



# **Living from Day to Day**

**A Research Project on Older Family  
Carers of People with Learning Disabilities**

**Undertaken by**

**Castle Douglas and District Branch  
and North Ayrshire Branch**

**ENABLE Scotland**

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# Preface to Report

Many people with learning disabilities still live at home with parents or family members who are aging and failing in their own health. As a group, older families are less likely to shout for help and so often their problems go unnoticed as they get by, as best they can.

We, as members of Castle Douglas and District and North Ayrshire branches of ENABLE Scotland, feel that we have a duty to try and raise the profile of a group of people who have provided care and love to their family members with learning disabilities, many of whom are now reaching middle age. We have described this group as 'older family carers' but they see themselves first, as mums, dads, brothers and sisters.

We planned and carried out this research project from September 2007 to May 2008. This was the first time that our branches had worked together and it was the first time we had undertaken such a focussed piece of planned work. On a personal level, we learned a lot from taking part. Some members of our research team, all volunteer members, grew in confidence and others rediscovered skills that they hadn't had the chance to use in a while.

You may be struck by the lack of positive experiences expressed by the people who took part in this project but as we listened to what people told us and revisited the written transcripts we believe that report is as a true reflection of what we were told and how life is for older family carers.

We hope that you find this report of interest.



**Brian Brown**

Chairperson

North Ayrshire Branch

ENABLE Scotland



**John Love**

Chairperson

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On behalf of the Project Implementation Team

# Background

## ENABLE Scotland

Founded in 1954, ENABLE Scotland is the country's leading organisation of and for children and adults with learning disabilities, their families and carers. ENABLE Scotland's vision is to achieve a society where children, young people and adults with learning disabilities are full members of the community.

## ENABLE Scotland Branches

ENABLE Scotland is rooted in volunteering. We have a network of 60 voluntary branches across Scotland bringing people together to support each other. People with learning disabilities, their parents and carers play a central role in how ENABLE Scotland is governed.

Many of ENABLE Scotland's branch members have been involved in the organisation from its early beginnings. We believe that we understand the problems facing people with learning disabilities and their families because of our own personal involvement.

Our members can recall when they were told not to expect their sons or daughters to live long lives. As health provision improves, we are now entering an era when, as many parents are getting older, their sons and daughters living at home are also aging. Through our branch networks these older family carers have been telling us about the lack of support and resources available to help them think about the future.

We know that two older family carers in South Lanarkshire have been so concerned that they formed a support group called the Murray Owen Older Carers Group. Through this group, they have raised the issue with the Scottish Parliament Petitions Committee. They have also encouraged South Lanarkshire Council to undertake local research and increase support to older family carers through a specialist worker.

As local members of ENABLE Scotland branches in Castle Douglas and District and North Ayrshire, we wanted to find out about what older family carers in our own areas thought. We also wanted to add our findings to the national campaign that is slowly growing across other areas in Scotland.

# Who is an Older Family Carer?

The term 'older family carer' is used to describe those older people, usually parents, who are looking after a person with learning disabilities at home. Older family carers may also be brothers, sisters or other family relatives of the person with learning disabilities. There is no fixed age that defines an older family carer. For the purpose of our research we have defined an older family carer as someone over 50. It is estimated that there are 120,000 people with learning disabilities living in Scotland. Of these:

25% have a carer aged 65 or over.

20% have two carers aged 70 or over.

11% have only one aged 70 or over.

*"The Same as You?"* 2000 (see glossary) made a series of recommendations for the future of services and the support people with learning disabilities needed in their daily lives. Recommendation 26 said that:

"Life plans for people with learning disabilities who live with their parents should include plans for a time when parents may no longer be able to provide care".

We believed that while the theory of good planning had been laid down in policy documents we were less sure if older family carers had plans for the future.

## Scottish Community Action Research Fund

In order to carry out our research the two branches applied for funding to the Scottish Community Action Research Fund (SCARF).

SCARF funded by the Scottish Government, gives community groups support to improve their skills and confidence to carry out their own research. The fund helps them to plan a project, collect information and understand it, use the information and learn from the experience. We also received mentor support to help us undertake the work.

# What did we hope to achieve from our research?

The focus of our research was on older family carers who are living with and caring for adult relatives with learning disabilities. For the purpose of our research we defined an older family carer as someone over 50.

