

Joining up care and support for the future

**Phil Friend, Chair, RADAR
25 August 2008**

The purpose of 'joining up'

We can probably all agree that social support and health services need to work better together. How could you disagree? It could make the customer experience much more seamless and less confusing. It could save money and time spent on unnecessary multiple assessments. I know someone recently admitted to one (just one) hospital ward, which involved them in 3 assessments – administrative, nursing and medical – that went over the same ground again and again. We were both left feeling rather unclear as to why the professions couldn't talk to each other. It wasted my friend's time and I can only assume it wasted theirs, not to mention taxpayers' money. And that is before we bring Social Services, Disability Living Allowance or Access to Work assessments into the mix.

But the case for 'joining up services' is not only about efficiency savings or even good customer care. More fundamentally, we need to ask what these services are for – and then direct their activities jointly to that purpose.

I believe that health and social services should have as their fundamental purpose supporting us (as people living with long term health conditions or disabilities) to live the lives we choose – with the power and tools to manage our conditions and support so that we can get on with our lives. It is not enough for health services to offer 'cure' and for social services to offer 'care'. We want support and health services that enable us to lead the lives we choose – to seize opportunities, to be equal citizens, to take risks if we want to, to be fully engaged in our families, communities and workplaces.

We expect more than earlier generations of disabled people (see DWP 2008). And our high expectations fit with a growing commitment amongst policy makers to an active welfare state – one that supports full participation, not one that offers 'care' to passive recipients. Rather than 'care' we want opportunities. Rather than 'cure' we want services on our own terms that we can use to help us manage our lives, with our condition or conditions (personally I have 3).

Take the example of services for people who are spinally injured. International evidence suggests that if services offer support from a very early stage to enable you to start considering and planning for employment – then you are much more likely to return to work. If, however, the main service focus is on physical treatment and rehabilitation – with employment and wider opportunities a marginal extra offered later, by the occasional social worker – then long-term unemployment is a much more likely outcome. The best spinal injury services have as their purpose enabling you to lead a full life – not simply fixing you up physically. All staff work towards that aim – and physical rehabilitation is just one way of reaching it.

In mental health services this approach has been strongly articulated under the concept of ‘recovery’ (Repper and Perkins 2003, Shepherd et al 2008). Recovery is a process, building a changed life following the momentous event of developing a major mental health problem. It is not something services do to the individual – but something the individual goes through, often with the support of services, including peer-based and user-led services. It involves grieving for the life you thought you would have and creating the life you want. It is about hope in new circumstances. Hope is dependent on there being real opportunities – which in turn is dependent on breaking down discrimination, for instance in employment. Services cease to have as their purpose the reduction of symptoms or the management of risk. Rather the purpose is to enable and support people through the process of recovery, so they can lead the lives they want to lead.

The independent living movement has at its heart the principles of choice, control and participation. From this have flowed services under the individual’s control – for instance, employing Personal Assistants using direct payments or using individual budgets to manage one’s support more broadly. Or indeed deciding you do not wish to manage personal assistants – but nonetheless securing services on your own terms.

Lest it seem that this approach works only for the least disadvantaged – like those ready to engage in the labour market – the principles have also been used with people with dementia. Even when choice-making is constrained, enabling people to make the choices that are possible – for instance to be in environments and with people with whom you are happier, calmer – is hugely valuable.

I believe that health and social services should take the core concepts of independent living and recovery and adopt them as their own fundamental purpose. Good practice can then be shared – whether from individual budget pilots or spinal injury units or dementia or mental health services – to put flesh on the bones of what this transformation entails. It is a transformation of health services as well as social care and support. It requires a shared sense of direction.

What should be joined with what?

Once we view the fundamental purpose of long-term health and social support services in terms of enabling people to lead the lives they choose, it becomes clear which services need to be more closely aligned.

Firstly, health and social services need to be incentivised to promote participation – for instance, in employment, education, leisure, social networks and family life. To take an example, the Public Service Agreement (PSA 16) target to promote employment participation for socially excluded people (including people with a learning disability or serious mental health problem) is beginning to raise this important issue up the agenda of local strategic partnerships and health economies. To create this type of incentive more broadly (eg for all disabled people/people with long term health conditions) would not require a plethora of targets. The key is to measure the most important outcomes – rather than to set targets that could distort activity. We should expect steady improvements in disabled people's participation in employment, skills, career progression, earnings and community participation. It is an expectation of both health and social services that they contribute to those aims.

