

**Focus on
Families:**
Messages from
family carers

Focus on Families

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Introduction

Background

IN October 2002 the Department of Health, Social Services and Public Safety (DHSSPS) launched a major, wide – ranging and independent review of law, policy and service provision affecting people with mental health needs or learning disability in Northern Ireland. The Review follows similar exercises in England and Scotland and is expected to take about 2 years to complete.

This report has been prepared to highlight issues that family members who support a person with a learning disability have told us need to be addressed in the Review. We hope that the report ensures that the voices of family carers are heard and acted on by all those who have an opportunity to influence the Review.

About the Review

The Review of Mental Health and Learning Disability (Northern Ireland) (The Review) could be described as having 3 distinct strands:

- a review of policy and service provision for people with a learning disability.
- a review of policy and service provision for people with mental health needs.
- a review of the Mental Health (Northern Ireland) Order 1986.

Whilst there are overlaps between each of these strands there are clear distinctions and in particular the Review recognises that learning disability and mental ill health are very distinct and separate conditions.

This is reflected in the way in which the Review is being carried out. An overall Steering Committee manages the Review. They are guided by inputs from *expert working committees*, each of which is examining a particular area namely:

- Adult Mental Health
- Alcohol and Substance Misuse

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- Forensic Issues
- Child and Adolescent Mental Health
- Mental Health Issues in Old Age
- Mental Health Promotion
- Learning Disability
- Legal Issues
- Social Justice and Citizenship

In recognition of the fact that the Learning Disability Committee has responsibility for one of the 3 strands of the Review, 6 Task Groups are taking the work of this committee forward. This will ensure that full attention is given to key issues facing people with a learning disability. The Task Groups are examining:

- Support for children and young people and their families;
- Housing and support issues;
- Issues in ensuring people with a learning disability have as full a life as possible;
- Ageing issues;
- Mental health issues; and
- Physical health issues.

The reports from the Task Groups, feedback from people with a learning disability¹ and carers, and information from research will form the basis of the Learning Disability Review report, which will be available for consultation from Summer 2004.

How did we prepare this report?

This report is based on feedback given by parents and other family carers. Their views were obtained in a variety of ways:

- Five open meetings were held in Ballymena, Omagh, Belfast and Armagh. Invitations to the meetings were sent to carers groups and learning disability services for circulation to family carers. In all 115 people

¹ Refer to We Have A Dream... the report of the Equal Lives Group, which is available from the Review Support Team.

attended the open meetings. At each meeting small groups discussed issues of importance to the family carers. There was a note taker in each group and their notes form the bulk of this report.

- ❑ A Family Carers Advisory Group was established to provide advice to the Review as work progressed. The Advisory Group has fifteen members all of whom have a son or daughter with a learning disability.
- ❑ Members of the Review Family Carers Advisory Group have met regularly throughout the work, helped to plan and attended the open meetings and commented on the draft of this report
- ❑ A Free Phone line was set up by the Review to provide an opportunity for carers to input their views in a confidential manner. This service was designed for those who could not, or were unwilling to, attend meetings and to ensure that carers from all over Northern Ireland could have their voices heard.
- ❑ Family carers took the opportunity to attend meetings of the Learning Disability Committee and shared their ideas
- ❑ Written comments were provided by a number of individual family carers and carers groups who took the opportunity to write to the Review expressing their concerns and ideas. Again this has proven to be an invaluable way of getting feedback from all over Northern Ireland.

In this report we have tried to summarise the key themes and issues that were raised through all of these methods.

KEY	
✓ Good Practice Example	While it has not been possible to repeat everything that we were told, we have included a selection of comments that were left on the Free Phone message line, a sample of direct stories told to us by family carers at the meetings and ideas that were shared about the sort of good practice that the family carers felt should be more widely available in Northern Ireland. In this way we hope we have given a real voice to those who have been involved in this work so far.
☎ Free Phone Message	
“ Carer’s Story	

If the Review is to make a real difference it must address the issues that are important to those who will be most affected i.e. people with a learning disability and their families. This report is aimed at ensuring that those who have influence in the Review and beyond are aware of the issues of importance to family members who support a person with a learning disability. It should be read alongside the various reports that have been produced over recent years to place carers centre stage in policy developments. It is based on the expert opinions of family carers and should inform the work of those who have the enormous responsibility of making recommendations that may change the lives of countless individuals and families in the years ahead.

Focus on Children

Breaking the News...

