

**Involvement in Action  
Not in Words**

**Brendan Mc Keever**

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**A special word of thanks to our daughter Ruth Hume and our son Jack Mac Íomhair for kindly sponsoring this book, it is a lovely Christmas (2025) present. Like your mum, Teresa you have supported my work and me over all these years, it is much appreciated.**

Sincere thanks are due to Shaun and Jennifer Monaghan for their skilful editing and proof reading which have ensured a much better presentation and content.

**B M K PUBLICATIONS**

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## **Where to Begin?**

This book is a **personal** reflection on my experience of involvement from my life and work in the community. It includes what I call “a model of good practice” from which I believe we can learn lessons – “Homes Fit for Children.”

Let me also introduce you to the Family Information Group based in Derry in Northern Ireland. I feel this is important because I with other parents with the help of several people employed locally in statutory Health and Social Care agencies in Derry came together to explore the possibility of forming a group.

This Group aimed to raise the profile of parents of disabled children and their experience of accessing services. We called this “the family view of disability.”

This was away back in 1997 when at a strategic level concepts around involvement, “lived experience,” Personal and Public Involvement,” Co-Production, User Involvement were not on the agenda.

Engagement did take place on the ground between individuals and parents with a number of enlightened individuals working in Health and Social Care, such as the individuals supporting our group.

But at senior management level and policy level it was virtually unknown, at least in our eyes. The agenda was always being set by others.

Working with parents together we helped to raise their profile by providing them with accurate relevant and accessible information. We organised courses for parents and opportunities for them to engage with a whole range of professionals both from the statutory and voluntary and community sectors.

Our major work was making presentations to a range of groups and individuals to help them understand what was meant by the “family view of disability.” At times sometimes the presentations were well received, sometimes they were not.

We began work with social work students at Magee Campus (Ulster University), through Huw Griffiths and through Joe Duffy at Queens University.



**Huw Griffiths**



**Professor Joe Duffy**

The work was with individuals and groups of students, alongside those from a “user of services” background and we shared that experience with the students.

This was at a time when the concept of User Involvement was becoming a key component in social work education. I also shared accessible publications from the Family Information Group.

**Family Information Group Publications**



  
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Huw was the first person to invite me into a university to engage with social work students. I was very naïve then but he was always very supportive.

I met Joe at Magee Campus and he invited me to Queens University when he went there to lead up Involvement with social work students there. I learnt so much from him and got an opportunity to try out a range of activities, particularly a number of research projects. I also got a unique opportunity to develop an innovative tool on engagement – “In Conversation.”

I felt like giving up this social work education on one occasion. For some time, I had felt that lecturing an auditorium of around 120 students was just not working for me. It was as if I was talking at people. Some of whom at times were preoccupied with other things. Worse still I was actually facing them.

I decided to talk over with Joe, an idea I had which I called “In Conversation.” It was very simple based on one-to-one interviews about my life, my “lived experience.” but as a learning tool. “Lived experience” is part of the curriculum of student social workers

In other words, I proposed having a conversation face to face with Joe on a platform in front of a studio audience.

Joe was impressed and he used all his skills to create a homely atmosphere with soft chairs on a platform, pinned on unobtrusive microphones and warm surroundings.

Although I knew Joe very well and vice versa, we put in a lot of preparation of questions and answers until we were comfortable with them. We prepared some prompting notes. Literally the stage was set, it was time to try it out.

The auditorium packed up before nervously we took to the stage. We sat down, made ourselves comfortable and just started chatting to each other as if there was no audience there. Personally, there was none as I became so engaged in Joe's questions and comments.

Time passed and then we decided to leave the notes on the floor and simply engaged with each other. At times it was emotional, on other occasions it was challenging and yet other times it was just two people chatting.

Finally, it came to an end and we looked at the audience. One look and we knew this approach had worked, they were engaged and then the questions just kept coming. At that moment we knew an innovative tool had come to fruition and we were proud of our experiment.

This was not the type of television conversation to promote a book or some product. Neither was it an attempt by an interviewer to catch out a guest or get an exclusive sound bite.

This was simply two people in conversation trying to engage an audience by discussing a topic that should be of interest to them. I never lectured after this. I went on with Joe and later some others using the same methodology. It works.

## **Making Involvement Work**

### **Involvement Without the Jargon**

The key to meaningful involvement is good communication and building relationships. The Group's accessible publications were part of this. Over the years the amount of jargon around involvement grew, the more its meaning dwindled, lost in words.

Jargon used internally can help people to understand what certain ideas mean. But that is within a workforce that already are aware of what the jargon relates to. Using the same jargon outside of these settings can be problematic.

I want to go back to basics to see can we learn anything that today would add something meaningful to how we relate to each other, how we could involve each other. Let's go back to the nineties.

### **Doing the Groundwork**

It must be stressed that not everyone wanted to get involved and the concept of the acknowledgement and value of the patient experience would not have been widespread at this period of time.

The value of contributions from those who use services was not always appreciated. Many “**experts**” would have frowned upon such ideas with an elitism that in certain circles still exists today. Qualifications, work experience rather than “lived experience” were the order of the day.

However, on the ground, there were people who genuinely wanted to get involved with each other for their mutual benefit. From them we can learn important lessons that could inform and educate us decades later.

By coming together in one-to-one **relationships** or in groups (the modern offshoot of this is Personal and Public Involvement) they developed what was later called **partnerships** or simply working together.

It could be a professional Occupational Therapist working with an individual adult or a family, **listening** to each other and through this trying to offer a service that was more tailor made for those who used services.

Already we are seeing key words that inform and shape the concept of involvement and need to be understood. Is there a sense of **equality** within these relationships?

Who has the **power**? What is really meant by **partnerships**, indeed are they real partnerships at all? And listening, really listening, does this take place at all?

Or is it all about talking shops with no concrete **action** forthcoming as a result? How does this listening fit in with **consultations** that sometimes seem to be concluded before they even start?

However, we are not ready yet to move forward with involvement. First, we must look at what is needed and to understand why some of these need to be addressed before we start the process of involvement. **Preparation** is a key word when it comes to involvement.

## **The Bread and Butter of Involvement**

Much planning in advance is needed to organise events around involvement. This is the bread and butter of involvement and if preparation is not in place, then it will be very difficult to get anywhere.

**Value** What values do you bring to involvement? Just think of involvement as relationships for a moment. What makes relationships work and not work for you personally? If you do this, you should begin to see what is important and what is irrelevant.

**Trust** is the cement that holds this concept together. Without it, the process will break down quite quickly. Trust does not happen, it is made to happen. Trust has to be built up slowly. To help build trust, where possible, everyone should be involved from the beginning and there should be no hidden agendas.

