

ACKNOWLEDGEMENTS

The Family Information Group would like to acknowledge the support and financial assistance from the Childhood Fund and NIVT. Without their help, the seminars, conference and this publication would not have been possible.

Also there is a deep sense of gratitude to Martin Mc Cafferty (Manager of Creggan Day Centre), all the staff at Creggan Day Centre and to Foyle Health and Social Services Trust for all the help in running the seminars and conferences.

Thanks are also due to all the speakers, invited guests, participants from parents, voluntary and statutory groups who helped to bring to the fore the idea of “professionals together.”

Sincere thanks to Briega Mc Laughlin for typing the manuscript.

The views expressed in this publication are the personal views of the contributors and do not necessarily reflect the policies of any organisations that they may belong to. However it is hoped that these contributions will lead to a wider debate of the issues and encourage those who are actively trying to bridge the gap between those of us who use services and those who provide them. This publication is just one more step in the process, there is still a long way to go.

December 2000



Professionals Together

INTRODUCTION

There is a distance, a gap, between those who provide services and those who use them. For a number of years this gap has been widening, despite various efforts that have been made to try and bridge it, “consumer involvement”, “involving users”, “Children’s Services Plans” – buzz phrases that up to now seem to have fallen on waste ground.

Of course there are people who believe all the hype around partnerships, inclusion and working together. In some cases genuine attempts at becoming inclusive have made some head way, but unfortunately at a tortoise pace. There have been difficulties over who is really representing who, how many people should be involved and questions asked around who is setting the agenda anyway.

Three years ago, the Family Information Group emerged to try and voice the concerns and raise the issues, as experienced by parents and families of children with physical and sensory disabilities. Since then we have been involved in the process of identifying this gap and directly experiencing the inability of some statutory agencies to listen, listen sensitivity to those who use their services.

In the recent past there seems, under the surface, a hardening of attitudes. This is not reflected in the rhetoric nor in the various attempts to develop partnerships. However it is reflected in the lack of response to identified concerns and needs. Also it is reflected in the cautious approach of some statutory agencies to becoming more directly involved with community organisations and groups.

Within statutory agencies, or at least some of them, there seems to be a mind-set, more so at the higher levels of decision making, which refuses to listen to those who use services. Unfortunately this stance is even more frustrating when the message going out to the public is that there is a willingness to listen and various schemes are highlighted as examples of this. It is proving very difficult to erode the well established stance that those who provide services, determine what those services are.

Another approach to services which does not seem to have been addressed, is the lack of forward planning needed to develop and integrate them. Many statutory agencies invest a lot of their energies into crisis intervention when

delivering services, rather than investing in preventative measures. Unpopular as it may be, to those in the financial departments, additional funds are needed, and needed now, to meet the needs, concerns and issues of people with disabilities. By investing now, there is a strong possibility that this will result in future savings. Again this approach does not sit well with the established mind-set reluctant to change.

CHANGE

Central to community work and community development, is change. It is a fallacy to believe that you can engage in the community and remain as you were before the engagement began. The community groups involved in this engagement must also be open to change, it is a two-way process.

For some time it has been recognised that service providers cannot be really effective, unless they engage those who use their services. Part of the change that is needed is for people in the community to begin to see the human face of those who provide services.

On the other side, there must be a recognition that people in the community have a certain expertise and a body of knowledge, they are professional. But what may be surprising to some people is that the professionalism in the community is not a threat to the professionalism and expertise developed within the statutory agencies.

If the attempts to develop this process of inclusion are realistic then there has to be fundamental changes also in approaches to planning. There can be no pre-set agendas – hidden or on the surface. Openness, honesty and straight talk need to guide these interactions if they are to lead to positive outcomes. One side or the other cannot dip in and out just when they feel like it or when it suits them.

During its short time in operation, the Family Information Group, seemed – in certain circles – to build up a reputation of being very anti-statutory. To some extent this was true. However some people misinterpreted criticism of agencies as criticism of individuals within those agencies. As a matter of fact the criticisms were targeted at the underlying ethos and policy that facilitated certain approaches to providing services.