The memory of how they were told about their child's disability remains fixed in parents' minds, regardless of the length of time that has elapsed since the diagnosis was first shared. Family carers made powerful pleas that professionals who are given the responsibility of breaking the news are properly trained for this role and approach the task with great sensitivity.

I was leaving the maternity ward with my son. I had noticed that his hands and feet were a bit blue and I asked a hospital doctor to have a look at him. The doctor turned my baby's hands over and said, "That will be the Down's Syndrome. We'll talk about it at the clinic." I left the hospital and went on the Internet with my husband to find out what Down's Syndrome was. I couldn't believe what I was reading (This happened within the last 2 years).

At all of the meetings, parents shared their dismay at having their concerns dismissed by health professionals. Terms such as *neurotic, obsessional, hyper-anxious* were used frequently at the open meetings to describe how parents felt they were perceived during these early years.

The need for follow up support was a regular theme and in particular parents stressed the need for:

- Accurate information about their child's condition and the support available.
- Sufficient intervention from speech therapists especially in the early years.
- Professionals to communicate better with each other and co-ordinate their support efforts.

Many parents found the process of assessment and diagnosis to be confusing and fragmented. They asked if consideration would be given a more comprehensive

process that helped the child to have easier access to the full range of specialists from an earlier stage.

Several carers, as a good example of what can happen when parents and staff from all backgrounds and professions work together, mentioned the Wraparound Project in SHSSB. Particular mention was made of the Child Assessment Clinics that are available in a number of locations where professions from a range of backgrounds come together under the one roof reducing the need for parents to travel to numerous meeting points.


In School

With a few exceptions, most parents fed back positively on the support provided by 'special schools' where teaching staff by and large understood their child's particular needs. Access to support from therapists, whilst never enough, was seen to be more accessible in the special schools than in either mainstream or post school provision. However several parents commented on the difficulties they have experienced in enabling their children to go to mainstream schools. These parents noted their frustration with the lack of encouragement and acceptance they had experienced. They perceived that this often came from an attitude by teachers that children with a learning disability were best placed in separate schools.

Regardless of which type of school their child attended parents who commented on this area confirmed their belief that where possible education in mainstream schools should be an option. In particular the benefits to other children of being in regular contact with children with a learning disability were highlighted. The impact in terms of raising awareness about the position and reality of learning disability was stressed.

There should be special units for example in 1 out of 6 primary classes. Special school staff should travel, not the child. Children with disabilities can then go to school with their brothers, sisters and neighbours. This will educate the whole population about disability because there will be no segregation.

Parents' experiences of the statementing process varied widely and most reported dissatisfaction with various aspects, most notably the length of time taken and their sense that parental views and concerns were not listened to. Some parents reported never having the process explained to them and a sense of shock when they learned of the impact that the *statement* would have on their child's access to education in the future. At each open meeting parents of children with an Autistic Spectrum Disorder (ASD) expressed concern that educational professionals often did not appear to know what advice or services to offer their children. In some cases parents felt that their children should not be in special schools but were there because teachers in mainstream schools were not skilful enough to deal with their children's particular needs.




An education psychologist arrived at my door. The school had never told me they were coming out. My child was taken out of mainstream school and placed back into pre-school and then put in a special school until she was 16. There still has been no diagnosis for her.

It was an appalling process- my child was made to perform like a seal in front of a stranger


Out of School

Feedback from family carers shows that access to after schools' activities is very patchy and varies widely across Northern Ireland. Where children were able to access out of school hours provision it clearly had a very beneficial impact not only on the child but also on other family members.



Lisburn Families Project, Positive Futures - This service uses a community development approach to open up access to ordinary leisure activities in the community for young people with a learning disability and their siblings. Parents gave examples of their sons' involvement in the project making it possible for them to go to a local archery club, join trampoline classes at the leisure centre and go to a local youth club.

Particular pressures were described in coping with the summer holidays when for some, alternative activities for the children were not available.



My son goes to an MLD school that is very good but he has nothing to do during the summer holidays; because of his complex needs nobody can take him.

Again even access to short-breaks or part-time activity programmes provides enormous benefits. Absence of such support can be almost unbearable in some cases.



I did not get any break at all until I threatened to take my own life.

Focus on Support

Throughout this Review family carers have consistently highlighted 4 areas as key to them receiving the right type and level of support:

- Information
- Respite
- Staff
- Aids and adaptations

Because these areas were raised so often and with such conviction this chapter will summarise the key themes.