We wanted to find out from older family carers:

- **What kind of supports and services they require at present.**
- **What kind of supports and services they will need in the future to enable them to effectively plan for the future.**

Specifically, we wanted to ask:

- **What was their view of respite?**
- **Could they get a break from caring now?**
- **Did they have an action plan if an emergency arose?**
- **Did they know how to make their son or daughter financially secure when they were no longer there?**
- **Had they thought about making arrangements for where their son or daughter would live once they were unable to look after them?**
- **Did they know where to get information to assist them?**

We also wanted to find out if older family carers were under greater physical and mental pressures because of their age. On an individual and community level we wanted to:

- **Have a better understanding of the needs of older family carers of people with learning disabilities.**
- **Establish personal contact with older family carers, many of whom experience social isolation because of their caring responsibilities.**
- **Encourage older family carers to become involved in planning processes and to have a 'voice'.**
- **Create a link network for older family carers to break down isolation.**
- **Create a climate of hope by re-energising the enthusiasm to take the agenda forward.**

- **Have more sustainable groups and to have more people involved in groups.**
- **Demonstrate that the issues are similar across geographical areas.**
- **Learn from our experience and to share our experience.**
- **Encourage older family carers to think 'out of the box'.**
- **Provide active solutions to problems.**

On the policies of voluntary and statutory agencies we wanted to:

- **Improve communication links between planners and people who use services by clarifying issues relating to older family carers.**
- **Influence future planning, and delivery of local services, as well as promoting meaningful involvement with planners.**

# Our Research Plan

We selected four key methods to carry out our plan. These were:

- 1. Identifying older family carers.**
- 2. Conducting focus groups.**
- 3. Conducting semi-structured interviews with older family carers.**
- 4. Making a DVD based on 'A Day in the Life' of one older family carer.**

## Project Implementation Team

We set up a group to oversee the research process, which we called the Implementation Team. Membership of the group comprised of ENABLE Scotland representatives from Castle Douglas and District, North Ayrshire, the Involve project (see glossary) and the research mentor.



### 1. Identifying Older Family Carers

We identified older family carers to take part through the Castle Douglas branch database, through members of our branches and from the Princess Royal Trust for Carers in North Ayrshire.

Also in North Ayrshire, we held a lunchtime social event to promote our research, which was attended by 35 older family carers.

One of our group members promoted interest in the research through a local radio interview.

While we were able to identify participants through carers' databases, we found that family carers themselves knew of others who were not known to any services. These carers helped us to distribute the information on the research project to others whom we could not have otherwise reached.

## 2. Focus Groups

Three focus groups were held involving a total of 26 older family carers. In addition to being facilitated independently, each focus group was also graphically recorded (see glossary). This enabled us to have a pictorial record of the issues raised within the group and will assist us in promoting understanding of our findings. The aims of the focus groups were:



- **To identify the prevailing issues affecting older family carers.**
- **To put into context their past experiences.**



## 3. Semi-Structured Interviews

We carried out a total of 20 interviews involving 33 older family carers and used 8 co-researchers (see glossary) to carry them out. All co-researchers were trained to carry out the interviews by the mentor and the mentor also assisted with the design of the interview prompts. All interviews were digitally recorded and transcripts typed and distilled down to key issues.

## 4. Production of DVD

We identified an older family carer who we felt best illustrated the issue in all its complexity and struggle. We used the resources of Cairn Productions to have the DVD made. We called the short film 'Some Days' and it will be used as part of the research feedback and as a way of promoting the issues raised in the research.

# Who Took Part

The following tables provide some information on the older family carers who took part in the research. *(There were some discrepancies in the completion of the data form we used i.e. some boxes being ticked twice and others where people did not specify information. In addition one carer was under 51 and not included).*

Table 1 - Age Range/ Gender (Older Family Carers)		
Age Range	Male	Female
51 - 65	10	30
66 - 80	6	9
Over 80	2	1
<b>Total</b>	<b>18</b>	<b>40</b>

Table 2 - Gender/ Status (Older Family Carers)		
Status of Carer*	Male	Female
Dual Carer	14	28
Single Carer	1	11
Sibling Carer	1	2
Family Carer	1	3
<b>Total</b>	<b>17</b>	<b>44</b>

\* See glossary for definition of status of carer

Table 3 – Relationship/Age Range (Adults with learning disabilities being cared for at home).			
Relationship	Under 30	31- 40	Over 41
Son	12	7	3
Daughter	7	8	4
Other Family Member	1	0	3
<b>Total</b>	<b>20</b>	<b>15</b>	<b>10</b>

## Additional Health Problems

Of those older family carers we asked:

**14 said that their family member had one additional health problem.**

**10 said that their family member had two additional health problems.**

**5 said that their family member had three additional health problems.**

**1 said that their family member had four or more additional health problems.**

*(See Appendix 1 for breakdown of health problems)*

# What we found out

## The Past

Many focus group members recalled a lack of information provided to them by professionals when their sons and daughters were born. The consensus was that there was little support and information available and what they were told tended to be negative.

