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## The Newsletter of The All Wales Forum of Parents and Carers of People with Learning Disabilities Winter 2012

### *Lobbying on changes to benefits: Introducing the Fair Society Campaign.*



Over the past twelve months the AWF has been working in partnership with other disability based

organisations across Wales and the UK to highlight the issues and concerns being raised by carers and people with learning disability over the proposed changes to Welfare and Benefits. We've lobbied the Westminster Government on behalf of families across Wales, putting in responses to key consultations on the Disability Living Allowance and the changes being made to the assessment processes.

Currently the UK Government is still pushing ahead with its agenda for change, despite clear and public concerns being expressed by individuals, families and disability groups. As a result of these shared concerns, a number of organisations have come together to start a campaign seeking fair changes to the system and calling for recognition of the needs and rights of the most vulnerable in society. This is called the Fair Society Campaign. In this addition, we include details of the campaign, its principles and aims, and we encourage carers, individuals and relevant organisations across Wales to get behind it.

### **Positive principles of the Campaign**

The Campaign wants power and control to shift from government to citizens, families and communities. But we don't want the government's 'Big Society' if that means a loss of basic human rights and unfair cuts focused on the most vulnerable. We want a fair society. We want to see the current broken system change. But change needs to be underpinned by fairness and a vision for the kind of society we want to live in.

#### **Seven principles for a fair society**

Everyone is equal, no matter their differences or disabilities. A fair society sees each of its members as a full citizen – a unique person with a life of their own. A fair society is organised to support everyone to live a full life, with meaning and respect.

#### **The seven principles below will help us create a fair society:**

**Family** – we give families the support they need to look after each other.

**Citizenship** – we are all of equal value and all have unique and positive contributions to make.

**Community** – we root support and services in local communities.

**Connection** – we all get chances to make friends and build relationships.

**Capacity** – we help each other to be the best that we can be.

**Equality** – we all share the same basic rights and entitlements.

**Control** – we have the help we need to be in control of our own life and support.

These principles can give direction to anyone making decisions about policy and funding. Using them to guide decisions will encourage greater independence and well-being for all vulnerable children, their families and to adults.

Individuals and families can measure the support and services they receive against them. They can also work with the Campaign to design a system based on these principles. The principles are inspired by the vision of equal citizenship in the UN Convention on the Rights of Persons with Disabilities, which the UK has ratified.

## Why we need change

You may think that these ideas are already widely accepted but they are not.

**Family** – The unpaid, natural support given by families is worth billions of pounds but the current system makes it hard for families to provide this support.

**Citizenship** – Too often, vulnerable people – especially people with learning disabilities – are marginalised and treated in ways most people would not accept for themselves.

**Community** – Too many services take people away from ordinary relationships in their community.

**Connection** – For anyone, a life without relationships is a miserable life that requires more and more support.

**Capacity** – Services are often organised in ways that makes people less capable and more dependent.

**Equality** – Disabled people face extra taxes, extra poverty traps and have limited entitlements to support.

**Control** – Decisions about how people lead their life and get support are often taken by professionals who don't know what people want.

## The Joint Statement from the Campaign:

Last month members of the Fair Society Campaign published a Joint Statement calling for a pause to the current review and changes being made to the Disability Living Allowance. It called upon peers to support the review of the current changes;

### Joint Statement — published by campaign members on 16 January 2012

We are calling on the Government to pause the Welfare Reform bill and carefully consider its reform of Disability Living Allowance (DLA). The Welfare Reform Bill which will implement these proposed reforms is now in the final stages of its Parliamentary passage but the details of how the reform would affect disabled people has not been fully investigated.

Last week a Responsible Reform report (known as the Spartacus report) revealed strong opposition from disabled people, charities and other interested groups to the Coalition Government's proposed changes to DLA. The report showed worrying evidence that the Government's decision to reduce DLA expenditure by 20% may have been based on incomplete or misleading data about the reasons for growth in DLA. It has also been revealed today that the proposed changes will lead to 500,000 disabled people no longer being eligible for this benefit.