Information


Without exception every meeting with family carers included concerns being raised about the difficulties that they experienced in obtaining information that could assist them in the caring role.

Carers described problems in finding out about:

- The nature of their child's disability
- Support available locally
- Benefits entitlements
- Roles of the various professionals
- Services in place now and for their child as he/she gets older.

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The degree to which this was a recurrent theme cannot be overemphasised and it was clearly a source of immense frustration to many parents that after struggling to cope with particular issues for years they found out *by accident* about a service or entitlement that has since transformed their lives.



Please show us respect by giving us the information we need to do our jobs as parents and carers.

During the open meetings family carers were particularly surprised to learn about:

- Direct payments
- Carers assessments.

Knowledge of both these key elements of current government policy was very limited.

A frequent suggestion was that a basic information pack should be provided to all parents as their child's disability becomes evident. Suggestions for the contents of the pack include information on:

- Child assessment
- Carers assessment
- DLA and other benefits
- Statementing
- Schools options
- Respite provision
- Name and contact details of key staff eg social worker
- Charities that can help
- Local support groups.


The type of information that is needed changes as the children get older and family needs change. There was a frequent recommendation that families should have access to a key worker who is responsible for ensuring that as changes happen to family circumstances, service availability or government policy, the family carer is informed.

Respite

Family carers often spoke about the pressures of their caring roles and phrases that came up with alarming regularity included:

- *Feeling worn out*
- *At the end of my tether*
- *I just feel like running away; and*
- *I need to escape from all this.*


It was clear from the feedback given that short breaks from caring make all the difference to whether or not family carers are able to keep going. Again where such respite was available the impact on the caring capacity of family members was massive. Often people wanted relatively small amounts of respite but they need the respite provision to be flexible, available in emergencies and bookable well in advance.



We ask for one week every March and September in life. Sometimes we don't know if we'll get it till the last minute. You need to book respite a year in advance but even then you aren't guaranteed this.

Where the family carers have only experienced respite provision in residential homes they wanted more of the same. Other carers had experience of services that provided alternatives to residential provision eg Breakaway Schemes, Adult Placement Services etc. These alternatives seem to be very much appreciated by carers provided appropriate safe guards are in place.

In several services parents felt that the people receiving respite were discriminated against in comparison to residents who lived permanently in the service. This led to requests from these carers that respite be offered separately from long-term residential care places.



Once my son goes on respite he does not get an outing until I collect him again – they don't have facilities to take them on outings.

Several parents expressed their view that the *people who shout the most, get the most*. They stressed the need for available respite to be managed very effectively so that

access to the services is prioritised according to need and in a planned way, rather than in response to parents' complaints.

In several locations carers told us that they believe respite provision has declined rather than increased over recent years. Some noted that this is in spite of the fact that more people with a learning disability are living longer and so their parents have more need of respite.

Staff

Who will or can understand my son?

Without a doubt the lives of family carers have been transformed where they have experienced timely inputs from skilful and sensitive staff. A recurring theme throughout the Review has been the beneficial impact that skilful staff can have and the devastating consequences for the family if such support is lacking. Carers frequently described individual staff that had changed their lives for the better.

My life has been totally changed lately. I got a new social worker a few months ago and suddenly I am getting a lot more help in the house. I got my first break ever a couple weeks ago (daughter is in her 30's).

The importance of staff having the *right attitude* was highlighted at all meetings and may be summed up as involving the following factors:

- Treating the carer and person with a learning disability with integrity and respect.
- Reliability and consistency of approach
- Well trained and particularly knowledgeable about learning disability
- Focus on supporting people to develop abilities – focus on the *can do's as well as the can not's*
- Encourage ordinary living.

The need for professionals to communicate well not only with parents but with each other was often stressed. Family carers noted their dismay at the lack of co-ordination between services and professionals especially across agencies i.e. between education and social services.

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There is too much red tape. The administration needs to be more organised.

There are 2 people from different districts in touch with us. They are not in touch with each other.

Finally in many of the groups the family carers suggested that there should be a key worker who helps parents to negotiate all the different systems, services and roles.


In the area of staffing in particular many carers noted that tremendous changes can be made, without additional resources, by a shift in attitudes.



This is not all down to funding, it can be management – there is a lot that could be made right by good management and by people who care.