**Openness** can sometimes be very difficult because it can impinge expectations. We have to be open to each other and open to the possibilities as well as the pitfalls. Openness is the gel that can ensure the smooth movement of the involvement process.

How often have enquires into failings concluded with a recommendation to initiate a process to start implementing a “Duty of Candour,” in other words – openness, but do we listen? It seems like common sense.

**Respect**, so often I heard from different people how disrespect muddied the waters of involvement.

It alienated them, hurt them. Respect is the heart of any relationship but it can be destroyed if people do not value each other, and do not value each other's experience and knowledge equally. Mutual respect is at the heart of involvement, move to the beat of that heart, do not kill it by being disrespectful.

**Commitment**, we are in it for the long journey, this is not a fly by night experience. When things are tough, when you want to walk away and feel you are getting nowhere. Remember most things worth doing take commitment.

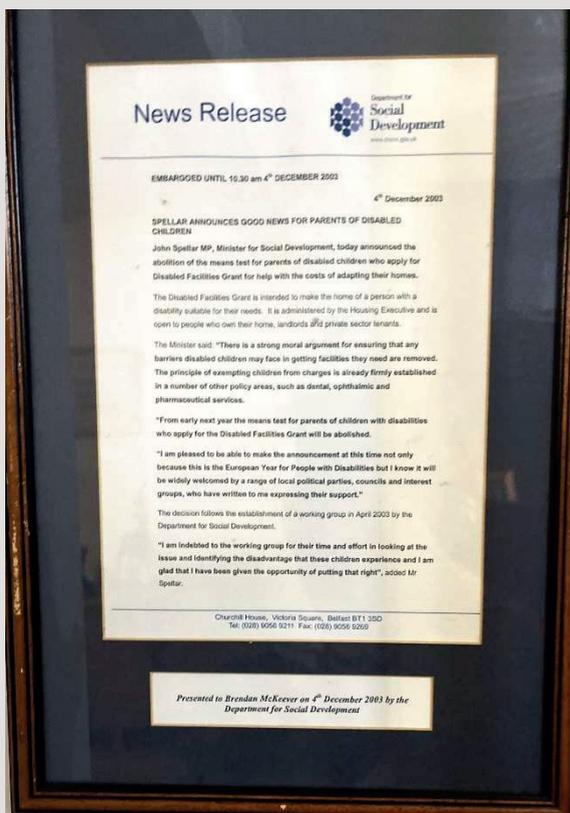
**Honesty**, an essential quality and value in life and in this process of involvement. We must be honest with each other and if in training with the facilitator. Honesty should be a core value.

These are my key values and an explanation of why they are needed in the involvement process. They were there in my experience of involvement as I say long before it became so popular in the many forms it is now in. It worked back then and it can work today, if we go back to basics and understand what it is all about.

Back then there were many people engaged in this involvement process who were committed and whose life have reflected these values featured here. But not just in that period. The same can be said of today too. In the community, in Health and Social Care, there are many committed to the concept of real engagement and involvement if they were only given the space, time and resources to carry out this work effectively.

## Involvement in Action

It is hard to believe that it is over twenty years since I stood on a stage in Derry and received a framed document which I had no prior knowledge of.



## The Framed Press Release

This document hangs proudly on our living room wall. It is a reminder, if I ever needed one, of the power that involvement can have towards positive change. In the words that follow you will clearly see what this is all about, so read on.

Initially a group “Homes Fit for Children” of concerned researchers, voluntary groups and a few parents of disabled children came together in England in 1997 to try and address the limitations of a grant. Jackie Hughes, one of the first parents to get involved stayed to the end.

A grant that was to help disabled people get better access in their homes (the Disabled Facilities Grant). Integral to this grant was a means test on parents which determined whether the parents would receive the full grant or not.

The Group members, small at first, through research, experience and knowledge (particularly from the parents of disabled children) knew that this means test adversely impacted families of disabled children.

Organisations such as the housing charity HoDis who have a special interest in housing provision for disabled people, Contact a Family, the Family Fund.

The Joseph Rowntree Foundation were very interested in the work we were doing to highlight issues impacting families of disabled children but of course could not get involved directly in campaigning, particularly when it got political.

Researchers who understood the potential negative impact of the grant aid which was supposed to assist families of disabled children also paid a prominent part from the beginning. Even a senior member of Health and Social care was also involved from the beginning.

As a result of the Disabled Facilities Grant process at that time, a significant number of parents, who could have been eligible for the grant pulled out of the process also because the process took so long.

It was also very bureaucratic and intrusive into personal financial affairs. Some parents even took out personal loans so that they could afford to carry out the necessary work that was needed.

Research also showed that the cost of disability on families was more significant than families who had no disabled children. This was never really factored in to this grants process.

Families however experienced this on a day-to-day basis - transport costs, caring costs, additional clothing, specialised equipment, on and on it went. Nor were the actual real outgoings of parents factored in as in the grants process these were worked out on a formula basis of allowances, not the money spent by families.

It was thought essential that parents got more involved in this campaign because this issue was of great concern to them.

Today this would be referred to as “**lived experience**” but to parents and their families it was just about life as they knew it and the quality of life, they wanted for them. User Involvement, Engagement, Partnership working and such wording and phrases would have meant nothing to them.

I was in contact with Frances Heywood, a researcher from Bristol who informed me about the housing campaign. She invited me to join. I had to think about this as it would involve attending several meetings in England and I did not really want to be far away from home.

Finally, I agreed. I knew all about the limitations and bureaucracy relating to this grant. We had just been through it. I also knew the benefits of having a safe accessible home when we finally got part of the grant with the help of the local Health Trust.

The Steering Group of “Homes Fit For Children” summed up the personal experience of our own family in a preface to a publication at the time. (See below):

“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.

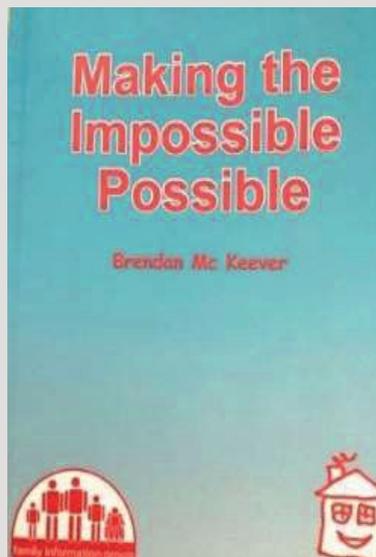
Then he had the three great virtues of faith – that something could be achieved; hope – to keep him going in the face of formidable obstacles – and always compassion towards the suffering of other families. And, mixing the three together, he had a dogged determinism that would simply not give up when 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.