Independent surveys carried out by some of the signatories to this letter have shown that cuts to DLA will force more disabled people into poverty, which is likely to increase the burden on the NHS and social care system in the long run. Such a potentially risky change in policy should not be taken forward without a robust and accurate evidence base and the support of disabled people and the experts in this field.

Last year the Government took the bold decision to pause and reflect on its reorganisation of the NHS after similar levels of concern and anxiety from medical groups and patients.

Today Papworth Trust, Action on Hearing Loss, Brandon Trust, Campaign for a Fair Society, Disability Rights UK, Disability Wales, Ekklesia, Leonard Cheshire Disability, MS Society, the National Autistic Society, Rethink Mental Illness, RNIB, Sense, Three Cs, United Response and the Westminster Society are asking the Government to show similar foresight and pause the

Welfare Reform Bill to investigate the strong concerns raised above. We ask Peers to support amendments to pause the legislation that will affect so many people's lives.

## Where are we now?

Currently the UK Government is pushing ahead with its plans to reform benefits and change the Disability Living Allowance into the new Personal Independence Payments. The House of Lords has rejected a number of issues attached to the Welfare Reform Bill in the past couple of weeks, although all parties agree that change is needed, there is still healthy debate on the details of the changes and the impacts these will have on the more vulnerable members of society and their families.

Therefore, although momentum is still with the change agenda, there is still space to consider concerns from outside parties and the opportunity to support those at Government levels who are looking for a fairer change to the system.

### **What can we do to support the campaign?**

If you support the principles of the Fair Society Campaign and are interested in lending your voice and support you can sign the e-petition attached to the campaign website

Campaign member, Pat Onions, has organised an e-petition calling on the government to 'stop and review the cuts to benefits and services which are falling disproportionately on disabled people, their carers and families'.

***You can sign the petition at: <http://epetitions.direct.gov.uk/petitions/20968>***

You can also write to your local MP asking them to get behind the principles of the campaign and to consider the importance of the details attached to the new Welfare Reform Bill. Local stories and cases can provide our MPs with a better understanding of the issues and concerns, as well as enable them to argue clear cases on your behalf.

You can find out the contact details for your local MP at;

***[www.parliament.uk](http://www.parliament.uk)***

click on the MPs, Lords and offices pager —on that page, top right hand corner there is the 'find your MP' tool.

You can also display a campaign poster in your window if you support the principles, but please check with the Campaign founders before using their posters at events etc.

Posters can be downloaded from the campaign website at;

***[www.campaignforafairsociety.com](http://www.campaignforafairsociety.com)***

Click on the 'tools' section.

The AWF remains concerned about the current proposals and the details of assessment and changes attached to the new Bill. On behalf of parents and carers across Wales we will continue to lobby the UK Government to ensure that they hear your concerns.

**In the meantime, if you have any personal concerns about what the benefit changes may mean for you and your family, you can contact Mencap Cymru Learning Disability Helpline on 0808 808 11 11.**

### **Carers Summit –Social Care Reform and Welfare Reform:**

Carers Wales will be hosting its Annual Carers Summit, which is open to all carers across Wales, on Monday 5th March at the Liberty Stadium, Swansea.

During the morning we will hear about the Welsh Government's planned reforms for Social Services, as well as the new Mental Health Law and how it will change the way that people with mental health problems are treated and the implications of the new law for you as carers.

During the afternoon, we will hear about Welfare Reform and its likely impact.

We anticipate a large response from carers and places will be allocated on a first come, first served basis. To book a place, please contact Carers Wales on 029 20811370.