As you listen to the pain – real pain and the voiced concerns of those who use services, a group such as the Family Information Group cannot tone down these issues. Our Information Group cannot tone down these issues. Our remit is to present the “family view of disability” and to try and influence policy by involving those who use services in the planning and provision of them. We recognise parents as professionals, and believe real progress can only be made when they are treated as such.

Recognising that there was a gap between those who use services and those who provide them, and wanting to explore if anything could be tried to bridge this gap a concept was hatched in 1999. This concept – “professionals together” was put into practice, bringing voluntary and statutory groups together with parents of children with disabilities to discuss common issues. A series of lunchtime seminars culminated in a mini conference, all held in Creggan Day Centre. Trust and cooperation with the local health trust was building up.

THE HUMAN SIDE

Before reviewing the work done through the “professionals together” seminars and conference, it may be interesting for some people to find out how we eventually worked so closely with Foyle Trust – despite our public stance.

As pointed out earlier, our public stance is anti-structure there is no apology for this. The stance has emerged as a direct result of the work we have been involved in. It is an honest, up front challenge to those who provide services.

Privately, on the ground and sometimes in public, we seek out ways in which we can build trust and develop relationships with those who work in statutory services. Such relationships have to be built on honesty and trust, never tokenistic. Sometimes it takes a little while for this trust to develop and grow. It is based on the human side – on people from both sides who are willing to work together for the mutual benefit of all. Sometimes it is not easy.

The manager and staff at Creggan Day Centre and our own group were very much aware of the needs of parents of children with disabilities and those who work with them. As a result of regular contact between the Group and staff, it

was agreed that a lunch time series of small seminars – bring together voluntary and statutory staff and parents would be a good starting point to try out this idea of working together.

Preliminary open honest discussions over a period of time led to trust building up. The human side had come to the fore. It was not meetings of representatives of a trust and community group. Rather mutual concerns, issues, and sensitivities emerged and discussions around how to address these.

Despite the emergence of the human side, professionalism and a professional approach to the seminars and later the conference also came to the fore. Indeed it was precisely because of the depth of feeling surrounding these issues that careful planning and organising of events was undertaken.

What emerged was a series of lunchtime events, with invited guests giving talks, concluding with a question and answer session. To open this to a broader audience, it was decided to run a mini conference on the same theme. This proved to be very successful.

A POSITIVE APPROACH

Against this background, the lunchtime seminars were seen as a positive approach of dealing with the issues that concerned parents as well as those who worked in the voluntary and statutory sectors. There was no watering down of the issues and often no solutions to difficulties were found, yet most of those involved gained a lot from the open honest discussion as well as gaining useful information.

For the Family Information Group it was a unique opportunity to work closely with Foyle Health and Social Services Trust, at a local level. This working partnership, which was very real, and which benefited both organisations at grass roots level, showed conclusively that statutory and voluntary can work together in certain circumstances.

In the early days of the group's work there was also this close working partnership when the Trust with the help of the Group became involved in the production of an information leaflet for parents. An informative leaflet resulted

reflecting both the views of the Group and those working in different departments within the Trust.

The flexibility, sensitivity and eagerness to get on with the job at hand were all characteristics that helped cement this grass roots partnership. Of course the individual approach by the Creggan Day Centre Manager and his staff which was so positive, went a long way to nurturing this on going relationship. Honest, open discussions and exploring various avenues, often not explored before, to try and reach an agreed accommodation were the tools that helped this trust grow. At times it seemed very risky to move forward together because of the different perceptions of each of the organisations in the community. However with the focus on 'professionals working together' and the realisation that damage was being done when professionals did not work together, this focus eradicated any of the minor difficulties that did arise.

