, anger and powerlessness sinks in. It is as if it will never take off and as if everything is totally spoiled, everything is exaggerated until the actual departure and then it seems it doesn't matter anymore, you are on your way. Waiting, waiting, waiting.

By the summer of 2005, everything was in place in England and we expected maybe some indication of what was going to happen before the summer recess. The charity consortium had fulfilled its role in raising the issue, as Caroline Gordon of Mencap (who helped lead up the consortium) moved on.

The EDM 160 had been well supported (and just after the summer reached the highest total of any of our EDM's at 158 signatures, later to rise to 160) and many individual parents, support groups and other organisations had done all they could, and were now waiting. Individual politicians put on increased pressure to try and find out what was happening, just as had happened in NI and Wales. We waited.

We waited further when information came out that there would be some further debates in the autumn. During the summer we waited as parents got more

and more frustrated. For some of us, any hope we had, was beginning to fade. It seemed that the delays were giving the impression that there was not going to be a clear-cut response.

Some information began to filter out, that there would be a consultation document and no one was sure if the means test would be consulted on further, causing even more delays. It was becoming increasingly messy.

Then indication that perhaps there had to be reviews of administration and even if abolition was considered, perhaps the whole area of resources would have to be looked at. Waiting, I had reached a point where I just felt that this was not going to work in England.

The summer came and went. MP's returned to Parliament. Indications were that there would be a statement from Baroness Andrews of the Office of the Deputy Prime Minister later in the autumn and the publication of a consultation report.

Nobody seemed to know the order of things. Then more concrete information – a statement due at 11.00 am by Baroness Andrews on Thursday 27 October 2005, in response to a question from Baroness Wilkins in the House of Lords. Waiting over.

It is 12.08 on Thursday 27 October 2005 at the House of Lords.

We now know what happened next. The impossible became the possible and eight years of hard work paid off. Real partnership working had worked, politics had responded and disabled children and their parents were listened to.

I heard the names in the House of Lords, Ginnie Shaw, Caroline Gordon, Brendan Mc Keever and all those who campaigned on this. I was shocked and surprised and embarrassed. It was so unreal.

Memories flooded back: London, Birmingham, Cardiff, Durham, Belfast, Derry and a special memory of Huddersfield. In Huddersfield, after a presentation on the issue, two parents approached me almost in tears. They blurted out that parents seldom achieved anything (referring to abolition in NI). It is 12:08 in the Lords, parents did achieve something, we all did, and nothing will ever be the same again.

Big Ben strikes 12:30, it is over!

It is a story, just a story. But it is a story that needs to be told. For all those who don't dare to believe that things could change, this is for you. For those caught up in jobs that have become meaningless because the pressures of life have got to you, this story is for you. For researchers who feel their findings are ignored, read these lines. For those who battle against other groups and organisations for funding and recognition, this is for you. For politicians

constantly under attack, criticised and abused, this one is for you.

When all is said and done, we did it! Together we pulled down the barriers and opened the doors to a better quality of life. It is a real story, born out of the pain, frustration and anger of individual families. It is your story, it is my story. The impossible was made possible, by people like you and me. Maybe there is some justice.

Background Information

OPINIONS

Opinion: Debate: Should the Disabled Facilities Grant be means tested? 01 March 2005 (Extract from “Children Now”)

No – Jan Morrison, Principal Policy Officer, Barnardo’s.

“Families bringing up a disabled child are far more likely to be living in poverty due to the financial constraints involved and so most find it hard to meet the cost of essential housing adaptations, which can run to thousands of pounds. Currently, the means test formula is unfair in that it does not take mortgage repayments into account, it does not accurately calculate the additional costs of bringing up a disabled child, and it penalises those parents who are in work.”

No – Ruth Owen, Chief Executive, Whizz-Kidz

“Independence is one of the biggest issues for disabled people and having a home that is fully accessible is essential. For families applying for a grant, is it really fair to have to go through such an intrusive, stressful and often time-consuming process that does not fully consider their individual families’ outgoings? Even where families do have a high income they face considerable expenses, such as the cost of specialised equipment, so means testing cannot give an accurate picture of the financial constraints.”

No – Philippa Russell, Disability Rights Commissioner and parent of a disabled son

“The test frequently fails to accurately assess the family’s real ability to contribute towards vital housing adaptations. For example, mortgage repayments are not taken into account. Also, one third of families who have to make a contribution towards the cost of adaptations are unable to meet the cost. There are anxieties about the cost of removing the means test. But the criteria for a grant are such that we are looking at a clearly defined and small group of disabled children.”

No – Jo Williams, Chief Executive, Mencap

“The existing grant process is failing even the worst-off families, who are left trying to find huge sums of money to allow their child to stay in the family home. In our submission to the Government’s review group we made a strong case for why the means test for the Disabled Facilities Grant should be abolished. A Prime Minister’s Strategy Unit report recently highlighted the need for urgent and radical reform of the grant and we hope this will happen as a matter of urgency.”

OPINIONS FROM OTHER SOURCES

Christina Biggs, Chair for the Duchenne Family Support Group

“The Duchenne Family Support Group sees the means test as being unfair and unacceptable obstacle to the provision of accessible accommodation for disabled children. We urge all MPs and especially government ministers to act swiftly in the overhaul of the legislation which at present serves as an additional burden for disabled children and their families.”

Paul Fitzpatrick, Chair of Parent Project UK

“Parents and friends of Duchenne Muscular Dystrophy children realise only too well the pressures and choices that have to be made because of this awful but aptly named “means test”. Children throughout the UK are living in poor quality housing because parents are having to make choices that affect the quality of life, of not only the disabled child, but all members of the family, through financial hardship or not being able to carry out adaptations. Parent Project UK and our members fully support the campaign to remove the DFG means test.”

Jill Harrison, Contact a Family

“Each year, Contact a Family receives substantial numbers of enquiries from families who find that they cannot afford to pay their assessed contribution to necessary work. We are in no doubt that the means test causes significant hardships for these families.”

Talya Hilburn, Family Support Worker, Rett Syndrome Association UK

“In my role as Family Support Worker for the Rett Syndrome Association UK, I have worked with many families who have been denied necessary adaptations for a safe accessible home for their disabled child, because of the present system of means testing. Therefore the Rett Syndrome Association UK fully supports the Homes Fit For Children Campaign in advocating the abolition of means testing of parents of disabled children (private housing sector) in England.”