## Social Services Bill update.

You will already be aware of the proposed Social Services Bill being pushed through by the Welsh Labour Government. The Bill seeks to streamline Social Care in Wales, to make it more accountable and to enable changes to take place for Wales to provide Social Care that is fit for purpose, both now and in the future. The Bill seems to offer recognition of the role of families and carers and the importance of real engagement. As members of the Wales Carers Alliance, the AWF will continue to support the Deputy Minister in the further development of the Bill and will seek to ensure the views of parents and carers are heard in the re-shaping of Social Care in Wales.

The Deputy Minister recently made a statement setting out some of the key changes that the Social Services Bill will bring and how the Welsh Government feels it will make a difference to the delivery of Social Care in Wales. The AWF has published this below to update all of our members on its progress and we will continue to play a proactive role by engaging fully in all consultations attached to the new Bill.



Llywodraeth Cymru  
Welsh Government

**TITLE** Social Services Bill

**DATE** 24 January 2012

**BY** The Deputy Minister for Children and Social Services, Gwenda Thomas AM

We have agreed on a number of occasions, and most recently in the debate on the 15 November, that without a programme of transformation, social services will not be able to meet the needs of the people of Wales. They are not sustainable. The Social Services Bill will be central to that transformation by specifying the core legal framework for social services and social care.

Our thinking has been informed by the debates in this Chamber; with stakeholders since Sustainable Social Services for Wales was published; and by a range of evidence; including that of the Independent Commission on Social Services, the Law Commission and our Review of Safeguarding. I also received before Christmas responses to Sustainable Social Services from the WLGA and ADSS, as well as the Care Council and CSSIW.

I am clear that we must draw on the strengths of people being members of their families, networks and communities. I am also clear that people are precisely that: individuals with their own particular needs. We want this legislation to underpin a common way of thinking, one that reinforces rights and diversity of need.

We want a legal framework that supports the delivery of services in an integrated way, to people as people, not to children and adults separately. This Bill will wipe away inappropriate distinctions between people based on predetermined categories of need such as age. Of course we recognise that there are differing implications for children, who do not have the same autonomy as most adults and we have been clear; for example with our seven core aims for children; about the particular services they need. We place very great store on their rights. But children, like adults, are not a homogenous group.

We will therefore define social services in a way that starts with a commitment to people in need; an active, not a passive concept. We will expect local authorities and their statutory partners to **maintain** and **enhance** the **wellbeing** of people in need, and the Bill will provide the definition for that.

Social services cannot be sustainable without delivering more early intervention. We are not prepared to sit by as fewer and fewer people receive the support they need. We will require local government to understand the dimensions and shape of the population in need in their areas, to make this public, and to have powers to make arrangements to provide a range of services to meet those needs.

Of course some people will require an intensive and comprehensive range of services. We will make it clear that local authorities have a duty to provide, or make arrangements to provide, social care services,

and will bring forward a definition of these services that will draw on the existing definitions and the Law Commission's proposals.

Sustainability depends on people having a stronger voice and real control. The starting point is enabling individuals to fully understand how care and support may help them. We want to make access to assessments a right, and for those assessments to focus on the outcomes that people themselves are seeking. They must be involved. Assessments must be about needs, not in the first instance about services.

The Bill will give people the right to access information, advice, and assistance in finding out about services. We need a more coherent framework for services and so we will improve consistency of access through the creation of a portable assessment of need and give Ministers the powers to establish a national eligibility framework.

The Bill will extend the range of services for which people have the right to a direct payment where that is their wish, and extend the rights of carers to an assessment, by introducing a single duty which will allow us to extend the right for a carer's assessment more widely, when circumstances permit.

We will also strengthen the complaints procedure and extend the Public Services Ombudsman's powers to consider complaints.

Sustainable Social Services and Together for Health make it clear that a step change in integrating services, particularly for frail older people, is an urgent necessity. This Bill will therefore extend the duty on social services and the NHS to collaborate in the delivery of integrated services, including the expectation of the use of pooled budgets and other flexibilities.

We have made it clear that social services need stronger national direction. The Bill will set out powers to establish a national outcomes framework and set standards for social services.