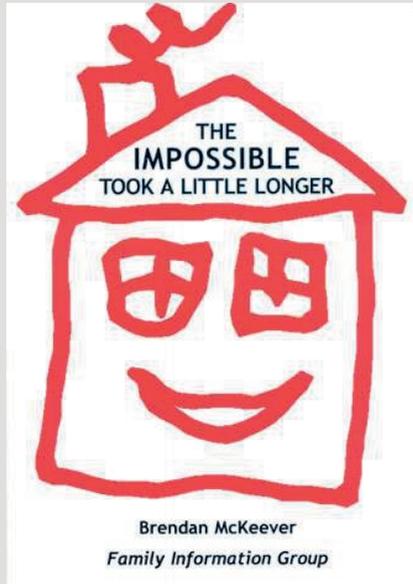
Some people stop when they reckon they have done enough. Brendan stops when he thinks there is nothing more he can do. And finally, Brendan McKeever is a part of a family, and always saw how, in the provision and funding of adaptations, the needs of children could not be separated from the needs of the 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, Jackie Hughes & Keith Bowen - Steering Group of Homes Fit For Children



## Homes Fit for Children

I insert below the logo which was on a book about the campaign.



It goes without saying that by this stage in my life with my work with the Family Information Group and personal experience that I was convinced of the power of parents of disabled children and their families, even though we seldom had our own voice.

I was equally at a point where I firmly believed that the experience and knowledge of parents had to be part of any planning of services for their children if they were to be effective.

This work on housing became a critical part of my work with our own group.

With the support of my management committee, I was allowed the time to engage fully in this campaign which became our number one project for a long time.

Looking back, I now believe that it was through this work on the housing campaign that my belief in partnership working as being the most effective way forward was strengthened as long as all participants are respected and valued equally.

Each of the key participants in the campaign group concentrated in their own areas and utilising their own experience and knowledge, but we also met regularly in England.

HoDis and Contact a Family had their own contacts which they developed further and several individual disabled people involved were also members of other groups which became very supportive.

Frances continued with her research concentrating on building up evidence of the impact of this grant on families. Her findings were eventually to have a great impact on helping to create the change.

Also, she linked with me in Derry quite a lot and came over on several occasions to attend workshops here on housing issues.

The Family Fund were working directly with families of disabled children so they too were very aware of the issues and could signpost parents to other supports.

Initially I was the sole representative from Northern Ireland and started to collect evidence from families here that could one day be useful. At one point I collated evidence from families who had children with Duchenne Muscular Dystrophy in England and fed the findings through to Frances.

Working in the community sector I also engaged with other groups to gauge their support for the campaign. Gradually, slowly at first, that support began to grow as people became aware of the issues. Never did we promote the image that families and their children as being “vulnerable.” We worked on their strengths.

Whether by plan or intention, Northern Ireland became the priority region to concentrate on in the campaign, while still England and Wales continued with their efforts.

We soon realised that although support was growing in the end it would be the Government and Assemblies that would have to make the change. This was unfamiliar territory to us, at first anyway.

We were told that Primary Legislation did not have to change, this would have taken many many years, but rather Regulations round the Legislation.

It was explained to us that this would not take as long. Suffice to say we felt we had at last a breakthrough.

But could we continue to work at this level. I was not sure as we stepped further into the unfamiliar and unknown. Tentatively, just as a few politicians in England and Wales were coming on board. It was time for NI politics.

Presentations on this issue had now become the norm for me. I would talk to anyone who wanted to listen and even those who didn't want to. Simultaneously we pumped out and distributed a variety of information leaflets.

## Images from the Campaign

### LOOK AT THE FACTS



**FACT** In NI on 16th February 2004, the Means Test on parents of disabled children was abolished.

It is time for England and Wales (where there is similar legislation) to follow.

**FACT** The right to a safe accessible home is being denied to disabled children because of the Means Test.

Parents are pulling out of the Grants Process because of the Means Test or going into debt.

**FACT** The Means Test is not an accurate calculation of actual income and expenditure.

Occupational Therapist identifies the need for adaptations, not the parents, so the identified need goes unmet if parents cannot afford the contribution.

### Quotes

"There is a strong moral argument for ensuring that any barriers disabled children face is getting facilities they need are removed."  
*(John Speller MP)*

"While amendments could be made to the current means test, some children could lose out... the only way of ensuring that no child is disadvantaged is to exempt the parents of disabled children from the means test."  
*(NI Disabled Facilities Grant Working Group)*

"Parents wish for the 'best' for all of their children, for our disabled child, we wish for the 'bestest'."  
*(Parent, Malinfrith)*



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O P E N  
Y O U R  
E Y E S

LOOK AT THE FACTS
LOOK AT WHAT IS POSSIBLE
LOOK AT THE FIGURES

**FACT** Parents' health at risk and families face additional hardships, stress and frustration.

Litigation claims due to inappropriate housing provision could arise, particularly for those working with families.

**FACT** Quality of life for families of disabled children is suffering and they are disadvantaged - lack of space, lack of access, development and growth stunted as opportunities for play are limited, siblings also suffer.

Generally more well-off parents will meet the cost of adaptations themselves and often they have less need for major work (just to target houses).

**FACT** Support for abolition is growing among parents, researchers, voluntary groups, Occupational Therapists and politicians (there is now a third EDM-298).

Additional resources needed from different government departments to meet the cost of abolition are comparatively small, most adaptations are for adults.



**ABOLISH THE MEANS TEST ON PARENTS OF DISABLED CHILDREN NOW!**  
&  
**RETAIN THE MANDATORY DISABLED FACILITIES GRANT!**

| TABLE 1  |      | TABLE 2 |       |
|--|------|---------|-------|
| QUESTIONS  | YES  | NO      | £1000 |
| Heavy with DFD process   | 2%   | 222     | £238  |
| Can't afford contribution  | 2%   | 430     | £298  |
| Consider paying last   | 66%  | 240     | £798  |
| Consider a ban   | 60%  | 456     | £1038 |
| Support abolition  | 100% | 260     | £1438 |
| <b>Summary of responses to key questions (simple majority of parents of disabled children)</b> |      |         |       |
|  | £70  | £1838   |       |
|  | 300  | £2338   |       |
|  | £90  | £2837   |       |
|  | £100 | £3288   |       |
|  | £110 | £3691   |       |
|  | £120 | £4028   |       |
|  | £130 | £4300   |       |
|  | £140 | £4518   |       |
|  | £150 | £4711   |       |
|  | £160 | £4858   |       |
|  | £170 | £5062   |       |
|  | £180 | £5282   |       |
|  | £190 | £5518   |       |
|  | £200 | £5748   |       |

**TABLE 3**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 4**

Examples of actual parental income at time of disabled contributions:

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**TABLE 5**

Examples of actual parental income at time of disabled contributions:

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**TABLE 6**

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**TABLE 7**

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| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 9**