Aids and Adaptations

Frequent examples were given of the importance of either practical changes to their son/daughter's environment or the provision of practical aids. However, whilst the timely provision of such assistance could be very effective, many people's experiences of attempting to obtain this help was fraught with difficulties.



I waited 2 years for an answer only to be told that we didn't meet the criteria.

Indeed several parents feel that the system was actually designed to put people off trying to secure aids or adaptations to their homes.




The system is geared to make you give up on your rights.

At each of the open meetings at least one account was given of a family that had experienced very long waiting lists for aids or adaptations with several examples given of situations where a child had outgrown a facility by the time the *red tape* was sorted.

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The essential need for staff to listen carefully to parent's views was stressed if the aid or adaptation is to be appropriate.



I asked for an extension to the house but they won't listen to my views. They want to put the room out the back downstairs. Our (the parents) room is upstairs. We won't be able to go to him when he has fitted.

Focus on Health

In the community

The key health professional identified as most significant by family carers was the local doctor. Where the GP has a positive relationship with the parents s/he can have a significant influence on the healthcare experiences of both the family carers and the person with a learning disability.

My GP knows us inside out. He knows I can't bring _____ to the surgery, as she'd wreck the place. He comes to the house and knows exactly how to talk to her.


The out-of-hours schemes could not deal with our problem. Our family GP followed us and gave us his own number.

However at each meeting poor individual experiences of GP's were described focusing on:

- Not being listened to
- Being treated in an off-handed way
- Having concerns dismissed.


As with other areas of looking after their son or daughter's welfare, many parents felt that they had to fight to get proper health care. At several meetings carers described situations where it appeared that the person's health was being put in jeopardy because the medics placed a lower value on their healthcare needs because they had a learning disability. The idea that each practice should have at least 1 GP with a particular interest in learning disability came up on several occasions.

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My son was born with only 2 chambers in his heart. He has Down's syndrome. I had to get a court order to force the doctors to operate on him. This was only eight years ago.

Among the most recurrent and distressing concerns about primary healthcare were those related to dental care. There are clear deficiencies in this area across Northern Ireland if the stories given by participants at the open meetings are in any way reflective of the level of service available.




My son has been on a waiting list for dental treatment for 3 years (Belfast).

My daughter has been waiting since January (11 months) to get 2 bad teeth removed. No reasons have been given to me to explain why the delay. She is suffering and in constant pain. She should not have to go through this (Ballymena).

Other people would not be expected or willing to suffer with acute dental pain for such lengthy periods. The effect on the individuals and the whole family is marked. This was clearly an area identified by parents as being in need of urgent attention.

In Hospital

Invariably when family carers described their experiences of hospital admissions they stressed the need for high levels of disability awareness amongst hospital staff. This was, they felt, often lacking resulting in the family feeling obliged to spend lengthy periods in the ward attending to their relatives basic needs.




When _____ was admitted to the men's ward we, (the family) had to do shifts 24/7. No one in the hospital had the skills to meet his needs.

The worst affects of the lack of understanding on the part of the hospital staff could be reduced if staff acted on the advice of family carers and did things a bit differently to take account of the specific needs of the person with a learning disability.

A particular bugbear of many parents is the fact that they have to repeatedly explain to medics details of medical histories, details of the learning disability etc. Where the individual experiences repeated and frequent hospital admissions this can be particularly tiresome for the family carer. One group suggested that an

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individual medical/health record sheet should be produced that summarises key factors of the condition, health emergencies and treatments offered.




In Foyle Trust people are given a card that identifies the person as having a learning disability when accessing health care at Altnagevin Hospital. It identifies the special needs to the medics thus hopefully reducing waiting time and tuning staff into the need to take account of the disability

Overall the key theme was that a special set of rules are needed if a person with a learning disability is in hospital:

- Parents to be involved and listened to where the person cannot speak up for themselves
- Community learning disability nurse should be made aware of pending admissions and treatment planned in advance where possible
- Special needs of each individual should be identified and taken account of
- Disability awareness training should be essential for all healthcare staff.

Carer's Health

Family carers noted that there is a cost to their physical and mental health that is caused by the stress of caring. Several stated that they put their own health concerns aside because they do not have time to look after themselves. Several individuals noted that this problem is worsened by the fact that they care for more than 1 person.




Our health is not good. It gets to the point where you don't want to go the doctor. You get no answers. Their attitude is what do you expect with what you do. Caring for your daughter, parents, and elderly grandparents.