There were isolated incidents where individual professionals had been very supportive but in the main families were left to their own devices.

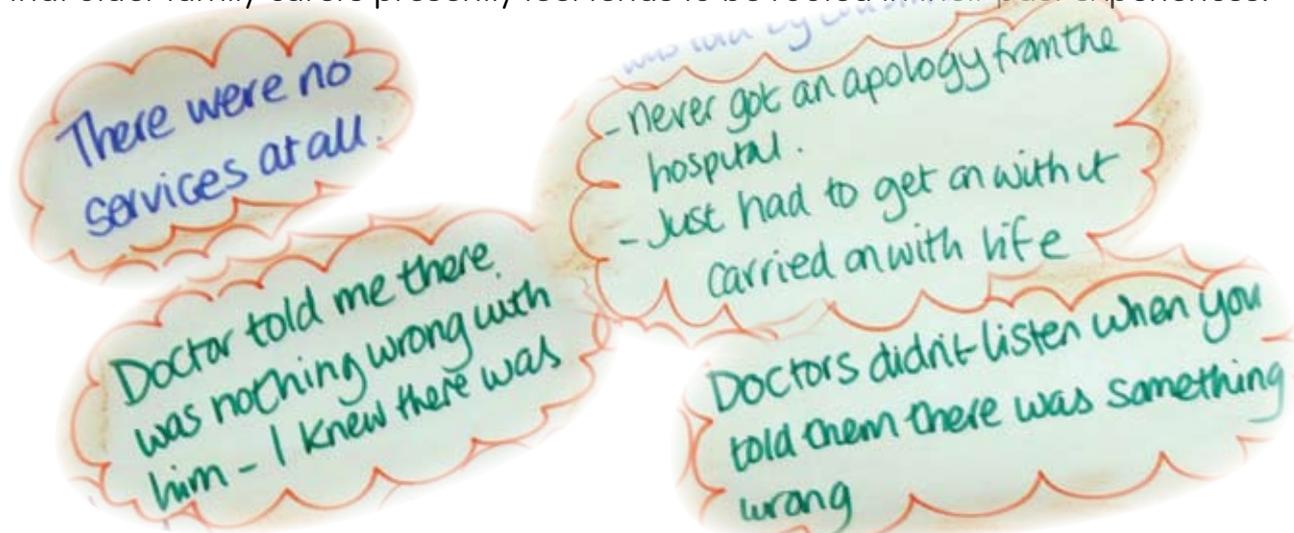
One focus group member described how she was told her son would be a 'vegetable,' that he would never walk, talk or be out of nappies. Another described how the hospital never informed her that her son had Down's Syndrome and she found this out only from a visiting cousin.

Overall, the general feeling was that professionals expressed very low expectations of people with learning disabilities, in terms of their lifespan and of what they would be capable of achieving.

**"It was a case of take him home and love him, he'll never amount to anything."**

Carers also described where health professionals failed to identify the disability. As one carer said, "you just had to get on with it."

This is the agreed historical context for older family carers in both Castle Douglas and North Ayrshire areas. While our discussion on the present times certainly showed a change in many professional attitudes, the lack of trust and frustration that older family carers presently feel tends to be rooted in their past experiences.



# Key Themes

We asked older family carers to tell us about their experiences under a number of key themes. These were:

- **Housing**
- **Service Provision and Opportunities for their Family Member**
- **Financial Provision**
- **Health**
- **Social Issues**
- **Respite Care**
- **Information, Communication and Consultation**
- **Attitudes and Feelings**
- **Emergency Planning and Planning for the Future**

## Housing

Generally older family carers felt that options at present were unsuitable for their needs as a family. Many people said that the best options would be:

- **If their relative could remain within the family home with a package of care and support service or**
- **If their relative could live more independently, in some form of supported living, in familiar surroundings with access to amenities to reduce isolation.**

"He's scared stiff he is going to be put in a house on his own."