The choice of Creggan Day Centre as a venue for the seminars and conference was very deliberate. This choice was agreed as a positive statement of what was and going on in the wider community in Creggan, as well as in the Day Centre itself. Agreement was reached on the timing of events, catering arrangements, choice of speakers, target audience and all the administration and back up support needed to carry such events off.

What seemed very encouraging about this working together was the willingness of both organisations to continue to work positively and to always look at ways that things could be done, rather than the opposite.

Perhaps if this positive approach could be repeated in other departments of statutory agencies, and with other voluntary groups, there could be a basis for trying to bridge the gap. The alternative is a repetition of what has happened before, with an increasing sense of alienation.



Professionals Together

THE SEMINARS

Seminars is a fancy word for a series of informal lunchtime discussions that took place in Creggan Day Centre over a period of a few months. Although the discussions were informal, detailed planning went into organising them.

The events always began with a light lunch, followed by a short presentation from an invited guest. Enough time was left afterwards for discussion and questions. The events were timed to end by 2.00pm, to allow people to return to work or go about their own business. Guest speakers usually stayed on a little longer, to allow individuals to discuss matters with them in more depth.

Invitations went out to parents from the Family Information Group, from those who attended the "Time For You Course" (created by Maire Gormely and Brendan McKeever in cooperation with NWIFHE and FHSST Creggan Day Centre), Foylevue School and those who were in contact with Creggan Day Centre. Contact was also made with relevant statutory and voluntary agencies, in an attempt to ensure that different voices were represented at the discussions.

Bringing together people from different walks of life can be risky, at times this proved to be very true in some of the discussions. However this openness and honesty in addressing some very emotive issues was what the seminars were all about. Those taking part, for the most part, knew the risks. Although the subjects were important, what was more important was the shared platform that emerged to discuss common concerns. In small groups, over a period of months, this opportunity was realised over and over again.

FAMILY INFORMATION GROUP PROFESSIONALS TOGETHER SERIES OF DISCUSSIONS

VENUE – CREGGAN DAY CENTRE

TIME 12.30 PM TO 1.45 PM

(Light snacks available)

<i>Week 1</i>	Thur 25 Nov 1999	Nuala Rowan (Contact a Family)
<i>Week 2</i>	Thur 20 Jan 2000	William Carlin Martin Doherty (NIHE)
<i>Week 3</i>	Thur 24 Feb 2000	Helen Ferguson (Carers National Assoc)
<i>Week 4</i>	Thur 9 March 2000	Brendan McKeever (Family Info. Group)
<i>Week 5</i>	Thur 23 March 2000	Marie Gormley (Mencap)
<i>Week 6</i>	Thur 30 March 2000	June Kerr (Family Fund)
<i>Week 7</i>	Thur 6 April 2000	Dr. Mary McGee (Time Out Training)
<i>Wee 8</i>	Thur 20 April 2000	Eamon Deane (Holywell Trust)

STRUCTURE OF LUNCHTIME SESSIONS

12.30	Snack Lunch
12.50	Introduction
12.55	Guest Presentation
1.10	Discussion
1.40	Conclusion
1.45	End of session

The Family Information Group recognises and acknowledges that parents as well as those who work with families are both equally professional and have a lot to offer each other. This series of discussions will give an opportunity to openly discuss areas of concern.

Please note timetable is subject to change

DISCUSSION SUMMARY

Week 1 – Nuala Rowen (Contact A Family)

Nuala gave a very informative talk on the role of Contact A Family. She pointed out some of the organisations main functions – providing information on rare conditions and syndromes, putting families in contact with each other and supporting families with no diagnosis.

Week 2 – William Carlin and Martin Doherty (NIHE)

Both representatives from NIHE gave a detailed description of the procedure involved in the Disabled Facility Grant. They explained the different areas that the grant covered as well as how the Test of Resources work. Brendan McKeever (Family Information Group) gave a brief outline of the Homes Fit for Children Campaign which is lobbying on the difficulties arising from the Test of Resources in relation to children with disabilities.

