

## Health Committee Consultation on Social Services and Well-being (Wales) Bill (Stage 1)

Joint response by Sense Cymru, RNIB Cymru, Action on Hearing Loss Cymru, Vision in Wales and Guide Dogs Cymru

### About the responders



**Sense** is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. We also support people who have a single sensory impairment with additional needs.



**RNIB Cymru** works on behalf of over 100,000 people in Wales with sight loss. We campaign to create a society more inclusive of people with sight loss and we promote eye health by running public health awareness campaigns. We also work in partnership with organisations across Wales to provide local services, providing practical solutions to everyday challenges.



**Action on Hearing Loss Cymru** is the new name for RNID Cymru. We are the charity working for a Wales where hearing loss

does not limit or label people, where tinnitus is silenced – and where people value and look after their hearing. We use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf.



**Guide Dogs Cymru** is part of the larger Guide Dogs charity which operates throughout the UK. Our purpose is to deliver a world class service as part of a range of mobility services and work to break down barriers to ensure blind and partially sighted people can get out and about on their own terms. Website: <http://www.guidedogs.org.uk/guide-dogs-cymru>



**Vision in Wales** (formerly Wales Council for the Blind) is the umbrella agency representing visual impairment within Wales. We work to campaign, lobby and support the improvement of services for people with sight loss. Vision in Wales seeks to expand its current remit to provide a platform for the voices of vision impaired people to be heard.

## **Response to Stage 1 consultation**

We welcome the opportunity to respond to the general principles of the Bill. While we deal with general principles we think it is helpful to illustrate our points with specific examples from the Bill but recognise that the committee will examine the detail of the Bill at Stage 2.

Throughout the response we use the term 'single sensory loss' to refer to people who are blind or partially sighted (i.e. with sight or visual impairment) and people who are deaf or hard of hearing (i.e. with hearing impairment). 'Dual sensory loss' refers to people who are deafblind, i.e. people who have combined sight and hearing difficulties that affect their day to day lives.

### **1. Is there a need for a Bill to provide for a single Act for Wales that brings together local authorities' and partners' duties and functions in relation to improving the well-being of people who need care and support and carers who need support?**

- 1.1 We support the principle of bringing together the various duties and functions of social services into a single Act. In practice, however, the challenge is to ensure that at the very least people do not experience worse services as a result of the changes and that there are no technical legal issues arising from the changes.
- 1.2 The Bill does not appear to state what will happen to existing duties in legislation. For example, the Chronically Sick and Disabled Persons Act 1970 placed assessment duties on local authorities following from the National Assistance Act 1948. There is no statement on revocations of these duties in the Bill or the Explanatory Memorandum. We would urge the National Assembly and Welsh Government to ensure relevant revocations are made or included in UK Parliament legislation.
- 1.3 We welcome the use in the Bill of 'care and support', which more fully reflects the range of support services that can be delivered. People with single or dual sensory loss often need

ongoing or one-off interventions of social care and support to help with a range of needs, including mobility, communication or access to information rather than personal care services.

## **2. Do you think the Bill, as drafted, delivers the stated objectives as set out in Chapter 3 of the Explanatory Memorandum?**

There are areas where we think the Bill falls short of the Welsh Government's objectives:

### **Voice and control**

- 2.1 We would recommend that the Bill needs to be changed to properly realise the aim of giving greater voice and control to people who use care and support services. For example, accessible information, advice and assistance are vital to making people fully aware of the control they have and options available to them.
- 2.2 For people with single or dual sensory loss we think the requirement should be for the provision of accessible information. This is notionally covered by Section 8(2), the requirement to "...seek to ensure that the service is sufficient to enable a person to make plans..." However, the requirement should be made explicit to reinforce existing provisions on reasonable adjustments in the Equality Act 2010.
- 2.3 Care and support plan provisions in Sections 38 and 39 set out the scope of future regulation in this area. The plans still appear to be presented as a process performed on a person rather than with them. There should be a requirement on the face of the Bill to set out in regulation the provisions to consult and involve the individual in their own care and support plan. Furthermore we believe a statement of principles to promote voice and control at the beginning of the Bill could guide future regulations and interpretation of the Bill. This is fundamental to the success of the planning

process and in keeping with the spirit of the Bill, to promote the individual's voice and control.

- 2.4 Sections 34-37 (direct payments) need to be amended to fully realise the Welsh Government's aim of voice and control for service users through direct payments. Research by Sense (2008) suggested that almost a third of deafblind people surveyed (31%) in England and Wales did not even know what direct payments were. The research also found there was geographic variation in the hourly rates offered to people with similar circumstances.<sup>1</sup> We think the direct payments sections must require minimum standards to promote awareness of the options that people have and ensure that local authorities offer a full breakdown and indication of the rationale behind the amount offered as a direct payment.
- 2.5 We believe proposals throughout the Bill to make regulations should include clauses to specify with whom Welsh Ministers may or must consult in the preparation of draft regulations.