Examples of actual parental income at time of disabled contributions:

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| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 10**

Examples of actual parental income at time of disabled contributions:

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| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 11**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
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| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

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Examples of actual parental income at time of disabled contributions:

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| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
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**TABLE 14**

Examples of actual parental income at time of disabled contributions:

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| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
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**TABLE 15**

Examples of actual parental income at time of disabled contributions:

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| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 16**

Examples of actual parental income at time of disabled contributions:

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| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 17**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
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| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 18**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 19**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 20**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 21**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 22**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 23**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 24**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 25**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 26**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 27**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 28**

Examples of actual parental income at time of disabled contributions:

| INCOME  | CONTRIBUTION | £1000 | £1500 |
|---------|--------------|-------|-------|
| £10,000 | £500         | £1400 | £1900 |
| £15,000 | £500         | £1400 | £1900 |
| £20,000 | £1000        | £1000 | £1500 |
| £25,000 | £2000        | £500  | £1000 |
| £30,000 | £3000        | £0    | £0    |

**TABLE 29**

Examples of actual parental income at time of disabled contributions:

| INCOME | CONTRIBUTION | £1000 | £1500 |
|--------|--------------|-------|-------|
|--------|--------------|-------|-------|

## Disabled Facilities Grant For Private Housing in N.I.



From Monday  
16th February 2004  
No Means Test On Parents\*  
Of Disabled Children

More Information from your Local Advice / Information  
Centre or from NIHE Grants Office



## N.I. Abolition Celebrated un Derry



**N.I. Launch**



**Welsh Launch**



**London Launch**

The day finally came.

I was going to meet my first politician. Mary Nelis of Sinn Fein a long-standing community worker in Derry.

Nervously I opened her office door in the Glen area of Derry. In that small office my political education began. I needn't have worried as Mary was a mother figure and I warmed to her immediately.

With her was her right-hand woman, Maeve Mc Laughlin who always was more than helpful.



**Mary Nelis (MLA) and Brendan Mc Keever**

I do not remember how long I spent there on my first of many visits but I know Mary listened attentively with a lot of understanding and empathy.

She offered several helpful ideas but most importantly she backed the campaign and promised to help in any way. There was a bounce in my step as I left that office and couldn't wait to phone colleagues in England and Wales.

Mary was never one to blow her own trumpet but I firmly believe that she was the major influence in ensuring several councillors, Members of the NI Assembly and eventually all Sinn Fein members of Westminster to come onboard to support the campaign.

Although Sinn Fein MPs do not take their seats at Westminster, they do in certain circumstances lobby other MPs and they undertook to make them aware of this campaign. They were very successful in doing this.

Next on my list was a well-known figure in politics who lived locally. Mark Durkan was John Hume's friend, colleague and right-hand man for more years than you can count.

He later became the Leader of his party, the Social Democratic and Labour Party. He was and is well respected widely and has had a great influence in working for peace for many years. He was also a Member of the Assembly before becoming an MP at Westminster and was well known to many other MPs there.

I went to meet Mark with the same apprehension that I had manifested when I went to Mary. This was a serious business, this lobbying.

But again, everything went well as I sat and explained the ins and outs of the housing campaign. He immediately offered his support and pledged to assist in any way.



**Mark Durkan (MLA, MP & Former Leader SDLP)**

Mark played an important role in Northern Ireland and at Westminster with politicians and families. I recall him phoning me one day to say that he had come across one of our leaflets in Armagh, some distance away.

I was delighted but never could understand how the leaflet got there as we had not been lobbying there.

An unexpected correspondence from Mark's fellow party colleague, Eddie Mc Grady, opened a whole new world to me. I had heard of Early Day Motions as some kind of MPs petition of support. Then he offered to set one in motion for us and get a number of supporters.

The signatures increased, this was another measure of support. Other MPs also initiated these petitions.

One of these MPs was Roger Berry as he persevered initiating Early Day Motions supporting the campaign to abolish the means test.

His first one on 9<sup>th</sup> September 2002 attracted 75 signatures. His last one on 4<sup>th</sup> March 2004 got an amazing 153 signatures. Politics were now working well for us. Eddie Mc Grady (MP) died in November 2013

The initial flurry of political lobbying is not finished yet. I continued this phase with a letter writing campaign seeking support from individual Northern Ireland MPs.

Unionist MP, Reverend Martin Smyth who was well known in the field of disability, offered his support and was very influential in engaging other MPs not just Unionists. Reverend Martin Smyth died in August 2025.

Eventually the combination of all these efforts led to an unimaginable outcome. As the campaign was reaching a peak, all MPs in Northern Ireland supported the abolition.

Also support through the Early Day motions continued to grow.

With the campaign now belatedly being launched in Wales, London, Belfast and Derry all on the one day we were ready for our next political move.

We invited parents to lobby their own MPs on this issue and they did. Also, at one stage I did an interview through BBC Radio Foyle with a radio station in England where parents were raising issues about housing provision for disabled children.

When all MPs from Mark's party supported our campaign and various Assembly members and councillors as well, I put this down to Marks advocacy work on our behalf.

Much later politicians at all levels proved that politics could help create change whether they were local councillors, involved in the Northern Ireland Assembly or Welsh assembly or MPs at Westminster, whether they took their seats or not.

But I have to say for someone like me the journey into politics was a baptism of fire. I was totally unfamiliar with this world. Politics in Northern Ireland had been mostly about conflict in my past experience. I never expected we could ever get agreement and support for such an obscure issue. But we did.

At this point in this reflection on the housing campaign I feel I have to introduce a concept.

A concept that was the basis of my presentation to an international conference on housing in Manchester.

It is a very simple but I feel an appropriate tool to illustrate involvement and partnership working. It is a jigsaw made up of several pieces.

Each piece symbolises diverse groups, organisations and collectives of people. It requires all these pieces to fit together to complete a picture. If one or more is missing you cannot complete that picture.

To me it symbolises what at this stage what was emerging through the housing campaign. For us parents and family members were a key piece. But they could not complete the picture themselves. Another piece represented the voluntary, community and disability groups.

Then there were those who worked in housing, and in health and social care particularly occupational therapists. Individual researchers and collective researchers such as Joseph Rowntree Foundation were also an important piece.

The media in its various formats had to be included. We cannot forget the government either, its various departments and manifestations such as Assemblies.

One final piece represented all those who supported us, especially those who never get a mention. When all these pieces were put together, they formed a complete picture.

The picture in this case was a photograph of our own accessible home, representing the aim of the housing campaign which was to try and ensure disabled children had access to a similar home and a quality of life that they and their family deserved. A simple concept,

But it took all pieces working together to complete the picture. Sometimes this is not easy at least at first.