"He wants his own house with a friend staying with him and care coming in."

"I hope he can stay in my house – I have spoken to the council."

Choices and information to help them plan was important but also key was the need to take things slowly so that people had the chance to build up good relationships and other supports around them. Older family carers were aware of examples where people with learning disabilities were suffering and unhappy because they saw no one but their support workers when they stayed in supported living arrangements. They did not want this for their family members.

# Service Provision and Opportunities

Older family carers felt that there were a number of areas that could be improved within day services provision. Their main concerns were for the opportunities afforded to their relative.

Older family carers whose family members attended Activity or Day Centres felt that:

- **They had little or no knowledge of what their family member did within the Centre.**
- **The Centres were not challenging enough or relevant to the needs of their family member.**
- **They had a lack of awareness of the purpose and the context of day services.**

**"We were told the day centre and not given a choice."**

**"All your back up of people disappears when they (family member) leave school or when they are 18."**

In addition, people had concerns about support workers through local authority provision and also through agencies providing day services. Their main points were:

- **There was a lack of consistency and continuity with support workers.**
- **There was a need for support workers to receive training in attitudes and values.**
- **Their own training to 'do it their way' does not respect the 'family way' of doing things.**
- **Older family carers want to be seen as the 'experts' in respect of their own family members.**

**"I see some good support workers and I see some terrible support workers."**

**"I don't want a buddy who is coming in one Saturday and the next Saturday you've got another buddy coming in."**

Overall, older family carers expressed the view that there was a general lack of knowledge or awareness of the criteria for access to services. There was also a general feeling that there was a lack of choice and a lack of services available.

# Finances

Many older carers felt that there were a number of financial issues which affected them due to their caring role. These were:

## 1. The Standard of Living for Older Family Carers

Some older family carers advised that they had to give up work or to change jobs and adjust to reduced earnings. The impact of this meant that they were in a worse state financially when they retired.

**“Our biggest gripe is the fact that we haven’t got any money.”**

When older family carers retire they find that they are short of money and feel confined to poverty. Also they no longer receive carers’ allowance, which is not felt to be helpful.

## 2. Complexity of Financial Arrangements

There was great uncertainty about what would happen when carers were no longer able to care and how this will impact on benefits for their family member. Older family carers don’t know how secure their family member will be if they leave the house in trust and the complication of financial arrangements between trusts and the welfare benefits system is regarded by them as very confusing. Older family carers felt that there was no good advice about financial planning to assist them to plan for the present and the future welfare of their family member.

## 3. Direct Payments

**“ I phoned Inland Revenue, Social Work regarding Direct Payments - same answer - it’s nothing to do with us.”**

While in principle, Direct Payments were seen as a good idea, the lack of support to access them made the system appear complex and difficult. Those carers who used Direct Payments and needed advice felt that no matter who they contacted they could not get guidance and that there was a lot of misinformation about Direct Payments. A few older family carers expressed a desire to have a personalised budget agreed and allocated to them and for them to prioritise and control it.

# Health

## Older Family Carers Own Health

A significant number of older family carers advised that their own health had been affected by their caring duties. Some had to give up work due to ill health. Some, as they had got older, had developed health problems or felt that their health had been affected due to looking after their family member. Examples included, continuous disturbed sleep patterns while tending to their family member during the night.

Many provided 24-hour care to their family member.

**“The doctor says to me, “You’ll need to go into hospital just now,” and I said “I can’t go in just now” and he says, “You’ll need to go.” - I mean I couldn’t just drop things. I said, “I can’t go in until my husband gets home.”**

Older family carers also described the rounds of hospital/medical visits they need to make on behalf of their family members who had additional health needs in addition to their learning disability and how this can take its toll.

In addition, many also experienced extra caring responsibilities as they were providing support to additional family members such as elderly relatives or partners.

# Social Issues

Older family carers felt that a number of issues affected them on a social level. Access to respite was crucial in how older family carers could develop any social life for themselves and their family relative.

Many felt that respite was inflexible and could not be accessed at short notice. This conflicted with the older family carers leisure activities.

**"You can't just say, "Fancy a weekend away this weekend?" and just go. People of our age should be able to."**

Couples said they spent less time together or doing things together as a couple. Some older family carers had experiences of not being able to take holidays due to the lack of respite being provided. Others said that they didn't holiday when they received respite because they couldn't afford to.

