ENABLE Scotland

Carers (Scotland) Bill – Stage 1

About this submission:

ENABLE Scotland is the largest voluntary organisation in Scotland of and for children and adults who have learning disabilities and their families. We have a strong voluntary network with over 5000 members in 44 local branches and via individual membership. ENABLE Scotland campaigns to improve the lives of people who have learning disabilities and their families and carers. ENABLE Scotland provides social care services to more than 2,000 people across Scotland who have learning disabilities or mental health problems.

Our extensive work with lifelong carers over the last 60 years underpins our evidence submission. From this work we know that planning for all eventualities reduces stress and anxiety experienced by carers. We believe that lifelong carers should be supported to make practical and financial provision for the individuals they care for. Furthermore, we know that the impact of the death of a parent / carer on a person with a learning disability is compounded by a lack of planning. We are clear that in supporting carers there should be an emphasis on early intervention and crisis prevention and, as such, our evidence submission reflects our belief that this will be delivered only if the provision for emergency and future planning is enshrined in the new carers’ legislation. As such we have focussed our response to the Committee’s call for evidence on questions 1, 3 and 4.

Within the national learning disability strategy ‘The Keys to Life’, the Scottish Government made a commitment (recommendation 37) to work with ENABLE Scotland to drive forward the recommendations from our Picking up the Pieces report, published in 2012.

As such, ENABLE Scotland is currently funded by The Scottish Government for two years to deliver a project called Picking up the Pieces to:

- work with all local authorities to implement emergency and future planning pathways, improve access to and quality of emergency
- improve access to and quality of emergency planning for carers
- analyse the impact of emergency planning on the health and wellbeing of carers
- research the barriers faced by rural and BME carers and facilitate access to emergency planning for these hard to reach carer groups

Our experience over the last 60 years working with family carers and more recently through our Picking up the Pieces project informs this submission.
1. Do you support the Bill?

ENABLE Scotland welcomes the Carers (Scotland) Bill. This legislation provides us with a unique opportunity to improve outcomes for all carers in Scotland. We support the intention of the Bill to extend and enhance the rights of carers, but believe that there are one or two areas which require further focus; and where the Bill could be strengthened to provide a more holistic approach to support for carers.

3. How do you feel the Bill could be amended or strengthened?

- Provision for emergency planning should appear on the face of the Bill
- Our initial reaction is that provisions should be made for emergency planning within Section 8 ‘Content of adult carer support plan’ and Section 13 ‘Content of young carer statement’
- Further, it is ENABLE Scotland’s position that provisions on the duty to provide information and advice contained in section 31 would be strengthened by extending this duty to include the provision of information and advice in regards to future planning.

ENABLE Scotland’s primary area of concern is the lack of emergency planning provision on the face of the Bill. It is our view that the Bill would benefit significantly from the inclusion of a specific provision on emergency planning, and we encourage the Committee to consider this point. We believe that there is scope for amending ‘Section 8 – Content of adult carer support plan’ and ‘Section 13 – Content of young carer statement’ to include emergency planning provision. Such an amendment has the potential to have a profound and positive impact on carers and the people they care for. ENABLE Scotland would bring to the attention of the Committee that emergency planning is relevant to all carers, irrespective of age or the needs or diagnosis of the cared-for person. The need for emergency planning provision is not unique to carers of people with a learning disability.

### Emergency Planning

An emergency is an illness, personal crisis or event which, unexpectedly, or at very short notice, results in either the carer being separated from the cared-for person on a short or long term basis or in the escalation of the cared-for person’s needs. It could include a family funeral, a transport delay, family illness, admission to hospital, last minute doctor or dentist appointment or a personal incident affecting the carer. An emergency plan sets out the practical arrangements for short term, unplanned circumstances when you are unable to fulfil your caring role.
These processes start conversations that result in considerable peace of mind for carers and the wider family, knowing that everyone’s hopes and fears have been discussed, taken into account, and that arrangements are recorded in a plan. Having a plan in place takes the guess work out of an emergency situation response for social work teams, and ensures that families are comfortable that their loved one will be cared for in line with their own wishes.

ENABLE Scotland have been mapping emergency planning provision across the country and provision differs greatly between local authorities, with some areas currently not offering emergency planning to carers.

It is our position that the failure to expressly include emergency planning on the Bill will be a missed opportunity to address this disparity in provision.

ENABLE Scotland suggests the Committee look to ensure standardisation of positive carer experiences nationwide and to increase access to planning by making recommendation to include express provision for emergency planning within the Bill.

