Carers Parliament 2012

Report

carersparliament2012
Foreword

We are delighted to present the report of the first Carers Parliament which was held on 1 October 2012 in the Scottish Parliament.

The report is comprehensive, covering all issues raised throughout the day. We are very grateful indeed to all the carers and young carers from all parts of Scotland who contributed freely to the discussion their thoughts, experiences, knowledge and ideas.

Carers and young carers spoke passionately about their lives and the lives of those they care for, what works for them and what needs to be done in order to improve services to the people they care for and support for themselves. Taking all of this together, and recognising the many different caring situations, the main themes included: early identification of carers and the role of health, social work and education in this; the need for flexible, personalised, culturally competent and consistent support suiting the needs of carers and those they care for; treating carers as equal partners, listening to them as the people who know most about the people they care for; what can be done to mitigate the impact of welfare reform; and support for carers to remain in employment.

We need to build on the work that is taking place to support carers and young carers in order to improve outcomes for individuals, families and the wider community. We know that progress can seem slow and that carers and young carers can feel a huge amount of frustration. Sometimes it can take time for change to become embedded in policy and practice. What we would say, however, is that the Scottish Government and COSLA are fully committed to ensuring that change for the better takes place. This means that, with partners, we are implementing the Carers and Young Carers Strategies, Caring Together and Getting it Right for Young Carers as well as taking forward a wide range of other initiatives and legislative change to support carers and young carers. We attach to this Foreword a summary of the action in hand, with some local illustrative examples, which we hope you will find helpful and informative.

The second Carers Parliament is to take place on 1 October 2013 at The Hub, Edinburgh. We know that many carers wanted the Carers Parliament to be held again in the Scottish Parliament. I can assure all carers and young carers that the change of venue does not have any impact at all on the importance that we attach to the Carers Parliament. What is important is that carers and young carers are heard and that progress is made in providing the necessary support.

Carers Scotland is sending a copy of this report to all carers and young carers who attended the first Carers Parliament, to MSPs, to local authorities, Health Boards and to a wide range of other organisations.

We look forward to meeting carers and young carers at the second Carers Parliament.

Michael Matheson MSP  
Spokesperson  
Minister for Public Health

Cllr Peter Johnston  
Health and Wellbeing  
COSLA
Introduction

The first Carers Parliament in Scotland was held on 1 October 2012.

By the kind permission of the Scottish Parliamentary Corporate Body, the Carers Parliament was held in the Scottish Parliament.

185 carers from all over Scotland, including 17 young carers attended the event along with 42 staff who attended to assist with the day, including as speakers, young carer support workers, interpreters and note takers. Of the 185 carers, 15 were from black and minority ethnic (BME) communities. A delegate list is available at Appendix 4.

The following report sets out the key issues raised at the first Carers Parliament during debates, workshops and at a question and answer panel session.

All sessions of the Carers Parliament, including the workshops, have been filmed and can be watched online. The film and further information can be found via the Carers Scotland website at: http://tinyurl.com/CarersParliament2012

A copy of this report can be also be downloaded at http://tinyurl.com/CarersParliament2012 or, for those carers without internet access, a printed copy can be provided by Carers Scotland by telephoning 0141 445 3070.
Process

The Minister for Public Health wrote to the national carer organisations asking for their support in organising the first Carers Parliament. The national carer organisations agreed that Carers Scotland would take the lead in organising the event.

As a first step, Carers Scotland established a steering group to guide the planning for the event. This included carers, representatives from organisations supporting carers and the Scottish Government Carers Branch.

A theme for the day

The Steering Group agreed that as a first step, we would consult with carers on the key issues they would like to debate at the Parliament. After taking advice from, and learning from the experience of Age Scotland who led on the organisation of the Scottish Older People’s Assembly, the Steering Group decided that to frame the day we should ask carers for their views on the most important theme for debate and key topics for discussion in workshop sessions.

To support this, Carers Scotland and the national carer organisations undertook a large consultation exercise with carers. This included sending out more than 10,000 printed survey questionnaires and disseminating the survey electronically to groups supporting carers across Scotland.

736 carers responded to the consultation and identified the theme of “services and support for you and the person you care for” as the most important for debate. They also rated the most important topics for discussion in workshops. These were:

- The financial impact of caring
- Availability of support services for carers
- Planning for health and social care services working more closely
- Your rights as a carer
- Accessing services for the person you care for
- Access to suitable, flexible short break and respite support

A breakdown of the responses to the consultation can be found in Appendix 1.

Identifying carers to attend the event

Following the consultation on the theme, the Steering Group discussed the best ways to ensure that carers from across Scotland and representing different types of caring roles were able to attend the Carers Parliament. The Steering Group agreed that to ensure that the process was fair and transparent, carers would be asked to register for the event and they would be then be
selected in a ballot based on their Scottish Parliamentary Constituency. The Steering Group also agreed that to ensure that there was representation from BME carers and young carers that MECOPP (Minority Ethnic Carers of Older People Project) and the Scottish Young Carers Services Alliance would identify carers through their networks. In addition, members of the Carers Reference Group which helps inform the implementation of the Carers Strategy were allocated places.

Registration forms were sent to all carers who responded to the consultation, every carers centre in Scotland and a wide range of condition specific groups across Scotland. Registration was also available to complete online and was advertised on websites and through social media.

326 carers applied to take part and two from each constituency plus reserves were selected. Carers who were successful in the ballot were then asked to complete a delegate registration and provide information on any support they needed to attend, for example, travel costs, accommodation and replacement care. Where this was needed, it was arranged by Carers Scotland. The delegate registration also asked carers to provide information on their age, gender, caring role and ethnicity. A breakdown of this information can be found in Appendix 2.

Questions for the Panel

Carers attending, those who took part in the consultation and groups were offered the opportunity to submit a question in advance for the panel of invited guests. These were themed by topic and then selected at random. The questions selected and responses are listed in Section 5. Those not selected were provided to the Convenors of each relevant workshop for inclusion in their discussions. Many of the issues covered in the questions were also raised in the debate.

Evaluation

Following the Carers Parliament, carers were asked to evaluate the day. Details and a breakdown from this evaluation can be found in Appendix 3.
Summary of Key Issues

• Information for carers needs to be available early and in one place. Carers suggested options such as “one stop shops” and that GPs should be taking a lead on this.

• The role of GPs is critical in identifying carers of all ages, sharing information and good practice and working with local carer services to better support carers.

• It is important to identify carers early in their caring. Small packages of support provided at an early stage can prevent crisis and breakdown and must be available close to where carers live.

• The role of young carers must be recognised by service providers, health professionals and educational establishments including further education. A young carer’s card for school and health services should be available for all young carers.

• Carers have rights but these must be real and professionals and carers must know about them. This includes ensuring that carers are informed of their right to a Carer’s Assessment as too few are carried out and the outcome is often ineffective.

• Services must be responsive and planned in a way that meets the needs of both individual carers and people who use services. They should also be appropriate to communities including BME carers, those living in remote and rural areas and young carers. Services should be flexible to meet the needs of carers and those they care for rather than designed for the convenience of service providers. Individuals should not have to fit into unsuitable services and assessment should be based on need, not available resources.

• Self directed support is a positive step forward but should not be linked to cuts.

• The availability of equipment presents a difficulty for many carers. It often takes too long to receive standard equipment e.g. shower chairs and the availability of specialist equipment, particularly for children with complex needs is inconsistent across Scotland.

• There must be more consistency of support for carers including training, breaks and counselling. This should be available across local authorities as carers feel there is a “postcode lottery” for support for themselves and the person they care for.

• Health and social care service providers need to listen to carers. This is particularly important in achieving successful hospital discharge and supporting people with mental ill health.

• The costs of caring can be high. Carers need better financial support and have significant concerns over welfare reform. Carers felt that Carers Allowance should be extended to be available to older carers and student carers. Although these benefits are reserved to Westminster, what measures can the Scottish Government take to provide financial support to carers? Suggestions from carers included free concessionary travel and help with heating costs. They also noted that they should not have to contribute financially towards the costs of care for the person they care for nor for support for themselves as carers.

• The integration of health and social care will be very important for carers but they must be involved at the “top table” and at the heart of planning services and support. It is also vital that GPs are fully involved in the integration agenda as they are often the first point of contact for carers.
• It is important to ensure that new technology such as telecare and telehealth is available across Scotland and access to this is not limited by difficulties with broadband or lack of backup in remote and rural areas.

• Carers need support to protect their own health and wellbeing including support which enables them to attend their own health appointments. Where this support cannot be provided by, for example, other family members, then the local authority should provide that support.

• Carers need support to enable them to have a life of their own outside of caring including:
  – the chance to go into further education and support to enable carers to do this including financial and practical support.
  – Flexible services to enable carers to stay in or return to employment.
    – Support from employers to help carers stay in paid employment.
    – Help and recognition for young carers at school and in further education, understanding of their role and recognition of this in deadlines for homework, study time and exams.
Introduction

The first Carers Parliament began with a formal welcome by the Deputy Presiding Officer, Elaine Smith. “I am delighted to welcome you to the Parliament for today’s event. We are joined in the chamber today by carers from every corner of Scotland, and they are, in turn, joined by representatives of national carers’ organisations, members of the Scottish Parliament, civil servants and other policy makers. You come together today as the Carers Parliament to discuss some of the key issues and challenges that are facing carers in Scotland today as well as to identify good practice to share.”

This was followed by an opening speech from Alex Neil MSP, Cabinet Secretary for Health and Wellbeing. Mr Neil welcomed carers and highlighted that the Carers Parliament had been established as a result of a manifesto commitment from the Scottish Government to organise an annual Carers Parliament. The purpose of this was to “learn from you and to listen to what you are saying about the problems and challenges that you face, so that we as a Government and as a Parliament can respond as much as we can to those challenges to help you do your job as a carer.”

Mr Neil emphasised that all parties recognise the importance of carers: “Every single party recognises that we need to do more to help our carers deal with the challenges that they face and we are working together as a Parliament, irrespective of our party loyalties, to try to deliver as much as we can for our carers.” and outlined key policies which aim to better support carers and those they care for including self directed support, health and social care integration, improving quality of services and specific strategies to better support carers caring for a disabled child or person with mental health problems.

The Parliament then heard from two carers. Paul Weddell, a carer for his wife and daughter from West Lothian and Lauren King, a young carer caring for her brother from North Lanarkshire. They spoke of the challenges that they face as carers and what support had been available to help them.

“The motion asks how we can best provide services and support carers in their vital role. During my police career, I was fortunate to get fantastic support from my employer, Lothian and Borders Police, which recognised my situation as a carer. Without their support, I am pretty sure that I would have crashed and burned long before I reached the age of retirement. For that, I will be eternally grateful. Carer-friendly policies by employers and raising awareness of carers are two things that could make a massive difference to our lives.” Paul

“Like many carers, especially male ones, I thought that I was some kind of superman and could handle everything that life threw at me. My body, on the other hand, had different ideas. Eventually, the sleepless nights took their toll and I burned out. It was at that point that I finally recognised that I needed some help if I was to continue in my caring role. It is very important that carers are recognised by our health services and treated accordingly, and that regular health checks become the norm.” Paul
“Getting short breaks away from my caring role with other young carers of my age was one of the most effective ways of helping me to cope. The Scottish young carers’ festival also played a huge part in my life; I managed to go to the festival four years in a row, which is a lot more often than many other young carers can attend.” Lauren

“As a young carer, I also found it frustrating that doctors would hesitate to discuss my brother’s illness with me. If I can be responsible for his care, I am surely more than capable of hearing about his disabilities. However annoying those issues are, they are easily solved by strategies to train doctors how to treat a carer and how to respond to a young carer—or even how to recognise them as a carer.” Lauren

Key issues raised in the debate

Carers then had the opportunity to debate the issue of services and support for carers and those they care for. The debate covered a wide range of issues, including:

- carers’ rights;
- financial support to carers and being able to balance work/education with caring;
- services to meet all needs in a flexible, responsive, culturally competent way;
- the integration of support for carers;
- carers as equal partners being involved in decision-making, planning and implementation;
- the early identification of carers;
- the need for empathetic and supportive professionals;
- the need to support carers’ health and well-being through the provision of short breaks, counselling and other forms of support;
- the need for carers to be able to balance work with caring
- the need for more support for young carers in schools.

The full debate is set out below:

Fiona Fisher: I am from Dunfermline in Fife. I have three children and I care for my son, Jonathan, who is 18 and has a rare genetic syndrome called Lowe syndrome. There are only two other people in Scotland with the condition. He has multiple and profound disabilities.

We talk a lot about rights and responsibilities in this country, and carers obviously have a lot of responsibilities but perhaps not so many rights. I believe that there are five fundamental rights for carers that should be addressed urgently. The first—which I know is a reserved issue—is the right to a living wage. At this point, we deserve at least parity with jobseekers. I find it hugely insulting that I earn £12 a week less than someone who, by definition, does no work.

The second is the right to time off, with regular respite breaks, including emergency and sickness cover.

The third is the right to work limited hours. Like many carers, I care for my son 24/7, and there is no other working situation in which that would be tolerated.

The fourth is the right to health and safety training, especially with regard to moving and handling.
To this day, I have never been told how to carry out personal care safely on my son.

The fifth is the right to an occupational pension. For most of my adult working life, I have been a family/unpaid carer, and I have had no chance to build up an occupational pension. However, during that time, I have worked over 100 hours a week—week in, week out.

I am concerned about other issues, too. I believe that the carers allowance should be restored to pensioner carers and student carers, and that people who care for more than one person should have more than one carers allowance. Also, the fact that my husband is in full-time employment means that I am excluded from many benefits for carers, such as free dental treatment. I will stop there.

The Deputy Presiding Officer: Thank you very much for your contribution, Mrs Fisher. I invite anyone else who wishes to contribute to put their hand up. I will try to fit in as many people as possible.

Alan Gow: I come from Glasgow and am a carer with an interest in mental health. I did not think that I would be diving into the debate as early as I am, but I thought that, as this is a very vociferous-looking crowd, I had better get my word in before I got drowned out.

I have been thinking about the diversity of carers—we reflect society—and the diversity of conditions, which include stroke, mental illness and dementia, and which cover childhood, adulthood and old age. Some conditions are short term and some are long term. There are rich carers and poor carers. There are carers who live in rural areas who have particular problems that might be intensified by their partial isolation and, while there are greater numbers of carers who live in the cities, the services there might be swamped by the numbers. We should remember that, as well as clever and able carers, there are stupid carers. Not everyone who is caring is that bright or clever or wants to do the business.

However, the one thing that unites us at the beginning, when a condition first bites, is that we are ignorant carers in the sense that most of us do not know about the condition—we do not know the details of it. That is when all the emotions, from fear to sadness and grief, kick in. I think that that first stage is an extremely important part of the process. Respite and whether you get X weeks or Y weeks is important, too—that is a structure that you can argue about—but once you step on the escalator of care, you find yourself in the situation of not knowing what you face. In such situations, the mind catastrophises. You create all sorts of scenarios about what might happen. It is at that point that people need intervention, and they need it fairly quickly.

Following a diagnosis, we start to fumble about. We ricochet backward and forward between social services and health services, as the person we look after dips into and out of different services. We get ground down by that, and we can become—although this is changing—the ragged-trousered philanthropists of social work services and the bare-foot nurses of the national health service. These issues have to be caught quickly. We have to identify those carers who want to be identified. We respect the point of view of those people who do not want to be involved. That process of identification has to be done fairly quickly, so that people are brought into the system.

The system for change is there—as the minister said earlier, it is an all-party structure. There are good strategies in operation at present, but how do we get what the statement asks for? How do we move things on? As Joseph Hill, a reformer in the last century, said, we need to organise. I do not mean organise by forming big parties or structures. We must use the structures that we have; we do not need to create new structures. We have to link those
structures together back in our own areas, and we have to tie into the national strategies. However, not everyone can do that—not everyone has the time to do it. We need to lift people up. If you can understand the condition and the various streams of things that oppose you, there is a possibility that you will be a better carer—[Interrupted.] I hear a cough. The big man who spoke—I forget his name—said that when the Presiding Officer coughed, he would have to stop. Do I have to stop speaking?

I am sorry—I put myself off my point. We need to combine the national structures that we have, the Coalition of Carers, Carers Scotland and our local groups. People need to look out over their town or city and they need to see what is being done elsewhere.

One of the musts is that we must get involved with the strategic thinking in the integrated partnerships that are developing. That involvement must be at the highest levels, because it is only at those points where we can see and meet people and influence the decisions about carers’ involvement in an integrated partnership. Not a lot of us want to do that, but some of us do. Integration is going to trickle down. In the care support system, we have the silo system of condition-specific structures and generic structures—horizontals and verticals. We have to integrate those systems.

Structures have to pay more than lip service to the idea of partnership. Everybody wants to be a partner, but nobody wants to lose their money and support, so they want to keep the numbers. People say, “I’ve got my carers and you’re no gettin any and I’m no gonnae tell you aboot them, because that decides my grant.” That sort of situation must be worked at over a period.

We are looking for integrated carer pathways, if we can structure those. We need more partnership working and we need to bring people together, with specific help at the early stage. We need identification, education and support, including psychosocial support, which is extremely important. One thing that should infect our thinking is to think about what we can do today that will allow us to do tomorrow what we cannot do today. There will be slow steps, but we can do that with the structures that we have.

**The Deputy Presiding Officer:** Thank you, Mr Gow. I should say that I am actually coughing just to clear my throat, but if everyone takes six or seven minutes, I am afraid that I will not be able to fit in very many people, so I make another plea for concise points.

**Christina Boyd:** I come from Greenock and I care for my mother, who is 100 years old. Despite her age, she is really quite well, so the problems that I have had are nowhere near as bad as the problems that others have. However, I have found that the health service wants to make its services fit what is handy for the health service; it is not interested in what the person who gets the service needs or what the carer wants.

I have two small examples of that. My mother needed an ECG and was reluctant to go to hospital. I knew for a fact that the local health centre had an ECG machine and would do ECGs at home, but I had a struggle to get somebody to come out to do that. The other real problem that I had was with chiropody services. My mother was again reluctant to go to hospital, so we needed a chiropodist to come to the house, but it was close to pulling teeth to get that. Finally, I had to give up and pay for a private chiropodist—that is how I got round the problem.

We need to make all the organisations understand that we need what we need and that our loved ones need what they need, not what is convenient for those organisations to give us because it is easier for them and their budgets. That is not what we are looking for.
David McIlwaine: I care for my wife, who has Huntington’s disease with secondary psychosis. Huntington’s is a neurodegenerative illness, so my wife’s disability progresses through time. I have cared for my wife for the past 10 to 12 years.

Services and support must be local and close to where people live so that we do not have to travel and take time off work. It should not be difficult to access services. Services need flexible hours of access and flexible means of access. I recently had to apply to the disabled persons housing service because we need to be rehoused, as our current house is not suitable for our needs. That service actually came to our house to fill out the forms and make the application. Services and support need to be specific to sufferers’ needs.

It is okay to have an umbrella organisation, but—as Alan Gow said—there are so many different illnesses and conditions that only specific services can cater for people and provide the best support. We need to be able to plan for future care needs. When illnesses are degenerative, what fits today certainly will not fit next week or next year. There needs to be a lot of planning for future needs regarding disability, care homes and so on. Services and support for carers need to be practical, they need to help to reduce the burden of caring, they need to provide proper current assessments and they need to be responsive.