**"Over the years you stop doing a lot."**

## Respite

There were a number of key themes emerging on respite. In the main, these were related to both to the flexibility of provision and the quality of provision for people with learning disabilities.

- People commented that respite patterns were prone to change and could move, for example from weekends to Monday – Friday, with not a great deal of consultation or negotiation.
- The variety of respite services were also found to be restrictive.

Another example cited by one older family carer was that when their family member was in respite they bathed and washed her hair prior to going in, as this did not happen when she was being looked after. She would only be given bed baths.

People were also concerned that respite was not a priority.

**"They (Social Work) wouldn't be so inclined to give us the respite if we were staying at home. They will give us it if we were going away, which I feel is not quite right either because if we wanted to just spend time in our own home together."**

In addition to concerns about quality and flexibility there was a lack of information on respite and also lack of clarity on how it differed from day services in some cases.

# Information/ Communication/ Consultation

We asked older family carers to tell us how they received information. The main sources where they were able to get information were:

- Through other carers.
- Their own research.
- Information from the Activity Resource Centre.
- Information through voluntary agencies.

**“Good communication from current social worker.”**

A few people said that they were very happy with how their social worker communicated with them but on the whole there appears to be a gap in communication channels between carers generally and social work and health agencies.

## Attitudes and Feelings

Planning for the future is a very emotional issue and the focus group members in particular brought out many strong feelings. People openly admitted to feeling so despairing that they hoped their children died before they did.

Older family carers also talked about the strong bond that existed between themselves and their sons and daughters.

They also shared the prejudices and lack of understanding of learning disability that they had come up against in their lives and their worries as they watched their sons and daughters age. As people told their stories it was clear that experiences were shared across the board.

**“ Always someone to care for.”**

**“ You know what causes these children.”**



# Emergency Plans

Older family carers we spoke to did not have emergency plans in place if a crisis arose. Some said that they would contact their nurse or their support worker. Others felt that social workers should encourage them to plan for emergencies.

**"3 years ago I had a broken shoulder and it took them 10 days to come in to do a risk assessment for their workers, not for the boys and all I needed was someone to come in every morning to put their socks on and tidy them up to go out to a day centre."**

**"It's not that you haven't thought about a plan. You don't know what the crisis will be."**

There was a general view that there was little information and advice available to assist in making emergency plans. All families said that they worried about the future and what would happen to their family member when they were not around. Not one person involved had an emergency plan in place. One person said, *"I have a plan in my head,"* but acknowledged that it wasn't shared widely with the services that might need to help in the future.

The reason people don't have plans is lack of information and being caught up in *"living from day to day"*.

**"But I mean, you get up every morning, you do your routine and you just pray that day that nothing is going to happen. Emergency wise or otherwise because there is no back up."**

Another concern was that it was difficult to predict when you may need to put a plan into action as what you thought may be needed might not be available. Needs also changed with time. People felt it important that any future plans should have a degree of flexibility and be reviewed regularly.

# Planning for the Future

Older family carers were worried about the perceived limited options available to them and their family members, which restricts planning. The main worries were about where their family member would live in the future, how they would be supported to live and whether they would have enough money to live on.

Just as worrying was the need for good friendships and relationships with other people who would love their sons and daughters and value them as people. At the same time many family carers did not want ongoing responsibility for care to rest with siblings or other family members. In contrast, some siblings in the research talked about how they had to persuade parents to share caring responsibilities.

## What Would It Take?

We asked people what it would take to help them plan for the future. The main things older family carers want are:

- **A bigger say in the services being provided which would include better consultation.**
- **Their views to be listened to and acknowledged as having relevance.**
- **Having access to good quality information on a range of issues that affect them.**
- **Being encouraged to think about the future in a positive way.**

What we know is that older family carers want their family member to have good relationships, be happy and to have their voice heard.



# Conclusions

Older family carers often think services ignore the intimate knowledge they have of their sons and daughters or dismiss it as over protectiveness. They can feel alienated despite providing a lifetime of care and support and this can mean a lack of trust in services.

Older family carers want to maintain a positive role and have an ongoing presence in their family member's life. In the main however they cannot allow themselves to think about the future because they are so used to living from day to day.