But we also want to be clear about local accountability. The Bill will therefore establish a duty requiring local authorities to appoint a competent Director of Social Services to lead and manage family focussed social services. This will include powers to share Directors of Social Services.

I have already announced that we will provide a statutory basis for adult protection, stronger national direction and establish clearer links between child and adult protection, through the new legal framework.

There will be strategic changes to the regulatory system for social care, including clarifying the responsibilities of employers, and the regulators role in checking financial viability of providers. We need to strengthen and build the confidence of our key professionals by regulating their training and conduct.

Finally, the Bill will also simplify arrangements in relation to adoption by placing a duty on the 22 Local Authorities to require them to come together to establish a single adoption agency.

The foundation for these changes has been made through the protection of Social Services budgets. Sustainable Social Services makes it clear that the changes proposed require stopping doing some things and working in new ways. The approach will reduce regulation and bureaucracy so that organisations can focus on delivery and re-prioritise to deliver efficiency as well as service change. I am sure that Members here today, and the public, will want to see and debate the details of the Bill; and there will be an opportunity to do so when we launch a full public consultation in March, with a view to introducing it into the National Assembly in October 2012. This is, however, only the first stage of our journey. Regulations and a Code of Practice for Social Services will be developed once the Bill has received Royal Assent.

This Bill provides us with the legislative basis that meets the changing needs of the people of Wales. I have valued the degree of cross party agreement about the job we have to do. I look forward to engaging with you on our proposals so that we can ensure we have all the tools we need to seize the opportunities ahead.

## **‘Winterbourne Not in Wales’ Campaign Update - an update from the LDI-AG.**



On 22 August 2011, a delegation met with Gwenda Thomas, Deputy Minister for Children and Social Services, to discuss the issues raised by the BBC’s Panorama investigation into the appalling treatment of people with learning disabilities living in Winterbourne View, a private care home in Bristol. Following the meeting, the Deputy Minister wrote a letter to the group responding to the actions proposed by the delegation to prevent people in Wales being placed in settings like Winterbourne View.

The campaign group ‘Winterbourne Not in Wales’ discussed the Deputy Minister’s letter and how they plan to respond. It was felt that accurate data is needed not only on how many adults with a learning disability and/or autistic spectrum disorder are placed ‘out of area’ but also the cost of these placements. There was some discussion about the added complication of adults placed out of area into residential settings during childhood and never returned. These ‘lost’ individuals often do not appear on any data lists and nobody seems to know how many people from Wales are in this situation. Members of the group expressed their concerns about the monitoring and inspection arrangements of services for people with learning disabilities.

Many felt that the current processes do not accurately monitor working methods or outcomes. Everyone agreed that people with learning disabilities and their families should be involved in the inspection process. The Public Appointments system for recruiting lay reviewers is too complicated and not accessible for people with learning disabilities and their families and there should therefore be an alternative method to enable this important group of people to be involved in the process. Healthcare Inspectorate Wales (HIW) has invited members of the campaign group to take part in a ‘Stop and Review’ meeting in the near future to look at the inspection process and it was agreed that representatives from All Wales People First and All Wales Forum of Parents and Carers should attend with the possible addition of a representative from one of the service providers. Jim Crowe, Learning Disability Wales, will be incorporating the group’s comments into his reply to the Deputy Minister’s letter of October 2011.

***Sam Williams - LDIAG Information Officer.***

### **All Wales Forum update:**

Pauline Young, Chair of the AWF and parent carer member of the campaign group says;

*“As an active member of the campaign group, the All Wales Forum will continue to work with our partner organisations and the Welsh Government to lobby to change the monitoring and inspection systems to fully include those groups that use services in a more accessible and comprehensive manner. We will also lobby for all supported living services in Wales, including private companies to adhere to the social model of disability, offering real choice and wellbeing for all residents as set out under Welsh Government Policies.”*

This is obviously an important ongoing campaign to ensure the safety, wellbeing and happiness of those that we love as families. As a result the All Wales Forum will keep all of our members and partners up to date on the progress of the campaign, as well as making you aware of your opportunity to feed into its work and take part in any local and national lobbying activities.