Shirley Young, Chair of Board of Trustees, Family Fund

“The Family Fund was delighted to hear about the success of the campaign for abolition of the means test in Northern Ireland. The Board of Trustees would like to offer our fullest support in this campaign.”

Christine Cryne, Executive Director, Muscular Dystrophy Campaign

“Following the success of the Homes Fit For Children Campaign in Northern Ireland, and the abolition of the “means test” for parents of disabled children, the Muscular Dystrophy Campaign is aware of the need to bring about the same change to England.”

Dr John McPeake, the Northern Ireland Housing Executive’s Director of Design & Property

Services said when reflecting on the change in NI after abolition:

“Children with disabilities are among the most vulnerable in our society, and we believe this change has been of **significant and lasting benefit** to many lives in Northern Ireland. The Disabled Facilities grant allows for grant aid of up to £25,000, reflecting the Housing Executive’s commitment to helping people with disabilities to live safely in their homes.”

Andrew Mc Kinlay, Labour MP.

“Unusually England is behind N. Ireland in legislation! All too often the other way around. I will ... be pleased to support this campaign on behalf of parents of disabled children”

Tom Brake, Liberal Democrat MP.

“You will be pleased to know that I have signed this EDM.”

Doug Naysmith, Labour MP.

“I agree it is important that families with disabled children are able to make necessary alterations to ensure their children have suitable access to their home. I have signed EDM 298 and will continue to follow developments with interest.”

ORGANISATIONS SUPPORTING THE CAMPAIGN

Adams Oliver Support Group
Asbah
Barnardos
British Heart Foundation
Care Co-ordination UK
Carers Northern Ireland
Child Brain Injuries Trust
Child Poverty Action Group
Children's Commission (Derry)
Children's Law Centre
Children's Society
Chip
City of Sunderland Council for the Disabled
Climb
Contact a Family
Contact a Family (Northern Ireland)
Contact a Family (Wales)
Council For Disabled Children
Creggan Early Years Network
Crossroads Caring For Carers
Crossroads (Wales)
Cystic Fibrosis Trust
Disability Action
Disability Alliance
Disability Wales
Down's Syndrome Association
Duchenne Family Support Group
Essex Coalition of Disabled People
Family Fund
Family Information Group

Foyle Downs Syndrome Trust
Foyle Newpin
Habinteg Disability Housing Service
HoDis (National Disabled Persons Housing Service Ltd)
Law Centre
Leonard Chesire
Lifestart
Local Aid for Children and Community Special Needs
Mencap
Muscular Dystrophy Campaign
Naiscoil Na Rinne
National Autistic Society
National Autistic Society in Wales
National Disabled Persons Housing Service
Ncb
Nch
Nch (Cymru)
North West Community Network
North West Forum of People with Disabilities
Parent and Carers Forum in Kirklees
Parent Project UK
Pdef Awda (Surrey)
Perthes Association
Phas
Radar
Research Trust for Metabolic Diseases in Children
Restricted Growth Association
Rett Syndrome Association UK
Scope

Scope (Cymru)
Scovo
Sense
Shelter
Shelter (Cymru)
Snap (Bexley)
Snap (Cymru)
Special Needs Activity Club (Port Talbot)
Spinal Injuries Association
Steer
TY Hafarn
Wales Council For the Blind
Welsh Federation of Housing associations
Whizz-Kidz

SUPPORT FROM INDIVIDUALS

Confidentiality and the restrictions around the Data Protection Act, prevents us from bringing into the public domain all those parents, family members, relatives, friends, occupational therapists, other therapists, housing officials, MPs, concerned individuals and others who were the backbone of this campaign. All over England, Wales and Northern Ireland, they contacted us to give support, lend a helping hand, doing more than their bit to move this issue along. Many had no or little experience of lobbying or campaigning but all were eager to work, to encourage and to stick with us through very difficult times.

However a special tribute must be paid to those parents, who for one reason or another, were unable to avail of the full grant, abolition came too late for them. Despite this, they stuck with us, encouraged us and inspired us. Over and over I heard “it may be too late for us, but not too late for others”. Such is the generosity of parents.

To my own family – Teresa, Donovan, Ruth and Jack, I also have to thank for their support, for putting up with me, particularly in those hard days when we seemed to be getting nowhere and to all the families. To everyone, and each of you know who you are, be proud that you were a vital part of the jigsaw that completed this picture, and know that we are very proud of you. You made a difference, a difference that will last.

EARLY DAY MOTIONS ON THIS ISSUE

Abolition of Means Test for Housing Adaptations

Edm 309 – 09/12/02 – 75 MPs signed

Mc Grady, Eddie

That this house notes the Steering Group of the Joint Fundamental Review of the Housing Adaptations Service, comprising officials from the Northern Ireland Housing Executive and the Department of Health, Social Services and Public Safety, earlier this year, recommended a change in Northern Ireland legislation to exempt housing adaptations for children from a means test, and calls on the Government to ensure that the amending legislation is tabled for debate and enactment at the earliest opportunity.

Disabled Facilities Grant

Edm 770 – 04/03/04 – 153 MPs signed

Berry, Roger

That this House affirms the right and urgent need of disabled children to live in suitable housing; and calls on the Government, in light of the recent decision that the means test on parents of disabled children for the disabled facilities grant has been abolished in Northern Ireland, with effect from 16th February, to abolish this means test in England and Wales, at the earliest possible opportunity.

**Review of Disabled Facilities Grant
Edm 298 – 06/12/04 – 119 MPs signed**

Berry, Roger

That this House is extremely concerned about the unfair nature of the Disabled Facilities Grant means test, particularly for families with disabled children; notes that many families who need to make vital adaptations to their home are often forced into massive debt by having to pay for the full cost of adaptations themselves or are unable to carry out the work, leaving their home inaccessible for their child; believes this situation is unacceptable; welcomes the ODPM's current review of the Disabled Families Grant and urges the Government to follow the recent decision to abolish the means test in Northern Ireland; and further believes that such a move would greatly improve the quality of life for many disabled children and their families.

Fourth edm – the last!