My experience of being a carer is tiredness, exhaustion, stress, financial hardship, isolation and exclusion. Other carers have talked to me about mental health issues. I believe that carers would benefit from regular counselling—that is the support that I would have benefited from most. There is no benchmarking for carers—you do not know when you are doing a good job, and you do not know what is expected of you. Counselling—direction—would be most advantageous.

The Deputy Presiding Officer: We do not have a huge amount of time left, so I would be grateful if people would be concise.

Marie McWaters: I have been in a spiral of caring for many years. I was totally unsupported for about 20 years, and reached the point where I felt like curling up and dying, to be perfectly honest. Six years ago we set up a direct payment system, which made a massive difference. It freed us up and made a massive improvement. There was a big change in quality.

I required sleep—that is probably the case for a lot of carers: they need sleep. My respite is for sleep, for a few nights a week, and it is on-going. The council where I am has been very supportive—from what I hear about certain places, I gather that that is not that usual. The fact of the matter is that it should not be about your postcode or how supportive your council is. You should not find yourself in a black hole before anybody helps you—20 years is a long time to be doing it on your own every day, 24/7.

A lot of the problem is that carers do not know what support is available and where to get it. In most cases, people do not even know whether they are a carer. It takes a long time for people to work that out. Once they work it out, if their council is supportive and does not close the door on them, it makes a massive difference in terms of how quickly things can improve for them. If they do not have a supportive council, it will not work out for them and they will be banging on doors continually. People do not have the energy for that—it is as simple as that.

Please help straight away, when there is quite clearly a black-and-white case and there are issues that need resolving. Funding needs to be found—it is as simple as that. I practically broke down, when we had 30 seizures a day on a running cycle and things could not be contained, and I was living in pyjamas for a month. The fact is, when a carer gets to that point, it is too late.
The care and the help need to be there and should not be based on your postcode. Legislation should clearly say “This is what’s here and this is how you get it. Go and damn well get it.” It is as simple as that. Thank you.

**Jim Morrison:** I am from Stonehaven and I was a carer for my wife, who had vascular dementia.

I will be very brief. From my experience of speaking to other carers and from hearing the speakers today—particularly young Lauren King—it is apparent to me that GP practices are one of the weak links for people with a mental health issue or any other health disability and their carers.

I suggest that, in relation to the proposed adult health and social care integration bill, we look carefully at the one-stop shop. GP practices should know about the health issues of the person with the condition and the issues—or potential issues—for the carer, and I would like that to be considered seriously as a matter of urgency.

**Sunna Kaleem:** I live in Giffnock in Glasgow. I am a carer for two people, including my mum, and I am a masters student in the respected field of psychology.

My initial experience of being a dual carer was quite horrific. I did not know my rights as a carer—quite frankly, I still do not. The social worker automatically assumed that I was aware of my rights and therefore did not feel the need to explain them in detail.

Social workers are—in the most polite terms—a constant headache. I am sure that a lot of the carers in the chamber would second that opinion. My mum describes social workers perfectly as following a take-it-or-leave-it system. They do not give you many options, and they dictate how you should lead your life. We feel intimidated—and in many cases bullied—by them. There is a constant reminder of the horrific emotional turmoil that we have to go through.

A social worker is the initial point of contact that a carer comes across in a Government body. If they are not doing their duty as they should be, what hope is there that the rest of the system will be implemented in the way that it should be?

There is a great deal of paperwork and legislation on the rights of carers and on the way in which things should be done. That is all good, and it sounds perfect, but, in practice, we as carers have nothing of what is written in those papers.

What is the Government doing about that? I have been a young carer since I was 15, and I do not know where my life has gone in the past 10 years—in fact, it is more than 10 years. I am still struggling, and I am still completing a university course that should have taken me three years to complete.

That shows the kind of education that I am undertaking. I want to live my life and have a bright future, and I want to see the world, but practically that is not possible. Organisations expect me to have great work experience in certain professions or to apply for different professions, but as a dual carer I do not have even a minute to myself. You tell me how I can leave my house, get work experience, apply for a job, have a great CV and put my opinion or myself forward as a human being to earn my living.

Those are just some of the issues. Another is the involvement of the council, which is not efficient. My mum is wheelchair-bound, and it took her eight months to get a shower chair. A shower is a basic need for a human being. Human rights should come into this, because everyone has the right to take a shower in the morning. It is appalling if someone does not have a chair to use so that they can take a shower, especially given UK standards.
Another issue that I would like to highlight is vacations. It is all very good having respite care or whatever, but I have not been on a vacation for the past 10 years. You have to fight for your rights as they are not given to you, and that is where the struggle comes in. We are already exhausted from our caring roles: we feel helpless and tired, and we are sleep deprived. The last thing that we need is to have to fight for our rights, which the Government should be giving to us. What is the Government doing about that?

Another issue that I would like to raise is the financial issue of the heating costs involved. My mum needs to have constant heating, even during the summer, to keep her blood circulation going. With the Scottish weather, it rains all the time and if you are feeling cold you need to turn on the heating. The decision is between having either heating or food on the table.

Similarly, I need to pay for my education, and all my carers allowance and benefits go towards that—a ridiculous amount of £4,000 just for one year. The individual learning account pays only £500 towards that. To go into a respected profession such as counselling, which is in my field of psychology, the costs go a bit higher still. What hope is there for me or my future there? So far, in my practical experience, I have not seen anything done. I have heard a lot of debates and things going on, but I have had no help whatsoever.

In response to the cabinet secretary’s statement, if you recognise everything and know our needs, my question is: why do you not listen and actually deliver on the talk? Why do you not do something about it, instead of just coming on to a stage and talking? We need to start doing something practical and get things moving.

Finally, self-directed support has been a great help and has been one of the best things that happened in my mum’s life. SDS is a step in the right direction, and I would highly encourage the Government to implement such things.

The Deputy Presiding Officer: Thank you. Let me just say that I have no hesitation in cutting off my MSP colleagues if they go over time, but I do not want to do that today. Unfortunately, we have only about 10 minutes left so there is now no chance of getting everyone in. If speakers self-discipline and make their points short, we might get more of you in.

It has been pointed out to me that I might be missing people at the back. I call the woman at the very back of the chamber.

Sheila Kerr: I am Sheila Kerr from Ayr. I just want to acknowledge that the key point running through all the speeches is frustration and stress.

I will try to keep it brief. I am a carer for my son. He is now aged 19. It took eight years to get the diagnosis of Asperger’s. Autism, Asperger’s and autistic spectrum disorders take a long time to diagnose so I take that into account, but, anecdotally speaking, I know many people who have taken this journey—I call it a journey. The key point is that going through the process of getting the diagnosis took a long time. Secondly—this follows up points made by other speakers—there are issues to do with confidentiality. I do not have guardianship of my son because he is high functioning, so once he turned 16 I could not be part of anything that he was told by the GP unless he permitted me to come and sit in the GP’s surgery with him. Although my son is high functioning, he will miss things although it seem s as if he understands.

As the full-time carer with responsibility for the paperwork associated with his disability living allowance—he cannot fill that in—I have frustration about that.

My second point, which I would like to put forward for anyone sharing this situation, relates to the fact that my son is high functioning and, following a lot of work that I have done with him,
he is fortunately at college. My issue is that he is old enough to go out on his own with certain friends, but he is not going to say, “I have got Asperger’s”, because, despite raised awareness, there is a stigma. I have been on to the National Autistic Society website, where you can download some sort of card to put on your wall that says, “I am on the autistic spectrum and I need certain support”. I do not say that this should necessarily be mandatory, but I am looking for raised awareness for carers who have Asperger’s adult children who are high functioning and doing well.

There should be more connection with health services, the police and so on. For example, my son can suffer from anxiety, which can happen in a public place and, if it was not for his friends, he would be arrested. However, his behaviour is because he has a mental health condition.

So, my two points are: first, perhaps there can be a voluntary or mandatory identification system, not just for carers but for autistic spectrum individuals; and second is the issue that sometimes makes me feel that my hands are tied behind my back, which is that I know what I need to tell the GP about my son that he cannot tell to the GP.

Those are my two points and I hope that I was not too long. Thank you.

**Mohammed Afzal:** I care for my mum and I live in Dundee, but I work for a voluntary sector organisation in Perth that has a remit to identify and support black and minority ethnic carers. The minister mentioned earlier the needs and issues of BME carers. I want briefly to highlight a couple of things in that regard.

As I said, I care for my mum, who is an 89-year-old. I became her carer because she suddenly took ill. It is a culturally sensitive issue being a carer in the BME community; if a carer wants to access any support services, he or she is seen as inefficient and there is a stigma attached to that.

There are language barriers to accessing services and, as a colleague mentioned already, doctors are reluctant to home visit. Any time that I needed help for my mum, they would say “Why can’t you bring her to the surgery?” It is very difficult.

The issue that I want to highlight is that there is an ageing population in BME communities who have paid taxes and now need a lot of looking after and caring, but there are no culturally appropriate services around. Services need to start planning for the future to ensure that they will meet the language and cultural needs of BME communities.

Those are just a couple of things that I wanted to bring to your attention. Thank you.

**Catherine Bingham:** I come from East Ayrshire. The Scottish Parliament is considering the Social Care (Self-directed Support) (Scotland) Bill, which has passed stage 1 and is now in stage 2 of its progress. Under section 16 of the bill, the Government proposes to make charges to carers for respite in relation to the people for whom they care. How can the Government make charges to carers who do not receive a suitable recompense for the services that they provide?

The help that is given to carers is a resource to help them to be supported in their caring role, not a service that they themselves use. No one is being paid to look after the carer—it is the cared-for who requires to be looked after—so they should not be expected to contribute financially to the cost of services provided to the person for whom they care or to the cost of resources that enable them to continue in their caring role.

Carers must be viewed as contributors to care provision rather than as users of services and should not be charged for respite. Thank you.
Fraser MacLean: Deputy Presiding Officer and fellow carers, I am from Cupar in Fife. The stated aim of today’s event is to stimulate debate on the issue of services and support for carers, but beyond the debate itself what action and improvement can we hope to set in motion if we do not first agree on our definition of a carer and our definition of a Parliament? Even with welcome professional support from the available agencies, caring for people is hard work. Carers, by definition, are workers. The right to work under article 23 of the Universal Declaration of Human Rights, which was adopted by the United Nations in 1948, states:

“Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.”

Although carers are often employed round the clock, very few ever chose freely to be employed in this way and, because we so often deal with unforeseen circumstances that are neither just nor favourable, we have to guess and invent our way through immediate, personal and often distressing challenges. At the same time, many of us have to wave goodbye to the careers that we originally planned and trained for.

I spent one year at university, four years at art college, one year in vocational training and 15 years working my way up from the shop floor in my chosen profession, only to find myself, at the age of 38, faced with the responsibility of organising, managing and providing care in all its forms for a mother with Alzheimer’s disease and a father with cancer. As they grew older, the shopping list of their combined needs grew and became both more urgent and more inescapable.

I am now 51. My mother is dead. My father is still alive, but he requires round-the-clock support and supervision. His savings are gone. My savings are gone. The house that we live in has had to be remortgaged twice. I have cashed in my life insurance and, in May of this year, the car that we depended on finally had to be towed away for scrap. Although I now have a wealth of knowledge and experience of all aspects of health provision and social care, away in the distance lie the smouldering remains my original career.

To qualify for the weekly carer’s allowance of £58.45, a carer must prove, among other things, that he or she cares for somebody for 35 hours a week. That amounts to £1.67 an hour—less than the minimum wage—for work that is often gruelling and uninterrupted.

Most dictionary definitions of the word “Parliament” emphasise the outcomes of debate—the law-making powers of the individuals who are gathered together. Can we honestly define an event such as today’s as a Parliament if it is only a once-a-year gathering and if we are not to be present when the resulting legislative powers are exercised? Please let us do this more often, and let us all work to forge meaningful legislation from meaningful debate.

Rucksana Mahmood: Thank you for giving me the opportunity to speak. I have listened to everybody and it has been interesting to hear what people have had to say, but when we talk about a carer, we first have to address the person whom they care for.

I have been caring for my son, who has Asperger’s syndrome, for 22 years. He has been to 13 different schools because the system sees everybody with autism as being the same. My son is different because he is an individual, whereas the system says that he has autism so he should just fit under the umbrella, which he does not.

Social services departments stereotype and discriminate. That needs to change. They offer services, but my son refuses to take them because he does not see himself as fitting into that category, and they take the services away. I have been fighting and advocating on his behalf to
have services provided that suit him and not John, Lisa or anyone else, but they keep on failing us. He is now 22 and he has no job, no friends and no education, simply because the system has failed us. My question is: when someone is a carer for someone like my son, where are the services that can make a change in their lives?

John MacDonald: I will keep it short and sweet, Presiding Officer. There is no need to cough. One of the common threads this morning has been the lack of finance. We know from what people have said that they need money for food, private respite care and heating 365 days a year. Alex Neil said that carers in Scotland save £10 billion. Let us get some of that money back into carers.

The Deputy Presiding Officer: A number of people still wish to make a contribution. The democratic way in which I can facilitate that is by asking you all whether you want me to extend the session by 10 minutes, which will remove that time from your lunch break. Can I see a show of hands from those who wish me to do that?

Okay, that seems pretty overwhelming agreement. The next speaker is Brenda Emmerson.

Brenda Emmerson: I am from East Ayrshire and I am going to go the other way and talk positively about what has happened during the past 12 years.

I have been fighting for carers since 1998-99. I used to be a constituent of Elaine Smith’s. The number of things that have happened now that we have our own Parliament is tremendous. I hear everything that everyone has said. I have a daughter who has a neurological disorder, which means that she can do nothing for herself. My grandson, her son, has epilepsy, autism, learning disabilities, and a blood condition called polycythaemia. I care for both of them.

For us to have reached this point within 12 years is great. Let us get to the other milestones that we need to reach in a shorter period of time.

Celia Sweeney: The Presiding Officer asked how all partners deliver an integrated service. I have listened to all the emotive stories and I think that getting back to basics is most important. We need to identify carers first and foremost, and I propose a standardised package of care for carers. It should not be proactive but reactive to their needs and it should be in place at the start of their caring journey.

Carolan Connolly: Despite the increase in respite weeks that we have been told about, some local authorities are decreasing them. Carers are not looking for a handout. Respite for carers is a hand up. We know that people keep saying that they recognise the amount of money that is saved through carers, but we do not see any of that coming back to the carers. We understand that that might be because we are saving it so it is not required in the first place.

Angela Kemp: I am from the Banff and Buchan coast. I want to speak about the awareness of invisible illness such as autism. My son looks normal, acts normal, and is pretty much normal to everyone else, but things are pretty difficult for me as his carer. He does not really understand or see things in the same way as we do. He was excluded from his school 13 times in one year.

My son is 14 now and from the age of 18 months I asked for assessments to be done. Nothing was done until I asked for assistance from social work and they took me to a children’s panel, said that I was a bad mother and that I could not cope with his behaviour. Seven court appearances later, I got a diagnosis of autism, pervasive developmental disorder not otherwise specified—PDD-NOS—and several other things.
I feel quite passionate about early intervention. At the point of diagnosis, why can we not see that there is a carer for that young person, or that mother, or that other relative that they are caring for? What happens with early intervention? Please, at the point of diagnosis, ask who is going to be the main carer and take it from there. Thank you.

Fiona Cameron: I am from Inverness and Nairn. I care for my son, Gregor, who is 13 and has autism and epilepsy. I would like to know why it is not possible for a family member who is living at the same address to be employed as a carer as part of a self-directed support plan when someone from outwith the home can be. Why are parents not allowed to have crisis, aggression, limitation and management—CALM—training when they have to deal with a challenging child, but people who work in the schools can get that training?

The Deputy Presiding Officer: Thank you. That is noted.

Tony Fitzpatrick: I am from Airdrie and Shotts. Thank you for the opportunity to speak. I feel that I know many people in the chamber today because I have been on a journey with them for the best part of 15 years. I know many of the faces and echo many of the points that have been made. Brenda Emmerson said that a lot of changes have taken place. There have been a lot of positive steps forward for carers. I would like to raise my concern that we do not take a step back from the progress that we have made. Many carers are getting more involved in the carers agenda through the current community health partnerships. They are sitting at the top table and are able to influence and participate directly in strategic decision making. Under the integration of adult health and social care, we will replace those community health partnerships with community health and social care partnerships, and it appears that carers will no longer have the same right to a seat at the top table. Is that not a backward step? Can we do something about that?

Chrys Muirhead: I am from near Cupar in Fife. I am a carer but I am also a survivor of mental ill health in the psychiatric system.

I have been a carer on and off for about 40 years; I say on and off because different family members have had mental ill health, recovered, been ill again and then recovered. It has been interesting for me, as a carer and as someone who has been in the system, to have dipped in and out over that long period.

There is a lot of talk about recovery focus in Scotland—there is a Scottish recovery network—yet some of the services are very maintenance focused. They do not help people to recover.

A lot of other folk were talking about social work not really helping. Social work has worked against me as a carer. I almost had to fight social work to have my rights heard, which has been very difficult. Something needs to be done about social work services. Risk is a big thing for social workers. They are always looking for risk, and some of us who are carers look like we are risky. Social work services write about us—they say that we are risky. We are the ones picking up the pieces. They need to get real about that. They need to help us because we are saving them a lot of money. If they keep picking on us as carers and saying that we are risky, it will cost them a lot more. We save £10 billion. They need to give the money back to us and support us.

Beatrice Cook: I am from Orkney. My query concerns the registration of care-at-home workers and access to respite care, which are problems not just for Orkney but for other remote parts of Scotland, be it Shetland, the Western Isles or the Highlands.

Care-at-home workers, for example Crossroads workers, are now required to undertake a Scottish vocational qualification in health and social care. Our problem is that many of our carers
are elderly and are able or willing to work only a few hours a week. They would have to travel to the Orkney mainland to go to college to take these courses. Many of them will decide not to continue with what they have been doing for years, which in effect means that we will end up without any carers available to folk living in the outer isles. I am sure that that is problem for other parts of Scotland as well.

**The Deputy Presiding Officer:** Thank you very much. I can take only brief contributions from the last few people who have their hands up.

**Heather McNaughton-Wilford:** I am Heather and with me is Hannah, and we care for Andrew—my son and Hannah’s brother. A big part of our job is advocating for Andrew, as well as fulfilling the caring role. Our job is made much more difficult by the fact that we are not seen as partners and Andrew is not seen as a partner. We feel as though we are fighting an awful lot not just with social workers, but with the local authority right across the board. We ask that they respect us as carers and that they respect Andrew as the service user. They should listen to what we have to say and take it on board when assessments are being made. The assessments should assess the need—not just the resources that they have and how they can fit us in, as other people have said. That is the main point that we want to make.

**Gillian Bolton:** I want to make a comment regarding carers’ health. I am at the stage at which I am delaying treatment for myself because of my caring role, which will be a common issue among carers. I cannot afford the time to go into hospital to have treatment. Last week, I was rushed to hospital but had to sign myself out the next day in order to be home to continue my caring role. That issue needs to be addressed.