### **Preventative services**

- 2.6 We welcome that prevention work will be recognised in law. However, without a proposed eligibility framework it is difficult to judge how effective the preventative measures will be in reducing care and support needs. At present we are concerned that in the Bill prevention services are not subject to a clear local authority duty and might not be interpreted as services specifically delivered to reduce individuals' needs for care and support. We are also concerned that the preventative services section lacks a requirement for local authorities to justify decisions to deliver or not deliver preventative services as they are currently supposed to do through the Fair Access to Care Services (FACS) system.
- 2.7 We would recommend that the future eligibility level should be set at moderate or at the equivalent of moderate in the current FACS system to ensure effective prevention work takes place. CSSIW research in 2010 found that local

---

<sup>1</sup> Sense, Deafblind people and families' experiences of direct payments, 2008

authorities that raised their eligibility threshold did not necessarily save money because of the preventative work missed as a result.<sup>2</sup>

- 2.8 Reablement aims to help people accommodate their condition by learning or re-learning the skills necessary for daily living through one-off or time limited interventions. It is based on the principle that a person should be encouraged and assisted to look after themselves. Reablement in particular is important to people who acquire single or dual sensory loss. For example, a deafblind person who has recently acquired sight loss in addition to existing hearing difficulties may find cooking more of a challenge and is therefore at risk of not maintaining a healthy diet safely and independently. One way to meet the person's needs would be to provide a communicator-guide support worker to help them cook food safely by supporting them to work safely in the kitchen, read food labels etc. However, while the communicator-guide service would meet a clear care and support need it would not reable the person to cook for themselves. At this point the reablement duty that we suggest would ensure the local authority makes upfront investment to provide the person with training tailored for people with dual sensory loss and aids/equipment that could help a person cook (e.g. tactile markers on cooker controls). This means that a potential ongoing care and support need has been reduced by a time-limited reablement intervention.
- 2.9 We believe that there should be a duty on the face of the Bill to provide preventative services to people with single or dual sensory loss. At present the Bill does not clearly how a preventative service for people with single or dual sensory would be triggered. In the traditional view of reablement for older people this might be triggered by a hospital visit, e.g. after a fall. The preventative services definition in the Bill (reducing care and support needs) suggests that the care and support needs are known to the local authority, which implies that people have had an assessment of their needs. We would suggest that assessment is the ideal time to consider prevention and reablement. Sensory loss registers

---

<sup>2</sup> CSSIW, National Review of Access and Eligibility in Adults' Social Care, September 2010, p. 5

provide a referral mechanism into assessment after single or dual sensory loss is identified.

- 2.10 We are concerned that if assessment is limited to outcomes someone wishes to achieve in day-to-day life this may restrict reablement. By definition reablement for people with single or dual sensory loss involves the uncomfortable process of learning or relearning tasks or doing tasks they may have thought impossible. For example, a blind or deafblind person who recently lost their sight might not say that they want to work during their needs assessment because they are unaware of the support, aids/equipment, training etc available. Without this information they may continue to believe they would never be able to work again. The person should have this information, so they can decide whether or not they would like to work.
- 2.11 In the current FACS eligibility system the risk is that work below the eligibility threshold that has a preventative effect is not carried out and people's needs are addressed only when they exceed the eligibility threshold. We would not want to see this reproduced in the new system, so would recommend Welsh Government guidance should further define the concept of 'disproportionate expenditure'. Upfront expenditure in early preventative services should not be deemed 'disproportionate' when the result is local authority delays until needs become more acute.
- 2.12 There is a need for support and the processes needed to access support to be timely. Needs that are unaddressed are likely to remain or become more acute. For example, a blind person consulted by RNIB Cymru and Cardiff Institute for the Blind (CIB) about the Bill said she had lost her partner and had to wait six months for a needs assessment. She said that if CIB had not been available to help she would have struggled to carry out every day tasks like food preparation and dealing with bills. A deafblind person surveyed by Sense said that one of their main concerns about the current system was "The fight and length of process, as well as the support needed to get [an assessment]...we had to engage a solicitor."<sup>3</sup>

---

<sup>3</sup> Sense Cymru, Fair Care for the Future, November 2012, <http://www.sense.org.uk/content/fair-care-future>

2.13 RNIB Cymru's Eye Clinic Liaison Officer (ECLO) service is based in ophthalmology departments in hospitals in Wales and provides information on the impact of a condition, help registering as blind or visually impaired, advice on reducing falls, emotional support and referrals. A City University study (2011) found 90% of clinical staff who work with an ECLO agreed that they significantly improve the patient experience. This kind of service, which is free at the point of use, has a preventative role.