Some barriers still remained but that did not stop us from assisting parents to recognise their own strengths, experience and knowledge so they believed they could engage with others equally. Such sentiments went to the core of the work of the Family Information Group.

When we had many of these pieces in place, we knew that unless we could influence government to make the change and abolish the means test, all our efforts were in vain.

Politics and research were now becoming our greatest allies.

Researchers such as the Joseph Rowntree Foundation and individual researchers such as Frances Heywood, Bryony Beresford, Paraig O'Brien were critically important.

As well as Hodis, Contact a Family (Wales and Northern Ireland) and our own Family Information Group collating information and evidence.

In Northern Ireland a review group was set up to examine the impact of this grant process.

Later there would be review or similar groups set up in Wales and England. I was invited to join the NI Review Group.

At the first meeting in Belfast there was much discussion.

At the end of the meeting we were all asked what we wanted. Our voice and that of Disability Action clearly stated that abolition of the means test was the only option.

I went home very disappointed even though Paraig O'Brien, his occupational therapist colleagues and housing officials from the Northern Ireland Housing Executive were tasked to look into the impact of the grants process and to gauge if parents were missing out.

Time passed, diligent work continued in the background as support for abolition was growing. The latest Early Day Motion was growing in support beyond our expectations.

The final meeting of the Northern Ireland Review Group was called. Honestly, I was not hopeful. Paraig on behalf of the research group presented their findings. Everyone was asked to respond. One by one the responses came. Abolish the Means Test. The responses kept coming until everyone had their say.

It was not a majority that supported abolition but it was unanimous, every single person in the room. I was delighted. But I knew it was not over yet. Our Northern Ireland Assembly had already fallen. The vote for abolition, the recommendation to abolish the means test would go to a British Minister not a Northern Ireland one.

The findings of this internal review were embargoed from going into the public domain.

We waited and we waited. I even occasionally wrote to the Minister for Social Development, British MP John Spellar to ask when he was going to respond. I did get the standard line that he was considering it from his senior civil servant in Northern Ireland, David Carruthers.

Life however goes on and the Family Information Group returned to working with parents and their disabled children in our advocacy role on issues. Wales and England were on standby.

One of our Groups regular activities was to organise workshops and conferences on a whole range of issues. Seldom if ever were we asked to work on behalf of another group to do this.

I have said already that the Joseph Rowntree Foundation had a particular interest in housing and disabled children. As a result, Alison Jarvis of the Foundation arranged to come over to Belfast to see if we could help them organise a conference on housing and children in Belfast.

I remember meeting Alison in the Europa Hotel in Belfast. The Europa had the unwanted fame of being one of the most bombed hotels in Northern Ireland. It was one of the most prestigious hotels at that time.

When I discovered the lunch menu had stew or sausages and mash as features, I nearly fell over laughing.

These were basic meals at home not a delicacy in a posh hotel. I think I had the sausages. I don't remember what Alison had.

Then I chanced my arm and hit Alison with a bombshell. I offered to host the conference in Derry, not Belfast as she had wanted. She questioned me on this and I explained that Derry was the main city in which the housing campaign had been based and where I had the most contacts. It was agreed; Derry would be the venue. Did you ever think you were in over your head?



**(One of the three publications about the Campaign)**

## **“Where Do the Children Live”**

Early in December 2004 everything was in place for the conference of our lives which on the day our group members helped out but had no intention of participating

On the morning of the conference as arranged I picked up Alison Jarvis (Joseph Rowntree Foundation) and researcher Bryony Beresford from their hotel locally. We were going to the conference after a brief interview at BBC Radio Foyle.

I did find out about Alison, much to my surprise, was that in her earlier years she was a great Punk Music fan, with one of her favourite bands being the Undertones. The Undertones were and are from Derry.

Mickey Bradley, the bass guitarist with the Undertones, grew up in the same street as me in Creggan in Derry. He also happened to be a producer in BBC Radio Foyle. After the interview he agreed to meet Alison after she had finished her interview. Think that made Alison's day.

Afterwards we made our way to the City Hotel.

By this time in the foyer of the City Hotel it was getting busy as guests were arriving to fill the hall. I joined Teresa, my wife and colleagues from the Family Information Group as we welcomed the guests and provided the administration for the event

The sound system was checked and working well.

The local community video company – the Nerve Centre were already starting to film the event. We had assurances that lunch would be ready on time.

Teresa and I were just finishing up as the last guests were arriving. We all had done well. Exhausted Teresa and I prepared to go home.

We were interrupted when my friend Paraig came out to invite me into the opening of the conference. I said I was busy and would come in within a few minutes. A few minutes later Paraig came out to say the main speaker, David Carruthers would not start until I was in the room.

Reluctantly I entered the room thinking he wanted to thank us all for organising this conference. David came to the podium with what I thought were his notes in his hand.

His speech began.....

David mentioned something about me being “a pain in his backside.” I was taken aback at his words and really embarrassed.

He invited me on to the stage to receive a certificate me believing it was “a pain in the backside” certificate. I thought I would play along, to the stage I went.

He handed me the framed certificate and asked me to read the first few lines. It was not a certificate but a framed press release from his Minister, John Spellar,

I read something about abolishing the means test in Northern Ireland from February of next year.

I stopped reading. Everything became a blur, perhaps I was in shock. David offered to read this for me, relieved I agreed.

The audience received the news with jubilation as David announced that John Spellar had abolished the means test in Northern Ireland, effective from the following February.

Still in shock, relieved and exhausted I thanked him and left the conference to go out to the reception to break the news to Teresa.

The long campaign was now over for me, except maybe lend a hand with the Welsh and English campaign from time to time.

Teresa and I went home as I had a few calls to make, arrange an interview or two and prepare a press release.

Over the next few weeks many emails went out to inform parents and groups in Wales and England of the news emerging from Derry. None of this would have been possible without the support from Wales, England and of course Northern Ireland.

It was not lost on us who lived in Northern Ireland that seldom does a policy change ever happen in Northern Ireland first and then other regions follow. It is normally the other way around. There were some people who believed that naturally Wales and England would now follow and abolish the means test. None of us who had been closely involved in the campaign believed this.

As I started to withdraw from the Campaign, we were caught out. Three of our key people were invited to become involved in the English review of the impact of the Disabled Facilities Grant process. Frances was tasked to carry out research and make independent recommendations.

As a result of all this I was invited to become more involved in England and Wales in the campaign. After a little thought I agreed and Joseph Rowntree Foundation decided to support a number of awareness sessions hosted by groups in England and Wales, including parents of disabled children.

I was to visit several cities in England and Wales over a period of time to highlight the issues in the campaign and to explain what had happened in Northern Ireland.

Sometimes, just sometimes you get a piece of luck usually when it is not expected. This was one occasion when I needed a break if I was to go on tour.