## 1. Older Family Carers are a Distinct Group

While we believe there are common threads between the needs of older family carers of people with learning disabilities and other carer groups there are some fundamental differences. The key difference is:

- **Older family carers have experienced a lifetime of caring and do not retire from their caring role.**

In addition:

- **Some do not follow the normal pattern of family life there is often little time for husband/ wife/ partner relationships.**
- **There can be a general lifetime of poverty and lost chances as older family carers don't pursue their own personal careers and life choices because of a lifetime of caring.**
- **Some family carers' physical and mental health suffer through a lifetime of caring.**
- **The lives of most older family carers are so tied up with the services to their family member that their own peace of mind is dependent on the continuity and quality of provision. As service models change and evolve this has intensified the worries of many older family carers.**

## 2. Similarities/Differences between North Ayrshire and Castle Douglas District

Overall there appears to be little difference in experiences across the geographical areas. In the main, people were resigned to making do with what support they had or spent much of their time challenging and fighting statutory services.

**“You’re just so frustrated because you have to fight for everything.”**

Some older family carers had a more positive view of their future but this small group were cushioned by having the financial resources to be in control of their own destiny.

**“ It’s difficult for one to imagine how some people make arrangements I have made without the resources I have.”**

## 3. Limitations of the Research

The study is focused only on carers and not people with a learning disability. We understand there will be a need to balance the different points of view of older family carers and their family members. As people with learning disabilities themselves get older they may too find themselves caring for their parents. Individual planning in the future must take account of what people with learning disabilities themselves want for their lives.

**“ My son knows we are getting older – he is worried.”**



# What needs to happen

## In Castle Douglas and District and North Ayrshire

### 1. Prioritise

Local Authorities and Health Boards in Dumfries and Galloway and North Ayrshire need to prioritise work with older family carers. This group have specific concerns which relate to their needs as a family unit. Presently carer assessments and assessments of adult family members with learning disabilities do not help people to think about the future or plan in a way which makes sense to individual families.

Local Authorities and Health Boards need to think about the transition into old age as a stage that merits as much support and resource and policy provision as the transition of young people into adulthood. This will include mapping the future housing needs of people with learning disabilities taking account of where people want to stay and whom they may want to stay with.

A one-size model of provision will not suit everyone.

### 2. Identify

The first steps will be to identify the number of older family carers living in the area. Many of these families will be known to local services already but others may not. Some families will be suspicious of involvement by Local Authorities and Health Boards and therefore this exercise should be carried out in partnership with local carer centres, GPs surgeries, churches, and other organisations that can help carers to seek support. Planning for the future of older family carers and their families needs to be seen as a high priority issue.

### **3. Provide Resources and Support**

Local Authorities and Health Boards in Dumfries and Galloway and North Ayrshire should identify specialist key workers to provide support for older family carers. These key workers should be established as a long-term service and not on a short-term funded basis. The first steps for these workers will be to help people think about the future and to promote emergency plans which are truly person centred and start where families are. Planning is highly individual and can be an extremely emotional issue therefore families have to be allowed to set their own pace when it comes to planning and involvement with agencies.

This will take time and should not be seen as a “tick box exercise”. We know that this exercise may highlight resource issues but it may also demonstrate how to make better use of existing resources.

### **4. Co-ordinate**

These emergency plans should be known to Local Authorities and Health Boards and therefore mechanisms have to be put in place to ensure that information can be accessed should emergencies arise.

Health Services need to work in partnership with older carers groups and Social Work services. There needs to be coordination of services across Health and Social Care.

### **5. Be Sensitive**

Underpinning all of the above, local authorities and other agencies need to understand that thinking about a future when you are no longer able to care is a highly emotional subject. The issue therefore merits sensitivity in the way it is treated. This will include awareness raising and training of staff that are in contact with older family carers. Only by listening and learning will the ‘powers that be’ gain the trust of older family carers.

## What ENABLE Scotland Branches need to do?

There is a role for ENABLE Scotland branches in Castle Douglas and District and North Ayrshire to help provide information to older family carers and to widen our present network of carers. We would want to do this in partnership with others where we could offer support and specific information on topics such as wills and trusts, welfare benefits and housing options which are priority concerns for older family carers.

After a lifetime of caring and dealing with services older family carers are realistic enough to realise choices are limited. Choices are dependent on both personal resources available and also local options available. Older family carers however need to know what can be possible for them and their family members. Only by having this information will they be able to think about planning for the future.

## What Can Older Family Carers Do?

This research has demonstrated to us the strength and character of a group of people who are often undervalued and unseen. They have spent their lives loving and caring for their learning disabled family members and have often sacrificed health, money and opportunities to do so. Their sons and daughters are loved and cared for but daily life can be a real struggle and "living from day to day", is the best that most can manage.

