

A stylized black and white line drawing of a house. The house has a triangular roof with a chimney on the left side. The main body of the house is a square with rounded corners. Inside the square, there are two square windows with a cross-like pattern inside, and a wide, curved smile at the bottom. The text "THE IMPOSSIBLE TOOK A LITTLE LONGER" is written in bold, uppercase letters across the top of the house's body.

**THE  
IMPOSSIBLE  
TOOK A LITTLE LONGER**

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## INTRODUCTION

Shocked and unable to speak, I stood in front of over seventy people as history was being made, in the City Hotel in Derry. In my hands was a framed press release which I could not even read. I heard David Crothers (Director of Housing, Department for Social Development) asking me if I could read the first few lines. I couldn't and handed the framed document to him.

In Derry on Thursday 4 December 2003, at a housing conference organised by the Family Information Group and supported by the Joseph Rowntree Foundation on the theme of disabled children and housing – “Where Do The Children Live?” David Crothers now had the audience's undivided attention. In his hands he had a press release from John Spellar MP, the Minister for Social Development – embargoed until 10.30am that morning to coincide with the conference. As the first few lines were read out by David, the audience – which included people involved in housing, health and social services, the voluntary sector and parents of disabled children – erupted. The impossible had happened, in Northern Ireland.

**“From early next year (ie 2004) the means test for parents of children with disabilities who apply for the Disabled Facilities Grant will be abolished.”** The words of John Spellar had brought to an end four years of campaigning in Northern Ireland, and over six years in the UK. I walked off the stage, press release under my arm, out to my wife Teresa in the reception of the conference and I remember little else of what happened

that day. Oh, I do believe that the conference we ran was a great success, the evaluations seem to point in that direction, but my mind was elsewhere. As this news broke, I wanted to cancel the conference and go home – we all had achieved what seemed so impossible. **The impossible turned into reality when on Monday 16 February 2004, the means test was indeed abolished for parents in Northern Ireland.**

This is the story of that achievement. The ups and downs, frustrations and high points. It is a story that needs to be told before it gets lost in that small world of disability, a world that seldom gets proper coverage and where issues are often misrepresented and misunderstood.

Although the campaign – Homes Fit For Children – is about trying to remove the means test from parents of disabled children who apply for the Disabilities Facilities Grant, and this campaign continues in England and Wales, this story is about much more than that. **We have to look on this story as how any concern, any issue can be highlighted. Once highlighted, campaigned on and driven through so that real positive change can take place.** It is not easy. In this case it took a lot of work by many people, so many people, and it is to all those people – the unsung heroes – that this is dedicated i.e. my own family, other families, disability organisations, voluntary and community groups, those who work within the various statutory agencies, the politicians (at all levels) and to anyone who played a part in this, especially my colleagues in the Homes Fit For Children campaign.

## THE ISSUE

Often I have wondered, when does something become an issue. I know that many parents of disabled children may not see things that affect them as issues, they are simply personal to them. When things are personal, people often feel that they cannot be changed, and at times begin to blame themselves.

So, for example, if they do not get enough time to themselves they may begin to think it is really that they are not coping whereas in fact they are coping well. Or if someone tells them they must contribute money to housing adaptations, because a means test dictates that, the parents may feel it is their own fault that they cannot afford this. In reality, it could be the means test is flawed, but very few in authority would acknowledge this.

It is also true in the wider community. **What begins as a very individual experience for someone can turn into a campaign, once that individual understands that there are others in a very similar situation, or have been in similar situations. If you feel something personally, firmly believe that the “problem” or “concern” has to be addressed, and you feel angry enough, or passionate enough about it – then this could be the beginning of moving what is personal into the arena of issues. Then you have to look at the possibility of working with others, who think the same, to move things forward.**

It does not matter what others say, it is your belief that matters. It does not matter that you have no experience in

lobbying, most of us did not and we probably broke every rule in the guidelines to lobbying. **You do not need to know the law, legislation, policies etc, all you need to know is someone who does and there are many out there.**

**The only area you need to concentrate on is the issue that is affecting your life and possibly the lives of others.** You do need to know this but you probably already do as this is what has motivated you in the first place. If a campaign for change comes out of this then it is vital that your own particular issue and how it affects other people is fully understood by you and those supporting you. Sometimes people are frightened because they feel others know more than them or go about as if they do. Be re-assured, very few people, except those who experience the issue, know the issue better.

Although everyone is different and has different views, **once the issue has been agreed then it is important that you try and agree how you go forward with this.** This will probably take some compromise and over time the priorities can change. **Do not fall out over this!**

## THE CAMPAIGN

To go back to our campaign. The issue was, as individual parents we were possibly going to miss out in adapting our home for our son, who was disabled, because we could not afford the contribution that the means test calculated we should pay. We were told there was nothing we could do about this as the means test was a government calculation for this and other benefits.