**Angela McVey:** Education is a major issue for young carers. In one of my schools, the teachers failed to recognise young carers. They ran support groups for homework, but I was struggling to meet deadlines for exams, and studying for exams was difficult when I was fighting for my right to get my wee brother’s medication. My wee brother, Peter, suffers from severe learning difficulties. Some areas have wee cards that people can hand over at the desk, but West Dunbartonshire does not. I wonder how long it will take for us to get those cards.

**David McElhinney:** It is hard being a carer. I have cared for my mum for a number of years. As well as cuts in the amount of money that carers get, education is a big problem for some people—they find it hard to find the time to study to pass their exams and tests. I have been diagnosed with Asperger’s and have still to be diagnosed with dyspraxia—I need that to be sorted out. It is sometimes nerve-racking when you have to do everything at the same time: school work, caring for your parent and dealing with your social life. I think that we need to get that sorted.

**Kirsteen Heneghan:** I have three children on the autism spectrum. I am a nurse to trade, and I also work for a third sector organisation that supports carers. As GPs are the main point of contact for carers and there are so many unidentified carers out there, surely it should be mandatory for GPs to refer carers on to us. They are simply not doing that. Instead, we are seen as some sort of Cinderella service, or as the enemy who is going to come in and tell them how to do their job.

**The Deputy Presiding Officer:** Thank you very much. I apologise to anyone who still wants to speak; there will be opportunities for you to do so in your workshops, I hope. I thank you all for your excellent contributions and the views that you have put across.
The Deputy Presiding Officer then introduced Colin Williamson who had agreed to summarise the debate. Colin has a wide experience of carers issues including his involvement in the creation of the Princess Royal Trust for Carers.

Colin Williams: Thank you. It is a privilege to be here today. I want to pick up on what Brenda Emerson said. Those of us who have been involved in this debate for many years would never, when we looked at legislation 10 or 20 years ago, have dreamed that we would be here. Those who have shared the journey—many of them are in the chamber—should celebrate the fact that we have reached an important point in the development of carers, but we should not lose the momentum, given the threats that we have heard about, the needs that have been expressed and the passions that have been aroused over the frustration and stress from relationships with departments.

It would not, however, be appropriate for me today not to acknowledge that we are here; we are at the table and have an opportunity to influence matters for the champions. Was it not great to hear from Paul Weddell, who has been one of the champions for many years, and from Lauren King, to whom we all owe great thanks for her contribution in highlighting key issues?

We know, however, that we have a mountain to climb. Despite the great strides in the current legislation and what the minister raised, which was encouraging in terms of new developments, there is much to do—as has been evident in what everyone has said today.

We must set the discussion in the gloomy context of the economy and public expenditure cuts. Only a fool would expect that situation to change—perhaps even in the next five to 10 years. However, we must take advantage of opportunities to influence budgets, such as those for the care information strategy, the change fund and short breaks for carers. We hope that opportunities will arise from debates about self-directed support and integration of services, which should include housing and welfare benefits so that there are holistic support services for carers and not just health and social work services.

From the briefings that I have had—I thank Moira Oliphant in that regard; what a superb lady we have in her in our carers branch in the Government—it is clear to me that there are more questions than answers and that there are difficult political decisions to be made. I do not envy the job that our politicians have in coming to a resolution on the issues of powers, responsibilities, budgets and criteria. However, we must work with them to achieve a sensible outcome that is realistic and addresses the issues that we have talked about today.

As several people have highlighted, we know that many of you live in what is a postcode lottery environment. It is just not good enough that some people have good access to services while other people have to fight for them. We have heard stories of people being isolated for many years waiting for basic things, including bath aids. That has to stop: we cannot expect people to struggle without the basic means of supporting themselves as carers, because they will become ill.

I serve on the implementation group on the change fund for West Dunbartonshire Council. That fund is meant to be the driver for fundamental culture change and is not to be used to develop additional projects that could die when the funding ends. It is going to be a major challenge to us locally and to the politicians to ensure that the change fund makes an impact on existing services through the millions of pounds that are being spent to change the culture.

We know from information across the board of the impact that is starting to be made by the care information strategy. I was delighted to hear the minister speak this morning about the
appointment of key workers in hospitals, but we need far more if we are going to make the
culture change and drive the agenda. Many people this morning have highlighted the issue of
identification of carers; many people do not know that they are carers. If they have not
understood that or are not locked into systems, they can retain that ignorance that some people
have highlighted—not that they are ignorant, but they are ignorant of the help that is available.

One of my major disappointments is that the aspirations in the care information strategy must
be revisited to give it additional impetus. However, in the context of the expression of all-party
political support, it is great to know that Alex Neil will continue to drive the impetus, particularly—
I hope—through the health boards, to ensure that there are systems to identify at the point of
diagnosis that people are caring, that support is offered directly from health services and that
carers are referred to appropriate agencies as a priority.

We know that there are frustrations about GPs. I have a fantastic GP, as many people here
have. It is a crazy contradiction that people who are trained to care for other people have not
yet got the carers agenda. When they send people home with heart, lung and cancer conditions,
who do they think is looking after them at home? We have not made those links. A fundamental
challenge for the carer information strategy, and for the Government and all the parties, is to try
to get GPs on board, because they are central to identifying carers. Why is it that, despite the
advances that have been made, we still have to battle to identify the people who need help?
That is one big priority.

Other speakers have highlighted the importance of money. Clearly, we need greater investment,
but much can be done for little expenditure, as is evidenced by what we have heard today. I
suggest that the agenda is not just about money but about something far more fundamental: a
culture change through which the time and focus of existing practitioners, as part of their job
remit, is realigned to include the involvement of carers.

When I ask social workers and home-care workers who go into people’s homes every day of
the week how many carers they are aware of, I just kind of get a stare. When I went with my
mum, who had dementia, to accident and emergency and told the people there that I needed
to be with her, I was told, “Oh, no. We’ll see her on her own.” She was very Welsh, partly deaf
and could not understand. I said, “You’ll waste the next 20 minutes of your precious time.” It
took three visits to accident and emergency to get the staff there to understand that I was
actually a help to them. We have been there, done it and won the T-shirt.

We still have not won the debate about the critical role of carers as key partners in the provision
of care. Until we win that debate, despite the enormous advances that have been made, that
will continue to be a major burden for us. It is critical that we drive the political agenda on health
and social work services.

It was disappointing to hear so much criticism of social work departments. I know that those
criticisms are valid from those speakers’ experiences, but I would not want all social work
departments to feel that they are not contributing positively. Experience will be mixed; we
probably need to look at the postcode lottery and element of luck that is involved in respect of
social workers.

We need to appoint champions to build carer awareness and to change the culture. The initiative
that has been taken with dementia champions is a good model that could be replicated for
carer champions. I know that Jackie Baillie and Michael Matheson are concerned about
integration of health and social care. It is partly a reflection of the fact that things are not working
that we need to talk that language. If people were doing their jobs professionally and were carer
aware, we would not need champions, because that would be part of the daily routine. However,
because things are not working, it is absolutely essential that we have investment in what I call intervention activists, many of whom are carers. There are examples of that in parts of the country, as I mentioned in relation to social care workers.

I understand that in West Dunbartonshire, about 1,800 home visits are made a week to people for what I call the all-home care service. We are starting to look at how we can identify the carers whom those people visit in order to ensure that they get adequate support, that they are locked into the system and that they are recorded. I think that we do our health and public service friends a disservice by saying that they are not helping carers, but we do not know whether they are. Until we evidence that, we will continue not to know.

Many of us receive information on flu jabs, and other correspondence from Government agencies. It would make an immediate impact on carers’ lives to receive information directly rather than to have to wait for a GP, carers centre or service to tell them. We should be able to use the tools and communication systems of Government to ensure that people know about such things. When there is a change in benefits, people are told, and we also have information about where people with disabilities live. Why, in that case, is it not possible to use those same structures to communicate directly? That could be communication once a year to ask, “If you are a carer, are you aware of your entitlement to help?”

We could have an incredible impact on the lives of carers in Scotland if we were to accept our responsibility to ensure that people are informed and that they do not wait 20 years to know what they are entitled to or to be able to access services. Many of the services that people need initially are about information, emotional support and awareness of where to go if things change, although other people will also need intensive support.

The issue of income is central to the debate and will be discussed more this afternoon. It is absurd that people do not know about the money to which they are entitled and which could ease their financial burdens. What a disgrace it is that we have the Department for Work and Pensions and welfare rights services, yet people are ignorant of their entitlements. Sometimes people feel embarrassed and think that it is charity. Given the cuts that we face, it is vital that we ensure that people utilise the income arrangements and benefits to which they are entitled. We need a major campaign on that.

The assessment process is central to a lot of this, but the problem is that people are not assessed if they have not been identified in the first place. The small number of assessments that are undertaken across Scotland reinforces our concern that implementation of the carers agenda is still greatly underdeveloped. Quality and competence in those who carry out assessments are critical if we are to have assessments of need and agreement about priorities that are needs-led as well as resource-led. All the anecdotal evidence that we have heard this morning has been about resource-led assessment—in other words, people are told, “This is what we’ll give you”, instead of their needs being listened to. I do not envy the people who have to do the assessments, but if they are not carried out openly and transparently and if there are predetermined limitations on what people can get, they will not get the help and support that they need, and nor will they have their needs listened to—albeit that some cannot yet be met. We should record that for future discussions with politicians.

As a community development wallah, I have a bee in my bonnet about engaging with other organisations—not only national carers organisations, but specialist organisations, housing associations and the church, which plays a caring role. We need all the energy and the creativity we can get in order to face some of the forthcoming cuts and ensure that we do not go backwards. It is not just about keeping our own momentum going, but is about looking for other allies.
As the evidence we have heard today suggests, other carers themselves are some of the best allies that we can have. For example, despite his other caring responsibilities, Paul Weddell is still fighting for carers; Brenda Emerson, whom I have known for a long time now, is doing the same. We are crazy people. There are huge stresses on us. People have talked about not getting any sleep, but they have still turned up this morning to discuss what needs to happen with carers.

I say to all Government ministers and politicians that this chamber contains one of the best resources in the country, if not the world. Without carers, the health and social services system would fall apart. I realise that it will be a major political challenge to understand that, to get rid of the rhetoric and to make all of this real but—as, I am sure, others sense from what has been said this morning and from support that we have received from different Parliaments—a national carers agenda is on the agenda, and despite frustrations and disappointments there is a genuine intent to start to get things right. If we work together, we have a much better chance of achieving that than we do if we simply fight with each other. If we give up momentum in the face of the cuts, we will lose a lot of the ground that we have made up.

Many of my friends in carers centres and other services are worried about the impact on them if there is an avalanche of referrals. However, we should not worry too much about that; instead, we should worry about what will not happen if we do not identify carers and make the case for additional resources. Rather than block change, we should facilitate it and take on those challenges in collaboration with our politicians.

We should draw on examples of good practice, one of which I was unaware of until this morning. You think that you know what is going on, but there is actually more going on than we can ever know. The appointment of carer support workers in hospitals is a fantastic initiative, but there are a number of questions that need to be asked. Where are they? How many are there? How can we link with them? What are they going to do? Who are they accountable to? They will certainly form an important resource. East Ayrshire GP practices have funded a carers support worker for years now; I understand that NHS Forth Valley has a strong carer information service; and there are good initiatives happening in places such as West Dunbartonshire, where a worker from our team has been appointed to the discharge team to ensure that it is carer aware.

At this point, I want to issue a wee challenge to the Royal College of General Practitioners, which I thank for taking the initiative and for raising the carers agenda with its colleagues. However, how many people have responded, and has it changed anything? I gather that the initiative will be evaluated; it will certainly be important to find out that information. I challenge the RCGP to get on board again, to identify two or three practices in every CHCP in the country and to link them to the carers centres in order to develop models of good practice that can be copied elsewhere. The RCGP knows who the good guys and women are. I ask that they be unlocked for us because some of us battle long and hard to find them and when we find them, they turn out to be treasures. We can use them to highlight what can be done if GPs in particular do the kind of job they are capable of and work in partnership with us.

The issues that are under review and their resolution will determine whether carers are truly partners in the provision of care. All the documents refer to the impact of our not being there on health and care services. If we are to be valued and respected as key partners in the provision of care, we need to turn the rhetoric into reality. That is beginning to happen, but we need to keep up the impetus and drive the agenda forward. The impetus of today’s event and previous events is clear for ministers and politicians to understand and to take forward with us. Nothing less will do.

Thank you.

*The Deputy Presiding Officer then closed the morning session.*
Themed workshops

Workshop Theme 1: “The financial impact of caring”

This workshop was convened by Michael McMahon MSP, Convenor of the Welfare Reform Committee and heard initial presentations from:

Geoff Kitchener, a carer from Scottish Gas who talked about his experiences of working and caring and the support his employer provided.

Isabell Donnelly from the Scottish Government Welfare Reform Team who provided information on the Welfare Reform Act and its impact upon Scotland.

Keith Willcock from the Scottish Government’s Fuel Poverty Team who discussed fuel poverty and energy efficiency initiatives that can support carers and those they care for.

39 carers attended the workshop and discussed a range of issues, the following of which were identified as key issues to be fed back to the main chamber:

- Carers felt that they should be eligible for free concessionary travel. At present carers of someone with a severe disability can travel with the individual free of charge but cannot travel without the individual.

- Carers felt that carers living in remote and rural areas needed additional support for the costs of caring, particularly help with heating and fuel.

- Carers felt that they need a realistic living wage.
  - Carers Allowance is only £58.45 per week and is only paid once, no matter how many people the carer is caring for. Moreover, many carers do not qualify including those carers who are studying full time.
  - Carers expressed that often they have to balance heating, bills and school bus fares and make choices sometimes between heating and food. To add to this, carers are being asked to make a contribution towards resources to help them care such as respite breaks and complementary therapies.
  - Carers are forced into poverty by having to give up work to care or reduce their hours. Supportive employers can help support carers to stay in paid employment.

Carers were disappointed that no representative from the Department of Work and Pensions had been able to attend to respond to these issues, even though they are reserved to Westminster. Key concerns included assessment and re-assessment for new benefits such as Employment Support Allowance, the impact of the “bedroom tax”, changes in Disability Living Allowance and concerns around the impact of the closure of the Independent Living Fund in 2015.
Workshop Theme 2: “Availability of support services for carers”

This workshop was convened by Bill Kidd MSP, Co-convenor of the Cross Party Group of Carers and heard initial presentations from:

- Carrie Ho from the Scottish Huntington’s Association who talked about support that they offer to carers.

- Robert Stevenson from NHS Forth Valley who talked about the carers’ strategy, support and training that is being provided in the area.

- Lily Trainer, a carer from Glasgow, who talked about the benefits of support from a carers centre and how this had helped her.

37 carers attended the workshop and discussed a range of issues, the following of which were identified as key issues to be fed back to the main chamber:

- Urban and rural issues were spoken about frequently. Carers felt that we need to recognise that one size does not fit all. Rural areas suffer from a number of compounding issues, including the geographical sparcity of carers centres and services and the lack of transport to access the few centres that are available. These issues need to be addressed.
• In addition, young carers’ life chances are often greatly reduced if they perform their caring role in a remote or rural area. In particular, if older brothers or sisters have left home to find jobs or education elsewhere, a younger sibling is often left behind in the carer role and is not able to access the education and job opportunities that their older siblings have accessed.

• Carers felt that services such as schools, colleges and universities need to recognise and identify carers and offer financial, educational and emotional support. Young carers in particular are still developing, but they do not always receive such support, which they require.

• Young carers can be called on at any time to look after a parent, for example, who requires their help. It is harsh and unnecessary for them to potentially lose something such as the education maintenance allowance because they cannot carry out those duties without being marked down as being absent and not taking their role as a student seriously enough.

• When a young carer has spent their formative years in a supportive group of other young carers and with professional expertise available to them, having to leave that group on turning 18 can prove traumatic. Carers felt that this should be addressed by more flexible local planning and management in care services.

Workshop Theme 3:
“Planning for health and social care services working more closely”

This workshop was convened by Duncan McNeill MSP, Convenor of the Health and Sport Committee and heard initial presentations from:

Callum Chomczuk from Age Scotland who discussed the ways in which integration could better support older people and their carers, including older carers.

Alex Devoy from the Scottish Government’s Health and Social Care Integration Team who talked about the proposals to integrate health and social care.

Nessa Barry from the Scottish Centre for Telehealth and Telecare who highlighted telecare and telehealth and the ways that they could support carers and the people they care for and be an integral part of integration plans.

37 carers attended the workshops and discussed a range of issues, the following of which were identified as key issues to be fed back to the main chamber.

• Carers must be at the heart of decision making. They often have the best knowledge about what support is needed for themselves and the person they care for. However, there is a lack of awareness about carers’ situations, knowledge and experience amongst professionals.

• Carers felt that there must be early intervention and support should not wait until there is a crisis. Carers need to know who (and should be advised) to contact for help as often this causes frustration and breakdown. Carers must be made aware of their rights proactively.

• Carers felt that it was important that best practice, for example in telehealth, should be shared across Scotland.
Workshop Theme 4:
“Your rights as a carer”

This workshop was convened by Mary Fee MSP, Convenor of the Equal Opportunities Committee and heard initial presentations from:

- Suzanne Munday from MECOPP who talked about the Equality Act and carers.
- Gill Walker from NHS Education Scotland who talked about workforce training to raise awareness of carers rights and role.
- Sue Kinsey from the Royal College of General Practitioners who talked about the role of GPs in supporting carers.
- Isobel Allan, a carer, who talked about her experience of “getting her rights”.
- Dr Alison Hosie from the Scottish Human Rights Commission facilitated a wide ranging discussion.

23 carers attended the workshop and discussed a range of issues, the following of which were identified as key issues to be fed back to the main chamber.

- The issues explored were stark. Although it was acknowledged that carers are aware that they have a number of rights and responsibilities, many still do not know what they are, how to access them, where to get the information from or who to go to for help. Carers have legal and human rights but the question was how to find out about them. Carers felt that this needs to be addressed.
- Carers felt that that carer’s assessments of need are not triggered unless asked for and that, as service providers, carers should be properly resourced. The feeling was that this is not currently happening and needs to be addressed.
- Isobel Allan, who contributed to the workshop as a carer said that when she went to school everyone knew the three Rs—reading, writing and arithmetic—and that carers have their own three Rs: rights, responsibilities and relationships. It is important that we do not lose sight of that.
- Carers felt that although the carers’ strategy is good it needs a lot more work to tighten it up. It is in place at the top, but it is not filtering down to ground level. There are just too many obstacles blocking its way and more work needs to be done in that respect.
- Carers also felt that there was not nearly enough information sharing between partners. Carers need to be a key and equal player in decision making and at the moment they are not. Although carers have answers, know what they need and know what is best for the person they are caring for, no one asks them the questions or, if they do, they do not ask them often enough or do not take enough notice of the answers.

Workshop Theme 5:
“Accessing services for the person you care for”

This workshop was convened by Siobhan McMahon, Depute Convenor of the Cross Party Group on Disability and heard initial presentations from:

- Ron Culley from CoSLA who discussed local government charging and eligibility criteria.
Craig Flunkert and Bette Frances from the Scottish Government’s Self Directed Support Team talked about the new Social Care (Self-directed Support) Bill (now an Act, 2013) and its impact on improving choice and control for individuals and their carers.