**Reform of the Disabled Facilities Grant
Edm 160 – 23:5:05 – 160 MPs signed**

Berry, Roger

That this House is extremely concerned about the unfair nature of the disabled facilities grant means test, particularly for families with disabled children; notes that many families who need to make vital adaptations to their home are often forced into massive debt by having to pay for the full cost of adaptations themselves or are unable to carry out the work, leaving their home inaccessible for their child;

believes this situation is unacceptable; welcomes the Office of the Deputy Prime Minister's current review of the disabled facilities grant and urges the Government to follow the recent decision to abolish the means test in Northern Ireland and Wales; and believes that such a move would greatly improve the quality of life for many disabled children and their families.

Political support was essential to the campaign. Initially we had looked for support from one or two MPs. In the end when all the MPs who registered their support, through EDMs or directly, were counted, the total came to just over 260. Quite an improvement on one or two, as we had originally hoped for.

IMPACT OF ABOLITION

Snapshot of Derry Office (Northern Ireland) – the Grants Office in the area with the highest incidence of recorded disability in NI. Private Sector grant aided adaptations for children since 16th February 2004.

Under Data Protection information excludes grants reference numbers and property addresses.

	Approval release date	Grant Value	Simult. Applic.	Nature of works approved
1	Mar 04	£1694.55	No	Hard Standing
2	Mar 04	£2762.41	No	Relocate WC/provide level access shower
3	Apr 04	£1518.81	No	Provide ramped access
4	May 04	£1691.88	No	Provide enclosed space, gate and fence.
5	Jun 04	£950.00	No	Provide enclosed space and fence
6	Nov 04	£1820.21	Yes & HRAG	Provide enclosed space, gate and fence
7	Nov 04	£820.53	Yes & HRAG	Shower over bath
8	Nov 04	£9063.30	No	Provide single bedroom +shower, WC & WHB
9	Nov 04	£5308.99	No	Provide handrails and ramped access
10	Feb 05	£3507.88	No	Provide GF level access shower, WC, WHB ramped access & heating
11	Mar 05	£24,765.97	No	Provision of bathroom, bedroom extension with shower, WC, WHB, ramped access & heating
12	Mar 05	£8506.79	Yes & NBG	Provision of bedroom shower, WC, WHB heating & fencing
13	Jul 05	£12,830.01	No	Provision of GF bedroom
14	Aug 05	£2340.91	No	Provision of shower
	Total	£77,583.24		

JOSEPH ROWNTREE PROJECT

Background

In Northern Ireland we have been over taken by events and both Alison Jarvis and researcher, Bryony Beresford witnessed the announcement in Derry of the abolition of the means test in relation to parents of disabled children, who live in the private sector and who apply for the Disabled Facilities Grant for their disabled child.

The abolition of this test in Northern Ireland is effective from Monday 16th February 2004 but it does not apply to England, Scotland or Wales.

It has been recognised that parents have had a powerful impact the Homes Fit For Children Campaign that has led the drive to abolish the means test.

This Campaign is not party political and draws support from all the main parties. Indeed the Joseph Rowntree Foundation, in the past, provided the early resources which helped parents become involved by paying for transport costs, childcare, subsistence and contributing towards the running of meetings.

There is a growing awareness in England and Wales of the issues in relation to the means test and it is definitely on the agenda. When John Spellar (MP) and NI Minister for Social Development was formulating his response, he did consult with his counterparts throughout the UK, so inadvertently he

drew all the countries into the debate. However concerns are also growing over whether the DFG will remain mandatory or become discretionary and this is an added worry which also needs to be addressed.

The Proposal

To engage parents of disabled children, in England and Wales, in an inclusive way to help change the policy on means testing, learning from the Northern Ireland experience and from the positive experience of the Campaign throughout the UK.

Aim and Objectives

The aim of this project is to enthuse parents as to the possibility of positive change but grounded on a realistic approach. The objectives include the “empowerment of parents”, the actual changing of policy in relation to the DFG means test, to show the real value of working in partnership and to develop the necessary skills and knowledge that can make this happen.

The Approach

To allow time for parents to discuss the issues that affect their lives with each other and with the Project Co-ordinator. This could be done through telephone contact, email, and fax or through face to face meetings. This will require dedicated time.

To bring together interested parents in the North of England, London and Cardiff at three separate

meetings to inform them of what is happening, to share experiences and to guide them as how to go forward. This will necessitate three visits to England/Wales by the Co-ordinator.

To support parents in co-operation with Homes Fit For Children campaigners, to ensure that they are not isolated or left despondent and to work with them inclusively, ensuring that meetings are accessible to them and they can play a full part.

To produce a Newsletter informing parents, the public, politicians and those interested in the Campaign as to what is happening.

To work with all the existing networks so as to avoid duplication, keeping up to date with correspondence and policy developments.

Conclusion

This proposal is for a time limited project to help build on the momentum already built up by the Campaign to date. Further projects may need to develop to carry this further. In Northern Ireland the strategic plan worked, much to the surprise of everyone. It is not unrealistic to believe that this is also possible in England and Wales if existing support can be built upon. This proposal, if successful, will help prepare the ground for a possible policy shift as more and more parents influence their politicians and help make change possible. A short summary report will

be drawn up capturing the essence of the project and evaluating its impact.

Time Scale

It is envisaged that this project will last from February 2004 to June 2004.

Final Comment

This proposal is for a time-limited project to help build on the momentum already built up by the Campaign to date. Further projects may need to develop to carry this further. In Northern Ireland the strategic plan worked, much to the surprise of everyone.

It is not unrealistic to believe that this is also possible in England and Wales if existing support can be built upon. This proposal, if successful, will help prepare the ground for a possible policy shift as more and more parents influence their politicians and help make change possible.

A short summary report will be drawn up capturing the essence of the project and considering its impact.

PARENTS INFLUENCING POLICY – THE MEETINGS

This was a series of meetings, sponsored by Joseph Rowntree Foundation, to explore how parents, and those working with them, can work together to help change policy. The example of **Homes Fit For Children Campaign** was used to describe how the abolition of the means test on parents of disabled children (DFG) was achieved in NI.

HUDDERSFIELD

Thursday 13th May 2004

Huddersfield Leisure Centre 10.00am gather for
10.30am start

Ginnie Shaw, Steering Group Member of Campaign
in attendance with Jackie Hughes (parent)

CARDIFF

Thursday 20th May 2004

1.00pm gather for 1.15pm start, HTV Centre
Keith Bowen, Steering Group Member of Campaign
in attendance.

LONDON

Thursday 27th May 2004

1.00pm gather for 1.15pm start
Contact a Family Offices, City Road, London
Frances Heywood, Steering Group Member of
Campaign in attendance.
Meetings lasted approximately two hours, with a few
people staying on afterwards for short informal
discussions.