So even though we knew that the means test did not take into consideration our true income and expenditure, and that genuinely we could not afford the several thousand pounds we were to put in to carry out the work, there was nothing we could do. We were angry, frustrated but could do nothing. It seemed we were alone and as if no-one had ever been in this position before because no-one seemed to be able to change it. The issue was individual to us, we knew the issue, we experienced the issue, it affected our lives.

It was only, some time later, when I became aware of "Homes Fit For Children" in the UK that I realised that there were others affected and who were questioning this whole process. I joined the small group of campaigners – knowing nothing about campaigning. All I knew was the issue and that I had a burning desire to change things, but I had not a clue how to do this.

This then is how it all really began for me. I never thought change would be possible, not the full change

that would have been needed, but that did not stop me from becoming involved in trying to create change.

**In this campaign, as in many others, there was a small dedicated team of people working very hard on moving things forward.** Surrounding then was a larger group of people who gave support when needed.

Beyond this again there grew a wider support network – some of whom knew the issue thoroughly, others who were just keen to support and help. All of these, no matter how much they were involved, were vital parts of the overall jigsaw. **The choice of how much commitment was up to each individual and that commitment was appreciated, no matter how much it was.**

The picture is now emerging. The individual's experience of a concern or a "problem", knowing that thoroughly and sharing it with others of a like mind. Agreeing what the issue is, as it affects a group of people, and working out together how to move this forward.

Gradually building up a support network who can help with contacts, experiences, skills and information that you and your friends do not have. Commit yourselves to change, even if that seems impossible. You now have a campaign!

## RESPECT

Many of the issues that people raise are sensitive and people can come at such issues from a variety of angles. Because of this, **it is important that everyone involved respects each other, it does not mean that you always have to agree but respect is vital.** Also people are bringing different skills to the campaign, have different time commitments and priorities – these are also very important – no-one can be seen to run away with things if the campaign is to be built on the group experience. If everyone is part of the jigsaw then **each person, no matter what they put in, must be valued.**

As a parent, from the outset, I felt respected in the Homes Fit For Children campaign. When I got the invitation letter from Bristol University Researcher Frances Heywood to become involved, she emphasised that parents of disabled children needed to be involved if this was to work. Frances and I had been in contact off and on before that but I was shocked she was inviting me to a meeting in England.

Belfast at that time seemed far enough away. It took a lot of convincing on her part to get me to that first meeting, almost five years ago in 1999. There followed a number of meetings in Birmingham and London, which I flew over to and back on the same day. The travelling was tiring, at times frustrating and often I was travelling home late at night wondering what it was all about.

Looking back, what it was really all about was respect and building up knowledge and information about the issue. It was about contacts, meeting people otherwise I would never have known. Out of those meetings there grew a sense of support, encouragement and respect that would be needed in the time ahead. So many times since I have at times felt like throwing in the towel, a call from Frances and reassurance from her would have been enough for me to carry on. With a small core group involving Frances, Ginnie Shaw and Keith Bowen, an informal support network was built up.

The reality for most campaigns is exactly that, small core group and larger support network. If this is accepted then things will run a lot smoother than if there is in-fighting over people feeling that they are doing too much. The building up of respect among those involved is one way of preventing any in-fighting which undermines any campaign.

## FLEXIBILITY

By the time I became involved in 1999, the campaign had already been established for two years involving researchers, volunteers, disability and housing groups as well as interested individuals. It had been covering England and Wales (Scottish legislation was different) and was now spreading out to Northern Ireland. Joseph Rowntree Foundation were very supportive of parents involved and in commissioning research.

During those early days the campaign hinged on the slogan “Means Test The Child”. It was the belief that as it seemed in legislation there had to be a means test, then one way of making sure parents were not means tested was to means test the child. In reality, only in exceptional circumstances will children have any substantial means, so you cannot means test the child and therefore the means test would be effectively abolished.

**Through time as the focus of the campaign switched to the rights of the child** and more understanding of the grants process meant that the necessity to means test someone was not enshrined in law – there was a move away from this original focus and a concentration on simply abolishing the means test in relation to parents of disabled children. This is the current position.

Again, respecting that priorities can change, that new information can help change direction if people are open to this, then a flexible approach to campaigning can be developed. **There is always room for diversity, as long as there is general agreement on core aims.**

As much as the core group respect each other, so too they must respect the views and opinions of those outside the immediate group. Again they may not agree with them but this should not be a barrier to working with them.

For example often people come at issues from their own vested interest, this is only natural. If they are giving support then this is what is important as long as they value the core principles involved in the campaign. So disability organisations may have a different slant from a housing group, a community group, a voluntary organisation, a parent, someone who is disabled, a politician (at local, national or regional levels).

Some people may have a more thorough knowledge than some others. For campaigners the support and interest is what is important but at all times this support and interest must fall within the value system set up by the campaigners.