Catherine Bingham, a carer, who talked about her experiences of accessing and using self directed support to provide care for her son.

31 carers attended the workshop and discussed a range of issues, the following of which were identified as key issues to be fed back to the main chamber.

- Carers main concerns were that self-directed support should not be a mechanism for cuts or a vessel for cutting services to carers.
- Carers also felt that self directed support must not become a postcode lottery. Instead, it must give individuals greater flexibility.
- Carers also felt that it is legitimate to choose to keep existing services and the processes for accessing self directed support must work for people, starting with the assessment itself.

Workshop Theme 6:
“Access to suitable, flexible short break and respite support”

This workshop was convened by Claudia Beamish MSP, Co-convenor of the Cross Party Group on Carers and heard initial presentations from:

- Don Williamson from Shared Care who talked about the Short Breaks Fund and how it is supporting the development of more flexible, innovative short breaks.
- Margaret Peterbridge from Falkirk Council who talked about the short breaks bureau in the area and gave examples of innovative breaks to support carers and the person they cared for.
- Dorothy Barton, a carer, who talked about appropriate breaks for her two children and about parents working together to organise adventure breaks so that breaks are mutually beneficial for carers and the person they care for.
- Ann Hammell, a carer, who talked about her experiences of having a suitable break from caring at Carlogie House in Carnoustie.

22 carers attended the workshops and raised and discussed a range of issues, the following of which were identified as key issues to be fed back to the main chamber.

- Carers believed that breaks should not be “take it or leave it”. There should be a sensible entitlement to individualised respite care which is flexible, which is appropriate to special needs including specific medical needs (e.g. oxygen dependency), to cultural needs including those of BME carers and to young carers.
- Carers believed that breaks from caring should be provided at an early stage. They should not have to be identified as “desperate” or “at breaking point” before respite breaks are made available.
- Carers believed that there was inequality across Scotland and that there should instead be consistent provision and quality across Scotland.
Panel session
Carers were offered the opportunity to submit questions for this session prior to the Carers Parliament. A full list of questions is available in Appendix 4. Questions submitted were themed by topic and then selected at random to be asked to a panel of policy and decision makers from national and local government and the NHS. These were:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael Matheson MSP</td>
<td>Minister for Public Health, Scottish Government and constituency MSP for Falkirk West</td>
</tr>
<tr>
<td>Councillor Peter Johnston</td>
<td>Spokesperson on Health and Wellbeing for the Convention of Scottish Local Authorities and Leader of West Lothian Council</td>
</tr>
<tr>
<td>Christine Ferguson</td>
<td>Vice Chair, Association of Community Health Partnerships</td>
</tr>
<tr>
<td>Dr George Crooks</td>
<td>Medical Director for NHS24 and the Scottish Ambulance Service and Director of the Scottish Centre for Telehealth and Telecare</td>
</tr>
<tr>
<td>Peter McLeod</td>
<td>President of the Association of Directors of Social Work</td>
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**Question 1**

**Catherine Paterson**

“I am from Argyll and Bute. I want to raise the problems that face remote and rural carers, many of whom in Argyll could not come today. The road was shut, as ever—if it is not the A82 at Tarbet that is closed, it is the A83 at the Rest and Be Thankful—but I made it because I came down early.

“We have particular problems covering all the workshop areas listed. I highlight the problems of living in areas in which there are high living costs; in areas of multiple deprivation when it comes to access to care and support; and in areas where all our costs are higher and the opportunities to access suitable, flexible short breaks are rarer. How can the Scottish Government show that all carers in Scotland matter and are treated fairly and equitably without discrimination based on geographical location?”

**Michael Matheson** noted that “as a relatively small country that has a large rural area, we have not been as innovative as we could have been in finding ways to support people in rural areas more effectively. Some of the issues are, for example, how health services are delivered and how telehealth can help to support individuals in rural settings more effectively. We have not grasped those opportunities quite as much as we could have, although I know that some progress is being made.” He then noted some initiatives the Scottish Government has undertaken including allocating additional funding through NHS Carer Information Strategies to Health Boards for the work that they do, often in partnership with carers centres. This funding recognised the extra costs in rural areas. He also highlighted that, in the most recent round of the short breaks fund, carers in rural settings were a priority group. The aim is to focus on trying to provide carers with a break and to find innovative ways to deliver that.

**Christine Ferguson** noted that she recognised the issues highlighted as someone living and working in Shetland saying that “In Shetland, at every point where we work in health and care, we always hear about transport and cost. Transport issues can often mean significant time
delays in getting to care services, even if on-island services are available. Some services are not available to Shetland residents, so they have to come to the Scottish mainland.” She noted that there is a need to ensure that people are individually assessed and that there is an understanding of each person’s individual circumstances, recognising the groups of people who struggle to access services, and support them in the best way possible.

Councillor Peter Johnston expressed his agreement with Christine Ferguson’s points and noted that “we need better use of technology. Local decision making must be at the heart of what we do to ensure that carers have a genuine say in shaping the service that they get. Local flexibility is the best way in which to meet local needs.”

Peter Johnston agreed with the earlier points and said that “carers should be at the top table, making decisions about how services are shaped” and that this is “critical” and essential for the future, including plans to integrate health and social care. He further noted that “we can deal with rurality… [but]… provision has to be local and based on individual need.”

Dr George Crooks noted that technology is a great opportunity but we must be “pragmatic” and use it “safely and effectively” and where it will “add significant value”. He noted that there were challenges in connectivity in some remote and rural areas but that he is working across sectors in Government, particularly digital colleagues, to see how this can be addressed. For example, health and care services can be delivered though satellite and digital TV into houses that do not have internet access to “people who are not used to using computers but are of an age that they remember Teletext.” He noted that these can help address needs identified by services users and carers but, whilst it might not produce a level playing field across Scotland, it “might get rid of some of the inequalities that were hinted at in the question.”

**Question 2**

**Tracy Johnstone**

“I am a carer for my four-year-old son who has profound and multiple disabilities and medical needs. Services and support for children with complex needs are basically a postcode lottery in Scotland. What is the Scottish Government doing to ensure that all children in Scotland receive the right equipment for their needs and have access to similar services regardless of where they live?”

**Michael Matheson** noted that the integration of health and social care will help but that local authorities and health boards must respond quickly when an individual’s need for equipment has been identified. He noted that whilst some specialist equipment has to be ordered and can take a bit longer to obtain “there is no real excuse for delay in the acquisition of standard items, once the need for them has been identified.”

**Christine Ferguson** said that professionals have waited a long time for new national guidance on equipment which has just come out. She believes that this will help to achieve greater standardisation. She noted however that once equipment is provided in must be kept in good working order and that national support through; for example, Scotland Excel has been able to improve this service.
Dr George Crooks reflected on his time as GP when an occupational therapist was employed as part of the primary care team and the difference that had made. “I think that a lot of GPs and primary care teams will benefit from that closer working relationship as we move forward.” He noted that not providing some basic pieces of equipment in a timeframe can cause significant stress or distress and can facilitate a breakdown in a hospital discharge, for example. He noted that by bringing health and social care teams much closer together, the integration process will mean that we will see the provision of joined-up occupational therapy in a standard primary care setting. That will involve NHS and local authority occupational therapists working together in a much more integrated way and educating other members of the primary care team about what needs to be considered.

Peter McLeod noted that the Change Fund has led to a lot more occupational therapist posts being put in place across health and local authorities. That has taken pressure off the wider system, and it should see faster response times across Scotland in the weeks and months to come. He also noted that “In my view, the transition points for people who are moving between services—for example, when someone moves from children’s services to adult services—are critical when it comes to working with carers and the young or older person who requires the services and identifying the equipment that is required. All of that can and should improve into the future.”

Councillor Johnston highlighted the need to engage with the child and their family and make a professional judgement that is based on the child’s needs to ensure that the right equipment is provided. He said “It should not matter where they live, as long as we look to meet their needs directly.”

Question 3

Ruth Forbes

“I live in Bonnyrigg in Midlothian. I look after my husband, who had a severe stroke just over three years ago and has since spent rather a lot of time in hospital. How could the procedure for being discharged from hospital, the communication between the ward and the community, and the patient and carer, be improved to lessen the stress involved, especially after several weeks or months in hospital?”

Dr George Crooks noted that care planning is increasingly important within a hospital setting and that staff are not only encouraged but managed to ensure that they take forward care planning in a structured way almost from the second of arrival in hospital. This is an improvement from the past. However, it is not enough for discharge to happen—more improvement is needed to ensure that the discharge is successful. He said “wearing one of my other hats—I am also medical director for the Scottish Ambulance Service—we often play that first role in taking people from hospital back home. My crews often report to me that they take people into a setting that is not fully supportive or aware of the care needs of that individual. There are sometimes quite stressful situations in which the crew wonders whether it can leave someone at home.” Whilst these situations are decreasing “we have [not] got it absolutely sorted”. To have success better integration is needed and hospital to general practice services is key. The situation can be improved by, for example carrying out a number of home visits in advance of a discharge, particularly after a long hospital stay, putting in aids and making the environment
safe. There will however sometimes be “unexpected things” and there needs to be a “responsive service in place to pick up those acute needs”.

**Peter McLeod** noted that investment through the Change Fund has resulted in more care workers and an ability to respond more quickly. However, he noted that Scotland needs more facilities such as intermediate care, so that people can be discharged to somewhere other than a hospital or a care home, to help them to recuperate and, with proper support, to enable them to get back home. “We should expand intermediate care throughout Scotland.”

**Michael Matheson** said that “planning for a discharge should start at the point of admission so that the issues that must be addressed are addressed not just when the consultant decides that a patient is going home, but right from the very moment that someone is admitted to hospital.”

### Question 4

**Pat Jeffrey**

“Will the Parliament inform the carers who are here who care for people who suffer from mental ill health whether any plans have been discussed or made to improve the crisis system for people who have mental health problems? Will the voice and knowledge of the carer be listened to on those occasions?”

**Christine Ferguson** said that “in Shetland it is very difficult when someone has acute mental health issues. Islands have limited resources so we are conscious of the need to be as well prepared as we can be for a crisis. Often, when we work closely with an individual and their family, we can predict the type of crisis that might come up. Again, we are talking about good care planning and trying as best we can to put plans in place that can be acted on very quickly.” She also noted that it was crucial that the carer is involved and listened to so that we can get the best possible outcome for the person who is being cared for.

**Michael Matheson** discussed the suicide prevention strategy in helping to identify people in crisis at an early stage. For example, if someone presents at an accident and emergency department in a state of distress or in a crisis then staff should be able to refer the person on there and then to the right crisis service, with appropriate follow up and tracking taking place thereafter. He mentioned a pilot project in Tayside that is working to improve coordination and that “a key part of that is working with carers, recognising them and listening to them when they say that things are going wrong and that they are not coping well, and responding to that much more quickly.”

### Question 5

**Bernice Lipton**

“I come from Eastwood in East Renfrewshire. When a person becomes a carer, why is the information required for them to give care to a loved one not compiled in one place? For example, a booklet could be given to them either by social services or by their GP, plus there could be co-operation between all services involved: social services, their GP and the NHS.”
**Councillor Johnston** recognised that this was a problem. In his own area, community partnership centres, which have a library, with a GP practice next to it and perhaps also a dentist—are all in the same building. There may also be leisure facilities. “*When someone goes in there, they are offered more than just one service in isolation, because they can access a range of information.*”

**Dr Crooks** noted that NHS 24 hosts a national web service called Care Information Scotland which also has a telephone line that is open seven days a week. The service has generic information about care services across Scotland, including care entitlements and so on. They also continue to work on a Carers Information Zone on NHS Inform that “*I hope will bring a comprehensive set of information that is freely available to everyone.*”

**Peter McLeod** said that in his area, the local carers centre has a Living Well at Home initiative which provides information, particularly through library services. He noted a model in England that could be explored is called the community signposting model where people are employed in the community to say to people “*There’s a service that you may want to consider. There’s information,*” and spend time talking to them in GP surgeries, libraries and other places.

### Question 6

**Mairi McLaughlin**

“Why are young carers not recognised in many situations?”

**Michael Matheson** agreed that young carers can “*quite readily be overlooked*” and therefore are not properly recognised by a whole range of professional groups including doctors, teachers or social workers. He noted that to get a clearer picture of how many young carers there are in schools, the Scottish Government has included in the school annual census this year a question about young carers. This will also help teachers to have better understanding of and to find out where they have young carers in their schools. However, he recognised that more awareness is needed and the Eryc and Trayc1 initiative aims to promote understanding of young carers in primary schools and we are working on a similar approach for secondary schools and further and higher education.

**Dr Crooks** noted that the Scottish Centre for Telehealth and Telecare is “*working with young carers and game developers on how we can use the gaming environment as a way of providing information, support and networking opportunities to young carers out there to learn more about the conditions that they may be supporting and managing and to improve their quality of life and connectivity.*”

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1. Eryc and Trayc are cartoon characters and are both young carers. At school they look like any other boy or girl, but when other children are having fun, young carers are at home helping members of their family who can’t do things for themselves. Find out more about them at: http://www.erycandtrayc.com/
**Question 7**

*Sue Beer*

“My name is Sue Beer, and I am from Shetland. I have a question for Dr Crooks. Telecare works wonderfully when connectivity works. My mother, for whom I care, has a homelink system. Unfortunately, BT has been unable to provide me with a working phone, and it decided to cancel the appointment that it made to fix that phone. Can we get some assurance that people in remote areas will receive the back-up from service providers that is needed to keep the telecare working?”

*Dr Crooks* said “That is a fundamental issue. I cannot give you a personal guarantee, much though I would like to, but I can give you a degree of reassurance. We are working with most of the telecom providers, including the mobile providers, and are telling them that we are no longer delivering simply bog-standard, conventional services. We are now delivering increasing numbers of significantly important health and care services—if not, in this case, a life and death service—using those networks. The simplest service is the 999 service, which everyone understands, including BT. However, BT have had difficulty understanding the significance of NHS 24 and the vital out-of-hours role that it provides from 6 o’clock at night until 8 o’clock in the morning as part of the NHS response.

As we put more monitoring devices into people’s homes, we are talking to the providers about how that is not an add-on to conventional care but is the way in which we are delivering health and care for the future, and that their networks therefore have to be robust and resilient.

The other thing that I have learned is that, as we move forward, we will no longer be dependent on a single channel of delivery. A service will not be delivered only by phone or only via the web; we will try to provide that service through at least two channels, so people have options.”
In this section, we provide the text of the Closing Speech by Michael Matheson MSP, Minister for Public Health, to enable carers, MSPs and others to see his initial response to issues raised on the day.
“I begin by thanking those involved in organising today’s event. Participants will understand that a tremendous amount of organisation has gone into our first Carers Parliament. In particular, I offer my thanks to Carers Scotland, which has been behind the scenes, organising the event with our officials to make a successful day. They have achieved that very well.

Throughout the day a range of different points has been raised, and it is entirely right that those points are duly considered and responded to. However, the short period of time available to me is not enough to do justice to many of those issues.

Today got off to a good start with Paul Weddell and Lauren King giving us their personal perspectives. Paul talked about his time in the police service and about caring for his wife and family, and Lauren talked about the care that she has to provide to her brother. Those examples illustrated where the system works well and the difference it can make to someone’s life when it is supportive and engages with them effectively. Sometimes, people can find that they are repeating themselves over and again to different professional groups, which can make them feel as if they are becoming problematic to those groups or that no one is listening to them.

I want to touch on several themes that have been highlighted over the course of the day. Frustration is one of the clear themes that have come through. There is frustration at the way in which the system seems to operate for its own sake rather than for the people it is meant to support and assist. Too often, it is about process rather than the outcomes for individuals. That frustration is reflected in some of the comments that we have heard about social work services and social workers—although I have to be careful what I say about social workers, as I am married to one. There is real frustration about the way in which social work services and social workers engage with cared-for people and carers in the sense of their listening to what those people’s issues are and helping support them to make the right decisions.

That led me to review something that underlies a lot of the issues, which is control. Who is in control of a care situation? Is it someone who comes in to carry out an assessment, or is it the carer and the cared-for person, who know more about the care situation than anyone else ever will? Something I will take away from today is the need to make sure that those who have greater knowledge and understanding about a care situation have greater control over how care is arrived at.

Self-directed support and the benefit that can come from an individual having their own care arrangement has been mentioned several times today. We heard from several people about their difficulties and the difference that self-directed support has made. They have been able to make direct payments and manage a care situation in a much more effective way.

The Social Care (Self-directed Support) (Scotland) Bill has been introduced specifically to deal with the postcode lottery issue. Too many local authorities do not provide direct payments in the way that they should. Too often, I hear people saying that a local authority has told them that they do not really do direct payments, although the neighbouring local authority may be more progressive and do more of it.

Under the self-directed support bill, local authorities will not have a choice, because people will have a legal right to direct payments or another option that allows them greater control. We need to deal with the postcode lottery issue, and the bill will help us to do that.

I also heard today about the frustration that families feel about being unable to employ a family member as a personal assistant to a person. Part of the reason for that frustration is that local authorities interpret the threshold of “exceptional circumstances” in different ways. Under the Self-directed Support Bill and the regulations that will come with it, we will replace the “exceptional circumstances” threshold with “appropriate circumstances” so that such
employment can happen when it is right that it should happen. We will remove the barrier to that, which is both artificial and unnecessary.

It is right to say that the issue of self-directed support is not about cuts. It is about enabling people to make decisions about their lives in a personalised way that suits their needs. The challenge to local authorities is to ensure that they order services in a way that helps to support the personalisation agenda. Some local authorities are doing that well, but I suggest that others have further to go.

Another key thing that came through today was the issue of identifying carers and the need for carers to be recognised at the earliest opportunity. We heard from some parents of children with autism about the need to recognise the role that parents have as carers who help to support their child and meet their needs. That leads me to believe that we need to do more work with general practitioners, social workers, educationists and others to explore what they can do to identify carers much earlier and provide them with the right support and information.

That is important, because another thing that came through today is a feeling that, at times, not enough information is available to carers. Despite the fact that a significant amount of money is given to carers information services, people feel that information is not getting to them, so we have to look at whether we can do that better.

The integration agenda, which was raised a number of times today, is not about focusing on process or bureaucracy but about finding the right outcomes for individuals and ensuring that services are focused and that they work together and share information. However, we should keep it in mind that integration is not a new agenda item. It was raised over 20 years ago with the National Health Service and Community Care Act 1990. We were going to get single shared assessments and much greater integration of services. It has happened on a patchy basis in some parts of the country, but not on the meaningful scale that would make a real difference in improving the outcomes for individuals.

Education is another area in which I recognise that we need to do more, particularly for our young carers. That is why we are taking forward the Eryc and Trayc programme and looking at developing a new programme to take into our secondary schools to raise awareness of young carers among both teachers and their peer group. It is important for pupils to understand that one of their friends at school may be a carer. Often, young carers are not asking for a lot. Sometimes it is just about getting a couple of extra days to complete an assignment or the understanding that a young carer might be late on a given day because of their caring role. Those small, practical things can make a big difference to young people who find themselves in that situation.