On preparing to go on tour I remembered that one of our regional television companies Ulster Television had done a feature with our son that they had broadcast on the news. Also, the Nerve Centre had recorded the Derry conference. Much to my delight the film crew had captured the moment when I received the press release.

I asked the film crew to enhance the announcement from David about the abolition of the means test. Then to join this edit with the Ulster Television report. This video I used as part of my presentations in England and Wales.

In just a few minutes of footage, you had a human-interest story featuring our son. A housing campaign highlighted in such a direct way. Also, you had the “underdogs” challenging the authorities. Finally at the end you had the positive outcome of the campaign and the reaction from the audience. Who could ask for more?

With confidence I prepared for my Welsh and English visits and meeting up with colleagues from the campaign and also parents of disabled children. See the itinerary below.

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 be 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.

## **The Fight Continued**

During 2004 it was obvious to those closest to the campaign that we had a fight on our hands, especially in England. We had a positive feeling from Wales as Keith Bowen from Contact a Family was making inroads with the Welsh Assembly, with support from parents and voluntary groups.

As a final push we drew up a plan, a strategy for the period from June to December 2004. Nothing much happened and 2005 came before we knew it.

## **2005**

We pulled out all the stops that we could during the first six months of 2005. By the end of the summer, we had a breakthrough as all the efforts of Keith and all his colleagues, including politicians worked together for the change. The Welsh Assembly announced that the means test would be abolished in Wales.

We were overjoyed as pressure now built up on England and its politicians. All our focus was now on England, how could they hold out when two out of three regions had abolished the means test.

But they did hold out.

We held our breath as the research was pending within the English Review Group.

People like Ginnie Shaw (HoDis), Jackie Hughes (one of the first parents to be involved in the campaign), Alison Jarvis (of the Joseph Rowntree Foundation) and of course Frances Heywood (the Bristol Researcher and campaigner of many years standing with the Homes Fit for Children Campaign).

Would the “experts” conclude what as families we knew that we needed, to abolish the means test so that families could fairly access this grant. It was a very nervous wait.

We had to wait until 12:08 on Thursday 27<sup>th</sup> October 2005 for an announcement of the British Government’s position on the means test. If the research group made a positive recommendation to abolish the means test then finally, we were there. In the House of Lords, Baroness Wilkins got to her feet and announced that England were abolishing the means test from December 2005.

There were no ifs or buts, it was abolished. Frances and her team had done a really good job.

It is 12:08 in the Lords, parents did achieve something, we all did, and nothing will ever be the same again for many families of disabled children.

I recalled my visit to Huddersfield, it was there after a presentation on the issue, two parents approached me almost in tears. I did not know what was happening.

They had just seen the video from Derry. They blurted out something about parents seldom achieved anything (referring to abolition in NI).

I felt their tears were tears of frustration that they could not see the same resolution ever coming in England. Along with tears of joy for the people in Northern Ireland. Privately that was the day that I decided that I was with this campaign to the end. The look on the faces of these two parents haunted and inspired me.

I have said before I never expected a positive outcome in Northern Ireland but now, we had that I was determined with my colleagues to go all the way. Abolition in all three regions. I was glad that I had stayed involved to the end.

I hope by now that you have some idea why I picked what may seem to be a very obscure “model of good practice.” Not only is it obscure but also it features what would be termed a very minority group – families of disabled children. I would argue however the fact that this campaign was successful for such a group is even more astonishing and was unexpected.

The fact that parents and disabled children were directly involved from the start made all the difference. They became the “experts” with “lived experience.” The base values underpinning Involvement were manifestly visible in all the relationships that developed between health and social care professionals, researchers, voluntary groups, supporters, politicians, special interest groups, the media and the parents themselves. There were no egos.

The focus was always on the quality of life for disabled children and their families and they would never give up. None of us gave up, that is why I chose this example.

## **Edited Feedback on the Housing Campaign**

Please note these quotes are from a range of individuals and from groups and organisations. For reasons of confidentiality surnames of individuals are omitted (except public figures) even though there has not been a request to do so. These quotes remind us of the incredible impact of this campaign.

Congratulations - have just heard the news on You and Yours! A momentous day! Brendan, hope you have a good party and some rest after! Have been keeping people in York in the picture all morning and I gather there may be some a press release from us welcoming the news. Best wishes Alistair, Family Fund

Congratulations. Just heard the great news. Well done!!! We will be celebrating across Calderdale and Kirklees. love to you, Katie.

This is great news and is the result of a concerted effort by a great many people. I just wish there was something we could do for those families who've already got themselves deep in debt. I assume the legislation will not be retrospective.

This is due, I am sure in no small way to all your personal and professional efforts for and on behalf of families everywhere in the UK. I am pleased that we have been able to play a small part.

Best wishes Athena - Rhett Syndrome Association

Here's a message from Alison (also a parent of a disabled child) Many congratulations, Ginnie - and please pass on my congratulations to Brendan too. You must both be delighted that all your hard work has paid off! 'Never underestimate...' and all that!

Well done. Alison

Many thanks - The phone and emails have been buzzing all day. A press release shaped for the people in Durham,  
Regards Paraig

Thanks Brendan. It's down to you that we managed to keep ahead of the subject. Samantha BBC Radio 4

I think Parent Power is going to "Come of Age" in the next few years. Keep up the good work. Brid Farrell (Consultant) SHSSB.

Fantastic news and thank you - without your efforts, John Prescott would have held out and we would have got nowhere! I wonder what the final trigger factor was with regard to changing hearts and minds? Anyway, it worked and thank you again. Best wishes Philippa

Fantastic news!! Janet well done you!! It's all down to your incredible tenacity Brendan - and now you will have to think of a new battle to start fighting..... Seriously - many congratulations and thank you on behalf of English parents  
Jill, Director of External Affairs Contact a Family.

I'm still shell shocked as you must be - thank you so much for all your efforts over the past years and months - you deserve a medal or some reward in heaven perhaps. It will make such a difference to the lives of so many families and will also increase my work load in the coming months but will be well worth it. Best wishes Pat (OT)

Fantastic news, well done Brendan....I would offer to buy you a bottle of bubbly, but Paraig says you don't drink. Hope to see you some time Kate

This is absolutely fabulous news, Brendan thank you so very much for being the driving force behind the abolishment for Ireland, Wales and now England.

Thank you. Best Regards Phil, Great,

FRANCIS (MP) Hello Brendan, Thank you for your e-mail, WOW-- what a result, you and your team should be very proud of all your efforts, letters and perhaps " bloody mindedness" in achieving such a result. Once again thanks for all your help, and bloody hard work.

It has been a real comfort for Mel, Sophie and myself to receive regular e-mails from you, with details of how things were progressing --- Thank you very much again. If you have any advice on the above, we would really appreciate it.