In Homes Fit For Children campaign, for example, one of the main core values was “**sensitivity to the parents of disabled children**”. Support from organisations, the media etc, which did not adhere to this core value would not have been welcome. Of course there are some things over which we have no control, but as far as possible core values such as this were continually raised. Respect ensures there is a dignified campaign, no matter what the outcome and hopefully those involved will feel enriched and valued.

## TAKING STOCK

Hindsight is a great thing. It is as if everything fell into sequence, ran smoothly and the goal was reached. Life is not like that, nor is my experience of campaigning. If the truth be told, although I was invited to take part as a parent, if I had not been working full time with the Family Information Group (highlighting the issues affecting families of disabled children) then I would not have had the time or energy to become involved as much as I did.

I have great respect for the other parents involved and although they could not all attend every single meeting, their commitment was still there. From them I learned a lot and began to have a fuller understanding of how devastating this means test was to ordinary lives.

However, to ensure that the government was not going to treat the issues arising from this campaign in an individual way, we had to take stock of where we were at. It became clear then that the influences of Hodis, Contact A Family, Frances Heywood's research and the Joseph Rowntree Foundation were vitally important. This was not a small bunch of aggrieved parents complaining about a very specific individual problem they had in common. Rather it was an organised campaign set up to address the negative impact of a policy which was causing great hardships to families, through no fault of their own.

These combined forces began to bring in the evidence that was needed to move the campaign on. From the practical day to day experiences found by Hodis and Contact A Family, to the research work of Frances Heywood, highlighting the positive impact of adaptations when carried out properly. The nature of Joseph Rowntree Foundation prevents it getting involved in party politics but it does not prevent it from commissioning research and some of the most powerful findings in relation to families of disabled children has come from their research.

Also by assisting parents to become more involved in informing the housing campaign (by meeting travel and childcare costs etc), the Rowntree Foundation made a great contribution to the development of the campaign. By coincidence, Joseph Rowntree funded the housing conference in December 2004, Alison Jarvis represented them and researcher Bryony Beresford was also one of the speakers.

As we were taking stock, we received a variety of advice and guidance – perhaps a large charity could lead with the campaign, detailed guidance on how to lobby and influence, who were the best people to contact, what was the best approach etc. We didn't ignore it all, **but instead concentrated on a launch, and a family launch at that.** It seemed the campaign had never been officially launched and this was now nearly the summer of 2000, three years on from the campaign first started.

As already mentioned, we had the four players emerging: Keith (Contact A Family, Wales), Ginnie (Hodis), Frances and myself. Also we had the regular support of a number of parents throughout the UK, who tried to attend most of the meetings. We also had a number of individuals and organisations that although they could not attend all the meetings regularly, were still able to make some of them. Also we had a growing body of support, organisations who simply wanted to lend their support to the campaign. Throughout all of this was the interest in the issue from Joseph Rowntree Foundation.

## THE FOCUS

Over the years, much of the advice was in keeping focused, this became extremely important as other related issues began to emerge. It is so easy to get distracted on what are important related issues but this distraction could lead to the downfall of any campaign as confusion and loss of focus can lead eventually to the loss of the issue itself. It is so easy for government to delay progress by dealing with all the peripheral issues without really dealing with the issue itself. It is easier for civil servants to weigh up the impact of proposed decisions on others than look at the actual decision itself.

It was not that the campaign was not interested in disabled adults or older people, it was that the remit of those involved was disabled children and their families. It was hard enough getting this across at times, at the same time there are many excellent organisations, better equipped, to work with these other groupings.

Of course campaigners were aware that the means test was not the only difficulty with the Disabled Facilities Grants process, but this was our chosen focus as one of the main barriers to suitable accessible housing. We are and were concerned about the high cost of carrying out work (not met by the maximum grant), the problem over builder's estimates being higher than the grants available, the bureaucracy, long delays in the process, potential differences of opinions between Occupational Therapists (OTs) and parents, the shortage of OTs etc.

But significantly we were and are aware that the policy of means testing parents of disabled children actually prevents many families from even entering the process, it causes great hardship for some that do, and is totally unfair and unjust. These thoughts and ideas were thrashed out at meetings, on the phone or in writing.

We began to understand that a safe accessible home is a right for every child and family. The campaign became rights based, within which discussion of the flawed means test became irrelevant. **The core point that emerged gradually from all this was simply: "It is the right of every child to have a safe accessible home. Means testing parents of disabled children is a barrier to that right. Abolish the means test."** This may not have been the government's priority when deciding to abolish the means test in Northern Ireland, but it was what our focused campaign was built upon.

## THE LAUNCH

As mentioned earlier, we never really had a launch, and as we took stock, focused on our priorities, 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 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 local supporters. Around the same time in Cardiff, there was a local launch there too; once again families were included as they were in Derry.