Secondly, the types of participation that disabled people want – things like a job with a decent income, the chance to gain better skills, decent housing, opportunities to influence local services and plans – are objectives already 'owned' by a number of Government Departments and agencies. Departments including DWP, DIUS and DCLG have objectives to increase the employment rate, to upskill the British population, to increase community empowerment and engagement. Health and social services need to own those objectives in relation to disabled people – and to see as a significant part of their remit linking people into the opportunities of housing, work, skills and community empowerment at local level. This means joint work between health and social services and the Learning and Skills Council (and in future local authorities taking on its functions), Job Centre Plus, employment agencies, colleges, housing providers and more.

The geographical areas testing new approaches in local economies – like Manchester and Glasgow in relation to skills and employment – will have key lessons in this regard and it is vital that they address disabled people's experiences in particular.

Thirdly, services need to be better joined from one geographical area to another. It is little short of a national scandal that disabled people are unable to move from one part of the country to another – or even one London Borough to another – for fear of losing a vital social support package.

Whilst the balance between national entitlements and localism is not easy to resolve, there are no excuses not to find viable options: for instance, honouring a previous care package for a specified period prior to routine reassessment. Surely freedom of movement is a fundamental human right?

Who does the joining – and how?

Lessons from direct payments and individual budgets suggest that where individuals hold budgets with some flexibility to spend across the boundaries that policy makers have created they can sometimes neatly step over the gulf between different services. If a family could easily buy a computer for a child with dyslexia to use both at school and at home it would not matter whether this was 'education' or 'social care'.

However, individuals cannot be expected to go it alone. There is a chronic lack of information and brokerage. How do you know which services are effective or cost effective, or how to get the best deals? The target to have a user led organisation in every area by 2010 – that can support disabled people to take control and manage their own services if they wish – is massively welcome in theory but challenging to deliver in the current funding environment. It is imperative that this is made a reality. Individuals and families need supportive structures so that they CAN take control. A purely individualistic model will simply not be effective.

In addition to individuals 'doing the joining' it is vital that local strategic partnerships develop approaches at local level that build partnerships for participation. Joint work happens locally but needs to be incentivised nationally – including through shared objectives, in line with the vision described above.

But local creativity must take place in a national, equitable framework. That is why I support the proposals in Lord Ashley's independent living bill, that would give disabled people rights to expect a decent standard of support: for example, the right to portability of social care entitlement. We do need to overhaul 1940s legislation. RADAR has produced a detailed briefing on independent living, available at www.radar.org.uk

It is also why disabled people's organisations are so important – as enablers, as information and advocacy providers – and as scrutineers. The commitment in the Independent Living Strategy to a scrutiny panel could be a huge lever for change. It is particularly important that disabled people and our organisations can get involved locally, feeding back expertise and experience of what does and does not work to each other and to policy makers. RADAR and our membership are keen to bring our expertise to bear in this process.

At RADAR all our work is based on the principles of choice, control and participation. Our Doing Life Differently series of publications, written by and for disabled people, is full of examples of how we are managing our own lives – our employment, our money, our careers and more (RADAR 2007, RADAR 2008). This sharing amongst disabled people is a critical aspect of independent living (and indeed 'recovery' in the mental health sense). RADAR also supports disabled people's leadership development – identifying and supporting the next generation of leaders, set to become the influencers and shapers in many sectors, including health and social services.

Conclusion

Health and social services must be joined up – under a new purpose that applies to health as well as social services, through a clearer legal framework, through excellent user-led support and scrutiny, through 'joined' services across employment, skills, housing, community engagement and health and social care. And most of all through a change in purpose that ditches for good the idea that 'cure' and 'care' are an adequate basis for health and social care – and that meets and supports our rising expectations for full and equal participation in British life.

Please note: The views expressed by the author may not necessarily reflect the views or policies of the Department of Health.

References

DWP (2008) The Experiences and Expectations of Disabled People. London: DWP

RADAR (2007) Doing Work Differently. London: RADAR

RADAR (2008) Doing Money Differently. London: RADAR

RADAR (2008a) Independent Living Briefing www.radar.org.uk

Repper JM and Perkins RE (2003) Social Inclusion, Recovery and Mental Health Practice. London: Balliere Tindall

Shepherd G, Boardman J and Slade M (2003) Making Recovery a Reality. London: Sainsbury Centre for Mental Health