Best Regards and thanks (again) Gary, Mel and Sophie  
Brendan Really pleased. Well done to everyone!!

All the best Roger - Roger Berry MP for Kingswood well done you!!

It's all down to your incredible tenacity Brendan - and now you will have to think of a new battle to start fighting.....Seriously - many congratulations and thank you on behalf of English parents

Ginnie excellent news indeed. Well Done, the hard work that you have put in has paid off, John & Barbara.

A truly magnificent victory. Great credit to you and everyone involved. A life lived in fear is a life half lived. Kindest regards Nick CEO Parent Project UK Muscular Dystrophy

What great news Tried to phone you yesterday but you were v busy! I am so excited but people around me don't seem to know why! The CCNUK conference is in Manchester in a couple of weeks so I'll make sure that people there know! unbelievable.

We have come a long way since that first meeting which Ginnie reminds me was 8 years ago! we want to celebrate! Jackie Yours was the hard work - we just jumped on the band wagon!! Fingers crossed and thanks! Becky

THANKS FOR ALL YOUR HARD WORK FOR THE HOMES FIT FOR CHILDREN CAMPAIGN, ANGIE FROM HUDDERSFIELD RANG ME YESTERDAY, FOLOWED BY A PHONE CALL FROM MY LOCAL M.P., IF YOU HAVE A PRESS RELEASE, WOULD YOU PLEASE EMAIL AS THE LOCAL PAPER HAS BEEN PHONING ME,

THANK YOU ONCE AGAIN AND I HOPE THAT THIS FANTASTIC NEWS REACHES THE NATIONAL PRESS!!!!!!!!!!!! BEST WISHES STEFAN AND FAMILY, FROM TODMORDEN

Hi Brendan, What fantastic news!! Well done! So many families will benefit from this - it is wonderful to see what can be achieved by those with a mind to do it! Thank you! Becky

As an OT I just want to say thank you for all your endeavours in getting the means test abolished.

I am re- reading your book for further inspiration as we have many challenges here in Liverpool at a local level e.g. funding for an Integrated Living Centre on Brunswick Dock, and combating the governments obsession with fragmentation and micro competition to already overstretched Health and Social Services community services. Thanks again for your vision and determination  
John Chair Liverpool Wheelchair User Group

I am very happy to hear that the means testing of parents of disabled children will be abolished, in England and Wales, in December.

Please allow me to congratulate you personally, as I would argue that your tenacity, in securing the same outcome in Northern Ireland, was a crucial element behind the House of Lords' decision on the 27th October.  
Regards John.

What wonderful news. You have achieved so much and I know our children and grandchildren will be so much better for it. Thank you, Maggi. Thanks for letting me know that is to

We never dreamed that a decision like this could be so close, especially after your NI experiences. It is through the dedication, tenacity and leadership of people like yourselves that such injustices are successfully resolved. Many Thanks Stuart, Linda & Ryan.

Just back from Edinburgh this evening. Frustrated by a complete lack of info in the press on the announcement: all we've heard was second-hand via the Radio Nottingham reporter who phoned Peter for a reaction/quote on Thursday lunchtime.

Thank you very much for the time and effort you have personally put into this campaign, it will make a huge difference to us and many other families. Can you confirm what happens next.

This is fantastic news. It feels good to know I was part of making this happen and I now hope that other people who are in a similar situation to how we were will now be able to receive the proper support they need and deserve. Once again, excellent news and please continue to keep up the great work. Rgds Nigel.

So almost two years on the seemingly impossible has been achieved!! What FANTASTIC news.

Your enormous efforts and commitment to this issue will make such a difference to the lives of so many children and their families. It's brilliant.

All best wishes Bryony.

The lives of many families will so much improved. It's fantastic news - well done.

Best wishes Bryony Beresford.

Thank you for your note. This is the final point of what I think was a remarkable campaign led by yourself. Congratulations. I can certainly see many hundreds of families with disabled children benefiting from this in the years to come.

I was away on Friday and missed the announcement which was a little unfortunate since I was actually at the House of Lords then – not actually in it but in one of their office buildings. David (NIHE)

Many thanks Brendan, I'm glad we were able to influence this, Janis.

That's great news. I passed the details on to one of our reporters, so hopefully we did something in our news bulletins about it. Jess.

That's great news... what a fantastic result!! We have a newsletter going out next week so I'll pass the good news on to all our families.

Well done on your relentless hard work, just goes to show keeping campaigns going does come to a lot of good!!! Hopefully now there are families we probably can all relate to will get the right kind of help they need. Well done, Helen.

Already parents in our area are contacting social services (who are also just as pleased as we are) to put our names down for adaptations we need. congratulations to all involved in the campaign. regards, Katie Clarke,

I'm pleased that OTN have contributed in some small way-it certainly makes work seem more worthwhile! Thanks, Sarah.

Thank you for letting me know. I feel very relieved - not quite sure why, probably for all the families who will benefit from this action in future.

I look forward to seeing it in the news. It can't be easy taking on the Government! Regards Allison.

Just wanted to say that the work you have put into getting the means test abolished for the dfgs must have been FANTASTIC and you must feel so proud.

Need I say more. If there is really such a concept as evidence-based practice, what more evidence do you need than the feedback from this edited version of all the feedback.

The time is overdue when we should really listen to those most impacted by policy. **Brendan**

## **Analysis and Acknowledgements**

It is a story that needs to be told. It is a story of real partnership working, of perseverance and commitment and how parents can work with others to create positive change. It is about involvement but without all the jargon and terminology that seems to surround the concept today.

I want to leave you with some final comments to ponder over. There are too many people that I could thank for this achievement so I will just say a general thank you because each of you know who you are.

As this is a personal perspective, I feel I can look back at those who have contributed much to my own personal development over the years. I learned so much from others and sometimes they do not get the attention they deserve.

As you get older and move on from a busy working life and the demands of life, you sometimes get a chance to reflect. For many people what emerges is an appreciation for your immediate and wider family.

My immediate family, my wife Teresa and our three children – Donovan, Ruth and Jack have been the bedrock of my support and encouragement over many years. Even when it seemed that during the housing campaign, I hardly seen them as I was so tied up in campaigning, they were never critical of what I was doing. They always saw the long “game.” They made many sacrifices for me.

When I had to take life changing risks such as giving up a permanent interesting job in the Library Service to begin work in the voluntary sector, with no guarantees, they were there with me all the way. On many occasions they, with some wider family members, participated in the work of the Family Information Group which I helped to found with others in 1997.

Family took on a whole new meaning when the Family Information Group was formed. There I met other families like us, with children with quite diverse disabilities but with the same aim. To improve the quality of life for their and other families by sharing their experience and knowledge. Without their constant support our Group would have floundered. We were in it together and learned so much from each other.