ENABLE Scotland would emphasise to the Committee that emergency planning is a health and wellbeing issue for carers and the people they care for, which can – and should – be addressed within robust legislative provisions:

- Outcome 1: people are able to look after their own health and wellbeing and live in good health for longer
- Outcome 2: People, including those with disabilities or long term conditions, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community
- Outcome 6: People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing

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**Future planning**

Future planning refers to the longer term plans for the cared for individual when the carer is no longer able to provide care – whether through illness, old age, change in circumstances or death. Future plans are more in-depth than emergency plans and the carer, cared for person and all other relevant family members, friends and professionals should be involved in creating the plan. The wishes and preferences of the carer and the cared-for person should be taken into account. It is a process which involves thinking ahead and should be developed over time. Issues to consider include, but are not limited to, current care and future care and support, living arrangements, practical, legal and financial provision including Power of Attorney, guardianship, wills and trusts (if relevant).
The ‘Scottish Government Response to Carers Legislation – Consultation on Proposals – January 2014’ states that, “some respondents called for the ACSP to include provisions about emergency planning. We recognise this as a concern for adult carers and young carers too. Since not all adult and young carers will however require discussion of, and arrangements for emergency planning, we propose to enable emergency planning to take place on an individual basis. Emergency planning will therefore be covered in regulations.”

ENABLE Scotland would contest that all carers require discussion of emergency planning. The completion of a plan would be dependent on personal circumstances. With the omission of emergency planning from the content of Adult Carer Support Plans and Young Carer Statements, there is the risk that carers fall through the net and do not have the opportunity to have that discussion at all.

We believe the inclusion of specific provisions on emergency planning and future planning within the legislation ensuring that carers have the opportunity to have that discussion is essential to provide a holistic approach to support for carers.

This approach is in keeping with established principles of early intervention and prevention recommended by the Christie Commission. Failure to support carers to plan for emergencies results in crises which put a strain on the health and social care services.

Furthermore carers who are not supported to plan find their caring responsibilities compounded by anxiety and stress, as exemplified by the following real life case study:

**Emergency Planning Case Study 1**

D. is a 47 year old man with a learning disability. He lived with his mother who was his main carer while receiving 8 hours support per week from ENABLE Scotland. When D’s elderly mother was hospitalised without any emergency plan for D’s care, he was placed in a care home which specialises in elderly, dementia, physical disability and sensory impairment. His mother died in hospital. There was no future planning. He has remained in this inappropriate placement since 2013. He wishes to move back into his community. A retrospective Community Care Assessment and capacity assessments in respect of Adults with Incapacity (Scotland) Act 2000 are ongoing.

An emergency plan could have identified informal interim care arrangements and prevented this crisis placement when his mother was hospitalised. Future planning would have highlighted the potential for crisis and provided a platform for the relevant professionals to work with the family to assess D., explore future care options and his legal and financial position should his mother pass away.

The STUCK! Report published by Learning Disability Alliance highlighted that people with learning disabilities living in elderly care homes are likely to be 20 years younger than the other residents and family crisis is one of the main reasons for their placement.
Former Minister for Public Health, Michael Matheson MSP stated his support for emergency planning in his foreword to ENABLE Scotland’s Picking up the Pieces’ research in 2012:

“Crucially, adult carers – and indeed young carers too – need to have peace of mind by knowing what arrangements will be put in place in the event of an emergency, either planned such as the carer going into hospital for planned treatment or unplanned such as the carer taking suddenly ill”

He continued, “I welcome the emphasis on carers taking control of their own arrangements for emergency planning through developing their own plans. This, combined with action by statutory and third sector agencies to support emergency planning, will help establish firm arrangements.”

Often carers know what would happen in an emergency but they need the support of professionals to formalise the plan and share it with relevant family members, friends and agencies. One carer told us, “I have a plan in my head”. Another carer commented, “no written plan. We had a recent experience which showed us that, while we all hold a good deal of information about my sister’s routines and needs, there is a great deal only in my Mum’s head. It probably would be a good idea to work with her to get it all written down.”

ENABLE Scotland is working with carers from the BME community to increase access to emergency planning. The case study that follows emphasises the positive impact that the process of emergency planning has on carer wellbeing.
Our position is underpinned by ‘Caring Together: The Carers Strategy for Scotland 2010-2015’ which states that the current carer’s assessment “should cover the need for emergency planning so carers have a plan to cover emergency situations”.

Emergency Planning Case Study 2

Carers from the BME community were identified as a ‘hard to reach’ carer group during the initial ‘Picking up the Pieces’ research.