The purpose of the visits were to give parents and those who work with parents, information on the campaign, where it is at and a brief idea of what happened with the campaign in Northern Ireland. But also to encourage those who attend, to work with others for real change. Brendan Mc Keever of the Family Information Group in NI and a member of the Homes Fit For Children Campaign Steering Group shared his experiences of this campaign in NI.

PROPOSED TIMETABLE FOR THE VISIT

Meetings will probably be for approximately one and a half hours.

The host organisation will give a short introduction.

This will be followed by an update from a member of the Campaign's Steering Group.

There will then be a summary from the Northern Ireland experience.

Time will then be left for questions and answers.

The visit will conclude with a summary and parents will be encouraged to get in contact with their politicians.

The purpose of the visit is to give parents and those who work with parents, what the campaign is about, where it is at and a brief idea of what happened with the campaign in Northern Ireland.

VIEW FROM HUDDERSFIELD – GINNIE SHAW

Brendan and I met a group of highly committed parents from Huddersfield and beyond (for example, Tameside). We did a “double act” to describe HFFC and how the Steering Group has worked together so effectively, both before and since the official launch in July 2000.

It was good to have Jackie Hughes with us, as another parent who has been actively involved over the years. We had various items of information available, including the latest issue of the Shared vision newsletter.

We particularly encouraged those present to ask their MPs to sign the EDM. After the formal business, Brendan and I spoke individually to parents present and I agreed to provide feedback to the Kirklees group via email at any time. Jackie told me she thought it had been a good meeting and I agreed. (Ginnie Shaw)

VIEW FROM CARDIFF – KEITH BOWEN

The Homes Fit For Children Meeting held on 20th May at HTV, Cardiff was a very successful event, bringing together 25 parents and professionals from across South Wales to look at the problems facing disabled children and their families. Representatives from the Welsh Assembly Government Housing Directorate and the Children’s Commissioner were present.

Brendan McKeever was able to provide an informative and inspiring update on the recent developments in Northern Ireland, followed by a wide-ranging discussion on the many difficulties families experience with the DFG system.

There were numerous examples given of how the parental means test in particular was causing extreme problems, with families having to borrow money from other family members, go into debt or have to withdraw from having the recommended adaptations undertaken.

One family in particular within the last 9 months, had gone from having an initial contribution of £1000 increase to £22,000 because in the meantime the father had been able to get back into work.

Most importantly the main outcome from the meeting was that a clear plan of action was agreed about how to move things forward in Wales, this included amongst other things:

1. Parents and professionals to have positive input into the recently commences review of the DFG system in Wales
2. Parents and voluntary organisations to write to Welsh MPs to ask them to sign up to EDM 770 (CaF Wales to pass on their letter to MPs, for people to adapt).

3. A list of affected parents to be forwarded to the Children's Commissioner for Wales, with a view to the issue being included in his annual statement to the Assembly.

4. Tabling the equivalent of an EDM at the Assembly and writing to AMS for them to sign up.

Contact a Wales were to take a leading role in co-ordinating the campaign in Wales. (Keith Bowen),

VIEW FROM LONDON – FRANCES HEYWOOD

Starting from a base of nothing, this meeting in London was a hugely encouraging event. The commitment and support of Contact a Family England was the first thing I noticed. Not only had they donated the venue but also they had brought workers, volunteers and parents (and a baby) together to the event. Then other key voluntary groups had come, including the so-important Family Fund and Yvonne Massett of MDC who has already done so much to help and is doing yet more.

It was great to welcome Alison, the OT from Suffolk and the parent who came with her and wants to help too; and Nick (parent) bubbling over with ideas and firing us all up. The only problem really, was so many ideas and the need to co-ordinate our efforts. People attending were pleased with their copies of 'The Impossible' and with the leaflets, and took more away. They watched the video of the campaign in

Ireland and clearly took great heart from it. More important still was the frisson that went round the room: 'if they've done it in Northern Ireland, we can do it too'

Everyone was moved by the plight of a parent who told her story. With three children, two of them disabled, she has spent five years already in temporary accommodation where no adaptations can be done because the private landlords will not agree to them and the London Borough has no housing to offer. This was a reminder of how many issues there are to address, but we know we have one objective that has to be achieved first.

People in this meeting raised the issue of whether responsibility for adaptations for children is shifting because of the DFES taking over all children's issues. This was reinforced when Yvonne showed us the letter she had had from the DFES inviting voluntary groups to send their comments to the Review Group. There was therefore a debate about whether letters should go to Margaret Hodge or John Prescott. But later we realised there is no need to make a choice- they can go to both.

So how amazing of Brendan to have made this happen. We've never had so many people at a meeting in all the years we've been going- and the energy was palpable. All we have to do now is use it!
(Frances Heywood)

THE VISIT

n **Introduction from host organisation**

n **Campaign Update**

n **NI Experience**

n **Questions and Answers**

n **Conclusion**

LONDON

18 PARTICIPANTS

7 PARENTS

5 VOLUNTARY REPS

4 OTs (3 STAT AND 1 VOL)

1 STATUTORY REP

1 OTHER

HUDDERSFIELD

14 PARTICIPANTS

12 PARENTS

1 VOLUNTARY REP

1 OT (STAT)

CARDIFF

23 PARTICIPANTS

13 PARENTS

1 VOLUNTARY REPS

2 OTs (STAT)

2 CIVIL SERVANTS

1 STATUTORY REP

Summary Findings – Joseph Rowntree Funded Project – Impact of DFG Means Test (Responses to Questionnaires)

A sample survey exercise was carried out, with the help of voluntary groups in England and Wales last year. This was not research, but a sampling exercise. The comments below and the tables that follow are based on the information provided by parents who completed a questionnaire. These were submitted to the English Review.

In their own words they reflect on the trauma that this DFG Process has resulted in, the impact on their lives – lives often shattered already by the impact of disability. It is their voices that we all need to listen to, it is their reality that matters and it is their demand for abolition that must be answered by us all.

QUOTES FROM PARENTS

We are selling our current home and downsizing to try to free up some money.

Both my husband and myself work so we do not qualify for a grant. Unjust should be based on child's needs not parental income. No account of financial outgoings. Child at home "cheaper" for the State than a child in care.