*It would help if the doctor would **listen** rather than attributing it all to caring for my daughter. If I were not a carer my symptoms would have been investigated.*

At 3 meetings it was suggested that carers health should be part of a Carers Assessment carried out on a regular basis so that carers are encouraged and supported to share concerns they may have about their own health before it becomes a crisis.

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Carers should be invited for a check up. Our health should be looked after. If I go down they will have to look after 3 people.

My doctor tells me to put my feet up and take it easy!

Focus on Money Matters

Cost of Caring

In addition to the physical and mental costs of caring; there are very real financial costs that were highlighted at many of the meetings. A double-bind was described where for many families having a disabled family member incurred specific additional costs, whilst access to paid work opportunities was often limited because of the demands of caring and the *benefits trap*.

I can't go to work even with my Degree training because of my son's needs. My husband had a heart attack, he needed to leave work, we got assessed, one benefit knocked out another benefit and I am now looking after 2 people.

A common message was that if family members gave up caring, the cost of replacing their caring roles would *bankrupt* the government. Carers asked why then are their contributions not better recognised within the benefits system e.g. why do benefits levels not keep pace with the minimum wage? The low amount given in Invalid Care Allowance contrasts sharply with the high contribution that family carers make.

Particular problems were highlighted with arrangements for accessing and maintaining Disability Living Allowance (DLA). This was described as a *harrowing and upsetting* experience at several meetings and pleas were made for changes to this system.


(Form filling) do we have to continue to be humiliated with repeatedly giving all the specific details in the forms? How often do we need to write out all the details?

The DLA system is harrowing. The panel is made up without carers and they've made their minds up before they see you.

Information (Again!)

As noted earlier (Chapter 3) many family carers experienced difficulties in accessing information about benefits especially in relation to:


- What benefits exist
- How the system works
- How to access benefits
- Where to get help



I hadn't a clue and my social worker advised me to go to CAB. They were brilliant. I got a lot of extra money I never knew I was entitled to. More people should know about them.

Direct Payments

There was a very low level of awareness about the possibility of people being able to directly access money to meet the support costs of someone with a disability. Where this option was raised at meetings family carers expressed interest in finding out more and recommended that much greater publicity be given to this aspect of government policy.




I contacted the Independent Living Centre and with their help was able to get a direct payment for my son. We've been able to pay someone to come in and take him out to the pub and to the café. He has a more normal life – not always going out with his mum or dad.

Focus on getting older


Becoming an adult

As with other life changing events parents shared their concerns about the move for their son or daughter from school to what was often described as an uncertain future as young adults. They spoke often about the dreams they had for their children and the pain involved in knowing that some of these dreams may not be realised. The need for particular support at this major transition period was stressed frequently.



I would love for my son to have lots of friends, his own wee flat, a girlfriend and a good job. Don't you want the same for your children?

In some cases parents described how they had received excellent support, which had helped them to be more optimistic about the future possibilities. One parent who had participated in a person centred planning process said that the staff involved had allowed her *to dream again* for her son. However there was a low level of awareness about person centred planning amongst the family carers and in many cases parents reported that they believed any planning as had happened *was too little, to late*.




As a carer for someone with learning disability, I think that the transition process is a total whitewash, as professionals don't talk to each other. I think there is a need for a transition coordinator in each school to bring service deliverers together. There should be good employment opportunities and job support offered and the chance to have trials in job placements to help young people make informed choices.

Community support


Many carers shared with us their fears for the future and the anxieties they have about what will happen when they are no longer able to care.

Some parents recognised that their fear about the future is so great that they simply can not bring themselves to talk about the issues as this would mean facing up to a reality that is too difficult to think about. It was mentioned at one meeting that most people in society do not have to confront the fact that they are going to pass on; why then should we expect that family carers are different and can readily talk about their own mortality? Yet in many sessions individuals asked for the Review to think about how they might be better supported to plan for the future. It was noted that this should be offered on a regular basis rather than put forward as a once off suggestion. The parent who cannot face looking to the future today may well be in desperate need of support to do this tomorrow. Social workers are asked to note that a refusal to future plan at one stage may well be completely retracted owing to a change in health or other crisis for the carer. Again, as in so many other areas, family carers highlighted the transformation that can occur if they are skilfully supported to look at the options.




What will happen when I get older? My son loves living at home. I don't want to put him in a home. I need to start looking to the future and preparing my son to move- somewhere in his own community where he can have regular visitors. Doesn't everyone want the same for their kids?