Week 3 – Helen Ferguson (Carers National Association)

Helen gave an insight into many of the issues facing carers (including parents), emphasising their rights. Also Helen outlined the role of Carers National Association, their campaigning work on the Carers Manifesto and the Invalid Care Allowance. Throughout the talk and discussion the emphasis was always on rights.

Week 4 – Brendan McKeever (Family Information Group)

Brendan gave an outline of the role of the Group and explained what is meant by “the family view of disability”. Also other areas of concern were covered e.g. issues facing parents and the importance of relevant information. The history of the Family Information Group, and why it was started were also outlined.

Week 5 – Marie Gormley (Family Adviser with Mencap)

Marie gave a summary of the role of Mencap with people who have learning disabilities and their families. However she also broadened out the discussion to include themes relating to education statementing, housing benefits, health and social services and support to parent and their rights.

Week 6 – June Kerr (Family Fund Trust)

June gave a full picture of how the Family Fund assists families who have children with severe disabilities. She explained how the Trust tries to be as flexible as possible by listening to the needs as identified by the parents themselves. She answered specific enquiries from the audience.

Week 7 – Dr Mary Magee (Time out Training)

Dr Mary painted a picture of the role of parents and the role of people who work with parents in a professional capacity. She explained the different pressures that people are under in their different roles. Using basic psychological tools, she demonstrated how people act towards each other.

Week 8 – Eamon Deane (Director of Holywell Trust)

By charting his own personal history, Eamon described the basic features of community development. He emphasised the importance of everyone, if they can, making a contribution to their own community.

FINAL THOUGHTS ON THE DISCUSSIONS

As pointed out earlier, the main aim of these discussions was to bring a variety of people together to discuss common themes and ideas. In that sense this series was a huge success as representatives, from the voluntary, statutory and parents attended regularly.

The choice of speakers was very important. All of them had a sensitivity towards their chosen topic but also a great deal of sensitivity towards the audience. The speakers were able to address any questions that were fired at them. There was also a honesty and directness in how each speaker got their point of view across.

It was quite deliberate to invite some of the speakers from outside Derry, as we often don't realise how much support there can be from outside the City. Many speakers commented that they received follow up requests for information as a result of attending the discussion series.

People hunger for information, this was proved over and over again. Many are taken aback by their own lack of knowledge as well as the lack of knowledge of those around them. In this series we only touched the tip of the iceberg of knowledge. There is still a lot of work to be done but in some small way at least we made a start.

QUOTES FROM EVALUATION – DISCUSSION SERIES

“They gave information which will definitely help me in my role”
(Olivia – Voluntary Family Visitor)

“Variety of topics very good”
(Rosemary – Social Worker)

“It was an excellent means of meeting people I had corresponded with previously”
(June Kerr – Regional Co-ordinator Family Fund Trust)

“The presentations I attended were very useful, informative”
(Bernadette – Social Worker)

“Having a forum for open discussion between parents and professionals offers great opportunities for learning and support”
(Sharon – Voluntary Family Visitor)

“Excellent range of informative courses”
(Kitty – Social Worker)

“It is powerful to hear and share views between parents and those working with them”
(Dr Mary Magee – Time Out Training)

“All speakers exceptionally good and informal”
(Brigid – Parent)

“Everyone listened and gathered information as equals”
(Jennifer – Parent)



Professionals Together

THE CONFERENCE

At the end of May 2000, months of preparation work resulted in another step forward for the Family Information Group. A conference was organised in partnership with the local health trust (Foyle Health and Social Services Trust - FHSST) as part of an ongoing process of exploring ways that people from different backgrounds can work realistically together.

Speakers from different backgrounds were invited to give their views on the theme of the conference from their own experience. They were invited to explore what this idea of “professionals” meant to them personally, what barriers there exists to prevent people working together and how can these be overcome, if indeed they can.

Many of these issues were touched upon during a series of lunchtime discussions, which had been taking place in the Day Centre for several months. These discussions again were coordinated by the Family Information Group and Foyle Health and Social Services Trust.