The Wales launch of Homes Fit For Children campaign, in July 2000 came together quite quickly and drew together a large number of supporters, including parents,

voluntary organisations and statutory professionals. Such a positive response from people on the ground at short notice highlighted the difficulties that disabled children and their families faced and acknowledged the frustrations of professionals trying to make a poor system work. People were keen to get the message across to the then new National Assembly for Wales that the existing system was not working and decisions needed to be taken to improve the lives of disabled children and their families in Wales.

The Wales launch was well coordinated between Ginnie at Hodis in York and Keith of Contact a Family in Wales that the scene had been set for a dramatic event in Cardiff. Once again Contact a Family need to be congratulated for putting so much effort into all the launches but particularly this one in Wales.

The key players – the parents – had arrived and with them were Ginnie, Keith and Frances, Frances had made her way down from Bristol for the occasion. They were joined in a room at the Welsh Assembly (this had been ably organised by Contact a Family Wales) by the two MPs who were actually hosting the event. The room was packed to overflowing with supporters of the campaign as well as those who were keen to find out what was going on.

Everyone was in place as Ryan Hawkins, aged three, presented Ginnie, the director of Hodis and co-chair of the campaign, with a piece of Lego, these were the walls of the accessible Lego house which was to be soon completed in London.

The Welsh members then went on to debate what they could be doing independently of Westminster, to move things on. Jane Hunt, the Health Secretary, broke off from an important engagement, to come down and express her support for the campaign. Frances stayed on to fully inform the guests about the campaign, as Ginnie rushed off, by train, to London to complete the launch, Lego piece in hand. It was a credit to Ginnie, Contact a Family Wales and all those who took part in the Welsh event that Homes Fit For Children was definitely part of the scene, after that summer day launch.

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 and ASBAH. But just when I was about to despair, Rev. Martin Smyth MP and Paul Clark of 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 – but only once Teresa, my wife, Donovan and I agreed.

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 MPs 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 Mattingley, 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 river bank near the 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 including Miranda Parrott and her secretary, from Contact a Family (that had been represented at all three venues). 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, 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 that we would concentrate our efforts on Northern Ireland first, while still continuing campaigning in England and Wales, but 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.

## THE REALITY

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 the Social Democratic and Labour Party (SDLP), Sinn Fein (SF), Ulster Unionist Party (UUP) and the Democratic Unionist Party (DUP). I am not sure if most of the people there knew what I was talking about.

Also some time before this 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 paid workforce of one – me, I was not alone. I would find it 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. Evidence from community paediatric Occupational Therapists, the experience of politicians working in the community, research findings from the Joseph Rowntree Foundation were just some of the voices challenging this falsity.

The reality too is that the media often home in on “the human interest” story and ignore completely the important broader issues. I forget now the number of times we were approached by the media to put forward families to be interviewed, we refused as 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.

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.

## MOVING FORWARD

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 – The Occupational Therapists Managers’ Forum – 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 and organisations as possible in this campaign and to sound out politicians at a variety of levels. On Friday 23 February 2001, twenty-six people turned up at Foyle Disability Resource Centre 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. There was a mixed audience of parents of disabled children, local councillors, representatives from the political party offices, representatives from the voluntary and statutory sectors including health and social services as well as 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, National Conference of the College of Occupational Therapists Specialist Section in Housing, Joseph Rowntree Foundation, Western Health and Social Services Council, National Children's Bureau, and locally to interested groups. Also, through our own workshops and 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 see 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 had so much to learn. Time was not on our side.

## HAVE A BREAK

At this point I need you to have a break. Before you turn the page, I want to explain a few things. Please bear with me.

The next section was the hardest part of this book to write. It deals with a subject that most of us have opinions on, and often they are very differing views. There are others who have no time whatsoever for the subject. As you flick over, stop!

Politics In Northern Ireland has a bad press, and for many years I would have been as frustrated as many other people with our political progress. What progress? I hear you say. But I am not talking about politics based on nationality or religious affiliation. Through this campaign, I learned about the politics that could lead to changing ordinary lives. I witnessed the politics that could find politicians agree on an issue, even while at the same time they could have fundamental disagreements on a whole range of other issues.

See the hidden face of politics, if you dare. Get behind the media images and see our politicians respond to parents, look on as they come face to face with the reality of caring for a disabled child. By now they should know how much I valued their support personally and as someone involved in this campaign. Spend a few moments, take a risk, and maybe you will see what I saw. Real people working for real change, could politics not be about that too? NI politicians have done what all the political resources in England and Wales could not do, and I am proud of them, Read on...

## POLITICS

If we had started to think about the complications of putting a jigsaw together, we had to wait to move into the 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 far 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 in Northern Ireland where the emphasis seems to be on religion and territory, sometimes we can feel even more alienated.

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 can be at local council level. I once thought local councillors only made decisions on emptying bins or street cleaning, I was rudely awakened. At council level, Assembly level (MLA), at Westminster (MP) and at European level (MEP), politics worked, as did our politicians, on this issue. 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 an 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 they 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 whoever you want to work on your behalf. In Northern Ireland, 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 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. We also had politicians such as Rev Ian Paisley asking questions on our behalf.

