

SCIL Submission: Hampshire Personalisation Commission

Evidence for Session 2: Partners and Funding: 12th June 2008
Or Session 4: The Local Authority: 19th Sept 2008

Personalisation and the partnership role of User-Led Organisations

In 2005, the Prime Minister's Strategy unit published its strategy document "Improving the Life Chances of Disabled People". This document marked a 'step change' in the Government's understanding and commitment to the empowerment of Disabled People and fundamentally a change in assumption about Disabled People:

From that of passive, dependent people, to independent and equal citizens, worthy of investment, worthy of life.

Whilst there have been many policy papers and legislation before and since, the "Life Chances Strategy" marked the Government's first serious commitment to what has become known as the Personalisation Agenda.

Importantly, this "Life Chances Strategy" also, in recommendation 4.3, committed to the creation of a "User-Led Organisation [ULO], modelled on existing Centres for Independent Living [CIL's], in every locality by 2010"¹.

This is particularly important for Hampshire. Hampshire was blessed with the birthplace of 2 of the first 3 CIL's in the UK in the early 1980's², The influence of these 2 CIL's undoubtedly led to the development of Hampshire's SOCS scheme, the national adoption of Direct Payments and provide a unique understanding of the gains to be had from individual Budgets (*and, importantly, the pitfalls to avoid*).

It is important to recognise that despite the wholesale nationwide loss of most of the Disabled People's Organisations over the last 5 years; HCIL & SCIL has managed to survive a funding climate which is particularly hostile to Disabled People's organisations, and to continue to lead the

¹ The term "User-Led Organisation (ULO)" includes organisations which are formed by Disabled People and run and controlled by Disabled People (such as a CIL). This paper prefers and uses the term "Disabled People's Organisation (or DPO)" as we consider it a less confusing description. However, we recognise that the Government prefers the term: ULO.

² Hampshire Centre for Independent (HCIL) & Southampton CIL (SCIL) were created by Disabled People between 1982 & 1984; Derbyshire Centre for Independent Living (DCIL) was also created at

national (and local) debate on the empowerment of Disabled People and their ability to live independently.

However, these organisations are also important nationally. Disabled People's organisations have been at the forefront of every important social policy development of the last 25 years. This provides definitive evidence that Disabled People have always had, and will always have, the best understanding of what services are required to enable them to live independently: meeting their needs, their aspirations and their dreams.

Disabled People's organisations have positively affected how we:

- Consult
- Involve
- Empower
- Treat people as equals
- Welcome radical solutions

This paper urges the Personalisation Commission to consider very seriously how Hampshire County Council should recognise, value, and enable Disabled People's Organisations with the contributions that they make to progressive social policy. We make the case that the Personalisation Agenda cannot be successful without the expertise and experience of Disabled People's Organisations.

This paper urges Hampshire County Council to celebrate, encourage and facilitate the development of Disabled People's organisations and to create a climate of genuine and equal partnership between "Disabled People", "commissioners" and "providers". Not the usual relationship where Disabled People are tagged on at the end, but a relationship where Disabled People are enabled to lead and develop partnerships concerned with their own empowerment.

We earnestly request that Hampshire County Council:

- Stop complaining about what we don't do (because often we are doing it)
- Stop hiding behind "the best interests of Disabled People" when you have not asked Disabled People what their best interests actually are (DPO's have, by the way)
- Remove the current barriers to funding, which have resulted in HCC no longer providing any core funding at all to any Disabled People's Organisations. (How can DPO's be expected to do all

- Encourage peer-support, peer-advocacy, self-help, empowerment and self determination, which are fundamental tenets of the Personalisation Agenda”. These services are acknowledged by Government to be best provided by Disabled People’s organisations
- Most importantly, provide real incentives for Disabled People to WANT to develop their own peer-support and self-help organisations.

We encourage Hampshire to understand that these organisations have 4 essential functions:

- Democratically represent the views of Disabled People (From a non-impairment specific perspective as we believe that dividing Disabled People along impairment groups is in itself, Disabling)
- Provide peer-led services to enable Disabled People to live independently
- Provide informed user input to progressive social policy developments.
- To campaign for the rights of Disabled People. We believe that Disabled People should have the same rights that non-Disabled People take for granted.

Believe it or not, there is more to life than Social Services! We urge this commission to highlight that every part of Hampshire County Council needs to take their responsibilities seriously when it comes to the empowerment and independent living aspirations of Disabled People. All too often Disabled People are viewed as a Social Services issue, when in reality Disabled People need all of Hampshire County Council’s services to be inclusive of their needs if they are to realise the ambitions of the Personalisation Agenda. Disabled People’s Organisations are well placed to help you deliver this message, and can do so far more effectively than Council officers.