We've had to double our mortgage to build major adaptations; it is discriminatory and unjust. If you work, you're assumed to be "loaded" and there's an

assumption that you should pay for adaptations. It puts unbearable pressure on families.

I feel disabled; people are entitled to adaptations to allow the same/equal opportunities to live as non-disabled people do.

All children should, regardless of parent's income, be entitled to live in a safe environment and have the resources they need available to them.

Cannot find £70 000 that extension has been estimated at.

Very unfair system, which is penalising families with, disabled children who only want to provide a safe home for them. Re-mortgaged our house in order to create an extension that would take new equipment needed.

Discriminatory to parents who work hard for a decent living.

Unfair, unjust, prejudiced and discriminatory.

I wish to do everything I can for my son, I do not see why I should be forced into poverty to achieve the house extension.”

These comments show clearly the depth of feeling among parents affected, on this issue. They give a glimpse of the reality that many of these parents are going through.

SUMMARY OF FINDINGS (STATISTICS)

In the tables that follow, the information coming from the parents, is broken down into statistics. The statistics also give further information, which should inform this debate.

The information in Table 1 reflects actual examples of parent/s income in relation to their assessed contribution. Summaries of responses in the questionnaires are in Table2, showing full support from parents for abolition. Table 3 describes the conditions of the disabled children whose parents completed the questionnaires. We finally see the relationship between assessed surplus income and the expected contribution (Table 4).

Table 1 – Parents Income and Assessed Contribution

From information provided by parents in sample exercise

Income	
Contribution	
£10,000	£500
£13,000	£727
£15,000	£600
£20,000	£36,500
£21,000	£13,500
£21,000	£13,500
£24,000	£4,000
£24,000	£18,000
£24,000	£50,000
£25,000	£10,000
£30,000	£3,000
£30,000	£20,000
£31,000	£25,000
£32,000	£16,000
£32,000	£29,000
£38,000	£85,000
£40,000	£40,000
£40,000	£65,000
£40,000	£81,000
£40,000	£120,000
£48,000	£30,000
£52,000	£124,874.36

Table 2 – summary of responses to key questions

Questions	Yes
happy with dfg process	2%
could afford contribution	2%
consider pulling out	64%
consider a loan	80%
support abolition	100%

Table 3 – Breakdown of conditions of children, whose parents completed questionnaires

Duchenne Muscular Dystrophy	24
Down's Syndrome	2
Cerebral Palsy	7
Rubinstein Taybi Syndrome	1
West Syndrome	2
Charge Syndrome	1
Mitochondrial Myopathy	1
Muscular Dystrophy	1
Learning Disability	3
Global development Delay	2
Total Number of Children	44

Table 4 – Surplus Income/Contribution to Grant

Surplus Income	Contribution to grant
£10	£200
£20	£399
£30	£599
£40	£799
£50	£1,039
£60	£1,439
£70	£1,838
£80	£2,238
£90	£2,637
£100	£3,528
£110	£5,125
£120	£6,729
£130	£8,320
£140	£9,918
£150	£11,516
£160	£13,113
£170	£14,711
£180	£16,308
£190	£17,906
£200	£21,469

**Official Figures comparing weekly surplus
income and assessed**

Contributions (supplied by NI Housing Executive)

Table 4 illustrates that the formula used to calculate contributions towards the cost of adaptations becomes more and more unrealistic as the surplus increases. It is also important to note that these are

estimated surpluses, in reality most parents have no surplus whatsoever because of the additional costs associated with disability and mortgage repayments.

CALL FOR ACTION TIME TO ACT

This campaign has always been about people genuinely working together for positive change. We may disagree over other things, but we agreed that there needed to be dramatic changes in the current situation if families of disabled children were to avail of their right to a safe accessible home.

Recently we have been in contact with a number of organisations which have been very supportive in the past and also some of them in the present. If we are to move this issue further on to the political agenda we now need all the support we can get.

To help us in the Campaign, which has now reached an important point, we are asking for organisations and individuals which have supported us in the past and/or do support the Homes Fit For Children Campaign and wish to see the means test in relation to parents of disabled children abolished, to contact us in writing to affirm this as soon as possible.

We do value all of the support, past and present, and we certainly welcome any new support. As we engage parents, we do feel it is important that

voluntary organisations assist parents to engage politicians but we do appreciate that resources are very limited. We are not asking for additional resources, but for organisations to use their existing expertise in helping parents to lobby MPs. The greatest resources we do have are people and time. It is time to act.

Confirmation of support (organisations or individuals) can be sent directly to:

Brendan Mc Keever
10-12 Bishop Street
DERRY
BT48 6PW
Tel: 028 7128 5675

or contact:

Frances Heywood
Ginnie Shaw
Keith Bowen

Bristol University
York
Cardiff

PLEDGE OF SUPPORT

I/We:
support the Homes Fit For Children Campaign to
abolish the means test on parents of disabled
children, as part of the Disabled Facilities Grants
Process (Private Sector).

Address:
.....
.....

Tel No:

Signed: Date:

POLITICS – NOTHING TO DO WITH ME!

And rightly so. For many of us politics are about other people, the big issues such as wars, education, scandals, spin doctors, leaks etc.... However sometimes politics can, believe it or not, be about the smaller things in life, the things that affect us.

However often we are tied up in the day to day cares of life, too preoccupied or even with little enough energy to delve into politics. Yet at the same time, without even knowing it, politics could be directly affecting us.

Whether we like it or not, the policy of means testing is political. If we cannot, as parents, afford the contribution as part of the Disabled Facilities Grants process, this has more to do with politics than our financial position at the time. We do not have to know the law or all the support mechanisms associated with the law (often called regulations).

What we need to know is that we can complain and argue, spend all our energies frustrated at the process, but change nothing unless we challenge the policy and regulations that support means testing. If we realise this then we will understand that politics do have something to do with me.

By channelling our energies into a campaign, we may feel less frustrated and angry, as we feel we are doing something. So what do we do. Simply write to your MP, and keep writing until you are happy with the response.

Perhaps phone or visit your MP, but whatever you do, try and make sure he/she understands how this process is affecting your family life.

Request your MP to support at Westminster Early Day Motion (EDM) 770, from Roger Berry (MP) and colleagues, which advocates the abolition of the means test. These motions often lead nowhere but they are an important measure of support. So the more MPs who sign up, often the more notice is taken of the issue.