### **The Assembly**

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 last December. Mary was also one of the first MLAs – there were three in total: Patricia Lewsley, David Mc Clarty and Mary herself – who asked questions in the Assembly which led to the setting up of the Review Group by Nigel Dodds.

Mary was also instrumental in setting up a meeting with SF party whip Sue Ramsey which eventually led to all four

Sinn Fein MPs coming in to support the campaign. Mary's personal assistant, Maeve McLaughlin (also a local Derry City councillor), was also instrumental in her influence on council but also on the Sinn Fein party itself.

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" campaign and as it moved into the abolition policy he subtly raised the issues with his Assembly colleagues. His role of Deputy First Minister was also of great help and influence as was Mark taking over John Hume's role as party leader.

He became very influential in ensuring all the SDLP MPs came in to support the campaign the way they did. Both his assistant Martin, and John Hume's assistant Paul Herron, were very supportive during this whole period of the campaign.

On other occasions during those months I met MLAs such as Patricia Lawsley, 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 overall responsibility for the Department for Social Development, the department which 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 the refurbished offices of Disability Action, on the Strand Road in Derry.

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.

### **Westminster**

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 Eddy McGrady and his assistant Teresa was excellent in guiding our campaigning work. Teresa explained how **Early Day Motions** 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, her sister Anne, our colleague in Wales and York, eventually seventy five MPs signed up to the Early Day Motion (in effect supporting the campaign) and with the support of the four Sinn Fein MPs who do not sign these motions, we had 79 MPs.

In the end we had the full support of sixteen out of our eighteen Westminster MPs. Although David Trimble and Nigel Dodds did not sign the Early Day Motion, there were indications from their offices, or from themselves that they could be supportive. Nigel had indicated that he would be supportive if the abolition applied to older people too while David Trimble's office were keen to point out that David would probably be supportive if any debate materialised.

### **Expanding Support**

As political support grew, I thought we should move from individual support from politicians to party support. Towards the end of the campaign in Northern Ireland, I do believe we had some of the parties on board and if things had dragged on perhaps we would have had all the main parties backing in full the campaign.

Through Mark Durkan we were able to contact Eddie McGrady's office. Before long we had all SDLP MPs signed up, all DUP MPs except one, and all Ulster Unionists except one and also through the work of Maeve McLaughlin, Gerry McLaughlin and especially Mary Nelis and Sue Ramsey, we had all four Sinn Fein MPs supporting and endorsing the campaign, even though they could not sign Early Day Motions (EDM) in principle. Sinn Fein have four MPs at Westminster. In principle, they do not take part in the business there so they do not sign EDMs but they still gave their support to the campaign.

**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, Eddy 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 MPs and MLAs. 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 British MPs Diane Abbot, Nigel Jones, followed by Hugh Begley and Roger Berry, also we had Ros Williams (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, it really was on the agenda in England and Wales. It was unbelievable how, within days, over four hundred MPs 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, resulting in each MP receiving 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. The political picture was widening.

## **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.

## **Politics Working**

So we had the MPs and now a selection of councils. Alongside of this was our MLAs, not just from the Derry area, but all over Northern Ireland, some of whom were also MPs. 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 all our local MLAs in Derry on board with one exception. We also had Gregory Campbell and Martin McGuinness who lived locally, but who represented constituencies outside the city.

How did this happen? It didn't just happen, we had to try and make it happen with intense lobbying. At first usually we would send out some brief information on the campaign and ask politicians to lend their support. Usually 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 three out of the four leaders of the major parties. 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 simply offered their support and this was our life line.

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, followed up by support from their offices and also as we moved into the Early Day Motion, from Eddie McGrady's office.

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 was suspended. Just a few weeks prior to this I was in Stormont with Mary

Nelis and Sue Ramsey building up our political clout 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 minister, followed by another Direct Rule Minister – John Spellar was now in charge of DSD matters. 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 to ahead and if it did what kind of authority the findings would have, with a direct rule minister.

In this section I have concentrated on the politics angle but politics also intertwined with other events. Just before intense pressure was built up on our politicians there was a dramatic development as a result of a joint DHSS&PS/NIHE Review – Review of Housing Adaptations Services – often referred to as the Fundamental Review.

## NIHE / DHSS&PS REVIEW

In December 2001 I finally got written confirmation from the NIHE/DHSS & PS 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 and Public Safety, a user representative from Disability Action and the chairperson of the Occupational Therapy Managers' Forum, 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.** This appointment was made to pursue the strengthening of both collaborative working between the agencies as well as user involvement in service planning. Paraig O'Brien, Occupational Therapy Lecturer at the University of Ulster, 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, on a two-year secondment as Housing Adaptations Liaison Officer, was working closely with Nuala McArdle (DHSS&PS) and colleagues from NI Housing Executive and DSD, some of whom found their way on to a later review. David Bass, Kathleen Hicks, Sean Cassidy and Michael

O'Connor. 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.