It is important to take that on to higher education to ensure that young people who go into our colleges and universities also have their carer status recognised. One university in Scotland now has a formal carers policy in place. Having recognised a student as a carer, the University of Glasgow will give them extra time for assignments and extra time off, if necessary. If they are having difficulty in making it to lectures, there is an understanding that they might require a bit of extra time to follow things up. The Scottish Government is now working with the National Union of Students to take that approach forward to every university and college in Scotland so that they all have such a policy in place to support young carers.

It is then important to take that approach on to employment and ensure that we encourage employers to do more to support carers who find themselves in employment as well. It is clear that we can do more in that field to support carers and allow them to continue their career, where that is possible, along with their caring duties. We have already convened a meeting with a variety of stakeholders, including employer organisations, to look at how we can introduce a carers
kitemark for employers around policies that they can put in place to support carers. A couple of big companies have already taken the initiative forward, and we want to introduce it nationally.

The other overarching theme that came through was carers’ rights. Carers have a right to certain aspects and services. That is why we have awarded a contract to Carers Scotland and the Minority Ethnic Carers of Older People Project—MECOPP—to take forward work in drafting what will be the first carers’ rights charter for Scotland. That work will start over the coming weeks and there will be an extensive consultation to take it forward.

In drawing my remarks to a close and touching on a range of issues that have been raised today, it would be fair for me to say that progress has been made. However, we should be in no doubt that much more needs to be done. From a Government perspective, I can assure you all that there is no lack of commitment on our part to do everything that we can to continue to take carers’ issues forward. We will have to work with our partners in the health service, the third sector and local government to do that as effectively as possible.”

The Deputy Presiding Officer then closed the day saying “Today’s proceedings are now at an end, but I know that the work has only just begun. Your thoughts and views today will feed into the Government’s and Parliament’s continuing support towards carers... Of course, you can approach your own MSPs at any time with issues that you want to have raised directly. I thank again all our speakers for today and, of course, each of you for bringing your knowledge, skills and determination and for the hard work done by carers across Scotland.”
Appendix 1

Consultation for the first Carers Parliament

It was vital that the priorities and theme for the Carers Parliament were set by carers. To support this, we carried out a large consultation of more than 10,000 carers. 736 carers responded and identified services and support (70.4%) as their top priority.

As these carers had identified “Your Rights” as the second most important, the carers’ parliament steering group agreed that this should be the theme for the Carers Parliament in 2013.
Carers were also asked to rate topics that they wished to discuss in themed workshops. The top 6 priorities identified took place as the workshops for the day.

The financial impact of caring including benefits, heating costs and… 49.0%
Availability of support services for carers including emotional support… 47.2%
Planning for health and social work services working more closely together… 46.7%
Your rights as a carer – do you and the professionals you deal with… 41.5%
Accessing services for the person you care for and how eligibility cr… 40.7%
Access to suitable, flexible short break and respite care support 39.5%
Having more choice and control over the support and services you and … 37.2%
Being an equal partner – having your voice heard and your knowledge a… 37.1%
Having a life outside caring – being able to work, study and take par… 33.1%
Your health and wellbeing, including health checks 30.3%
All other responses 17.5%
Appendix 2

Breakdown of carers attending the Carers Parliament

Profile of carers

1. Age Category
Almost half of the carers attending the first Carers Parliament (49.4%) were between 40 and 59 (the peak age for caring). 31% were aged 60 or over and 8.2% were young carers aged 20 or younger.

2. Gender
The largest proportion of carers attending the Parliament were female (74.3%) with 25.7% male. There were no transgender carers in attendance.

3. Ethnicity
Carers were asked to provide their ethnicity on registering. Of those attending, 93% were White, 2 6.5% were Asian, Scottish Asian or British Asian and 0.5% were Arab British3

2. This includes white Scottish, British, Irish and Welsh, Gypsy traveller and other white ethnic groups.
3. A full breakdown is available on request from Carers Scotland (info@carerscotland.org)
4. Disability or Long Term Condition
Almost a quarter of carers attending the Parliament had a disability or long term condition.

5. Sexuality
The majority of carers were heterosexual (86.4%), with 1.2% gay and 1.2% bisexual. 11.1% of respondents preferred not to answer this question.

Caring Role

1. Number of people cared for
The majority of carers cared for one person (75.4%), but a significant proportion care for 2 or more people.
2. Why does the person you care for need help?

Carers were asked why the person or persons they cared needed their help. Carers could tick all options that applied. The chart below reflects that the person(s) who are receiving care may have one or more disability and/or has complex disabilities. For example:

- Spina Bifida Occulta; Raynaud’s; Cerebro Vascular disease; Osteo Arthritis of Both Hips and Spine; Tendinitis of right Groin.
- M.E. and Mental health issues
- Profound learning and physical disability
- Sub arachnoid haemorrhage left her blind and disabled
- Heart defect, stroke, autism, low immune system, and more
- My son has Autism and Epilepsy, my daughter has learning difficulties and mental health problems
- Multiple Sclerosis (wife) Cerebral Palsy (son)
- My eldest son has Asperger’s and varied other conditions
- Blindness, Deafness, Hydrocephalus, Autism, Asthma, Epilepsy, Dysphasia.
- Chronic lung disease in addition to severe Cerebral Palsy, oxygen dependent
- Secondary Progressive Multiple Sclerosis & Non-Hodgkin’s Lymphoma
- Bowel cancer, osteoporosis, macular degeneration

Most carers were caring for someone who had a physical or learning disability or long term condition. 25% were caring for someone with mental ill health. No-one was providing care linked to drug or alcohol dependency.
3. Who do you care for?

Carers were asked who they cared for and, again could tick more than one option. The majority were caring for a close relative such a spouse/partner, child (under or over 18) or parent/parent in law.

4. Duration of caring role

Most carers had been caring for 5.9 years (33.9%), with the same proportion caring for between 10 and 19 years. More than 20% have cared for 20 years or more.
All carers attending the event were asked to evaluate their experience of the day. Carers were asked to rate the Carers Parliament. 74 carers (51%) responded to provide their views. The following is a summary of these responses

1. Delegates were asked how they rated the morning session with the majority (85%) saying that it was good or excellent.

“Overall it was very good and the Young Carer’s contribution was outstanding and gave much food for thought. It was a pity that the Minister for Health [was the Cabinet Secretary for Health and Wellbeing who was unable to be there for the whole day. The Minister for Public Health attended all day]] was unable to be there for the whole day but it was understandable given the newness of his appointment. The debate following was most interesting as it was an opportunity to hear other people’s stories which were, in some cases, very moving as well as inspiring. It was good that people from different situations were able to contribute including ethnic minorities and young people and those living in remote and rural areas.” Carer, Edinburgh

“I think there could have been more time, longer debate would have been good, it would have been nice to have more MSP there and made themselves known to us as I saw some but not sure how many were there.” Carer, East Ayrshire
2. We asked carers whether they felt there was sufficient time for the morning session, including the debate. Opinions were divided with 54% that the time was about right and 40% that more time was needed.

“Interesting listening—the time left for debate at the end too short even so it was extended. Carers views are the most interesting stories/experiences—it should have been the most important part of the meeting. Ministers learn from carers what it is like to be a carer.” Carer, Aberdeenshire

3. Part of the afternoon was set aside for workshops on 6 key themes selected by carers. We asked carers how they rated these workshops. The majority (62.5%) felt they were good or excellent with 24% believing that there was room for improvement. However, the majority of respondents (65%) felt that more time was needed for these workshops.
4. We asked carers to rate the final question and answer panel with representatives of national and local government and the NHS. Carers submitted questions in advance and these were themed by topic and chosen at random. Again the majority (58.5%) rated this as good or excellent but 40% felt that this needed more time.

“Having preselected questions for this was a good idea but as one of those who was fortunate enough to be chosen I would quite like to have been asked why I asked that particular question! It was an interesting selection of questions and the comments from the panel were by and large helpful.” Carer, Edinburgh

“If the panel had the questions before hand they should have chosen the best person to answer even if this was a collective answer, that way more questions could have been answered. Not sure this session was helpful… certainly wasn’t for me. I do hope some answers to the personal issues will be addressed?” Carer, Glasgow

5. We asked carers to rate the Scottish Parliament as the venue for this and future Carers Parliaments or if they felt this was not the most appropriate venue, to make suggestions. An overwhelming majority of carers (91.7%) felt that the Scottish Parliament was the right venue for the Carers Parliament. However, suggestions for alternative venues included conference centres, council chambers and to move it across Scotland within major cities.

6. Finally, we asked carers to make any further comments. Below are a selection but all responses, including the full evaluation are available from Carers Scotland.

“I think this was a great idea and made us as carers feel that we were being taken seriously and that the Scottish Parliament does want to make changes for the better for carers and for those for whom we care. I had a wonderful day and was on a high for days afterwards! There was so much optimism and hope for the future. I felt that despite the long hours we give to those we love who need it, we were getting this great chance to have a say in what we feel as carers and so make life better for others. I enjoyed meeting other people from all over Scotland and hearing their stories. So many different issues were touched on during the Parliament and I have every
faith that much good will come of this. It will not happen overnight but I would like to think that the Scottish Parliament has listened to us and will do its best to improve some of the conditions in which people struggle as carers and have better communication at all levels. A fairer system would help us to lead more normal lives and to feel less isolated with more freedom to do some of the things we LIKE to do rather than only having time and energy for what we HAVE to do. Thank you for including me.” Carer, Edinburgh

“A very important day right in the heart of the Government. I hope it will continue. I found it engaging and informative. Thanks to Carers Scotland for making it possible.” Carer, Dundee

“Hopefully just the first in a series of Carers Parliaments.” Carer, Fife

“One great disappointment was the lack of MSP’s; I am sure a large number of delegates would like to have met their MSP’s and informed them first hand of carers issues in their region. If you really want to make real improvements for carers, then concentration on more workshops will allow us to get over the carers perspectives and issues to MSP’s. The general feeling amongst the delegates was we had our say, sort of, but our real issues weren’t really understood and suggestions for change not taken on board. In all this is a good start and its heartening to see some MSP’s are wanting to engage carers, to a limited extent. Hopefully this yearly event will continue to inform political opinion and shape policy in future years.” Carer, Glasgow

“The topics were interesting and the subject for debate relevant but I still have grave doubts about any real change it will make to carers and the person they care for. The problem is not strategies, policies and legislation – the problem is local authorities implementing these things. Most authorities thrive on crisis management and not strategic planning and prevention.” Carer, West Dunbartonshire

“It was a good start. There is plenty of room for improvement. Carers have a lot to say – give them more time to speak. The words what “should happen” must be replaced by “it will happen”. Implementation of promises from Ministers must have timing attached to them. Otherwise it all sounds like a whaffle.” Carer, Aberdeenshire

“I would simply reiterate what I said during the debate itself: “Most dictionary definitions of the word ‘parliament’ emphasise the OUTCOMES of debate, the law-making powers of the individuals gathered together. But can we honestly define an event like this as a ‘parliament’ if it is only a once-a-year gathering – and if all of us are not to be present when the resulting legislative powers are exercised? Please let us do this more often – and let us all work to forge MEANINGFUL LEGISLATION from meaningful debate.” Immediately after the event I e-mailed as many people as I had time to – pleading for monthly meetings to be held between now and the next annual event. By no stretch of the imagination can the organisers continue, in all seriousness, to refer to this as a parliament when/if a) it occurs only once a year and b) there is no guarantee of continuity with/for the invited participants. As is invariably the case in politics, the biggest challenge is to narrow the gap between the words used and what those words actually MEAN in cold, hard practical terms. It’s not a question of how convincing the words SOUND in a press release, it’s a question of whether or not those are the correct and appropriate words in PRACTICE.” Carer, Fife

“I know we were promised some sort of minute and response; however I would like to think we don’t wait a year to see if there have been any changes/ developments. Perhaps every 3 months we could hear if there have been any developments and if these were directly because of the event. This way it will be known if the Parliament was worth the stress, time and struggle for some carers to get there. Can I just say although not all positive comments, I enjoyed meeting fellow and like minded carers from all over Scotland. I also realised the amount of time and effort that was put into
getting this event together and also want to thank everyone involved. Good luck for next year and I hope all carers feel it is worth their effort to continue attending the event.” Carer, Glasgow

“I was happy that the event was held at the parliament venue itself because it gave us carers a sense of being recognised as important and crucial part of the society. It is important that for future years the same venue is kept because carers should be given importance as we all are heroes in our own right to voluntarily help the most vulnerable people of society but we are greatly neglected by the government.” Carer, East Renfrewshire

“Overall had an enjoyable day was good for networking, excellent narrative stories from carers. Felt it was a bit disorganised when the numbers were held up, a bit overcrowded. I was with elderly carers and was a long climb up the stairs. I believe if the Government is truly interested in carers it should not be just a yearly event. And be more interactive i.e. group work, less formal more off a day out for carers.” Carer, Renfrewshire

“I thought that the whole day went well. It certainly gave Carers the opportunity to express how services for their loved ones are delivered through their Local Authority. I would like to see some follow up with MSP’s; especially around some of the action points raised from the committee/workshop discussions. It would be encouraging if MSP’s had a ‘live’ debate on the issues raised. I think the report of the event should be available across the country. How many MSP’s attended? I would like to see some changes being implemented based on issues raised.” Carer, East Ayrshire

“Realise this was the first time this had been done. Massive amount of organisation and planning involved. However it is not entirely clear what exactly will be achieved from it...what actual difference it will make. Yet again we hear the same struggles and challenges that carers are facing...what we do about this is what is important. Would like to see two or three key actions that Ministers, NHS and local authorities will address as a result of this event.” Carer, Paisley
Appendix 4

Delegate List
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Appendix 5

Questions submitted by carers

Topic 1 – The financial impact of caring

No recognition if caring for more than one person:

• Both my parents have been assessed as requiring full time care. Why is it that although they receive 24hr care 7 days per week from me (and after he comes home from work, my husband helps too) in my family home (which was extended and specially adapted for their requirements, funds coming from the sale of my parents' home) the only benefit to which I am entitled is Carer’s Allowance of approx. £58 per week but for only ONE of them! Sorry, my mistake- because of my father’s age our house is entitled to a free TV license. What a saving to the government.

• I care for 5 sick/disabled people – why is it that only 1 is counted as far as government concerned

Independent Living Fund:

• Independent Living funding (ILF) is to be devolved to Scotland in 2015. This funding is currently ring-fenced by the National Government. Will the Scottish Government also ring-fence this funding? If not, why?

Concerns over welfare reform:

• With the welfare system starting to bite hard and deep – how will you ensure that when those in receipt of DLA lose it under the new PIP will still be able to afford the care they desperately need without putting even more strain on unpaid carers?

• Why is my carer’s allowance taken into consideration in my other son’s application for funding at college as an income? Surely this cannot affect his amount of funding as it is well below the minimum wage. Yes it has affected his funding.

• An implication of the welfare reforms by the Westminster government may mean that some people who currently have access to welfare benefits may be reclassified and not receive the new PIP payments. They will still have the same support needs but their carers may no longer receive carer’s allowance. How can those affected be protected, and what will happen if carers not receiving benefit can no longer provide support to those they care for due to the loss of carer’s allowance?

• What can we expect to happen when the Pip benefit change occurs from the present Disability living allowance?
• What will the implications be for carers when the benefits change from carers allowance to the universal credit and personal independence payments for cared for? Why is carers allowance considered a conflicting benefit and pensioners lose carers allowance at a time when their caring role may increase and financial problems may get worse? How much is it costing to change the welfare system and could this money not be better spent providing care?

• Re the impact of changes to DLA – if someone currently receiving DLA at the higher rates stops receiving this when PIP starts this therefore means that the carer’s allowance will stop for the carer – if the carer is not receiving any other benefits how can they be expected to provide caring for nothing at all? Also if appeal is instigated what does the carer live on while waiting for this as I understand if you are waiting for an appeal no benefits are now to be paid.

Carers and employment:
• How can carers get back to work to recoup lost careers/income? Get fast track access to medical services since they often put their own health needs "on hold" out of necessity?

• I have applied twice over the past two years to my employer, Fife Council, for early retirement which I am eligible for from the age of 55 as my doctor stated that I either work or care, not both, owing to the stress and depression of combining both roles. I have been refused twice. My only option is winding down/reducing my hours to a minimum of two and a half days per week. The minimum hours allowed under the wind down scheme. This is more than the 16 hours allowed to claim carer’s allowance. This is a Catch 22 situation. What can the panel do to make employers more carer friendly?

• I work for a local authority. What support do local authorities actually give to employees who are carers?

Cost of caring:
• In many families, the caring is left to a single member – it’s a common issue among carers. If it is correct for LA to take funds to pay for care, wouldn’t it be possible for carers with a proven caring input to recover some of the loss out of the estate post death of the person whom they care for? Perhaps more family members would take on/share the "burden" of caring if they could afford it.

• Why do the authorities purposely delay, using underhand tactics to undermine carers desperately trying to obtain any finance that was within Human rights?

• Why does the government discourage relatives from becoming carers by bending over backwards to prevent any payments going to relatives, a non cost effective measure surely?

Low level of carers’ allowance:
• With Carers Allowance of £55, how can the Government expect that Carers will continue in their role when they feel so undervalued and struggle with the financial implications as well as their caring role?

• Do you know the current rate of Carers Allowance for providing the minimum of 35 hours care per week and do you think this is a fair payment?
• Why is carer’s allowance consistently considerably less than benefits paid to the unemployed, given that, in order to even be considered eligible, one has to be “judged” as being “employed” in a caring role for at least 35 hours a week? Is there a belief that a carer expends fewer calories than a jobseeker and is, consequently, expected to eat less?

• Why is a state pension regarded as a benefit and Carers allowance which was previously paid then taken away, a person does not cease to be a carer just because they reach the age of 65? They are both a pensioner and a carer and should be compensated appropriately.

• I resent respite as why should someone be paid a proper wage for doing what I do 7 days a week for the pittance of Carers Allowance? Why are carers penalised for having savings? What other group of workers are penalised for having savings? We should not be classified as beneficiaries of the state but vital contributors to the state. What other group of workers would tolerate such blatant exploitation by Government? Why do politicians of all parties churn out the same banal platitudes when questioned about carer poverty? We are not wanting bankers salaries but a decent living wage. I do not want respite but the financial security which enables me to make my own choices.

• Why is there monetary discrimination of carers? Most of us are ‘shared lives carers’ why are we not valued at the going rate of said attached advertisement?

• How can the Government justify £58.45 per week to care for a family member when a professional would receive a similar or higher amount per day? While benefits are being cut, families and charities suffers but there seems to be plenty in the pot for paying for over tendered projects i.e. Edinburgh Trams awarded tender £375 million however cost so far £592 million – £275 million that could have assisted carers.

**Motability Scheme and Blue Badges:**

• Motability cars, why are carers not eligible for this, as many carers use their car to assist and take the person they care for out but, if they have not had Motability car before retirement age they are not able according to the rules to be eligible??

• Why does the family/legal guardian of a family member with a life-long severe disability have to re-apply for DLA, Blue Badge etc. when it is medically impossible for this person to ever be cured? Why does the new Blue Badge application form penalise, yet again, the weakest members of society and their family members who have to deal with the bureaucracy (nearly 30 pages long application form, even for a lifelong condition)? Why is legal guardianship not granted for a reasonable amount of time for a life-long chronic and untreatable condition? Why are parents applying to become legal guardians of their profoundly disabled child treated like criminals?

