

Consultation response

Response to the Health and Social Care Integration Consultation

5 September 2012

LCiL is a user led charity, working with disabled people to enable them take control of their lives and live independently in the community. All our services respond to needs identified by disabled people and offer a range of practical and emotional support to promote their equal participation in all aspects of society.

This submission has been drawn up using the experiences and views of disabled people across Lothian and users of LCiL services. For more information visit our website:

www.lothaincil.org.uk

- We welcome the move towards a more integrated system for health and social care services, as we see its value in potentially:
- Easing people's pathway. People of all ages should not have to jump through hoops to gain access to support they require. Continuity as well as quality is crucial to our experience of health and social care services and avoids repeating our story to lots of different workers. There has to be clear mechanisms in place to hold services to account so we know who is responsible for delivering packages of care and support. This will prevent people falling through the gaps, particularly during transitions between services (e.g. from child to adult services, as well as adult to older people's services).
- Working towards individual outcomes. At present much of what is delivered is based on service outcomes. Although we recognise the value in this, in terms of setting standards at a wider level, we also want to be able to determine outcomes based on our own individual circumstances. We have to be involved in deciding what care and support is most appropriate for our needs, and be given choices and options, rather than being told *'this is what you'll get'*.
- Enabling a more effective use of resources. We welcome moves to remove institutional boundaries which restrict the allocation of resources. Often it has been the case that agencies have dictated how and when support can be provided which limits our choice and control and acts as a barrier to take up our rights as active and equal participants in society.
- Helping to shift investment from acute services to prevention. Investment in preventative services is crucial to enable people to live independently in their

Consultation response

communities and preventing unnecessary hospital admissions. Voluntary sector agencies can respond flexibly and adapt their response according to individual needs at a local level. They also bridge some of the gaps that currently exist between health and social care services. Their role should be recognised and enhanced through integration.

- We also fully embrace, and were involved in, two key collective responses:
 - Independent Living in Scotland (ILiS) - the 5 asks document
 - Long Term Conditions Alliance Scotland (LTCAS – Shared statement from 3rd sector organisations).
- Although the Health and Social Care policy may improve the wider framework of health and social care, we are aware that the devil is in the details and urge the Government to accept and remain fully aware of this when implementing it. This is particularly important in respect of decision making processes and governance structures which may serve to exclude the involvement of disabled people, and others who are at risk of being marginalised.
- Human rights, citizenship and Independent Living principles and outcomes should be embedded in the integrative approach. The independent living philosophy provides a strong foundation on which to build policy, values and practices, particularly during a time of change when structures and silos are being broken down and anxieties may exist around roles and responsibilities.
- The whole integration process should involve disabled people, people with long term conditions and older people, working in co-production.
- Developing a framework with appropriate recognition and resources targeting the promotion of this. Partnership arrangements must be representative and be able to distinguish between the unique contributions of service users, carers and third sector. Investment to support disabled peoples' view early on will save resources in the long term and avoid unnecessary 'fire fighting' later in the process. This has to be done meaningfully and support offered to respect the right of disabled people to solve issues and provide creative solutions to problems.
- Access to services and eligibility criteria should be led by individual need and requirement, rather than focussing on the condition or diagnosis. Although we can see the rationale for starting the integration process with older people at a political level, we are concerned that this will enforce a culture of setting eligibility criteria that doesn't address underlying inequalities faced by those across the age range. For example, people in rural areas are often disadvantaged in terms of access -

Consultation response

a 'postcode lottery' exists where care packages vary greatly across local authorities. If people move home to another local authority area will they be able to take their package of care with them?

- For this the change should also include considerations on genuinely enabling people to have a say and shape the system:
- Developing collective advocacy as part of the process enables disabled people to have a representative and well informed voice. They should be involved in decision making at a planning and commissioning level to represent the experience and views of service users.
- Supporting independent and user led organisations which can offer independent information, advice and support. Agencies like LCiL have well established and trusted methods of engagement with disabled people on an on-going basis, therefore their role must be recognised and utilised to inform and engage disabled people on developments.
- A progressive process carefully evaluated so that people in receipt of care/support and user of health services are confident that they can achieve their individual outcomes and move beyond the concept of just 'being cared for'. Disabled people should be involved in determining how success will be measured for them so that the right questions are asked instead of using scales and other methods which are often informed by medical models.
- A strong emphasis on the social model of disability being at the heart of development and services so that change is influenced by equality of opportunities and inclusion aims rather than by power and cultural interest. We are concerned that the integration agenda could serve to maintain and enhance the role of clinicians in decisions made about our care and support. We don't want to see a reversal to the medical model with disenfranchises us of our rights and choices. We'd like to see training for all staff on the social model of disability to make them aware of its benefits and the evidence to back up this model.
- A clearer fit with Self Directed Support (SDS) because without it we are risking failing on the principle and outcomes of the change. SDS will help move towards individual outcomes rather than institutional boundaries. Resources will be made visible to service users so they can choose which options will be most effective to meet their needs. All partners must recognise and implement SDS as part of the integration process to achieve better outcomes for service users.

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