### **Child wellbeing and eligibility**

2.14 We are pleased that Section 2 recognises the principle that there are aspects of wellbeing that are unique to adults and children. We would expect that the future eligibility framework will also take account of this by setting out separate eligibility tests for adults and children and for disabled children to continue to be 'people in need'. We think that restricting "physical, intellectual, emotional, social and behavioural development" to the wellbeing of people under 18 represents an artificial distinction that does not match the reality of children and young people with single and multi-sensory loss (and may also apply to other groups, such as people with learning disabilities).

2.15 The nature of single or multi-sensory loss means that children and young people often acquire knowledge and skills at a slower rate than hearing and sighted peers. Partly this is because of the reality of sensory loss - they do not have full use of hearing, sight or both senses. Sometimes their single or dual sensory loss is not identified early or misidentified, which leads to delays in support that could help development or inappropriate support given. The result is that some young people with single or multi-sensory impairment may still be developing intellectually, emotionally, socially and behaviourally beyond the age of 18 and after they have left the statutory education system. We would suggest that the development aspect should apply to people of all ages (or at the very least it should be extended to age 25, which appears to be the Welsh Education Department's definition of a young person).



**3. The Bill aims to enable local authorities, together with partners, to meet the challenges that face social services and to begin the process of change through a shared responsibility to promote the well-being of people. Do you feel that the Bill will enable the delivery of social services that are sustainable?**

3.1 Some social services interventions interact with NHS budgets. For example, care and support services for someone with recent visual impairment (e.g. mobility training) could result in fewer and less severe falls, which would save NHS treatment funds. Delivering preventative services to people should be done in collaboration between the NHS and social services.

**4. How will the Bill change existing social services provision and what impact will such changes have, if any?**

#### **Role of suitably qualified people and assessments**

4.1 We would want to ensure that duties that currently provide for minimum standards in the system are continued. For deafblind people the current statutory duty is to provide an assessment by a 'suitably qualified' professional. While this will be dealt with in regulations we would recommend that the Law Commission recommendation that deafblind people show always have a specialist assessment is followed to ensure that expertise is brought to bear in the assessment process.<sup>4</sup> Therefore, without this regulation the legal reform will have resulted in a worse service.

4.2 Likewise, there is a need to engage specialist knowledge at different points in the process for people with single or dual sensory loss. We would like assessment regulations to ensure that people with single or dual sensory loss are assessed by a person with appropriate knowledge and experience of sensory loss. People should not be 'pre-assessed', e.g. generic staff at a telephone contact centre should not be relied on to decide what a person's needs

---

<sup>4</sup> Law Commission, Adult Social Care, 2011, para. 5.86

may be. A blind person consulted by RNIB Cymru and Cardiff Institute for the Blind about the Bill said: “Many local authorities use a central contact centre these days. I phoned about a talking book machine and they had no idea what it was. One person cannot possibly know everything.”

- 4.3 In the current system we are aware that local authorities in England and Wales have not always maintained a clear separation between assessment to gauge a person’s needs and decisions about the eligibility of the needs. We welcome that the Bill will require decisions about whether to undertake an assessment are taken regardless of the level of likely needs and a person’s financial circumstances. We think the assessment should also consider needs that are currently being met as well as those that are unmet. We believe that assessment should be the starting point for someone with apparent needs even if the result is that they do not receive care and support services.

### **Charging and finance**

- 4.4 Regulations on charging and financial tests are forthcoming and we understand the rationale behind not putting these on the face of the Bill. However, provisions in the Bill to allow for charges may have an unwelcome effect on social services provision.
- 4.5 Section 54 allows for provisions to regulate the charging for information, advice and assistance services. We do not welcome the principle of charging for information and advice and continue to believe this should be considered a universal service. Charging for assistance would be problematic because Section 8(1)(b) suggests that assistance means “assistance in accessing care and support”. There will be cases where someone needs assistance during the assessment, eligibility and care planning processes to help them access care and support services. If their receiving assistance will determine whether or not they end up with a service this would cause problems and may lead to people not receiving care and support services because of the cost involved in accessing them.

- 4.6 We would like regulations on information and advice to re-affirm the Equality Act 2010 principles that people with dual or single sensory loss who require accessible formats or languages (such as British Sign Language) should have equitable access to these.
- 4.7 There are also standards we would like to see maintained in the area of charging. For example, the income threshold for charging should remain at two times income support plus 50%.