**In the meantime, if you have any personal experiences of poor support services, out of county placement issues etc, please let us know via the contact details at the end of this newsletter. These personal accounts are essential in helping to shape the way forward for the campaign.**

## Mencap Cymru announce a follow up session to last year's successful joint conference:

### Lets talk about sex!



An information and advice session about sex, sexuality and relationships for **parent carers** of young people with a learning disability aged 16-25 living in West Wales

Monday 27<sup>th</sup> February 2012  
9.30-12.30

With guest speaker Fiona Speirs

Gorseinon centre, Millers Drive, Gorseinon  
Swansea, SA4 4QN

**Free for parent carers**

Contact the Wales Learning Disability helpline  
**0808 808 1111**

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**CARERS** UK  
the voice of carers

### ***Free membership to Carers UK***

It's not too late to take advantage of our free membership offer. We're passionate about making life better for carers and with the help of our members, have fought for and won benefits and other legal rights for carers.

We need you to join us to strengthen our voice. It's a great way of showing your support for this important cause and in return you'll be kept up to date on everything relating to caring.

You will receive:

- 24/7 access to our online forum; a vibrant carers' community where carers can chat, share problems, and offer solutions and support.
- The opportunity to shape the direction of our organisation with voting rights at our AGM.
- An invitation to our annual National Carers Summit.

[Join today by visiting the Carers UK website on www.carersuk.org](http://www.carersuk.org)

## Upcoming events:

### ***Carers and their Rights A Training Seminar with Prof Luke Clements – author of Carers and Their Rights***

Hosted by Powys Carers Service with support from Powys Social Services and Powys teaching Health Board

Thursday 10th May  
9.30am – 4pm  
The Pavilion, Llandrindod Wells

Lunch & Refreshments provided  
We have a limited number of free places

For more information and booking form visit [www.powyscarers.org.uk](http://www.powyscarers.org.uk) or call 01597 823800

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### ***Free spaces available on a Mencap Cymru wills and trusts event "planning for the future"***

18th April 12.30-2.30 at the Brangwyn Hall ( Lord Mayors Reception Room) , Swansea.

Parents and carers can book by calling the helpline free on 0808 808 1111

### **~~Mencap Cymru: Looking After Me Course. Helping parents/carers take time to look at their own needs.~~**

This spring they are offering a course held in partnership with EPP Cymru (Education Programme for Patients) that encourages parents and carers of people with a learning disability to come and find out more about looking after their own needs.

The specialist learning disability focused course will run from Monday 13<sup>th</sup> of February to Monday the 26<sup>th</sup> March 2012. 10 am to 12.30pm. Cardiff.

Contact Sue Edwards on 07881 908911

~~We're always interested in hearing from Carers and their supporting organisations and groups.~~

Local issues and news stories are always welcome, as is feedback and responses to any consultations or articles that we publish. If you would like to send in an article/event info etc to be included in Abl please email us at [kate.allwalesforum@comeuro.co.uk](mailto:kate.allwalesforum@comeuro.co.uk).

The AWF is a small organisation covering a large geographical area and any contributions to the costs of producing our newsletter are always welcome - the more carers we can reach, the more families can have an active and informed voice.

If you would like to make a donation to the organisation, please contact Anne-Marie Carpenter on [anne-marie.allwalesforum@comeuro.co.uk](mailto:anne-marie.allwalesforum@comeuro.co.uk) or you can call the office on 029 20811120 or post it to All Wales Forum, Elliott Buildings, 21 Cardiff Road. Taffs Well. Cardiff. CF15 7RB.

**Finally, we would like to thank Jill Thomas for her very kind personal contribution to the All Wales Forum Charity and its work.**