If you are in a support and/or voluntary group, ask your group to support the campaign. If you work in the statutory sector and are not allowed to get involved with politics, do still lend your support in whatever way you can. To make changes in policy it is important to realise that it takes a combined effort, all support is needed. You have to decide for yourself whether politics is for you. The simple writing of a letter can lead to many positive changes. It is the small things that matter, Can you help with the small things? Get that pen out now, make the first move.

WHAT TO DO – PARENTS

If you are a parent of a disabled child, you know how the Disabled Facilities Grants process affects you and your family. But many of those who make decisions about your life do not. Politicians who make such decisions and who can change things need to

know what your experiences are, if changes are ever to be made. Perhaps you do not believe that politicians will never change anything, maybe most times they do not. But they can, and already a number of politicians have shown an interest in this Campaign. We need you to phone/write and/or visit your MP. Tell him/her, in your own words your experience. Ask them to support **Early day Motion 770, (in this case) sponsored by Roger Berry, Hywel Francis** and Paul Burstow and help make a difference.

You can get information on who your local politician is from the local council office, the local library from many voluntary and disability organisations or through the Internet at the site below by inserting your postcode:

www.locata.co.uk/commons

WHAT TO DO – VOLUNTARY/COMMUNITY SECTOR

Confirm your support for the abolition of the means test and for the Homes Fit For Children Campaign's efforts to achieve this.

Collect evidence of the impact of the present DFG process.

Assist parents in lobbying their politicians.

Use your own existing skills to bring this issue on to the political agenda.

Contact the government with your concerns over the present system.

WHAT TO DO – RESEARCHERS

Simply research the impact of the current system, collate this evidence and present it to the Review Group.

WHAT TO DO – OCCUPATIONAL THERAPISTS

Collate the evidence that you come across on almost a daily basis, in relation to the current process

Present this evidence to your manager/ess

Present this evidence to your professional body

Present this evidence to the Review Group

Lobby your professional organisation to support the abolition of the means test

Below is an extract from the professional occupational therapists' body, which has a specialist interest in housing – COTSSIH, which has just recently been released. Clearly they see that there are some problems with means testing parents.

Review of the Disabled Facilities Grant in England and Wales (March 2004)

“The College and COTSSIH are concerned that many people who have had their housing needs assessed by an occupational therapist, subsequently withdraw from the Disabled Facilities Grant system due to financial difficulties, which they may encounter later in the process. One of these issues – means testing, has been identified in research undertaken by the Joseph Rowntree Foundation and by Occupational Therapists as a specific cause of withdrawal among families with disabled children. Joseph Rowntree/Occupational Therapy research evidence of unmet need among families with disabled children and effective parental lobbying, combined with a Fundamental Review of Housing Adaptations Services in Northern Ireland have resulted in the abolition of means testing there (February 2004).

The College of Occupational Therapists has also requested representation on the review group. We have ongoing concerns about the health, social care and for children, educational consequences of not being able to afford essential housing adaptations. The College of Occupational Therapists and COTSSIH are currently seeking evidence of unmet need in the form of short reports on the circumstances people experience where there are financial constraints to providing essential adaptations. We would like to thank those occupational therapists who have already forwarded reports to the College. COTSSIH members are encouraged to contribute positively to policy development in this area and to assist with the identification of unmet need in accordance with professional standards.”

Paraig O’Brien, Chair COTSSIH

COTSSIH in collaboration with the College of Occupational Therapists dedicated considerable resources and expertise to supporting the reviews of adaptations funding in both Wales and England.

COTSSIH activity included:

- 1 Raising public and professional awareness of unmet need and inequalities in relation to the funding of housing adaptations via research, publications, conferences and newsletters.

- 1 COTSSIH/COT publication of *Building in Evidence: Reviewing Housing and Occupational Therapy* by Darren Awang. This comprehensive review of research evidence involving occupational therapists in housing has been substantially referenced by the review teams in England and Wales and has helped to underpin the rationale for change.
- 1 Creating a focal point for research, debate and influence at the COTSSIH National Conference in Durham, which was attended by key housing policy makers from our four countries.
- 1 Contributing and assisting the ODPM research project led by Frances Heywood at Bristol University.
- 1 Compiling evidence of unmet need for the College of Occupational Therapists representative on the ODPM review team.
- 1 Providing platforms for service users to express views on housing adaptations issues to policy planners and service providers
- 1 Support and advice for a delegation from the Welsh Assembly when they visited Northern Ireland to examine research findings and funding arrangements following the abolition of DFG means testing for families with disabled children in February 2004.

- ¹ Contributing papers on adaptations funding to the College Of Occupational Therapists *New Visions* Conference in April 2005.

COTSSIH believe disabled people throughout the UK must have adequate and equitable arrangements for funding housing adaptations regardless of location or tenure.

WHAT TO DO – HOUSING OFFICIALS

Collate the evidence that you come across on almost a daily basis, in relation to the current process

Present this evidence to your manager/ess

Present this evidence to your professional body

Present this evidence to the Review Group

Lobby your professional organisation to support the abolition of the means test

WHAT TO DO – EVERYONE ELSE

Support the campaign to abolish the means test, and let politicians know that in Northern Ireland the abolition of the means test was found to be the way forward and that England and Wales should follow as families of disabled children are the same, no matter where they live.

HOMES FIT FOR CHILDREN – ENGLAND AND WALES

The Final Countdown – Six Month Strategy/Plan June/December 2004

Building on the work already carried out by Homes Fit For Children, after the breakthrough in Northern Ireland and following the series of discussions, “Parents Influencing Policy”, involving all core members of the Steering Group, the following plan/strategy is being put forward to be endorsed. There is an awareness of a sense of urgency, in response to what seems a railroading exercise by government.

- 1 Build up support for EDM 770, by encouraging parents to write/contact MPs in their own constituency.
- 1 Ask voluntary groups/organisations to support the campaign by verifying their support to us and by informing John Prescott’s office of their support for abolition of the means test.
- 1 Encourage voluntary groups to use their expertise to assist parents to find out who their MP is but also to use their own knowledge to lobby as well, from their own group’s perspective.
- 1 Everyone should be encouraged to collect evidence:

- Occupational therapists can present through their professional associations.
 - Parents can present their evidence to MPs, through voluntary groups or through members of the Steering Group.
 - Voluntary groups and researchers can present their evidence directly to the Review Group, John Prescott's office and Education and Skills Department.
- 1 MPs should be encouraged to ask targeted questions.
 - 1 Publicity, sensitive to parents, should be stepped up.
 - 1 Option of parents or open meeting, including parents, should be planned for north of England, or London if political, in September as one last push.