Despite undoubted advances in the equality and quality of life of Disabled People in recent years, we still live in the shadows of society; and are often seen by Social Services, we believe, as a drain on resources. We urge this Commission to change this perceived culture, so that investing in Disabled People’s futures is accepted as a valuable investment in the future social prosperity of Hampshire.

There are currently many tens of thousands of Disabled People being prevented from contributing to the richness and wealth of Hampshire.

passivity? Disabled People and Disabled People's Organisations provide the key to unlocking the aims of the Personalisation Agenda. We strongly advise this commission not to allow this rich vein of expertise to continue to be repressed.

We heard much of the importance of Self-Assessment Advocacy during session one of this Commission. Much of this talk sounded as if these ideas were new ideas, new innovations. We feel the need to put the record straight here. SCIL has always supported people to self-assess and always provided advocacy when needed. Well, at least we did so until Hampshire County Council explicitly banned us from doing so. (Under the terms of the support contract we have with Hampshire Social Services to provide Direct Payments support). Disabled People's organisations have always understood and advocated the importance of self-assessment and advocacy.

There are many, many, examples such as this where Hampshire's contracts are counter-productive to the empowerment and independence of Disabled People, but also counter-productive to cost-effectiveness. We urge you to work WITH Disabled People's Organisations to examine and remove such perversities. Hampshire has a duty to promote Disability Equality. We urge this Commission to help us to help you to help us.

We remind this Commission that "Cost-effective" consists of two words, "cost" and "effective". Far too much money is still invested in services that promote dependence. Let us work together to ensure that resources are prioritised on services which empower and create independence. Services which allow Disabled People to be "givers" and "contributors" to society, not just "takers".

Disabled People's Organisations demand the recognition of the RIGHTS of Disabled People. Disabled People want to work with Hampshire to secure these rights and to create an environment where social justice, dignity, respect and social inclusion become more important than financial risk. Let us work together in an equal partnership to develop services which "enable" rather than "disable".

Individual Budgets, and the Personalisation Agenda, implicitly require that users of services are made familiar with how much their services cost. We welcome this transparency which would be a radical improvement in social care.

Why is it seen as radical? Would you see it as radical to know how much your accountant charged you? How much your bank charged you in interest? Of course you wouldn't. It says something, maybe everything, about how little we think of the abilities of Disabled People that somehow we are subject to a system which believes that Disabled People should be "protected" from such transparency. It is only by understanding the cost of a service that a Disabled People will be able to assess its cost-effectiveness in meeting their needs. This radical transparency is a challenge, but one for which it is an obscenity that we do not already have.

In the first session we heard that, nationally, 40% of total Social Services expenditure is spent on the infrastructure of the system. The same speaker urged that the implementation of the Personalisation Agenda, doesn't add to this expenditure, but significantly reduces it. We wholeheartedly endorse this.

But more than this, we urge that you allow users of Social Services the dignity and honesty of transparently discussing the cost of infrastructure and engage with Disabled People and their organisations in a cost-effectiveness debate of this and all other costs.

This must include an honest discussion on the issue of charging for Social Care. We welcome the acceptance, in session one, that this issue needs re-examining. The current charging policy in Hampshire has a major detrimental effect on many of the poorest members of society and makes a mockery of the Government's commitment to ending poverty. We and every other organisation of Disabled People have argued for many years that charging, for social care services, penalises people for being old or having impairments and that it is counter-productive to independence, dignity a social inclusion. In effect, charging is seen by Disabled People as a tax on disability. To date, discussions and consultation with Disabled People on charging has always been biased and inevitable. We now have a system which charges Disabled People more than the basic cost of care workers, and a system which socially excludes, discourages prudence and saving. But most importantly, we have a system which is so draconian and socially unfair that it encourages dishonesty. We urge this Commission to work in partnership and transparently with Disabled People's Organisations on this fundamentally important issue.

Indeed, much, if not all, that was said by the various "national" speakers

Disabled People and Disabled People's organisations. We urge you as a commission to use the resources and real expertise you have on your own doorstep.

Let us respect the expertise of Disabled People in a transparent discussion on the future priorities and resourcing of social care. We believe that discussions on resources should focus on creation of independence and to create an understanding of what Hampshire's citizens should expect of their lives. These principles WOULD create a level playing field for all citizens and a basis for prioritising limited resources.

In closing, we urge you to resource existing Disabled People's Organisations and encourage the development of new Disabled People's Organisations to become leaders in progressive social policy development and provision.

We envisage a future where it is a "given" that Disabled People work together to provide their own "peer-led" services. It is only peer-led services of this nature that can be empowering. Disabled People are experts in their own lives, they know what they need and have excellent abilities to empathise with the needs of others.

Work with us, not against us.

Ian Loynes
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