The willingness of those professionals who worked in health and social care to go beyond their involvement with our own family to also engage with our Group was a great asset. From them we learned the true nature of engagement and involvement. This was long before these became fashionable.

The community sector in Derry and especially in Creggan were exceptional in their support and teaching us the real meaning of community development. There were so many other individuals and groups who shared with us their expertise and from whom we learned so much.

I hope it is now clear that we were a learning organisation who came from nowhere but “the lived experience.”

A long-standing friend, Professor Joe Duffy, who worked at Queens University for many years is someone who saw the validity and relevance of the housing campaign and how it would be useful to social work students.

A student came up to me once and asked me why I was surprised that our Group could not continue to work when our funding was stopped. He said we had cost the government millions of pounds.

In the world of evidence-based practice, I have no evidence to back this up. I will just say if there was any truth in this then it was such a small price to pay for such a tremendous victory.

Before the next comment I do I want to say when all this was over, I thought it would be lovely for a family to access the grant when previously they would not have been eligible.

At the end of another one of my presentations a student came up to me. He said he was the parent of a disabled child and had availed of the Disabled Facilities Grant and never had heard of the campaign.

It was a lovely inspiring comment from this student which reminded me of what the hard work and effort had achieved.

A critical thought - just remember that those of us who were at the forefront of this campaign did not create the change, it was all those involved.

Remember the jigsaw, remember the housing campaign if you ever really want to understand involvement.

Through all of this my family have inspired and supported me. Also, my wider family and friends helped me get through life to a happy retirement.

One of the first professionals to get involved in our family was Paraig O'Brien, the local Trust's Manager of Occupational Therapy who deserves to be acknowledged.

But more important than these memories were as a result of seeing our son benefit from independence and be part of our family in a very inclusive way, due to Paraig's housing design.

Working with the Family Information Group (1997 to 2008) will always be a lasting memory. I never had a job like it that was so demanding yet so rewarding.

The late Martin Mc Cafferty, Manager of the Creggan Day Centre who was like a mentor to me for many years. He supported and encouraged our work and often offered practical assistance and was never too busy not to help.

The NI Minister John Spellar, David Carruthers, all those involved in the NI Review Group, research team and of course campaigners often still come to mind for their commitment to seeing this through.

Joe and Paul, of community publishers Guildhall Press ensured we always has high class accessible publications.

I know Dany Cassidy from Creggan for many years. He has had many roles particularly in Early Years work. He also has a key role in developing Gaelic Football. Danny invited me to do a presentation to parents of children in an Irish nursery, who work through the Irish language. A very minority group like ourselves.

One beautiful Saturday morning I found myself travelling to a remote place in Donegal, Gweedore, to a hotel in the middle of nowhere. There the parents were ready for my workshop. When it was over I knew they had got the message from their feedback.

They understood fully the barriers facing us parents just as they had to face them. They understood the isolation and frustrations that we felt just as they felt. When it came to the housing campaign, they appreciated the success that we all achieved and acknowledged this.

I did not need any theories on involvement. I did not need to explain all the different names and concepts of involvement. They saw for themselves the power of partnership working and understood what it takes to get there.

I could spend the next few pages with names who have supported our Group and the campaign. Without their help none of this would have been possible.

As parents of disabled children, we always felt marginalised and isolated but not by those most involved with us.

The housing campaign opened many doors for us and we found new friendships there. **The message however is often missed, it was not just about housing. It was about us discovering that there are also many other minorities whose voices are not heard.**

“Friendship is built on trust, honesty and mutual respect.”

I will leave you with the words from a Beatles song.

“What would you think if I sang out of tune? Would you stand up and walk out of me? I get by with a little help from my friends.”

Thanks Brendan

| Every Picture Tells a Story  | Every Picture Tells a Story   | Every Picture Tells a Story  |
|--|---|--|
| <p><b>The Story</b></p> <p>Linda and Sam Bowers live in Belfast with their sons, Jonathan and Chris. Their story is about the means test on parents of disabled children, and the Disabled Facilities Grant.</p> <p>“The means test being abolished has meant so much to us as a family. Before we were never able to afford the extension because we could not afford to borrow the amount of money it needed to do our home. As the means test was abolished we were able to afford an extended holiday while the work was being done. We all enjoyed this as it took the stress out of the whole situation. We were able to upgrade our kitchen, our doors and tiles to what we wanted.</p> <p>It has made such a difference to our son Jonathan's quality of life. Jonathan is now in his new room, and is loving all the new space so that he can get about in his wheelchair and we are not tripping over him. The final inspection will soon be upon us and we can say goodbye to the builders and get on with our life in our new purpose built home, thanking everyone that made this possible for us to enjoy.” (Linda and Sam Bowers)</p> | <p>“Through Contact a Family, we became aware of the housing campaign. However we were not very familiar with political lobbying. But we were angry so we went to see our local MP Iria Robinson, and simply explained how this grants process was affecting us. She was very supportive and also immediately offered her support to the Campaign by signing her support to an Early Day Motion (EDM). I couldn't tell you what an EDM does but I did know it was a indication of her support. That was enough for me.” (Sam)</p> <p>“While our application was in process, we got news the means test was abolished. This news has taken such a burden of us and our family, not only financially, but also has relieved us of a lot of stress. We had the pleasure of being able to tell Chris that we can afford to go on holiday this year.” (Linda)</p> <p>Help make this story become a reality for families in England and Wales. Abolish the means test on parents now! Time is running out.</p> <p><b>Time to Act</b></p> <p>The Homes Fit For Children Campaign is trying to ensure that families of disabled children have, as a right, access to a safe accessible home. As the</p> | <p>means test on parents of disabled children is seen as a major barrier to achieving this, campaigners have been asking for this to be abolished for some time. It has been abolished since February 2004 in NI but not in England and Wales where there is similar legislation. As Housing Reviews in England and Wales come to an end, there has never been a better time to get this issue on the agenda.</p> <p>Just like Sam and Linda Bowers, people do not need to be political experts. Parents know how this Grants Process is affecting them and their families. But to make things change, they need to tell politicians what it is like, it is the politicians who can politically change things for the better. MPs can show support for abolition by signing what is called an Early Day Motion (EDM) to you and me. It is just the same as a petition. The more signatures, the more chance of this issue being taken seriously. Each EDM has a number, the one on abolition is EDM 298. Parents should ask their local MP to support EDM 298 now.</p> <p><b>Contact Your MP</b></p> <p>Write to: House of Commons, London, SW1A 0AA<br/>Telephone: (020) 7219 3000 and ask for your MP.<br/>Find your MP: <a href="http://www.beebomms.com">www.beebomms.com</a><br/><a href="http://www.beebomms.com/commms/">www.beebomms.com/commms/</a></p> |