ENABLE Scotland are funded by The Scottish Government to deliver an emergency planning project for BME carers in Glasgow. The aim of the project is to facilitate access to emergency planning provision for BME carers. Furthermore, the project will seek to identify the unique barriers which exist for BME carers and make recommendations to address them.

Ms. A moved to Scotland 16 years ago. She has 6 adult children. Her youngest daughter has a severe learning disability and autism. Being a single Pakistani mum to 6 she has had to heavily rely on services available to her. She knows limited English and communicates in Punjabi. Ms. A spoke about her difficulty in approaching agencies and her frustration at not being able to communicate with them.

Ms. A wanted to know more about emergency planning for the care of her youngest daughter as she has multiple health conditions and her health has deteriorated. She has stressed that she is not oblivious to the fact that an emergency could arise at any time. The project worker facilitated a family planning session – focusing on the benefits of planning and which specifics they should consider. Each member of the family discussed what role they could play in their sister’s care should an emergency arise.

The family were then put in touch with an emergency planning worker from Glasgow Carers Pathway to formalise their emergency plan. Once the emergency plan had been completed Ms. A was very emotional and said she felt overwhelmed that her children would all step in at a time of crises. She said she felt very proud of her children for fulfilling her expectations.

Feedback received from the carer:

Ms. A: “I feel a huge weight has been lifted from my shoulders. I can now rest assured that my R will have familiar and friendly faces to take care of her”.

Ms A: “a gust of cold air has entered my head and given me peace” (a Punjabi saying when someone overcomes a worry or fear)

Feedback from her daughter:

Daughter “I’m grateful you have come and helped our family have these crucial discussions that would otherwise probably would have been done in a hospital waiting room”.

Daughter “Your service has allowed my mum to speak about things she probably would never be able to… She has been able to open up her heart”.

This position is further supported by 22 of 29 local authorities who responded to our recent survey on emergency planning, stating that emergency planning should have a high priority within carer’s assessments (4/29 – medium and 3/29 – on an individual basis).

Scotland’s Carers\textsuperscript{vii} evidences the need for a preventative approach to supporting carers and draws a parallel between the quality of support offered to carer and the person they care for. Emergency and future planning with carers and the individuals they care for benefits all parties within the caring relationship. Furthermore, carers providing more than 35 hours of care per week are more likely to suffer lower mental wellbeing and there is strong evidence that carers are likely to neglect their own physical health.

ENABLE Scotland would emphasise to the Committee that with an emphasis on early intervention, crisis prevention and personal outcomes for carers; emergency planning can alleviate carer stress and anxiety and provide carers with peace of mind that contingency care arrangements can be put in place to allow them to address their own health concerns – including attendance at GP and hospital appointments, as the following case study demonstrates:

### Case study 3

Having an emergency plan in place has been invaluable for Jeanette Kelly when she faced health concerns of her own.

Jeanette cares for her daughter Vanessa, who has Down’s Syndrome, and was finally convinced to put together a plan when she was told she would need to go into hospital to have a knee replacement. Her doctor told her she would be off her feet for a long time and that she would have to make arrangements for Vanessa.

Jeanette said: “I had thought about having a plan for a while but always put it off. The knee replacement pushed me into action and I’m glad it did.

“It took months to put the plan together, starting with sheets of paper for every day of the week and talking to Vanessa’s support workers about when they could help by giving a bit more time when it was needed.

“The key thing was to provide continuity and security for Vanessa – keeping the people she knew around her even though I wasn’t going to be there.

“When I had another accident a few weeks ago, where I collapsed at home in the wee small hours, the emergency services were able to look at my plan and contact the right people to make sure Vanessa was looked after when I had to go to hospital.

“Within an hour of phoning the services, I was in Hairmyres Hospital safe in the knowledge there was someone Vanessa knew caring for her when I couldn’t.

“I’m on the mend now, but I shudder to think what might have happened if I didn’t have the plan in place.”

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4. **Is there anything you would add to the Bill?**

As per our response to Question 3 ENABLE Scotland would suggest additions should be made to the Bill to include:
• The provision of support for emergency planning. Ideally this would sit within the prescribed contents of Carer Support Plans set down in Section 8 of the Bill, and prescribed contents of the young carer statement set down in section 13.

• The extension of the section 31 duty to provide advice and information to include the provision of information and advice in regards to future planning.

ENABLE Scotland would be happy to work with members of the Committee to consider these issues in further detail at Stage 2.

ENABLE Scotland

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Case Study 1: STUCK!, Learning Disability Alliance Scotland, 2010 (http://www.ldascotland.org/docs/stuck.pdf)