Compile answers to contentious questions and feed these through to MPs and press.

BACKGROUND (Questionnaire)

HOMES FIT FOR CHILDREN CAMPAIGN

For a number of years campaigners have been trying to get the means test (Test of Resources) abolished for parents of disabled children, who apply for the Disabled Facilities Grant for their disabled child (private housing sector).

Parents working with housing officials, occupational therapists, politicians, researchers, disability groups, voluntary and community organisations as well as concerned individuals, helped make a dramatic shift in policy in Northern Ireland, which resulted **in the means test on parents of disabled children being abolished from February 2004.**

WE ARE NOW DEMANDING THAT THE MEANS TEST BE ABOLISHED IN ENGLAND AND WALES.

Legislation is very similar in England and Wales, Scotland does not have a mandatory disabled facilities grant.

To try and make this happen we are calling on all parents, and those who work with parents, urgently to contact their MP and ask them to sign Early day Motion 770 (MPs will know about this) which supports abolition.

Also we need evidence from parents as to how the DFG process has or is affecting them. This

questionnaire is only going to collect brief details, if you wish we could collect more details later. We need your **replies by 6th August 2004**. You will also be asked for your permission for us to use this information in the campaign, and whether you support the campaign. Please fill in the form urgently if you want to do this.

Thank You, Brendan Mc Keever – Homes Fit For Children

Questionnaire (evidence from families)

Please send completed forms to your local support group or directly to: b.mckeever1@ntlworld.com by 6th August 2004.

Please put a circle around Yes or No, whichever answer applies to you.

Personal Details:

Name:

Where do you live? Town/City name:

Email:

Are you the parent of a disabled child? Yes/No

Disabled Child's Condition:

No. of other children:

Are you happy with the Grants process? Yes/No

Give a few main reasons:

If you have ever been assessed to make a contribution towards the grant, how much was this? Could you afford this?

What was your total annual income at the time?

If you faced any problems with the process, please list the main ones:

Did you or would you consider pulling out of the grants process or not even going into it in the first place? Yes/No

Why:

Did you or would you consider taking out a loan or an additional mortgage to help pay the cost of adaptations? Yes/No

Sum up in one sentence your own feelings about this grant:

Do you agree that this information can be used in the campaign and details shared with others, including government departments? Yes/No

Do you wish later to be contacted for further details: Yes/No

Do you support the campaign to abolish the means test on parents of disabled children? Yes/No

NEW EVIDENCE (30th JUNE 2004)

All this evidence, which is only summarised here, has been gathered this year, just as the English Review began its work and as plans were being put in place for the Welsh Review.

It is acknowledged that the brief summarising of this evidence cannot reflect fully the views of the parents involved. As a result, avenues will be explored, to seek ways in which this information can be submitted, in a fuller way, to the Review Groups. We are indebted to the parents for allowing us to use this information.

Parents are saying that the means test must be abolished, it has been in Northern Ireland, so England and Wales should follow. Some have identified that they will no longer stay in the process or in some cases enter the process because of the punitive nature of the means test. As a result some parents will go into debt, debt which they say they cannot afford.

There are parents who are very angry at the means test being imposed on them and anecdotal evidence indicates that a way around this would be to give up a job, even temporarily, and/or go on benefit, even though these scenarios were not attractive to them. Generally there seems to be no logic for the means test as parents themselves say they invest so much

of their time and resources into their disabled child anyway, it is seen as an infringement, what are they actually being tested on. The mechanism of the test is criticised by parents who acknowledge that actual expenditure is not taken on board.

Parents do acknowledge the pressures and strains of life that result from caring for a disabled child, indeed many of them take these for granted. But the imposition of a means test when applying for a housing grant, is seen by many as an unwelcome additional stress and pressure that could be done without.

As already highlighted, there are a number of other problems associated with the grants process, which are also frustrating, annoying and at times demeaning, but none which compare to the means test.

SUMMARY OF NEW EVIDENCE PRESENTED TO DEPARTMENT OF EDUCATION AND SKILLS

- 1 Means testing is an unnecessary pressure on family life
- 1 There is no reason for the means test
- 1 Unrealistic parental contributions are being estimated
- 1 Present system is excluding some parents

- 1 Parents are going into debt, that they cannot afford
- 1 Means test is unfair and does not include actual expenditure
- 1 Quality of life suffers as a result of the means test
- 1 Abolition already in NI, other regions should follow

The evidence is there for people to read, but more importantly if people could, to listen to. There are many families who have no voice, they will never be heard. Both the old and this new evidence, along with the comments from parents themselves, all clearly show that there is no room for this means test in a community where the rights of disabled children and their families are paramount. Through this work we are only touching these issues on the surface but what we are already finding is that the means test is affecting families throughout the various regions, it does not matter where you live. Also the increasing costs of building means that what may once have appeared as substantial incomes, are no longer such in relation to paying for adaptations. Families deserve a better deal, all the evidence points in that direction.

PARENTS' COMMENTS

These comments have been taken from actual parents who have agreed that this information could be shared. For reasons of confidentiality, names have been changed but this takes nothing away from the depth of feelings in response to the means test

and the whole process associated with it. This is the real new evidence that has to be taken on board.

“we are putting ourselves into debt for the next twenty years to pay for it (the adaptations).” (Bronagh)

“The system positively discourages families like ours in our circumstances from applying.” (Donna)

“...professionals too bothered by my income and not with need of family.” (Kathleen)

“It would seem that parents in our situation have enough to try to cope with without added financial pressure. We also have a duty to our other children to provide as near normal family life as possible. Ordinary financial planning does not provide a contingency fund for situations such as this.” (Peter)

“It’s (the means test) a nonsense, it discriminates against the disabled child” (Pat)

“Because we cant afford to do the alterations ourselves, we have already had to restart another 20 years with £40,000 mortgage just to move to a more suitable home for our son and it still needs about £30,000 in alterations.” (Jane)

“I loathe every thing about it, the reason it’s happening in the first place to the intrusion in our lives of the insensitive people dealing with it.” (Jane)

“the emotional trauma, which often reduced both myself and my wife to tears, that we had to go through in order to secure acceptable living accommodation for our son” (Gary)

“The pain and suffering caused by the implementation or lack of implementation of this grant to families with severely disabled children is beyond the comprehension of those who have not been through it.” (Gerard)