Castle Douglas and District and North Ayrshire branches of ENABLE Scotland would like to encourage older family carers to look beyond tomorrow. We know this is not easy and some of us who are personally involved in this research have to take the same small steps. If we support each other we can get where we want to be.

# Did we achieve what we set out to achieve?

Overall we had high expectations of this research and we achieved a lot of what we set out to do. Appendix 2 outlines how we have evaluated our achievements.

We haven't yet "influenced the future planning, development and delivery of local services." This report may improve communication links between planners and people who use services as we have gone some way to clarifying issues relating to older family carers. Our research has, we believe, highlighted the complexities that older families experience who have a member with a learning disability.

We do feel however that if older family carers of people with learning disability are to get a better deal as they move into their later years a lot still needs to happen.

## Glossary of Terms

### **The Same As You?** (Scottish Executive 2000)

This was a wide ranging review of services for people with learning disabilities which resulted in 29 recommendations.

### **Graphic Recording**

This is often called graphic facilitation. It uses words and images to record what has been said. The method helps to link ideas and encourage participation.

### **Involve Project, ENABLE Scotland**

Funded by the Big Lottery, this project supports people with learning disabilities and their carers to be involved in planning on matters that affect them and their communities.

### **Co-Researcher**

Those community members who helped carry out the research.

### **Dual Carer**

An older family carer who has a son/daughter with a learning disability living at home. A dual carer has the support of another family member such as a spouse or partner.

### **Single Carer**

An older family carer who has son or daughter with a learning disability living at home. A single carer cares on his or her own.

### **Sibling Carer**

A brother or sister who supports their family member with a learning disability at home.

### **Older Family Carer**

A close relative or friend or guardian who supports a person with a learning disability at home.

## Acknowledgments

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- Lynne Robertson, Mentor
- ENABLE Scotland, Involve Project
- The Project Implementation Team
- Co- Researchers, Castle Douglas and District
- Mansefield Trinity Church, Kilwinning

And finally, to all older family carers who gave up their time to talk to us and share their experiences with us, without which, this research could not have been undertaken.

## Appendix 1

### **Type of Health Problems**

(Adults with learning disabilities being cared for at home).

Epilepsy	•••
Hearing problems	•••••
Thyroid	••
Heart problems	•••
Mobility problems	•••••
Spastic quadriplegia	••
Cystic fibrosis	••
Spina Bifida	•
Diabetes	••
Cerebral palsy	•••
Alzheimer	••
Hydrocephalus	•
Breathing problems	•

## Appendix 2

OUTCOME		EVIDENCE
Have a better understanding of the needs of older family carers of people with learning disabilities	<b>Achieved</b>	Research complete and report produced
Establish personal contact with older family carers, many of whom experience social isolation because of their caring duties	<b>Achieved</b>	Involved through social event, focus groups, semi-structured interviews and through launch events
Encourage older family carers to become involved in planning processes and to have a 'voice'	<b>Achieved</b>	Involvement through research process and encouraged to express views
Create a link for older family carers to break down isolation	<b>Partially Achieved</b>	Through involvement in research process and through creating links with Princess Royal Trust for Carers
Create a climate of hope by re-energising the enthusiasm to take agenda forward	<b>Partially Achieved</b>	We have created great interest with older family carers who took part in our research and within ENABLE Scotland
Have more sustainable groups and to have more people involved in groups	<b>Achieved</b>	Our groups have stimulated interest in them and have identified additional, older family carers to be involved. In North Ayrshire we have set up an information event on Wills and Trusts
Demonstrate that the issues are similar across geographical areas	<b>Achieved</b>	Our research findings were the same for both areas covered and also concurs with research carried out in South Lanarkshire
Learn from our experience and to share our experience	<b>Achieved</b>	We will share our research findings during Carer's Week and Learning Disability Week.
Encourage older family carers to think 'out of the box'	<b>Partially Achieved</b>	We believe that we have started on the process by talking to older family carers about their issues
Provide active solutions to problems	<b>Partially Achieved</b>	Within our research we have made recommendations in how to progress some of the issues raised in our report and who should take them forward

Own Future

Peace  
of mind

doing things  
on the spur of the  
moment



Castle Douglas and District Branch, ENABLE Scotland, SCO12677

North Ayrshire Branch, ENABLE Scotland, SCO21047

June 2008

Can't see beyond  
Just now

living day  
by day.