Concerns were examined over waiting time for adaptations, the scarcity of Occupational Therapists, heating problems, how generally to improve the service, a closer look at 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.

**Then 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 and social services as well as housing recommending exemption – surely this would now happen.

## **Despair**

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 at the Assembly. Through our political lobbying of all the members of that committee, they would be aware of the issue and as we had support from

some of its members, I thought we would get a good result. 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, Nigel Dodds, and then go on to the full Assembly for ratification.

What seemed a high turned quickly to a low when instead, Nigel Dodds set up another review. 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 **DSD 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 as the Joint Fundamental Review Group's recommendation formed the basis of our Early Day Motion through Eddie McGrady at Westminster.

## DSD REVIEW (MEANS TEST)

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 DSD Review Group which 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.

Once the announcement of the setting up of the DSD Review Group was made, community and paediatric Occupational Therapists, diligently began to identify unmet need. The information gathered helped inform a very influential **article written by Paraig O'Brien, which was published in the British Journal of Occupational Therapists**, later in the year (June 2003). This article brought the debate around the means test to a wider audience. The timely contribution also verified the scale and some of the reasons why people were withdrawing from the DFG system.

It was extremely difficult to gauge unmet need because of the way records are kept by different agencies and often the formats prevented even non-confidential

statistical information from being shared. Sometimes the situation was worsened when applicants withdrew without formally notifying the authorities or even giving a reason why.

Hazel Winning co-ordinated the data collection from the Paediatric Occupational Therapy Service, while Brid De Ornellas collected information from the Occupational Therapy Managers Forum. Both these individuals, and the teams who worked with them, including Brid's predecessor Roisin Wylie, had gathered essential information, yet this could so easily be overlooked in a story such as this. **Unsung heroes, such as these, have a critical role to play in any move towards change. Information on the scale of unmet need and the reasons why parents withdrew, was essential for the Review Group to make any kind of recommendation to the Minister. Similarly in England and Wales.**

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, Sharon Milner (a researcher from Queens University), Brid De Ornellas (an Occupational Therapist manager from Belfast), Elizabeth Brisbane from Disability Action and myself. The first meeting took place in Belfast on Monday 2 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 Action's representative – indicated that abolition of the means test was the only option, while Paraig O'Brien, following

preliminary investigation into the nature of withdrawal from the DFG system, identified abolition as one of the options to be considered.

### **First Meeting**

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 factual meeting. Hard evidence of the scale and nature of unmet need was presented from the Occupational Therapy studies, which confirmed the issue identified by the Family Information Group and the Joseph Rowntree Foundation. 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 how that issue affects people. Those most affected know but often those outside the situation do not. **This is why the lobbying of MPs 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" etc

but it could be as simple as walking into a politician's 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 actual 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.

More information on costings and the scale of unmet need was required to build on the Occupational Therapy Findings. This would involve NIHE Grants. David Bass and Paraig O'Brien were asked to carry out further research. Paraig looked in depth at what happened families over a three year period in the Derry area. This involved collaborative working between the NIHE Grants Office and the Occupational Therapy Services in Foyle Health and Social Services Trust (that is in and around the Derry area).

David Bass and Kathleen Hicks identified the general level of family withdrawals from the DFG system throughout Northern Ireland using NIHE statistics. **These findings identified high levels of withdrawal and the parental contributions, although high for some individual families, were not large in statutory terms.** It was also recognised that they could not fully identify the full cost of potential parent contributions because of withdrawal before all potential contributions were calculated.

**When you look at this, clearly it can be seen in any campaign 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.

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 throughout Northern Ireland 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.

## A BREAKTHROUGH

### Second Meeting

Just before the summer of 2003, a meeting (the second) was called for Tuesday 1 July. I did not know what would happen but I really had few expectations that we could have moved on. 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 the 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 were excellent with providing information on this), and 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, it was incredible.

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 in the NIHE Grants Offices and Occupational Therapists throughout NI. 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 which 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 to us, but also what was more important was 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 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 were 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 MPs continued, with parents encouraged to bring their issue to their own MP. Although this is a slow process, the number of MPs 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.

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 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.

## PRESSURE BUILDS UP

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 MPs and MLAs were asked to write to John Spellar, simply to ask him what the recommendation was from the Review Group and what his response was 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 frustrating time but we were used to this by now, but it wasn't any easier to deal with.

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

## FROM ISSUES TO POLITICS

As we move towards the conclusion of this story, let's pause 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, captivated the audience as she expressed her anger at leaving her home to build a new home as this was more affordable than having to make the contribution towards the Disabled 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. I went on to explain that we could not build up parents' expectations unrealistically on this issue, just for them to possibly be dashed later. Parents were the backbone of this campaign, we respected them too much to do that. We had to remain realistic, while still working to achieve the impossible. I believe parents would understand that.