On the day almost twice as many people as expected, attended the conference in Creggan Day Centre, which belongs to Foyle Trust. At one point there were more than sixty people in the room which had been converted overnight from a day centre facility to a conference platform. The staff at the centre had pulled out all the stops to make the day such a success.

Speakers on the platform included: Siobhan Livingstone (Community Health Visitor, FHSST), Gerry Conway (Family and Childcare Team, FHSST), Marie and Karen (Enabling Access Research Consultants), Marie Ferguson (Director of Carers National Association NI) and Brendan Mc Keever (Parent / Family Information Group).

Each speaker brought their own perspective to this theme. However without fail, all the speakers acknowledged the wealth of experience that families, parents and carers have to offer. Also many of them pointed out that often those who care for children with disabilities are not listened to when it come to the planning and provision of services.

Siobhan Livingstone challenged parents and those who work with families, to recognise the human side of what they are doing. She identified clearly the feelings of a “professional” when confronted with a very challenging situation. However she also outlined the “mind set” of some professionals who seem to focus more on their career than those they work with.

The parent’s view was highlighted by Brendan Mc Keever, and many of the views expressed were confirmed by the Enabling Access Research Team. The findings of their research, commissioned by the local Health Board, are now with the Board. The perspective from FHHST, as detailed by Gerry Conway, recognised the role of parents and carers as well as those who work within the statutory system.

A general overview of the role of the carer finalised the contributions from the speakers as Helen Ferguson described the duties of many carers and compared this work to the meagre financial benefit of the Invalid Carers Allowance. It was very clear from her contribution that parents and carers do act in a very professional way with little or no recompense.

Unfortunately time limited fuller participation and discussion of the issues raised. But this conference is only part of a process and there will be other days. Over the following few pages, there is a summary of some of the main presentations of the day.

There was much food for thought, it is up to all of us to turn these thoughts into action.

SIOBHAN LIVINGSTONE

COMMUNITY HEALTH VISITOR – FOYLE HEALTH AND SOCIAL SERVICES TRUST

In her presentation, Siobhan gave an insight into how she felt many people who work professionally with parents and families operate. However she also emphasised the importance of treating everyone as human beings whether they are family members or those who work with families. This idea was central to her talk. Below is an extract from that presentation.

“As a professional, I look back on the time when I was a family health visitor. I know that I was terrified going into families, absolutely terrified particularly if I was going into a family with a child with a disability. I knew nothing about it, I was very fearful. With my fear came suspicion as well. Suspicion goes hand in hand with fear”.

Siobhan continued then to outline what the professional fears and suspicions were:

- Professional Fears I want to be accepted by these people.
I want to be able to do the job.
I will fail
If I fail, it is my fault
- Suspicions: Who exactly are the people I am working with
I don't know if I can work with them
Are they capable of understanding me?
They don't trust me and they never will
- Fears: I don't have any control over the situation
My boss won't be pleased with me
I might get the sack if I'm wrong
- More Suspicions: They will blame me if it doesn't work out
Everyone will blame me, I am accountable
I carry the can
I don't mean anything to them

These were some of the fears and suspicions outlined by Siobhan. At first Siobhan listed them out for people who work professionally with families and then she repeated them again for family members. The fears and suspicions, she argued, were the same for both groups of people. “We are human beings, all of us together”, Siobhan concluded at this point in the presentation.

In the second part of her talk, Siobhan outlined in more depth how she felt people who work in a professional capacity do operate.

“Professionals begin to think that this is too much. I can’t cope and begin to revert into a professional prison or silo. Being a real professional – building a lovely brick wall, built on foundations of being a real professional. Start to use jargon. Remain objective, at all costs do not get involved in that person’s pain. Do not let your feelings be shown. Get ready to give, give, give ...

Plan – implement plan, evaluate plan. My plan has nothing to do with anyone else.