The need for locally based housing options to be developed was a recurrent theme as was the belief that such local options are thin on the ground. A number of carers raised concern about the impact that planned resettlement of people from hospitals will have on the availability of already stretched community support. Whilst not wishing to keep people in hospital indefinitely, these carers expressed a view that the resources in the community will be stretched to breaking point if the resettlement goes ahead with current funding levels.



The community can't get finance for those living in the community never mind for the resettling


Many of the parents noted their concern that siblings are freed from the prospect of a lifetime of caring and a concern that professionals can assume that sisters will simply step in and take over where the parents leave off. Adequate attention to planning for the future would greatly assist in avoiding this outcome where it is not wanted by the siblings involved.



It's not fair to give this responsibility to her siblings-they have sacrificed and gone without for their sister and we do not think it is fair to put this responsibility on our other children

The importance of their sons and daughters having activities during the day was highlighted regularly. Where this was provided within day care centres, many parents noted problems with a shorter than full day. Difficulties with transport, especially in rural areas, were highlighted both in terms of being a barrier to people having a longer day at centres but also in terms of people being able to access a wider choice of alternative activities in the community.

Many parents commented on how important day care is to them in terms of providing a break from caring. However a consistent theme was that some day centres are overcrowded and mix people with too wide a range of abilities and needs



I could not cope without the centre but in all honesty I think it is past its sell by date. Water runs down the walls of the canteen yet people are still queuing up to try and get a place there

Without day-care I couldn't possibly cope. There are things I would like to see expanded-better range of activities... not sure what desktop activity means-difficult when adults have such poor concentration... could anything be done to stimulate her mind more?


There is a problem with people with suits saying there is always a choice, that everyone with a disability can make a choice – that is not necessarily true. Day care is really needed by some.

The idea that people should have the opportunity to work and have access to education after leaving school was mentioned by a small number of parents. In many cases many carers were not aware of any option other than day care and the need for **information** about future planning possibilities was again highlighted.

Carers are getting older too


Throughout the Review family carers have highlighted the fact that more people are getting older and that there is a pressing need to ensure that the particular needs of older carers are met. Many of the carers spoke of their own ill health and their fears particularly about what would happen if their health suddenly deteriorated. One carer suggested that parents of people with a disability should be given the option of a phone alarm link so that, should they fall, help can be immediately obtained. In this group the message that support to older carers needs to be prioritised was graphically summarised in this comment from a mother :

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Over the last few months I have been to three funerals of adults with a learning disability. Each time I hugged the mother and told her “now you can let go”. Parents worry so much about what will happen to their children after they die that they pray that their son or daughter dies first so they will not be left to fend for themselves

As has been noted earlier, at all the meetings, there was a remarkably low level of awareness of the introduction of Carers Assessments. There was agreement that this is a step in the right direction and in particular would give family carers the chance to focus on their own needs without feeling guilty or selfish. A consistent message was that Carers Assessments should be more publicly promoted and that account should be taken of the needs that the assessment identified.



I am 84 and I have been caring for my brother on my own for years. He is 74. I did not know until the last few weeks that I was entitled to help with benefits and that there was such a thing as respite. A nurse sees my brother now every fortnight and arranged a 3-day respite last week for the first time.

A comment by some carers was that in many cases they found the most helpful support to have come from other carers who understood their situation and could offer practical help. In some cases this support was available through carers groups attached to existing services, which had the added benefit of being local and linking in to community networks.



The local SEC set up a carers group. This has been a great help. You realise for the first time that you are not on your own. (Armagh)

Again it was interesting that at 2 of the public meetings people heard for the first time about carers groups in their locality reinforcing the need for information on existing resources to be shared effectively. However many of the carers highlighted how effectively parents can help other parents and called for information about carer support groups to be shared more widely.

Conclusion

This report has attempted to give a voice to the many family carers who have shared their ideas, hopes and worries with us. As every family is different; so it is almost impossible to present one view that may be called *the view of family carers in Northern Ireland*. To attempt to do so would be simplistic and fail to do justice to a complex web of issues.

The report cannot cover all the issues or record the detail of all the stories we heard

It does however give a snapshot of what is troubling family carers in Northern Ireland, of the types of support that can change lives and help make people dream again and the long way we have to go to make sure that everyone who wants and needs it gets this level of support.

We hope that people with influence will read the report and do what they can to make a difference to the future experiences of family carers across Northern Ireland.