Derry Children's Commission were 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 all now making their influence felt as they wrote to ministers. Helen Ferguson of Carers NI and Nuala Norris with Fidelma 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 colleague 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 as we wanted to attract a wide audience and broaden the discussion to the wider issues affecting disabled children, in relation to housing.

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 proposed 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 O'Brien, 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 he had two other engagements. 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 in the main conference room.

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 something! Next he went on to mention the Homes Fit For Children campaign. 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, as I pointed out earlier, was to look generally at housing issues for disabled children and their families.

As if this was not enough, he referred to me as being annoying because of my letter-writing campaign to MPs, MLAs and other politicians. Then I found out what it was about. He had a certificate for me. So I thought I was to get a certificate to acknowledge my letter writing but soon discovered differently when I was invited onto 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 in front of seventy or eighty people, unable to speak. **Instead of a certificate it was a press release from John Spellar, embargoed until 10.30am that morning (to coincide with the start of our conference), 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 for some time later. We all had done the impossible, what we were told we couldn't do, we did.

## THE AFTERMATH

The applause faded, the congratulations offered, I got through the day, I got through the weeks. The limited press coverage has now been exhausted, yet the significance has 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, Occupational Therapists, NIHE staff, campaigners and everyone involved. 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 loss focus. We persevered, committed to change and change we did.**

Radio Foyle (Susan McReynolds) and the *Derry Journal* were very encouraging and covered the story, the *Belfast Telegraph* had John Spellar's press statement, and later the *Newsletter* gave it coverage as did the newsletters from Contact A Family and North West Community Network. 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.

## CONCLUSION

### Every Little Counts

It was hell of a journey. What once seemed an individual problem, something maybe even to do with our own failings as parents turned out to be something completely different. There will be some people who would say they couldn't do this about their issue. Perhaps it is true, but this story – if it does nothing else – should show **that it only takes some people doing small things, rather than a few people doing large things to create change.**

A letter, a word of encouragement, attending an odd meeting, sticking stamps on envelopes maybe this is what it will take to remove the barriers that impinge our quality of life. This is not a story about housing, it is a story of people genuinely working together for change, even if they all have different agendas. **Politics is not about other people, it is about you, how you live your life, what controls, who controls, it is about you and your children and you really can change injustices.**

### The Bigger Picture

To those who still cannot see what happened, who still see it as a human interest story about one person, there is nothing really I can say to change your mind. Certainly in Northern Ireland I led this campaign up through the Family Information Group, I worked hard but so did many others. I attended meetings so did many others, I wrote letters, so did many others.

In the background, unknown to many, people were working on this issue and it is really to them the credit is due. This

is not an attempt at being humble – it is honest. Those politicians, at all levels, who agreed to run with the issue, even though disability is not a priority issue, took real risks.

Writing letters to ministers, lobbying, engaging in conversations with senior civil servants, encouraging political colleagues to become involved, giving advice and guidance to a very naïve parent as I was then, and probably still am, encouraging, pushing forward, being there.

There are those, including myself at one stage, who question what MPs, MLAs and local councillors are paid for. However, in championing this issue, they earned their money. **To highlight, at this stage the role of one politician over the other would be unfair, already you should have a good picture of their involvement. They deserve much of the credit for this change, a change that they made happen in Northern Ireland first and a change that it is hoped will follow elsewhere.**

In a political system that is often criticised, demeaned and made fun of, our politicians pulled off what very few others could and I thank them for that. **John Spellar too would need a mention** in that he took the responsibility into his own hands and acted on the recommendation of the Review Group, he could if he had chosen, ignored this.

### **Behind the Scenes**

Busy as bees, again in the background where the researchers, the paediatric Occupational Therapists and NIHE Grants Departments, gathering information,

collating evidence – evidence that was needed if an objective decision was to be made. In this story, this vital work has often been ignored, **yet without the evidence there could not have been a decision.** Whether it was commissioned work by Joseph Rowntree Foundation or the painstaking work of gathering statistics etc from local records in Northern Ireland, this was really the work that had to be done. To all those unsung heroes we are grateful.

Those involved in **both Reviews (Fundamental Review and the DSD Means Test Review Group)**, of course had a pivotal role in bringing the issue on to the agenda. Even yet I can remember how overwhelmed I was when I learned that officials from NIHE and DHSS&PS had recommended the abolition of the means test – challenging for what I would have considered were seasoned civil servants. Then for our own DSD Review Group, congratulations on agreeing unanimously to recommend the abolition of the means test. Sometimes it is better to be working on the inside than to be criticising from the outside. Well done to all involved!

## **Support**

When support was needed, it came. From the early days of the campaign in England and Wales as groups and individuals signed up, to the later days in Northern Ireland where from every part **groups – who even had nothing to do with disability – came forward to lend their support.**

The support of this sector came in different forms, letters, telephone, advice but also encouragement and guidance on how to keep going. **Again to name individual organisations would be unfair**, the positive relationships built up through this campaign reassure me that those who work closest with us already knew how much we valued their support.