Keep to the task.

Focus on outcomes – my outcome, Trust outcome, Board outcome.

Remember time is very expensive.

Communicate.

See how much I know.

Sympathise with them.

Keep your hopes and worries to yourself.

You’re the most important thing in their lives.

This is only a job, you go home at night.

Work is for work hours.

Be prepared to fail – if you do, it is your fault.

Treat everyone the same – don’t forget equality and equity.

In the end you’re accountable – I’m accountable.

Remember you’re in control.

Remind yourself who pays you.

He who rows the boat falls in.

That's some of the barriers I know I have built up, they are very, very hard to break down, because they keep me in a job, they keep me functioning and they keep me involving myself with people”.

Siobhan finished up by reciting a poem, which gave much food for thought for everyone attending the conference.

MARIA HERRON AND KAREN CASSEN

INDEPENDENT RESEARCHERS

Marie and Karen were invited to the conference to give an outline summary of their research into families of children and young people with disabilities. This research was commissioned by the Western Area Childcare Partnership as part of the work of the Children's Services Plan – covering those who use services as well as service providers.

As the research findings have not yet been publicly published, full details of the findings, as yet, are not in the public domain. It would not do justice to the work of the researchers to try and interpret and summarise their work. It will be interesting to see if their findings are published so that the general public can access them.

In their presentation Marie and Karen outlined how they approached this project, gave information on the current literature available and discussed the relevant pieces of legislation. Also the feedback from young people was outlined and summarised.

GERRY CONWAY
MANAGER, FAMILY SUPPORT SERVICES – FOYLE HEALTH
AND SOCIAL SERVICES TRUST

In his presentation, Gerry Conway gave some details of how the general childcare programme of care responds to need but also how more recently children with disabilities are included, within his department. Also he described the role of the Trust itself, in response to how it carries out its duties and how the Children Order has impacted on this.

“It is very humbling, in some respects, standing here. My role is as Manager with responsibility for Family Support Services. What Siobhan (Livingstone) said earlier, really struck a chord with me for a number of reasons. The wall that Siobhan outlined, Yes I have heard myself say that. I’ve heard others say that. This is a form of self protection, which we will have to get beyond.

The list of attributes about being a professional, that left me wondering. In the field of disability, I have to be open and honest and say I know nothing. My area of expertise is general issues around families in need, not about specific issues relating to disability.

Very briefly the Trust’s responsibility in relation to the Children Order. As a trust we have a general duty to provide social services for children in need and their families, for the first time, with regard to the Children Order, children with a disability are regarded as children first”.

Gerry then went on to give more details of the types of services highlighted in the Children Order e.g. to help children with a disability to have as normal a life as possible. However Gerry went on to highlight some of his own concerns around children who have disabilities, concerns over marginalisation, over a fragmentation of services on offer and he went on to suggest a possible answer. “There is a growing feeling that the services, for children with a disability, in the face of competing demands, remain marginalised, and a lower priority ...

Maybe there is an argument for setting up a Children’s Directorate within an organisation like ours. Services must be available in an accessible manner, locally where possible and building on what is available in local community. Services must be delivered with families”.

Gerry went on to give information about the Children's Services Plan, who is involved in it and how it was set up, about involvement he said:

“the involvement should not be allowed to be merely a tokenistic one. That's the challenge we have to be faced with on any ongoing basis. We don't do it well at the moment, I think we have a lot of ground to make up. The second challenge is to plan services in a more joined up way. I think that through the sort of dialogue people are having now, hopefully that better understanding will lead to better services in the future, and certainly I wouldn't be arrogant enough to think that I could go on and plan these things without listening to the people who really care.

HELEN FERGUSON DIRECTOR OF CARERS NATIONAL ASSOCIATION (N.I.)

Helen started her talk with the description of a very detailed job description. It became obvious that this description was of the caring duties of many people who have to care for others at home. What shocked most people was the financial details which, when worked out, for recipients of Invalid Care Allowance, came to 24p per hour of care. This really showed how valued carers are. Helen then went on to explore the theme of the conference – professionals together.