**Topic 2 – Availability of support services for carers**

**Support for remote and rural carers:**

• How can we ensure that the needs of carers in remote and rural areas are adequately addressed in the planning and delivery of support and services?

• The cost of providing care in rural communities is much higher than those in towns and cities. Especially in remote Islands, where many services just do not exist and public transport is
very poor and usually not accessible for a lot of disabled people and their carers. Will these local authorities be eligible for more funding to provide better services?

• I don’t know how many remote and rural carers are able to attend today’s parliament but we have difficulties in all areas of the 6 themed workshops from high living costs; living in areas of multiple deprivation for access to care and support; and costs are far higher and opportunities far rarer for access to suitable, flexible short breaks. How can the government show that all carers in Scotland matter and are treated fairly and equitably without discrimination based on geographical location?

Training staff to understand carers needs:

• How do you propose education for authorities such as social work to understand a carer’s needs more specifically rather than as text book. For example, when I approached social work for help they went through procedures however as with autism for example the spectrum is so wide how can they follow one procedure for all cases? There needs to be more communication to understand individual needs and less text book procedures.

The need for a central point of information for carers:

• PLEASE could there be a central information point (paperwork AND person) who could lead the carer through the beginning process in an easy-to-understand way – pointing them in the right direction for their particular needs. Having just one person as a starting point of contact would help to ease the extreme stress and isolation felt by the carer. The extremely dedicated and hard-working professionals (Social Workers, CPNs, etc.) have so many necessary but often extremely lengthy requests for their time and expertise that they cannot allocate as much time to each carer as they would like. Is this a feasible request or am I being unreasonable? I do not think I am. It would certainly have made my life much, much easier than it has been over the last eight and a half years

• Please can we work towards a fully-staffed, adequately-funded 24 hour centralised Carers’ Support & Advice department? Repeatedly over the last 12 years, when asked how best to describe my role as a Carer, I have said “Air traffic controller”. Again and again Carers like me are told by one or other agency, department, charity or organisation, “All the information you need is available on our website...” when, of course, all the information I DON’T need is there as well, and I will be the one who, weary after a long day of caring for one parent with Alzheimer’s and another with cancer, will have to sit up until 2.00 or 3.00am, printing out all the relevant documents and then going through them with a hi-lighter pen to find those parts of the information that MAY be relevant, those parts of the available provision for which my parents MAY be eligible. Once assigned, a Social Worker can sometimes help with some of this fact-finding but neither Social Services nor CAB have the resources to deal adequately with this increasing demand.

• DEMENTIA: I am the one of my mother’s daughters. We are struggling to cope with our mother’s dementia. What we have found is that there is NO ONE POINT OF CONTACT to co-ordinate services. OTHER ISSUES: Companionship, Feet, Food, Hair, Happiness, Hearing, Isolation, Memory Loss. FUNDING: What can we access? Not looking for handouts. Just, what are we entitled to. Otherwise we are happy to self fund. WHO CAN HELP US? Where is the first port of call when you find you have a problem?
• When a person becomes a carer, why is the information required for them to give care to a loved one, not compiled in one place? For example, a booklet to be given to them either by social services or GP. plus co-operation between all services involved, i.e. Social services, GP, NHS.

**Disabled carers:**

• My particular interest is disabled people as carers, in particular Autistic people as carers. We often seem to be forgotten, how can we ensure that our needs are met, how can we improve access to services and remove the barriers and prejudice we face not only for those we care for but for ourselves as carers. Who cares for the carer? Why is there a lack of follow up support? Why do we feel alone if we can’t get out to join a support group during the day? Who makes sure we are ok to not only do our role of caring, but quite often having to hold down a full-time job?

**When caring ends:**

• What assistance, guidance and advice is available to those who come to the end of their caring role who find themselves not only exhausted but, dealing with a bewildering range of emotional and financial changes? (Full time carers lose not only their loved one but, their role, identity and in some cases income). For example what help is available to those who have given up careers and their own financial security to become carers when the person they care for dies and they are faced with perhaps a decade or more to retirement.

**General:**

• What help and support is going to be made available for those carers that look after someone that does not have one of the main illnesses (cancer, Alzheimer etc.) and is not either a child or an OAP as at present they are forgotten about. Be a, or care for a child and you get help, care for or be an OAP and you get help, but be or care for someone in between that doesn’t have a “headline illness” and your forgotten about, you become a non-entity with no where to turn.

• Why do Carers not have their own Advocate?

• Given the demographic change towards a more elderly population, would the panel not agree that enhanced support for carers in their role maintaining their cared for person at home must be a priority, the better to save public money in the longer term.

**Topic 3 – Planning for health and social work services to work more closely together**

**Care for people with dementia:**

• I believe the Scottish Government has pledged support for sufferers of dementia and their carers for 1 year after diagnosis. This is excellent and much needed. However dementia is a
degenerative disease, please could the panel say if support would be ongoing as the disease progresses, and what form it would take.

Long term vision:
• What is the panel’s vision for the future medium term (~5yrs) and long term (25+ yrs). Will your medium term vision try to harness the growing numbers of retired adults to supplement current voluntary services while keeping health & social care jobs safe from cuts? Longer term, what will you do to transform our culture to one of a more caring community with greater resilience to developing dependencies on tobacco, alcohol and drugs?

Hospital discharge:
• How could the procedure for being discharged from hospital and the communication between the ward and the community and the patient and carer be improved to lessen the stress involved especially after several weeks or months in hospital?

Working with the voluntary sector:
• We have been talking about prevention, early intervention and partnership working between Sectors, especially the public and voluntary sectors, so why is it still so difficult to get Health and Education professionals to link up with Scotland wide carers groups and charities (i.e. referrals, training, information, etc.)?

Change Fund:
• 20% of the Change Fund for supporting Reshaping Care for Older People is to be spent on supporting carers. How much of this available resource is being spent on indirect support as opposed to direct support for carers? It is difficult to evidence outcomes for carers from indirect support, so is there a case for tightening up the guidance to NHS Boards and/or new Health and Social Care Partnerships to ensure this money is spent primarily on direct support and, where it is not, that there is robust evidence of outcomes for carers?

General:
• There is a shortage of in patient resources capable of handling challenging behaviour for under 65s in Fife, Dundee and Edinburgh. Would it be possible to dedicate facilities to meet this need?
• In relation to the current proposals for the integration of health and social care, how will the Scottish Government ensure that carers are treated as equal partners within the new structures?
• Why is it often left to carers to co-ordinate NHS and Social Service input in addition to caring? Why is there no functioning interface between the two major services to update critical information about those who need help? Lack of shared information, continuity etc. leads to long and costly delays.
General rights:

- How do we ensure that carers, the cared for person and the statutory services are genuine key partners in care? (What mechanism is available to ensure this?) Lost the term “key partners in care”. Now have “Equal partners”. Ambiguous! Carers should be equal partners in decision making.

- There is a major discrepancy between what carers and those they care for are legally entitled to, and what they are told they are entitled to by service providers such as social work and education. This often leads to carers being told they are not entitled to services when they actually are. Sometimes this occurs because of a genuine lack of education on the side of the service providers. They often don’t know what carers are actually entitled to. It is also the case that, on some occasions service providers, such as local authorities deliberately misinform carers about what they are entitled to because there is a lack of funding. This leaves carers and those they care for, in a position where they either do without the services they are entitled to, or have to fight to get services that they shouldn’t have to be fighting for. What changes to the current system is this government willing to make, in order to ensure that all service providers are properly educated in the legal entitlements of carers and those they care for, and to enforce the fair and honest provision of those services, across the board?

- What measures can be taken to help unpaid carers now. What steps should be taken to improve things for the future. In 18 years full time caring, I feel totally undervalued, taken for granted, stressed out, having lost £250,000 in lost earnings and saved the taxpayer over £2M in care and therapy costs. 5 rights for carers that we do not have. 1. The right to a living wage. 2. The right to limit the hours we care. 3. The right to health and safety training. 4. The right to emergency/sickness cover and days off. 5. The right to an occupational pension.

Young carers:

- Why have not all young carer cards been issued?

- Why are young carers not recognised within many situations?

Carer involvement:

- Why do professionals not listen to the carer regarding the needs of the person they care for? They do not see the person as an individual and can not or do not want to use strategies put to them.

- I sit on my local carers strategy meetings but I don’t feel it represents carers’ views at all! Myself and another carer sit round a table with about 15 officers from the council. Anything I bring up is never considered for the strategy I feel I’m there just so the council can say they have consulted with carers! I’ve even left these meetings very angry and also been upset too! I feel this is a waste of my time which is very limited! I feel I’m blackmailed into going as I’ve been told to attend or the funding to my support group will be stopped! I would like to ask if anyone from the parliament actually reviews council’s strategies???
We have a national mental health service user organisation (Voices of eXperience, VOX) which disseminates information to mental health service users, provides opportunities for user involvement and participation in decision making to do with mental health services, strategically and operationally. We could do with a similar organisation for carers. Are there plans to have a similar national mental health carer organisation? Run by carers, for carers. If not then what can you do to start such an organisation? To enable mental health carers to have a voice nationally that is united?

BME carers:
- What is the Scottish Government doing to make sure that Ethnic Minority Carers understand what services are available and how local systems work?

**Topic 5 – Accessing services for the person you care for**

**Service cuts and lack of appropriate services:**
- How can the Government ensure that national policy and intention is not put at risk by local decisions which see cuts in key services for carers and their families?
- What does the panel think about the inequality of care home costs? For example where people who have worked all their life, saved, bought their home and then had it all taken by the Council to pay for their care home costs, but others who have not saved, don’t own their own home, get the same care at no cost?
- Why is there such long waiting lists for every resource that would suit my daughter? I had to wait over two years for respite (3 hours a month!!!!) when she was under 16 and now that she has reached 16, she now has to go on a waiting list for a befriender. The only resource that she has been able to access has been one that we have to pay for as everything else that is free has enormous waiting lists. She is placed on the waiting list but then seems to be forgotten about.
- Why have the east end of Glasgow been left without a day centre facility when over 500,000 million is being spent in the area, one of the poorest and highly populated areas of Glasgow. Why are learning disabled people being forced to take personalisation mostly with huge cuts and it leaves people unable to buy the support they already had and were assessed as requiring, before personalisation? Leaving lots of people isolated and spending all their time with provider companies and sharing houses with people they do not get on with or even know.
- The assessment of the cared for person’s is made by agencies – health and social care – who have a primary interest in cutting spending. In my mother’s case this repeatedly led to an under-estimation of what she needed, and the failure to provide any ‘re-enablement’ services until there was a complete crisis. When will there be a genuine needs-led assessment and the services to match. Until then, carers will continue to handle the crises and plug the gaps in service.
- Why is money being spent on making the town look good when my mother who is in need of end of life care not getting the proper services?
Services for young disabled adults:

- My son is 25 years old now. I would like to know why he from the age of 18 should be put in the same category as someone aged 65 years in adult services. Surely age appropriate activities and support should be channelled properly to suit every adult and not allow young men and women to be treated as if they are all pensioners. My son and my young women of his age should be with their peers.

- My son was awarded the 1st year Modern Challenge Award (which means that he was chosen as the best 1st year apprentice that year.) He was also awarded The Leader’s Legacy Award. He was the first person ever to be awarded this which essentially means that out of several hundred nominees throughout every department in the council he was chosen as the council’s finest apprentice. He was also asked to attend Anniesland College a few weeks ago (Young Scots got Talent) to describe to school leavers from many of the CDU units in Glasgow who teach special needs pupils how GCC supports and encourages their apprentices! He had an excellent attendance record and has never had a disciplinary; He was given excellent reports from every park he worked under. He was told at his interview that his accomplishments where quite an achievement by the panel; especially considering he has Asperger’s Syndrome. My question is: What kind of incentive is this to young people when even if they are chosen as they very best the GCC has in their modern apprentice scheme they will be paid off and others kept on without any explanation. How can someone who by the Council’s own admission was the best apprentice they had last year be one of 8 boys who were paid off and TWELVE people offered a post instead of him! What did the other 12 have that he apparently doesn’t. I’ve asked for an explanation but as yet I have received no reply. I am currently in the process of appealing against this decision. My son has been put on a pedestal by the Council, been given two awards, used as a shining example of what type of employee they want and then basically used and discarded without explanation. I and other families have been left to explain to their children why being the best doesn’t seem to be good enough.

- I can choose to go to any university where I meet the entrance requirements. Why does my brother not have the same choices?

- When children with special needs reach a certain age they are expected to move on to adult hospitals that cannot cater for their needs i.e. my son and possibly my daughter will not be able to be left in a normal adult hospital due to their mental age capacity and will need a parent with them for constant support. At this point in time this facility is not available for adults therefore, when my children are too old for children’s hospital where will they go for their needs to be met?

- Children with disabilities grow up and become young adults with disabilities, while they are at school they are in a secure, supported and structured environment, however once they leave school it is as if ‘society’ expects them to be ‘cured’ given the lack of support many of them can expect. What does the panel propose should be done to address the lack of suitable support, work or other placements available to the 18-25 age groups?

Disabled children:

- Is it possible and financially viable for all teaching staff in Scotland to be trained properly and fully on the rights and the understanding of difficulties faced by disabled children?

- My son has complex additional support needs as a result of a stroke before he was born and it took almost 12 years of fighting for him to be placed in an education setting which meets
his specific needs. During those 12 years his health and education suffered as did our family life. We have all sorts of lovely pieces of legislation in place which, on paper, means my son should not have had a nervous breakdown, he should not have endured the hell that was mainstream primary school and we should not have had to engage lawyers to fight on our behalf. The reason we had this battle was that our local authority did not believe the law applied to them. Is there anything the panel can put in place to ensure that Scotland’s Disabled Children are not failed by their local authority that families don’t need to fight, and that children receive the same quality education afforded to their non disabled peers because right now Local Authorities are failing our kids.

• The services and support for children with complex needs is a postcode lottery across Scotland, what is the Scottish government doing to ensure that all children in Scotland receive the right equipment for their needs and have access to similar services regardless of where they live.

• My son requires a specialist further educational resource. What can you do to ensure he has this opportunity?

• Caring for a child with a disability is a lifelong family commitment, through many difficult transitions. What is the parliament prepared to do to ensure that parent carers get the relevant support they need?

• I’ve recently had to deal with the transition service from children’s services to adult services and it has been fraught with unimaginable difficulties. Although our local authority has a very good transition policy on paper it doesn’t happen. Would the panel agree that government legislation, giving clear guidelines and time scales for transition, would ensure that authorities don’t fail young people as they move to adult services?

Preventative care v crisis care:

• Since it is generally accepted that preventative care is better than crisis management, why is there no early preventative support for the frail, elderly or people with dementia and their caregivers in Sutherland? Support seems only to kick in once a family hits crisis status.

• Why is it so difficult to get domiciliary visits? I had this problem with chiropody, ear syringing and portable ECG. I eventually got them all but only after a fight.

• Those who lack capacity have more need for their loving relatives to speak for them but there are hugely increased difficulties. -e.g. re Basic healthcare for those in residential units etc.- maintaining self-help

Service quality:

• What steps can be taken to reduce the anxiety of carers about the people they care for being abused in residential or other settings – now and in the future?

• What strategies have been put into place (for the person that is being cared for) to make sure everyone is treated as an individual & not stereotyped to fit a certain criteria whereby very little help is available.

• Does the panel feel the quality of care will be reduced due to the time clocking system that has been implemented by the council? Also, how much extra stress and pressure is it putting on the carers/clients/family?
Mental health:

- Can the Parliament inform the carers of people suffering with Mental Health, if any plans have been discussed or made to improve the crisis system for people with Mental Health problems and will the voice/knowledge of the carer be listened to on these occasions of crisis?
- What steps or initiatives can help in overcoming the stigma associated with mental illness?

Self directed support and personalisation:

- With the move to Direct Payments/Self Directed Support, few carers understand the implications of employment law re training, dismissal, etc. There have been cases of carers facing a tribunal for unfair dismissal because they didn’t understand employment law. Employing paid care can be more stressful than caring. If carers buy care from an agency, admin costs charged by most agencies reduce the "caring" budget by 30%. Individual carers do not have the same negotiating "power" as the local authorities to set preferential hourly rates (i.e. less bang for the buck)
- Re personalisation. What monitoring of LAs to ensure they meet legal requirements of personalisation?
- What do they think of Self directed support? In their experience has it helped families to improve their lives and the people they care for and has it relieved the pressure on Social work services? Also how have the one stop shop for autism services helped autistic families in Lothian and Glasgow and how soon can we expect to have this in the Highlands.
- When will Carers see, as promised, a Direct Payment in our own right to bring much needed support and ultimately enable us to continue caring?
- Why do direct payments only cover the PAs wages and does not cover their travelling costs or the entry fees to facilities such as ten pin bowling, soft play centres, swimming pools, cinemas etc. thereby leaving the employer to decide whether to cover these costs or to limit the amount of activities the child can access whilst in the care of their PA?
- Why is it that support from the authorities to Carers and those who they care for is not readily available when something goes wrong with their Direct Payments/Personalisation support package, e.g. when a personal assistant has caused serious and long term harm to the person they were supporting, help/advice was not available?
- By which date will all carers and their carees be offered a flexible direct payment such as "In Control" as an optional alternative to directly provided services?
- Is it possible to consider perhaps a national SDS proactive watchdog who can intervene AS THE PROBLEMS OCCUR without the lengthy process of a complaints procedure? This would provide more accurate feedback of where problems exist, this then could also be fed into the monitoring process of SDS. With the developments of SDS, carers are being required to become ‘unpaid managers’ as well as ‘unpaid carer’s’. When are carers going to be really recognised as ‘Key partners’ in the care of vulnerable people?
- When can we expect the new carers’ bill to come into existence?
- Carers have expressed various concerns around the current implementation of Self Directed Support in some areas of Scotland. How will the government ensure these concerns are addressed through the Social Care (Self Directed Support, Scotland) Bill and how do they plan to monitor the future implementation of SDS to ensure it delivers on its promises?
“Section 16 in the draft Bill addressed what should happen, in terms of self-directed support duties, where functions or responsibilities are delegated from a local authority to a health board. This might be strategic functions, such as the responsibility for all of adult social care. Alternatively, it might be at an individual level, such as responsibility for someone’s social care assessment or the method by which they receive that social care. Where this occurs, we proposed a duty on the local authority to take "reasonable steps" to ensure that the health board has regard to the general principles of self-directed support.”

Rhetoric often heard is that MSP’s cannot interfere in Local Authorities’ business.

Can you tell me what the Scottish Government is doing to strengthen the Self Directed Support Bill, and ensure its commitment to Scotland’s estimated 650,000 unpaid carers, so that carer’s rights are protected in law, and not left to the arbitrary decision process of Local Authorities?

Self Direct Support – As an unpaid carer, I support a team of 7/8 personal care assistants

There should be a management fee proportionate to staff levels included in the budget (paid to the carer) or a team leaders post built into the budget? Why is this not provided?

Why is there no provision for providing a pension for the personal care assistants which would allow equity with Local Authority Employees? Training

There is no allocation in the SDS budget to provide training for paid staff (it has to come from contingency and a prudent employer is wary of using this until the year end) This causes difficulty in planning training for staff. This is important in providing the correct care and support to the individual. Why is this not built into the budget?

