



Claire Griffiths  
Deputy Clerk  
Legislation Office  
National Assembly for Wales  
Cardiff Bay, CF99 1NA

14 March 2013

Dear Claire

### **Stories in response to the Social Services and Wellbeing (Wales) Bill**

I enclose our response to Stage One of the scrutiny process for the above legislation. These stories are based on comments raised during a stroke survivor consultation event held at our office in Tongwynlais on Wednesday 20 February 2013.

At the Stroke Association, we believe in life after stroke and it runs through everything we do. Our work includes helping people at risk of stroke know how to better prevent it, funding ground breaking research, campaigning for change and producing support to over 35,000 stroke survivors across the UK through our Communication and Information, Advice and Support Services.

We believe that all stroke survivors should be supported to make their best possible recovery. Working across both health and social care, our co-ordinators offer stroke survivors a lifeline by helping them to understand what has happened to them and guide them as they navigate the often complex social and health care systems.

They are able to give practical advice and assurances to get people home as quickly as possible and work to prevent hospital readmissions and future social care interventions.

The Stroke Association does not offer these comments from a legal perspective; rather they provide an insight into the experiences of stroke survivors as they seek to navigate the social care system once they return home from hospital.

### **Names have been changes to protect the identity of those contributing:**

#### **Paul**

Paul got up in the night to go to the toilet and had his stroke. He fell flat on the floor. He was lucky, he was allowed home from hospital at the weekend, though no assessment was carried out on his home.

“I was discharged, and then nothing – no-one got in touch – I had to muddle through and my wife became my carer. She had to push for everything, eventually she got a handrail for the bath, but it was not fitted properly and because of my one-sided weakness, I fell and hurt myself. No-one really knows what you go through - you need to fight every day”.

In December following his stroke, the heating in Paul’s house stopped working. From December to February he did not have any heating in his home and was left with a £400 electricity bill. No-one from Social Services called to his house to check that he and his wife were coping with the aftermath of his stroke.

### **Jane**

Jane had her stroke 12 years ago. She was in hospital for eight months.

When she came home she didn’t have any speech or mobility.

“I’ve had to fight for everything I’ve had – give up and you’ve had it”

Jane is lucky, she has a carer. She thinks this is because she does not have anyone at home who could have looked after her once she returned home from hospital.

### **Gareth**

Gareth had his stroke on his way home from work. He felt hot, sweaty and confused. He collapsed metres away from his front door. He spent six months in hospital. He lost his speech, mobility in his right side and was unable to swallow.

“I didn’t receive an assessment from social services. I’ve had to pay for all the adaptations in my house myself. I devised my own physiotherapy routine with the help of a gym instructor – 10 years later – I’m still getting better, but I’ve lost everything except for the love of my family”

### **Assessment and Eligibility**

Two of these stroke survivors did not receive an assessment to see whether they were eligible for help from social services. It seems that as there was a carer at home, an assumption was made that this person (in this case the wife of both Paul and Gareth) would automatically take on the role of carer. Neither were offered a carers assessment.

Not one of the three was given a Care Plan

In May last year, The Stroke Association launched its report *Struggling to Recover* which demonstrated that stroke survivors are being denied the chance to make their best possible recovery because of lack of post hospital care and poor coordination between health and social care services. The report surveyed over 2,200 people affected by stroke and showed that:

Health and Social Care Committee  
Social Services and Well-being (Wales) Bill  
SSW 24 - Stroke Association

- 51% of stroke survivors had not received an assessment of their social care needs and 33% didn't know they were entitled to one
- Almost half (42%) of those receiving services said that health and social care services did not work well together – forcing families and carers to take on the responsibility for co-ordinating care
- One fifth (18%) reported services being withdrawn even though their needs had stayed the same
- 51% were unaware that their carer was entitled to an assessment to help them in their caring role

The Stroke Association feels this is an unacceptable bleak picture for life after stroke services and hopes the reforms that the Social Services Bill will bring into effect will go some way to ensure that these trends are reversed. In particular we want to see appropriate assessments and provision of services at the right time to ensure that best possible outcome for stroke survivors.

Whilst we realise we cannot offer comment on how the legislation should be framed, we hope our insights demonstrate the impact this vital legislation will have on people's lives. We are incredibly concerned about assessments, eligibility and care planning and would want the committee to consider robust direction in relation to these issues.

For further information, please do not hesitate to contact me on 029 20524400 or email [Lowri.griffiths@stroke.org.uk](mailto:Lowri.griffiths@stroke.org.uk)

Yours sincerely

Lowri Griffiths  
Head of Communications and External Affairs, Wales