“Carers are partner professionals. They have their own experience, their own knowledge that they have developed over the years that they bring to every encounter with professionals, I mean professionals in statutory and voluntary organisations.

Many of the parents in this audience, who are parents of children with disabilities, are professional – maybe come from a job, vocation, that they had to give up. Equally many of the professionals here have direct experience of caring for a member of their family. There are points in common between us. It is back again to Siobhan’s (Livingstone) notion of a human being. Human beings that are trying to work together for the good of someone, whose best interests we all have at heart. But it doesn’t seem to be that easy for some season.

Different needs have to be recognised and respected by everyone involved.

If I think of the thing that it is hard to ever estimate is the importance of professionals in the life of carers”.

Helen went on to emphasise the importance of support from Health Trusts as identified by carers themselves. Support is also available from family, friends, voluntary organisation and neighbours. Helen then went on to say:

“It is all the more critical that those involved do understand each other’s role and do respect each other and do recognise the different contributions that each can make to the relationship.

QUOTES FROM EVALUATIONS – THE CONFERENCE

“It was good to see parents and professionals being so open”
(Debbie – Voluntary Worker)

“Very pleased by the interest shown by both parents and professionals”
(Muriel – Parent)

“Today was a great support and hopefully some change will happen and everyone will benefit from it”
(Anne – Parent)

“I found the whole session extremely informative”
(Parent/Voluntary Worker)

“I found out about rights I didn’t know I had”
(Jennifer – Parent)

“Beneficial both professionally and on a personal basis”
(Sharon – Health Visitor)

“Definitely will make many inroads”
(Victoria – Student Health Visitor)

“They were very straight to the point and I just felt we were all equals”
(Donna – Parent)

“Thought provoking”
(May – Voluntary Worker)

“I found it very beneficial and would be more aware of my own approach”
(Gabrielle – Voluntary Worker)

“Things will change through work like today – bringing people together”
(Marie – Researcher)

POINTS FROM FEEDBACK (THE CONFERENCE)

- Not enough time
- Appointment of Key Worker (from time of diagnosis)
- Initiation of a care plan
- More specialist clinics in Derry
- Parents should lobby
- Parents not treated with respect, not listened to and not treated as professionals
- Better co-ordination of services, organisations not working together
- Bridgeview House seen as a good interim model
- We are all human beings
- Better childcare facilities with child minders specifically trained to work with children with disabilities
- More real listening and counselling
- Resources needed, too much pressure in voluntary sector when lack of finance presents statutory agencies offering services
- Rights of child and parent are paramount
- There are gaps in the services
- Social workers should have more specialist knowledge and have more time to listen to children
- Lack of information and communication, should be a central base of information.
- More sign posting, sharing of information between service providers – less need for parents to explain everything

CONCLUSION

Everyone had different views of the value of the seminars and the conference. The points made in the feedback and evaluations serve as the best summary of, or conclusion to these events. Some people came away very much informed and enthusiastic about what happened, others felt threatened and some even were upset at the depth of feeling.

As stated previously, the seminars and conference are part of an ongoing process. It is hoped that this process will lead to a better understanding of parents and those who work with parents, in a professional capacity. If this happens then perhaps genuine efforts can be made to bridge any existing gaps

Change is difficult and this process reflects that difficulty. For many, “parents as professionals and professionals together” are not easy concepts, nonetheless they are viewpoints that the Family Information Group promotes and firmly believes in. If we seriously want to move forward and enhance the quality of life for all our families then we must begin to address the issues that these concepts give rise to.

In Creggan, our Group found a genuine positive approach to parents and families by parents themselves and by the manager and staff of the Centre. We hope to build on this in the future. As professionals together, it is hoped in some small way that quality of life is improved and that we can work constructively on what we have in common, rather than what we see as our differences. This would be positive professionalism for all.