Accessing relevant and appropriate training for staff is problematic. This is like searching for a needle in a haystack due to economic cuts to National Care Organisations ability to provide training. Why can’t SDS staff access Local Authority and Health Service training? Also there should be a ‘broker service’ who not only points to training providers but who will also set it up. New SDS Bill

The new Bill for SDS is being considered, in it, it is suggested making a charge to Carers for respite. The ‘Carer’ is in effect a service provider, no other service provider is charged to take their holidays. Are you aware of this and what will you do to ensure that this is not included in the new bill?

Is it possible when introducing changes to the SDS Bill that a provision be made to introduce a National Independent helpline/advocacy/negotiation service to support Carer’s to ensure compliance that Local Authorities will adhere to and promote in a timeous manner the effective use of SDS.

Asperger’s and Autism:

Parents and carers of adults with long term disabilities such as Asperger syndrome often face years of frustration with Health and Social Work services in obtaining the appropriate level of support. The reasons for this often revolve around ignorance, indifference and lack of funding. The effects on parents/carers can be disastrous and can in turn lead to a greater burden on these services. How are the responsible departments in local and national government addressing this issue?
• There needs to be more understanding and support for adults with Attention Deficit Hyperactive Disorder and Autistic Spectrum Disorders across all services and more support and understanding for their Carers, do the panel have any ideas to resolve these issues.

• Why are there no Autistic specific schools in South Lanarkshire, there are only bases. Given that there are over 650 children with Autism living in South Lanarkshire does this not merit consideration for the need of an ASD school to be established for our special children? Instead, we have pockets of bases spread throughout.

• Would it be possible to introduce a scheme for people with Autistic Spectrum Disorder to carry a card explaining this to allow various agencies to meet DDA requirements e.g. police, health services etc.? Card is currently only available via the National Autistic Society website and not everyone is aware of this.

Remote and rural:

• Accessing support in remote and rural areas is particularly challenging due to the higher costs associated with service delivery and difficulties around recruitment. How can government help to redress this balance and ensure carers in remote and rural areas receive an equitable service?

General:

• To be considered for a possibility of caring for my wife at home if it is possible.

• The individuals and families needs when looking at issues of housing. For example overcrowding and the current house not meeting the needs of the young adult and the ongoing impact on all the family. What are the alternatives for families in these situations?

• When the aging parents of a disabled daughter/son are not able to care anymore the future of the person cared for is bleak. This is a worry which comes to mind every hour of the day – who is going to ensure the quality of life the person have had when parents were around. The services are few and stretched to their limits. Paid carers working in residential establishments are untrained and very poorly rewarded. The quality of care is often basic and not adequate. My question: what is government doing to protect the most vulnerable against mistreatment and ensuring that people with learning difficulties lead dignified and full life?

Topic 6 – Access to suitable, flexible short break and respite support

• What provisions do you have in place or plan to for BME carers in respite centres?

• Why is it so difficult to get respite care? This is what I’ve experienced. Communications between departments are diabolical (social work – care homes etc.)

• The cuts to services and respite in some Local Authorities are having a huge impact on carers; some carers feel they have no choice but to provide more care and support at the detriment of their own health and well-being. What steps will the Government propose, to assure that adequate assessments are fulfilled and where issues arise they are addressed in time to prevent a break down in the caring situation?
• With regards to direct payments for respite, why do we have one size fits all, when respite requirements vary, depending upon the nature of the illness and/or disability. For example, my wife receives the equivalent of 42 nights annually in a care home. Most care homes couldn’t meet my wife’s needs but Leuchie House can but the payments don’t meet even 22 nights at Leuchie.

• Which agency has responsibility for standards of hotel/B&B/self catering accommodation suitable for persons with disabilities and how are the standards enforced? Why is it so difficult to obtain accurate information about the essential facts of shower/bathroom facilities for persons with disabilities to be able to have short breaks?

• When will the government deliver its commitment to a legal entitlement to respite, and when will other parties commit to improved carers rights?

Other Questions that do not fall into topic headings

• I was unsuccessful in obtaining a place this year on the Carers Parliament. Can you tell me if you are intending to have an annual ballot for a place on the Parliament please or is it the case that once you are selected then you have that position indefinitely?

• What do you expect the Carers Parliament to achieve (other than highlighting what carers do which in its self is good)?

• How serious does the Scottish Government take Carers? Talking is easy.
Caring Together and Getting it Right for Young Carers

The Carers and Young Carers Strategy for Scotland 2010 - 2015

Progress Report on implementation and related developments to support carers and young carers (since the first meeting of the Carers Parliament on 1 October 2012)

May 2013
Introduction

This report summarises the action in hand to support carers and young carers. It addresses many of the issues raised by carers and young carers at the first Carers Parliament. It also takes on board some of the concerns raised. Better outcomes are being achieved for some carers and young carers. For others, there is much more to do. Work to support carers and young carers is through implementation of the Carers and Young Carers Strategies and through wider legislative opportunities and policy and practice-based developments.

The Scottish Government has invested, and is investing, over £98 million in supporting carers and young carers between 2008 and 2015. This is supplemented by resources through the dementia and other strategies and through funding to individual condition-specific organisations which support carers. Moreover, over the next 10 years the Life Changes Trust will invest £25 million in supporting people newly diagnosed with dementia (and as the illness progresses) and their carers. The allocation of the £98 million is set out in Table 1 on page 3.

Local authorities, with Health Boards, the voluntary sector and other partners are responsible for supporting carers and young carers within their areas. This report includes a small selection of local initiatives gathered by the Scottish Government’s Carers Branch over the past year.

The first part of the report addresses support to adult carers but since some of the initiatives are relevant to all carers, including young carers, we highlight where they apply to young carers. The second part of the report is relevant to young carers only.
<table>
<thead>
<tr>
<th>Year</th>
<th>Initiative</th>
<th>Description</th>
<th>£,000,000</th>
</tr>
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<tbody>
<tr>
<td>2008 - 2015</td>
<td>NHS Board Carer Information Strategies (CIS)</td>
<td>Identification of, and a wide range of support to, carers and young carers throughout Scotland, including in rural areas and also including Black and Minority Ethnic (BME) carers</td>
<td>28,900,000</td>
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<td>2010 - 2015</td>
<td>Voluntary sector Short Breaks Fund run by Shared Care Scotland and the Family Fund</td>
<td>Short breaks for carers and young carers: Creative Breaks, Better Breaks, Take A Break and Time to Live. Better Breaks and Take A Break specifically support disabled children and young people and their parent-carers</td>
<td>13,000,000</td>
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<td>2008 - 2015</td>
<td>Support to young carers</td>
<td>Includes the annual Young Carers Festival and the Eryc and Trayc initiative in primary schools</td>
<td>3,750,000</td>
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<tr>
<td>From 2011</td>
<td>Short breaks</td>
<td>To help local authorities maintain the extra 10,000 respite weeks</td>
<td>2,820,000</td>
</tr>
<tr>
<td>2011 - 2015</td>
<td>Reshaping Care for Older People Change Fund</td>
<td>At least 20% of the Change Fund is to support carers of older people</td>
<td>46,000,000</td>
</tr>
<tr>
<td>2008 - 2015</td>
<td>Support to the National Carers Organisations</td>
<td>Core and Project funding covering a wide range of initiatives</td>
<td>3,723,000</td>
</tr>
</tbody>
</table>
Supporting Adult Carers
(with reference to young carers where appropriate)

Income maximisation to help deal with reform of the welfare system.

Support to organisations and to individuals

The Scottish Government is working with a range of organisations to help it better understand the impact of the UK Government’s reforms of the welfare system on different groups in Scotland. Carers Scotland is represented on its Welfare Reform Scrutiny Group.

The Scottish Government is doing all that it can to mitigate the worst impacts of these reforms on people and organisations across Scotland. This includes: providing an additional £7.9 million for organisations to give advice and support to those affected; an additional £9.2 million for the new Scottish Welfare Fund, giving a total Fund of £33 million; and providing, with COSLA, a total of £40 million to protect people in Scotland from the UK Government’s 10% cut in Council Tax Benefit.

The Scottish Government’s guidance to NHS Boards on Carers Information Strategy (CIS) funding includes, as one of the priorities, income maximisation and financial inclusion for carers and young carers.

NHS Board CIS funding has been allocated locally for initiatives such as Money Matters surgeries and specialists in financial advice (eg VOCAL, Edinburgh). Some Change Fund Partnerships (eg South Lanarkshire) are also employing Welfare Rights Officers who have a focus on financial inclusion for carers.

Using CIS monies, NHS Fife supports Kindred in Fife which promotes resilience amongst parent-carers. Over the last year Kindred has supported 179 families in Fife. Some key achievements of the project to date are:

- 115 families were assisted with financial matters including benefits and trust fund applications;
- 113 families were assisted with educational matters;
- 21 families were assisted with housing issues (housing benefit, adaptations and rehousing);
- 39 families were provided with advocacy for health related issues;
- 29 families were provided with advocacy with social work; and
- 37 families were referred to specialist voluntary organisations.
In Highland, as part of the work of the Carers Centres and as an integral part of the Carer’s Assessment and Support Planning process, carers are referred to a local Citizens Advice Bureau, Highland Council’s Income Maximisation Scheme and Energy Assistance Scotland to ensure that they are receiving the correct amount of benefit and are able to maximise their income.

The integration of health and social care will be important for carers.

Legislation for integration

The Bill which will establish the arrangements for the integration of health and social care will shortly be introduced into Parliament. The integration of health and social care represents the radical reform required to improve care, particularly for adults with multiple complex needs, many of whom are frail older people, and to make better use of the substantial resources that are committed to adult health and social care.

The proposals of the Bill are based on four key principles:

- nationally agreed outcomes which will apply across adult health and social care. One of these outcomes relates to carers;
- statutory partners to be jointly and equally accountable for the delivery of those outcomes;
- integrated budgets to apply across health and social care; and
- the role of clinicians and care professionals to be strengthened, along with engagement of the third and independent sectors, in the commissioning and planning of services.

From the perspective of people who use health and social care services (patients, service users, carers and families) there are a number of issues that the legislation aims to address including:

- the inconsistency in the quality of care for people, and the support provided by carers, across Scotland, particularly in terms of services for older people and adults who access a range of support services across health and social care;
- the unnecessary delay in hospital when people are clinically ready for discharge;
- the services required to enable people to stay safely at home which are not always available quickly enough. This can lead to avoidable and unnecessary admissions to hospital; and
- carers to be supported to continue to care and to have a life outside of caring.

Locality planning offers a particularly significant and important opportunity for the effective involvement and leadership of non-statutory partners in the delivery of services in the third and independent sectors, and for representatives of patients, people who use services, and carers. Carers will be fully involved in decisions about how best to put in place local arrangements for planning service provision.

Self-directed support is important both for cared-for persons and carers.
Statutory guidance on the carer’s assessment and preventative support

In January 2013 the Social Care (Self-directed Support) (Scotland) Act (“the 2013 Act”) received Royal Assent. The 2013 Act will commence in April 2014. The Act makes provision about the way in which certain social care services are provided. In particular, it provides a variety of choices as to how a person wishes to arrange their care and support. The Scottish Government is presently consulting on draft Regulations and statutory guidance to accompany the 2013 Act. The consultation period ends on 10 July.

Part of the guidance covers carer’s assessments and the benefits of preventative support. The link to this consultation is below:

http://bit.ly/17nNsDr

Directions about the carer’s assessment

The Scottish Government is consulting on Directions to local authorities about the way that they should approach “the substantial and regular test” on access to the carer’s assessment. The aim of the Directions is to reinforce existing guidance about the interpretation of providing a substantial amount of care on a regular basis and to encourage local authorities to adopt a broadly consistent approach to the carrying out of the carer’s assessment. The guidance allows for a broad interpretation of “the substantial and regular test” related to the impact of caring and also builds in significant safeguards about the interpretation in relation to young carers.

The link to the consultation is below:


Carers and young carers will not be charged for support

The 2013 Act provides for the first time a power in social care legislation to support carers and young carers in their own right. The Minister for Public Health, Michael Matheson MSP said during the Bill’s Parliamentary passage that carers should not be charged for the support that they receive as carers. The Scottish Government is consulting on the Regulations and statutory guidance that give effect to this commitment. The link to this consultation is below:


Employment of close relatives

The Scottish Government proposes to change the present situation where service users can only employ family members under self-directed support in exceptional circumstances. The Scottish Government is consulting on draft Regulations which, amongst other things, set out appropriate (and inappropriate) circumstances where the supported person, carer and professional are considering the option of employing a close relative as a personal assistant. The range of appropriate circumstances include those where the person requires palliative care, where there is a limited choice of service providers and where there are religious or cultural beliefs which make the provision of support by a family member preferable. The link to the consultation is below:

http://www.scotland.gov.uk/Publications/2013/04/6823/0
It is important to identify carers early in their caring.

Early identification

Early identification of carers and *young carers* is the key to providing a carer’s assessment and support. The following example shows what is being done to identify carers and *young carers* at an early stage and to support them:

In NHS Lanarkshire the Carer Support Team has developed a staff “Carer Champion” Training Programme in partnership with the Princess Royal Trust Lanarkshire Carers Centre, North Lanarkshire Carers Together, South Lanarkshire Carers Network and Action for Children North Lanarkshire Project. This training session has been delivered to targeted staff within acute and community settings and aims to **enhance the ability of staff to identify and support carers and young carers**. The training programme aims to build capacity within NHS Lanarkshire to support carers by ensuring that each ward/community location has a “Carer Champion” working in partnership with the Carer Support Team. Delegates attending the “Carer Champion” Training Programme also agree to ensure that the knowledge gained at the training is cascaded to their colleagues. The intended outcome for carers is that they will have improved access to appropriate information and support from staff. Initial evaluations, immediately after the training and after an 8 week implementation period, indicate that staff feel more equipped to identify and support carers and recognise that this is integral to their role.

With partners, the Scottish Government is taking forward a range of initiatives to help identify and further support carers and young carers. These include:

**Health and social care workforce**

- funding of NHS Education for Scotland (NES) who are, with the Scottish Social Services Council (SSSC), taking forward workforce development in relation to the health and social care workforce. Following engagement with a range of stakeholders, including carers, NES identified the need to outline core values, knowledge and skills which will help staff to work with carers as equal partners and achieve better outcomes for carers and *young carers*. In response NES, with partners, developed “Core Principles for working with carers and *young carers*”. Central to the implementation phase will be the development of a network of Equal Partners in Care or EPIC ambassadors across Scotland. The role of EPIC ambassadors or facilitators will include disseminating information and knowledge in relation to working with and supporting carers and *young carers* and sharing practice, issues and challenges across the health and social care workforce in Scotland;

**Further and Higher Education**

- funding of the College Development Network (formerly Scotland’s Colleges) for a workforce development initiative so that staff in the Further Education sector can identify and support learners who are *young carers* and carers. The second phase of the project has now
commenced. The emphasis is on the further development of resources and support materials, identifying the support needs of learners with caring responsibilities, encouraging learners with caring responsibilities to recognise their existing skills and future aspirations and adapting college support structures to respond to young and adult carers. Some Higher Education Institutions such as Glasgow University are taking forward their own initiatives to help identify and support carers and young carers. The Scottish Government is exploring further options for universities;

**General Practitioners**

- A number of changes and improvements to patient care through the General Medical Services Contract Agreement in Scotland for 2013-14. It also transfers a number of current indicators from the Quality and Outcomes Framework into the core part of the GP Contract. The current indicator about carers is transferred into the core part of the GP contract. This means that all GP practices in Scotland are expected to identify carers and young carers and have a mechanism in place for the referral of carers, including young carers, for assessment. At the Carers Parliament carers said that they wanted more support from their GPs. The above initiative on the GP contract will help. It builds on the Royal College of General Practitioners Scotland electronic guidance specifically designed for GPs and practice staff to help identify, signpost and support carers. This Guidance can be accessed at:


The following example shows the outcomes that can be achieved when a GP identifies a carer and makes a referral.

Claire (name anonymised) is a 49 year old mother with a dual caring role. She supports her 23 year old daughter with complex learning and physical difficulties and her 84 year old aunt who is frail elderly with a mild learning disability. Claire’s aunt recently moved in with Claire. Claire made initial contact with VOCAL via a referral from her GP. At this stage she was interested in a short break and had been told that VOCAL could help her access some breaks. VOCAL supported Claire in this. Claire also attended a seminar about telecare and assistive technology. Following this, she reported big improvements in her knowledge, her confidence in the caring role and in her ability to shape services. Claire said, “I feel less anxious and stressed.” Claire then registered for the Caring For an Older Person training course. Following this five-week course, Claire reported a big improvement in her knowledge. Claire also pursued other courses and support, commenting, “Everything feels more manageable now.”

The following example demonstrates action to enhance GP awareness of carers:

In NHS Tayside through the GP worker input, effective partnerships are being built with GP surgeries, pharmacies and other health professionals to ensure early identification of and support to carers, young carers and their families. This provides person-centred 1:1 support for carers and is key in signposting carers on to specific services such as counselling, welfare rights advice, group support and training.
There is a need to improve the uptake and quality of the carer’s assessment (carer support plan).

The Carer’s Assessment
A good quality carer’s assessment carried out in an empathetic and supportive way is the building block for support. A meaningful assessment process assists carers to discuss and record the care they provide and any support they may require to sustain them in their caring role.

- With partners the Scottish Government is producing Practice Guidance on the carer’s assessment with the aim of improving outcomes for carers. This will be published later this year.

There are developments locally on the carer’s assessment. Some councils, Health Boards and Change Fund Partnerships are rolling out the carer’s assessment. For example:

A number of local authorities including Edinburgh and Glasgow are offering carer self-assessment. Then, on the basis of the self-assessment, if the carer is assessed as providing a substantial amount of care on a regular basis, a full assessment will be carried out.

In Angus, all carers identified by social work are offered a carer’s assessment and a record is held of whether the assessment has been accepted or declined. Assessments are carried out by social work and carer centre staff. A Carer Self-Assessment (CSA) is also in use. The self-assessment was refreshed in consultation with carers.

In Midlothian, the focus is on having meaningful and outcome-focused conversations with carers and then recording and acting on these conversations.

Carers have rights. Professionals and carers must know about them.
- The Scottish Government has commissioned Carers Scotland and the Minority Ethnic Carers of Older People Project (MECOPP) to produce a Carers Rights Charter. Carers Scotland and MECOPP are working with the Scottish Consortium for Learning Disability and the University of Glasgow on this important work. They are now consulting carers and professionals. The Charter, which will be widely circulated, will be published later this year.

There is work at local level to ensure that carers and professionals are aware of carers’ rights. For example:

Inverclyde Carers Council is revising its local Carers Charter. The Charter aims to inform carers about their rights to access services and support and the ways in which Inverclyde Council and the CHP can assist them.
Information for carers needs to be available early and in one place.

- On a Scotland-wide basis, the Scottish Government is working with NHS Inform to provide a new service through Care Information Scotland. The existing helpline and website service currently provides a wide range of information on community care services for older people. The new revamped service will include a service for carers and young carers. Development work is underway.