## **5. What are the potential barriers to implementing the provisions of the Bill (if any) and does the Bill take account of them?**

### **Registers of sensory loss**

- 5.1 Section 9 deals with registers of sensory loss. We welcome that the inclusion of this section means the Welsh Government is committed to registers as a tool for referral and has accepted the Law Commission's recommendation to continue sight impairment and deafblindness registers.
- 5.2 At present registers of sight impairment, hearing loss and deafblindness need to be renewed because not everyone who is eligible to register had done so. We recognise that some people simply would not want to be 'on a list' and this should be respected. However, research by RNIB in England found that there were other reasons why people were not registering as sight impaired, including inconsistent or poor practice by healthcare professionals and lack of awareness of the reasons for registering among those advising people who were eligible.<sup>5</sup> It would be reasonable to assume these might also be factors in Wales.
- 5.3 To link registers to local authority practice we would recommend that Bill includes a further duty to proactively

---

<sup>5</sup> RNIB, Certification and Registration processes: Stages, barriers and delays, 2012

identify people who may join the registers and to keep in periodic contact with people on the registers.

- 5.4 We would be anxious to ensure the role of registers should be clearly defined as primarily a referral tool for individuals between health and social services rather than an overall indicator of the number of people with single or dual sensory loss (because of the factors mentioned in 5.2). We would like to see the benefits and rationale behind registration to be promoted to healthcare professionals, social care and support workers and people eligible to register.
- 5.5 We would like to eliminate use of outdated terms, such as 'blind' to refer to all people with any level of sight impairment or 'deaf' to refer to all people with any level of hearing loss.
- 5.6 9(1)(a) uses the term 'blind', which we believe should be 'sight impaired or severely sight impaired' instead, to match the categories in the Certificate of Visual Impairment (CVI). The CVI is necessary to register and the use of identical wording would link to the existing sight impairment register.
- 5.7 Likewise the register for 'deaf' people should also include people with hearing loss (i.e those who are hard of hearing) and not just people who are deaf.
- 5.8 Deafblind registers include people with combined sight and hearing difficulties that may give rise to care and support needs. We are concerned that current wording in 9(1)(c) 'both blind and deaf' might be interpreted as medically registerable as blind and deaf, which would not count people who have relatively 'milder' dual sensory loss that still affects their wellbeing and gives rise to care and support needs. We would suggest this is made clearer on the face of the Bill and also in regulation.

**6. In your view does the Bill contain a reasonable balance between the powers on the face of the Bill and the powers conferred by Regulations? Please explain your answer.**

- 6.1 Major provisions that will determine the success of the Bill have been left to regulation. We understand why this is

necessary but would like to see an indication of the timetable and intent the Welsh Government is pursuing.

- 6.2 We are pleased that there will be a single duty to assess where needs appear to be present and that there is a duty to meet eligible needs. However, with no knowledge of the eligibility framework we are unable to say how the Bill will affect social services delivery. We would like to see a formal timetable and statement of intent from the Welsh Government on the eligibility and charging frameworks.

**7. What are your views on powers in the Bill for Welsh Ministers to make subordinate legislation (i.e. statutory instruments, including regulations, orders and directions)?**

- 7.1 We have tried to indicate throughout our response the areas we think should be elevated to the Bill.

**8. What are your views on the financial implications of the Bill? In answering this question you may wish to consider Chapter 8 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the Bill.**

- 8.1 While we are satisfied there is a compelling case for reform of the care and support system we are concerned about the financial implications. We are not reassured that the Regulatory Impact Assessment has calculated the full implications of the Welsh Government's proposals. We note that in the Explanatory Memorandum the Welsh Government said cost and benefits of the reforms "will be realised over time".<sup>6</sup>
- 8.2 We are particularly concerned that the Social Services Minister responded recently to an Assembly question that "Statistics are not collected centrally on the numbers of people who had their needs assessed through FACS, nor on the number of services they received."<sup>7</sup> We would have expected that the Welsh Government collects these

---

<sup>6</sup> Social Services & Well-being Bill, Explanatory Memorandum, para. 132

<sup>7</sup> WAQ61984, 24 Jan 2013

statistics, which are necessary for deciding whether to continue FACS or to introduce a new system. It is essential that the Bill commands broad support across Wales and that the calculations behind it are realistic, so we would urge the Welsh Government to collect these statistics.

## **Contact**

Nick Morris - Sense Cymru and RNIB Cymru

Email: [nick.morris@sense.org.uk](mailto:nick.morris@sense.org.uk)

Telephone: 0845 127 0090

Address: Sense Cymru, Tŷ Penderyn, 26 High Street, Merthyr Tydfil, CF47 8DP