“I do not believe that the DFG should be means tested especially as I have worked hard all my life since school to ensure that I have provided for my family, paid my NI and taxes and when I need to provide most I will not be able to afford what my son needs and I will be let down by the system. This is a total disgrace to humanity. How dare the government decide who does and who does not provide the essentials for their child whom is disadvantaged by a disability. It is shameful, disgraceful, archaic and sickening, words alone cannot describe my feelings, there are some things in history we have regretted this is one of those decisions.” (Pascal)

“This grant is absurd, unfair and appalling.” (Samantha)

“It is grossly unjust that we, and other families, have had to “pay the price” of our child’s disability.” (Ann)

“Apart from complaining and campaigning, we’re not sure where to go from here. We certainly cannot countenance borrowing more than we have already to buy the bungalow. What other strategies do families in our situation follow?” (Frank)

“The form did not ask for any information about our expenditure whatsoever (the only three categories allowed were maintenance of a former spouse and family, contributions to a student grant, and childcare). What was most galling was that it asked for details of all three children’s savings accounts.” (Joanne)

CONCLUSION AND RECOMMENDATIONS

From the new evidence – the voices of parents of disabled children, from the increasing political support, from the support of individuals and organisations, it is clear that not only is the bureaucracy inherent in the Disabled Facilities Grant Process is a problem but equally so is the means test.

In all of this debate there is little mention of rights, the rights of disabled children and their families. Nor is there much mention of quality of life nor indeed a holistic approach to supporting families. Housing affects all areas of life, inadequate housing much more. Research has shown this, as have parents

themselves and indeed those who work with them, particularly occupational therapists.

Any attempt to “make things better” within the existing process will fail, just as attempts in the past have failed because some people inevitably will be left out. At some stage there needs to be an understanding that a safe accessible house is a right, not based on levels of income and expenditure. Also there has to be some serious thought given to “need”, need as identified by an occupational therapist, and what happens this need if it goes unmet if parents cannot afford the assessed contribution. These should be the focus of debate. Based on this information, it is impossible to make all recommendations within the existing process.

Recommendations

- 1 Abolition of the means test on parents of disabled children
- 1 Allocation of sufficient additional resources to enable all disabled children to have access to a safe accessible home
- 1 Retention of mandatory Disabled Facilities Grant
- 1 “User involvement” ethos to be central to DFG Process
- 1 A more streamlined grants process with less bureaucracy and more sensitivity

Brendan Mc Keever (30th June 2004)

Final Press Release...
For Immediate Release (27th October 2005)

VICTORY FOR COMMON SENSE

Baroness Andrews (Office of Deputy Prime Minister), today announced that English parents of disabled children will no longer be subject to a means test (private housing sector), as part of the Disabled Facilities Grants Process.

This follows similar announcements that led to abolition of the means test for parents at the end of last month in Wales and over eighteen months ago in Northern Ireland. Scotland does not have the Disabled Facilities Grants Process. When this takes effect in December 2005, it will mean that no parent of a disabled child in England will be subject to a means test when they apply for the Disabled Facilities Grant (private housing sector), as is currently the case in NI and Wales.

Homes Fit For Children Campaign has been highlighting issues around the means test, which is part of the Disabled Facilities Grant process, for over eight years. Families were being penalised by an unfair and unjust means test, imposed upon the parents of disabled children who live in privately owned homes.. A safe accessible home was being denied to some families because their parents could not afford an assessed contribution, based on the means test (Test of Resources).

Some families were going into debt, pulling out of the process or indeed not even applying because of the means test. The means test was not based on actual income/expenditure, did not reflect the additional costs relating to disability nor the current housing mortgage cost. It was a mean test rather than a means test.

Parents (relatives and friends) , working closely with politicians, a variety of housing, disability, voluntary and community organisations, researchers, occupational therapists, housing officials as well as concerned individuals brought about this change. Evidence was gathered from parents directly and via a number of organisations , from occupational therapists and through a government commissioned research project. This evidence certainly informed this decision.

It would be impossible to mention every parent, researcher, family member, organisation, individual and politician who helped make this happen. All of them know we value their support and those who worked with us understand how valuable their input was, to name one would be to leave another out.

However we have to thank specifically all those involved in the English Housing Review Group (including politicians and civil servants) and the researchers from Bristol University. Your commitment and hard work has ensured that parents voices are

heard, through politicians who have been sensitive to this issue and through those working with families in the voluntary and statutory sectors. Also the previous work both in NI and in Wales, which helped lead to this day, cannot go unmentioned, where so many tirelessly worked on this issue, when there seemed so little hope.

Political support came from all the main parties in England, NI and Wales. Early Day Motions on this issue were led by in the past by Eddie Mc Grady (MP) and currently Roger Berry (MP), the current EDM 160 has attracted well over 150 signatures, the highest ever for this issue. Thanks to all the MPs who made this happen.

It is a victory, a victory for common sense. It will be that common sense that drives us on to ensure now adequate resources are invested to make this work, and to eradicate some of the other issues around this grant. We again thank sincerely all those who publicly and privately helped make this happen.

Brendan Mc Keever, Co-chair Homes Fit For Children
(Tel: 028 7128 5675)

Disabled Facilities Grant is only available after the recommendation of an occupational therapist. In the private sector the means test inhibited some parents from getting this grant. Grants help with adaptations e.g. extensions, showers, toilets etc..

THOUGHTS FROM OUR CAMPAIGN

- 1 Know your issue thoroughly
- 1 Be certain that you can build a campaign around your issue
- 1 Be prepared to work hard
- 1 Use research or simply find out more, information is useful
- 1 Value each individual and the little or the lot they contribute
- 1 Build up a support network from the wider community
- 1 Tap into existing expertise and knowledge
- 1 Respect each other
- 1 Focus on your issue, do not be distracted but be flexible
- 1 Launch your campaign
- 1 Contact a number of politicians at all levels
- 1 Simplify your case as much as possible

- 1 Provide information, people need to know what it is all about
- 1 Remember it's the issue, not the "human interest" story that matters
- 1 Write **letters** to the appropriate authorities and ask your politicians to continue to write **letters** and ask questions
- 1 Never under estimate your own strength and expertise
- 1 Don't give up, even when all seems lost
- 1 Win or lose, always acknowledge those who supported you
- 1 Go for it, what have you got to lose?