There are local initiatives to provide comprehensive information to carers in a more accessible way.

In Renfrewshire, the Carers Centre now provides comprehensive information and advice to carers using various formats – a web-site, information leaflets and a quarterly newsletter.

In Forth Valley, the Carer Hospital Support Worker is working with staff at the hospitals to identify carers and provide them with information and support whilst the person they care for is in hospital (or the carer is in hospital) and during discharge planning.

NHS Fife opened a Carer Information Centre in Phase 3 of the Victoria Hospital site.

New technology (telecare and telehealth) should be available across Scotland. There should be effective broadband and the necessary back up in remote and rural areas.

Scotland’s Digital Future

*Scotland’s Digital Future: Infrastructure Action Plan* sets out the steps the Scottish Government will take to deliver a step change in broadband speeds, paving the way for delivery of world-class, future-proofed infrastructure across all of Scotland by 2020.

The Scottish Government has allocated more than £240 million of public sector funding to deliver the Infrastructure Action Plan. Fourteen local authorities have signalled their intent to commit up to £50.65 million for investment in their own areas.

The plan addresses the current digital divide and puts in place infrastructure that will have the capacity to deliver next generation broadband to between 85% to 90% premises and a significant uplift in speed for the remaining 10% to 15% that have no service. The Scottish Government has launched Community Broadband Scotland (CBS) to assist rural communities.

National Delivery Plan for Telehealth and Telecare

The Scottish Government’s National Delivery Plan for Telehealth and Telecare will identify solutions for the delivery of telehealth and telecare services to people who live in areas with limited or no mobile or broadband connectivity. This can include, for example, the use of satellite broadband.
In Ardnamurchan, the use of satellite broadband allows emergency responders to video conference through a dedicated bridge (link) to the Emergency Care Centre in Aberdeen Royal Infirmary where a senior clinician can talk them through appropriate actions.

Carers need support to protect their own health and wellbeing. The support should include regular planned personalised short breaks and emotional support. The support should take account of the needs of carers from BME communities and the needs of other carers too.

- Short breaks
- Emotional support
  - Advocacy
  - Training
- Multi-component support
- Cultural awareness and responsiveness

Short Breaks

Scottish Government Funding to support the delivery of short breaks is available through the Change Fund for older people, NHS Board Carer Information Strategies, and the voluntary sector Short Breaks Fund run by Shared Care Scotland and the Family Fund. Funding was also included in local authorities’ budgets to maintain the extra 10,000 respite weeks. Local authorities can supplement this funding themselves. Some of this funding supports young carers.

One example of provision funded through the Short Breaks Fund is as follows:

Crossroads in Orkney managed a local Time to Live fund that distributed micro-grants of up to £100 to carers so that they could take advantage of preferential ferry fares to get off the island for one or two nights and have a break from caring. Because many of the carers look after older people with complex needs, Crossroads provided replacement care to make the break possible. 25 carers benefited from a break. An older carer on one of the remote outer islands cares for her friend who is 103. Crossroads provided a grant of £100 to allow her to attend the wedding of a relative on the mainland. Crossroads looked after her dependent while she was away, and without this help she wouldn’t have had a break as there is no residential respite on the island.

More areas are setting up Short Breaks Bureaux to manage and coordinate short breaks provision and are working more strategically. For example, Scottish Borders Council, in partnership with NHS Borders, carers and the Third Sector has developed a Short Breaks Strategy and work plan.
There are also many good local examples of short breaks provision across Scotland supporting both carers and the people they care for. These include playschemes and activity holidays for disabled children, befriending schemes for both cared-for persons and carers and many other types of provision.

The Take A Break short break scheme for disabled children and young people up to the age of 20 is funded by the Scottish Government and run by the Family Fund.

Through Take A Break, over 1,200 families, with a disabled child or young person have been able to take a much needed short break in 2012.

The Scottish Government has provided a total of £1.3 million funding to the Family Fund for the Take a Break Programme since 2011.

The Take a Break Programme enables families with disabled children, up to the age of 20, to access a grant directly to purchase a holiday, play scheme place, or such items as computers or camping equipment.

The Scottish Government also provided £2.7 million to the Better Breaks Programme, which provides grants to third sector organisations working in Scotland to develop additional creative short break opportunities for disabled children and their families.

There is more to be done in order to ensure better provision of short breaks through well-developed local strategies with clear improvement targets. The Scottish Government is working with partners to take this forward.

It is also important to reflect on, and to learn from, different experiences and to establish the impact that initiatives have had and the outcomes achieved. With Scottish Government funding for a Short Breaks Learning Exchange, Shared Care Scotland has produced an Evaluation Toolkit. The aim of the toolkit is to help short break providers and others to evaluate the outcomes of short breaks in any setting. The toolkit will be available later in May.

**Emotional Support**

Different types of support to carers including the provision of information and advice, the work of the mental health development co-ordinator based within the PRTC Scotland, short breaks and training enhances carers’ wellbeing. Equally, some carers do want, and benefit from, counselling services. NHS Boards with partners offer counselling and other low-intensity treatments to the general population, including carers. There are however local examples of counselling services for carers.

In West Lothian, three counselling sessions continue to be fully booked. The Carer Information Strategy monies pays for the counsellor to provide two sessions and the counsellor then provides the third session on a voluntary basis.
There are also local examples of emotional support to carers through support projects.

In Midlothian, the Café Support Group for people with dementia and their carers provides invaluable support to the carers. The café numbers continue to grow and the carer support group time has needed to be increased to meet demand. The group continues to be an open forum that allows carers to share problems and solutions and to talk freely with others in the same situation. Many carers who attend have stated that the café group is a vital support to their role as carer and appreciate the reliability the group offers. The carers also find it very useful to have somewhere sociable to go together with their husband/wife/family member which accommodates both their needs in a supportive and friendly environment.

Multi-component support

Dementia Advisory Clinics for service users and carers are in operation in East Dunbartonshire. They provide better screening and identification, whilst providing support at diagnosis, post-diagnostic support and support to carers. Intensive, multi-component interventions to support carers can delay nursing home admission for people with dementia. By enhancing the coordination of existing activities the dementia clinics provide:

- multiple points of entry for information;
- signposting;
- anticipatory planning for people with dementia;
- carer support;
- implementation of dementia care standards;
- hospital, GP and care home in-reach; and
- a dementia training hub on dementia.

Carers Link is one of the partners who deliver the clinic service. There is specialist service provision for carers from Black and Minority Ethnic (BME) communities through the BME Dementia Advisory Clinic. There are also developments expected later this year to support young carers of people with dementia.

Advocacy for carers

The Scottish Government is convening a group involving the voluntary sector, including VOCAL, the Scottish Independent Advocacy Alliance, Health Boards, local authorities and others to produce guidance on advocacy for carers.

Local advocacy services for carers have grown over the past few years. There are a number of advocacy services provided by carers centres and by other organisations, for example, in Fife, Grampian, Perth, Edinburgh and Dumfries and Galloway.
One example of successful carer advocacy in South West Glasgow is as follows:

Amanda (name anonymised) cares for about 70 hours a week for her mum who is immobile following a stroke. Amanda also has a brother who has Huntington’s disease. He was admitted to a mental health hospital after his symptoms worsened. The hospital was three bus journeys away from home. When Amanda visited her brother he was alone in the ward with nothing to do and no one to interact with. Also, the outside lights did not work which meant that Amanda and her friend were walking in the pitch dark when they walked to the bus stop after visiting time. Amanda called the carers advocate to help her get her brother transferred to a hospital that was both closer to home and more suited to his needs. Amanda said that things seemed to get moving after a call from the advocate.

Training for carers

One of the priorities of the Carer Information Strategy funding is training for carers and young carers across a whole range of different areas. The Scottish Government has also funded the National Carer Organisations for a carer training programme.

There are a large number of local examples of training including:

In Glasgow, training pathways are being developed by the Carers Planning and Implementation group to support carers. Some of these are generic and available to all carers, for example, personal effectiveness and others are condition specific, for example, dementia awareness and moving and handling. NHS Greater Glasgow and Clyde CIS funding has been instrumental in supporting the development and delivery of the training pathways allowing greater strategic spend of this fund.

Carers have said about training courses provided by VOCAL, Edinburgh:

“I attended a course for carers of people with dementia. It made a huge difference to me, equipping me for dealing with potential future problems (many of which have since occurred!).”

“The moving and handling course I attended helped me to avoid injury as my relative’s condition deteriorated.”

Equalities: Cultural awareness and responsiveness

All Scottish Government Carers Branch Strategic documents reinforce the importance of the equalities dimension in identifying and supporting carers. However, concerns were raised at the Carers Parliament that BME carers are not adequately supported nor their needs fully recognised.

- The Scottish Government will continue to give a strategic lead and have, for example, funded an audit tool produced by MECOPP and a Gypsy Traveller project.
Some local examples are provided below:

In Dundee, CIS funding is used to employ two development workers for South Asian and Chinese communities to provide a range of services including advocacy, support groups and welfare rights capacity.

In Glasgow, there are dedicated multi-lingual staff located with the voluntary sector supporting carers from Asian communities. The diversity of Glasgow has changed dramatically over recent years as a result of the city’s support to refugees and asylum seekers and all carer services make use of the Interpreting Services to support a range of carers whose first language is not English. Links are also being built with organisations including Deaf Blind Scotland and MS Revise to identify disabled carers.

In Lanarkshire, the BME development worker post is hosted within the carers centre. This post enables BME carers to receive individual support and encourages growing numbers to utilise the carer services available. This post supports the continued development of the International Women’s Group which helps provide mutual support, relevant information and relief from isolation for BME carers.

**Alcohol and Drugs Partnerships (ADPs) should support carers of people with substance misuse problems.**

ADPs are working locally to identify and support carers and young carers of people with substance misuse problems.

In Angus there is a dedicated carer development worker based within Angus Carers Centre which is funded by Angus ADP to work with adult carers and family members affected by substance misuse.

In East Renfrewshire, current work specifically relating to addictions includes the following:

- A clear referral pathway between Social Work and Health and the Young carers services
- Close links and referral pathway between Young carers service and Youth Addictions Project
- Young carers staff routinely attend social work case meetings
- Young carers Voices Peer Education Project delivers sessions in local secondary schools and to health and social work teams

Falkirk ADP is mindful of the role played by carers in relation to recovery from alcohol and drug problems. The ADP supports Grangemouth Family Substance Abuse Support Group (GFSASG) which provides services to family and friends (adults) of substance users within or outwith the treatment setting and where a young person is identified as the carer they would be referred to the most appropriate services.
Carers need support from employers to help them stay in paid employment.

Employers Kitemark

The Scottish Government is fully committed to ensuring that carers and older young carers too can access employment and remain in work. It can be frustrating for carers if they feel that they have to give up work or reduce their working hours when they don’t want to but feel they have no option. Employment provides not only an income but a life outside of caring. There are some good employers across the country who support carers well but more needs to be done. That is why there is a Manifesto commitment to produce and implement a Caring for Carers Employers Kitemark which will recognise those employers which support carers.

The Scottish Government knows that industry bodies, trade unions, employers and others are committed to this initiative. Carers Scotland, which is working in partnership with the Scottish Government to deliver this commitment, appointed a Kitemark worker in April to drive forward the necessary work. The Scottish Government has also funded MECOPP to look at the experiences of Black and Minority Ethnic carers in employment and the Princess Royal Trust for Carers in Scotland (Carers Trust) for work through carers centres.

Carers should be equal partners.

Carers as equal partners

Carers are rightly concerned to be treated by all professionals at all levels in organisations as equal partners. Therefore, carers need to be fully involved in decision-making about services for the people they care for and support for themselves. Carers need to be equal partners in decisions about planning, shaping and delivery of services and support.

Much has been achieved and there are many good local examples. Equally, there are concerns that this is not fully understood or implemented. The Carers Rights Charter will provide an additional impetus.

- The Scottish Government also funded the Coalition of Carers in Scotland (COCIS) to produce Best Practice Standards for Carer Engagement. The Standards are to be finalised and disseminated.
- The Scottish Government has worked with a number of Change Fund Partnerships on carers as equal partners.

The Carers Parliament said that health and social care services need to listen to all carers, including those carers who care for people with mental ill health. The Scottish Government is taking this forward:

Commitment 2 of the Mental Health Strategy for Scotland 2012-2015 states that the Scottish Government will increase the involvement of families and carers in policy development and service delivery. We will discuss how best to do that with VOX (Voices of Experience) and other organisations that involve and represent service users, families and carers.
As a first step, we have asked VOX to run a series of events with service users to understand how families and carers can be more involved in people’s care and treatment. This approach with service users first of all recognises that service users may sometimes have reservations or objections to involving family members in their care or sharing information. We will build on the work with carers.

We have also established an Implementation Group to oversee a suite of commitments in the Strategy including family and carer involvement. That will meet in June 2013.
Part 2
Supporting Young Carers

Introduction
Part I of this report covers young carers throughout. This is because some of the initiatives to support adult carers such as the voluntary sector Short Breaks Fund and training apply in equal measure to young carers.

In addition, specific policy and practice in relation to young carers is set out in this Part, as are wider developments such as Additional Support for Learning and the Children and Young People Bill.

The Scottish Government is committed to ensuring that young carers have the same opportunities as other children and young people who do not have caring responsibilities and that they are not disadvantaged. It is important, therefore, to support young carers in primary school and through transition to secondary school to Further and Higher Education and employment.

Initiatives to support young carers
Some of the Scottish Government initiatives to support young carers include:

• funding of the Eryc and Trayc initiative being taken forward by the Scottish Young Carers Services Alliance (SYCSA) in primary schools;

• funding of a toolkit for secondary schools – to be launched later;

• funding of the College Development Network to raise awareness of young carers (and carers) in colleges and to support young carers (and carers);

• funding of the voluntary sector Short Breaks Fund over four years, a proportion of which is supporting young carers. Following a short break on the ocean waves with Ocean Youth Trust Scotland, one young carer said:

> “I’ve never done anything like this before. I’ve made new friends as a result. I used to be nervous talking to new people but this has given my self-confidence a boost. I don’t have a job, but since I got back from the expedition I’ve got back in touch with the local guides as a leader to give me something to do”

• funding of the annual Scotland-wide Young Carers Festival;

• funding of NHS Board Carer Information Strategies (CIS) to 2015 (£29 million), a proportion of which is supporting young carers;

• development and funding of the Young Carers Card pilot in all of four NHS Board areas and in parts of two Health Board areas. The card is to be used in both health and educational
settings. Some of the areas have negotiated discounts for young carers with sports and leisure providers. The Scottish Government recently invited all Health Boards to consider introducing a card into their areas. We await all replies.

**Telecare**

Work is ongoing with Glasgow Caledonian University to explore new technologies to support young carers. The project seeks to identify a technology solution to support young people with caring responsibilities who are disadvantaged due to barriers created by their caring role, through the provision of access to information, advice and peer support.

**Additional Support for Learning**

Under the Additional Support for Learning Act, education authorities have responsibilities to identify, make provision for and review the additional support needs of all their pupils. Where a child or young person may have an additional support need as a result of being a young carer, these responsibilities apply. This means that a plan would be put in place to help those pupils who are young carers with their learning. Information for young people on the Act is available from [http://enquire.org.uk/yp/](http://enquire.org.uk/yp/).

In February 2013 Scottish Ministers provided their second report to Parliament on the implementation of additional support for learning. This year the report had an additional focus on how young carers are supported in schools. The report sets out examples of positive practice in meeting the learning needs of young carers. The report can be found at: [http://www.scotland.gov.uk/Publications/2013/02/7808](http://www.scotland.gov.uk/Publications/2013/02/7808).

**Training, skills and employment**

Through *Opportunities for All* the Scottish Government has made an explicit commitment to an offer of a place in learning or training to every 16-19 year old not engaged in education, training or employment.

From 2012, the Scottish Government is providing £1.5 million over 3 years through the Employer Recruitment Incentive (ERI) to encourage employers to recruit the most disadvantaged young people, including young carers.

Skills Development Scotland (SDS) has introduced *My World of Work* which is a new online resource helping people to plan, build and direct their careers and is central to developing individuals’ career management skills. At local level, SDS teams are working with carers and young carers centres and projects to raise awareness of SDS’s services.

**Young Carers Rights Charter**

Due to the existence of the UN Convention on the Rights of the Child, there was no action point in *Getting it Right for Young Carers*, to produce a *Young Carers* Rights Charter. However, the Scottish Government has now asked the Scottish Young Carers Services Alliance (SYCSA) to work with partners, including young carers, to produce such a Charter.
**Children and Young People Bill**

The Children and Young People Bill has now been introduced into Parliament. Its provisions cover, amongst other things, children’s rights and putting Getting it Right for Every Child (GIRFEC) on a statutory footing.

Subject to Parliamentary approval, under the GIRFEC part of the Bill, all children and young people from birth to 18 years old will have access to a Named Person, there will be a single planning process to support those children who require it, there will be a definition of wellbeing in law and duties will be placed on public bodies to coordinate the planning, design and delivery for services for children and young people with a focus on improving wellbeing outcomes.

All of these provisions will cover children and young people who have caring responsibilities.

The link below provides further information:
http://www.scotland.gov.uk/Topics/People/Young-People/legislation/proposed-bill

**Local initiatives**

The examples below set out some local initiatives supporting young carers:

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**Education Maintenance Allowance:**

At Stevenson College, when a young person was identified as struggling to meet 100% target, as part of their learning plan, they were given a lower target and were supported to try and make it up to 100% by the end of their course. The Bursary Department was in Student Services so they worked with us and were able to record this so that when the bursary software ran at the end of each month it took the lower target into account.

In Forth Valley, if the college identifies learners who are young carers normal procedure would involve the student providing some sort of evidence (usually a GP letter) and then contacting Finance Office and the Department whenever they are off in relation to this to allow the college to authorise the absence. This would protect the funding for the young carers.

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**Young Carers Project: Western Isles**

In partnership with Comhairle nan Eilean Siar and Action for Children a young carers project is being piloted in Pointers Youth Café. The Young Carers Project will support the identification of young carers in the Lewis and Harris areas through a local advertising campaign, awareness raising in schools, colleges, youth groups and through the Pointers Youth café Facebook page. The project will provide advice about young carers rights, as well as supporting access to relevant services.
Young Carers Project: Stirling

Through the delivery of the 2011-12 Stirling Young Carers Rural Project, research found that the young carers consulted felt they faced additional issues such as lack of transport, lack of services, small, if any, shops, with little fresh produce to enable healthy eating, long school journeys and few leisure opportunities. Therefore, when developing a support plan for young carers identified, we will continue to ensure that we consider these barriers (complex issues that require attention on an individual basis) that the young carer may face, and put in place supports to prevent this from being a barrier to them accessing the appropriate support including respite short breaks.

Information and training: Fife

Information and training for young carers. Health information is provided to young carers along with a variety of information and workshops (for example, First Aid) to help them cope with their caring role. We provide young carer awareness sessions for primary and secondary schools for pupils, teachers and other professionals. We developed an E learning resource which is now attached to the ‘Getting it Right in Fife’ website. The website for Fife Young Carers signposts young carers and their families to support. We also produce a quarterly newsletter. Young carers have improved access to advice and information and increased confidence and self-esteem. They have also have increased respite opportunities.