



Health and Social Care Committee
Social Services and Well-being (Wales) Bill
SSW 43 – Grwp Mynediad Arfon Access Group



Chair ~ Vin West ~ Cadeirydd

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Friday, 15 March 2013

Health & Social Care Committee

National Assembly for Wales Cardiff Bay Cardiff CF99 1NA

Attn: Sarah Beasley, Clerk to Health & Social Care Committee, Legislation

Hi Sarah,

Please find a brief note that I would be very grateful if the Committee could consider when scrutinising the Social Services & Wellbeing Bill.

I am a full time Carer for my 29 year old daughter, Chair of my local Access Group in Arfon in Gwynedd, Secretary of the Gwynedd Direct Payments Forum, a Council Member of the Wales Alliance for Citizen Directed support, and a member of the North Wales Citizens' Panel on Social Services whom I represent on the Partnership Forum.

Disabled people and Carers were very hopeful about the potential for transformational change promised by the Deputy Minister in the Sustainable Social Services policy document, along with some very excellent co-productive work on the Independent Living Framework and the I Matter We Matter work on the Outcomes Framework and the earlier consultation document on the Social Services Bill.

From discussions today with Welsh Government officials in the All Wales Citizens' Panel meeting it would seem that there are some misunderstandings regarding terms that we had thought were widely understood and unanimously agreed:

- Many of us were dismayed to see the term 'choice' lost from the phrase 'choice and control' to be replaced by 'voice and control'. This it seems is as a result of rejection of the direction of travel of developments in Social Services in other countries towards a commercialised approach. While voice is important we feel that choice is critical and it is important to bring it back into the Bill, albeit accompanied by a clear definition strapping it firmly to the Sustainable Social Services agenda.
- Similarly, there seems to have been concern expressed that the term 'independent' in 'independent living' refers to managing without support. This is

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very worrying indeed since we thought that the Framework for Action on Independent Living had pinned down disabled people's preferred definition of independent living as:

- *"Independent Living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves."*
The document goes on to state that "the term 'independent living' is used in two ways: - to express the aspirations of disabled people as set out above; and - to describe an approach to public service provision that supports and empowers this aspiration." We hope that your committee can urge the Deputy Minister to use this agreed approach in this Bill, not least to ensure consistency between it and the Independent Living Framework

- The third area where confusion seems to have seeped in is the concept of Citizen Directed Support. Again we thought that consensus had been broadly achieved here and we were surprised and disappointed that after a great deal of work on the consultation paper on CDS by members of WACDS and an apparently firm commitment to CDS in the Welsh Local Government Implementation Plan, the paper had somehow slipped beneath the surface and the language in the Bill has shifted back a decade or two and now talks about 'citizen-centred' instead of citizen directed. From discussions it would appear that a concern was expressed that not every disabled person wanted to control the provision of their services, but this is not news and no-one ever anticipated forcing everyone into a managerial position.
- We have been constantly available to discuss any and all of these concerns as they arose and it is frustrating that decisions have been taken that radically change positions that we thought had been agreed without consultation. This is particularly frustrating given the groundbreaking establishment of the Citizens' Panels which, while a little late in the process, we nevertheless all welcome . So again we would be most grateful if the Committee could encourage the recovery of the consultation on CDS and bring the appropriate progressive language back into the Bill
- The next area of concern that we feel goes to the heart of Welsh Government's approach to and respect for disabled people is the definition of 'disability' - this is crucial because it sets up a whole sequence of positive connections and attitude shifts if the language is right but reinforces decades of institutionalised disablism if not.
 - In adopting the Social Model of Disability in 2002 the Welsh [Assembly] Government committed itself to distinguishing between 'disability' and 'impairment', where 'disability' exists exclusively in the barriers with which society excludes and marginalises people with 'impairments'. One cannot therefore 'have a disability'.
 - I am sure that Miranda French, Paul Swann and I would be happy to sit down with the Welsh Government legal people to arrive at wording that is legally acceptable while fully supporting and promoting the Social Model so that government are meeting their Public Sector Equality Duties. It would seem

that since the Social Services & Wellbeing (SSW) Bill is primary legislation it is the perfect opportunity to correct the drafting error in the Equality Act 2010 that used a regressive 1995 definition of disability rather than the 2005 definition based on substantial and long term impairment coupled with societal barriers, which disabled people had been promoting since the early 1970s.

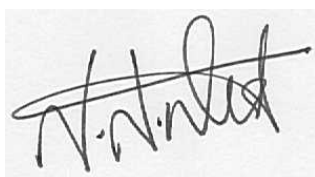
- Getting the language and terminology right is the beginning of applying the Social Model across the piece so that removal of barriers to inclusion is the goal rather than the (unintentionally) patronising and paternalistic 'care' approach to the aspirations of disabled people. As was unanimously agreed in the Partnership Forum meeting, Carers provide care for family or friends whereas disabled people require not care but 'support' from local authorities.
 - This then leads to reviewing the use of the term 'care' in relation to services that local authorities may offer. Again, this is not a matter of semantics but of being clear about what service or support can be offered and who can provide it.
 - The logic here is that once the title 'Carer' is defined as someone providing support without expectation of financial reward then the only people who can provide 'care' are 'Carers' because everyone else (Support Workers, Personal Assistants, Local Authority Support Staff, Commercial Support Agencies etc.) provide support in return for payment, either from the individual, their employing agency or through the Revenue Support Grant.
- The next key definition then is Independent Living, and Disability Wales has of course provided this as the basis for the Framework for Action on Independent Living, so compatibility between these two strands will obviously avoid confusion and strengthen the Bill and the Act.
 - In order to achieve Independent Living the mechanisms of support need to meet individual requirements, whether through Direct Services, Agency Staff, co-productive arrangements or directly employed Personal Assistants under a Direct Payments scheme. Citizens therefore need a clear summary of their options, so plain language definitions will be needed for all possible options or combinations and the personnel involved.
 - There is a huge difference between a citizen choosing between services and that same citizen directing their own services, so again we need I believe to return to the consultation on Citizen Directed Support so that both individuals and local authorities are clear about the degree to which individuals can and should have autonomy over their support and are encouraged to design their own support plan and package. One of the North Wales Panel members reported that her daughter was supported to write her own Care Plan and having done so discovered that she was the first person in Wales to have done so.
- Lastly, that same citizen may need advocacy in constructing both support plan and support package and there is an urgent need for clarity about what

constitutes independent advocacy. There is a very strong argument in favour of Centres for Independent Living (CILs) as the natural home for independent and peer advocacy, which of course is why the Deputy Minister chose to launch the consultation on the SSW in Dewis CIL.

- There were detailed discussions about independent advocacy in the consultation events on the earlier version of the Bill so it is extremely discouraging to have lost the notion of advocacy from the current text to be replaced by references to information and advice, both of which are important but neither of which can replace independent advocacy by someone who is not controlled by the local authority and who is a peer so understands many of the relevant issues.

Thank you for your attention,

Vin

A handwritten signature in black ink, appearing to read 'Vin West', written over a light grey rectangular background.

Vin West