Of course there were individuals, from all walks of life, who helped us along – mostly in private. Individuals also from statutory agencies who came along to events, to support or to find out more. Individuals who will never be named because they would not want to be acknowledged, their involvement is acknowledgement enough for them. **There is always a role for an individual in any campaign and we were glad we had ours.**

### **England and Wales**

Then we look over the water. **The team from England and Wales, the circle of support around them and the wider broader support. The campaign, strategically planned for Northern Ireland, would not have had a positive outcome if it had not been for this connection.**

From the early days, to the present – commitment, perseverance, words come easy but we have been on an emotional bandwagon, with so many disappointments. Again the names do not matter, we have built a strong band and we value each other and we respect even our different stances. We have been through a lot together and it is not over yet.

## **Parents' Crucial Role**

But, and I make no apology for this, last but not least we have the parents of disabled children.

From the early days in London and Birmingham where parents made me aware of the horrendous impact that means testing was having on England. To our own home, our own family, who had to put up with so much because of this grants process and then see me thrust into a campaign which seemed to preoccupy every living hour.

To the families of our own Group, to those who took time to support us, to those throughout Northern Ireland and the UK who telephoned, wrote letters and/or contacted their political representatives. This kept the campaign on the ground. We parents knew the issues, felt the issues and lived with the consequences. Either directly or indirectly we helped drive this campaign forward.

**Years ago the campaigners were right, we needed parents and we needed them much more than they needed us. As one parent said at the end of our Derry conference: "It is too late for us, Brendan, but it is not to late for others."** As emotion came to the surface I knew what she meant and I was very proud for all the work she had done for the campaign, even though she could never benefit. **She will never know how influential she and all the other parents were. In reality, the campaign is and was about them, the rest of us were just players, important players, but players all the same.**

## NOT OVER YET

The story is not concluded yet. We are committed to changing the policy in England and Wales and abolishing the means test there too. This was always part of the plan. Much work has already been done. Even if the “rumours” coming across the sea are true, that there may be the possibility that mandatory grants will be replaced by discretionary grants in relation to Disabled Facility Grants, this will not deter us.

We remain focused. We want the abolition of the means test in relation to parents of disabled children and we want this in relation to the mandatory grant. A mandatory grant is a right, if you are eligible, you have to get it. A discretionary grant means it is someone else’s choice. We are still a single issue campaign, tied in to the mandatory grant.

The story is now over for me in Northern Ireland. It will continue elsewhere for a while longer and I will be involved somewhere. After the announcement in Derry I wanted just to go home and close the door. Life is sometimes like that, you just want to get on with your everyday living. Unfortunately too many families cannot do this. We owe it to them to remove these barriers that prevent family life, means testing is one such barrier. **If this story shows nothing, it shows how genuine people can work with each other and help each other to move on.** I moved from issues to politics, now I just want to go back to the concerns of life before they were issues, that is the real challenge.

I am sure I did not thank everyone so now I do and I say **that I am very grateful to all those who were with us in any way.** As a parent I cannot believe that we all achieved this change, but even as Facilitator of the Family Information Group I also still find it hard to believe.

But if justice is real and if we live in a fair inclusive society, then this will not be the first nor the last change. We all deserve better, thank you all for helping make it better. Let us now concentrate on the unfinished task. **In Northern Ireland we did the impossible, in England and Wales we will do the possible!**

Remember that Monday 16 February 2004 will go down as the day when the impossible happened, the day that the means test in Northern Ireland was abolished for parents of disabled children who were eligible for the Disabled Facilities Grant for their disabled child, and who were living in the private housing sector.

It was also the day we will look to when things get hard again, when the pressures of life are coming on that bit stronger, maybe when things seem impossible and maybe we will recall the words: "The Impossible Took a Little Longer" and we will realise, if it can be done once, it can be done again.

"Hand me over that phone... Give me over that pen, I want to write a letter... Who did you say my MLA is? Or was it MP?" That is all it takes, and the story begins again. Thanks to all who helped make this story.

## BACKGROUND – 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 and NI involved  
“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 OT Managers’ Forum (Belfast)

(February) Homes Fit For Children Workshop, Derry, with Frances Heywood

(December) Notification that Fundamental Review Steering Group recommended abolition

**2002 (June) “From Issue to Politics” Conference in Derry with Frances Heywood and Parent. Book published.**

**(October) “Beyond Words” Conference in Derry**

**2003 (December) “Where Do The Children Live?” Conference (Derry) with Joseph Rowntree Foundation**

**4 December – Announcement at Conference of abolition of the means test**

**2004 16 February – NI means test abolished**

**There were many other events, just as important as these, which significantly helped the campaign along but they will be highlighted another day. This is just a short summary.**



## THOUGHTS FROM OUR CAMPAIGN

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

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



