Social Care (Self-directive Support) (Scotland) Bill

HUG Action for Mental Health

Please see below our previous submission to this bill, this was agreed at our last meeting we would also like to state the need for people to have access to advocacy when you consider the progress of the bill.

The following are the comments of HUG members on the consultation on self directed support. We have not answered each question, the length of the consultation document and the timescale prevented this.

HUG is a network of 400 people with experience of mental health problems. It acts as a voice for people with a mental illness in the Highlands through its collective advocacy function and through its awareness raising activities. More information can be found about it at hug.uk.net. The HUG Friday Forum is a forum of our more active members that allows members to respond to such things as consultations. This response came from 12 people.

We have concentrated our views about direct payments and self directed support on how they may apply to people with mental health problems. We have spent most of our time addressing the central assertion in the consultation document that self directed support would eventually become the principal mechanism by which social care services are delivered in the future.

We have been consulted on and off for at least the last decade about the need to get a higher uptake of people with mental health problems using direct payments. We would imagine that the continuing extremely low use of direct payments by people with mental health problems is partly due to lack of publicity about them and simple mechanisms to use them as well as a reflection that many people who receive support do so principally from health services. However we also think it may because people with mental health problems are often not interested in them. We would hope that the value that they have to people with physical and other disabilities has not been transferred wholesale to people with mental health problems without reference to their particular needs.

We would hope that in the future that it becomes easy for those people who have mental health problems and who actively want self directed support to obtain this but we strongly oppose the idea that self directed support becomes the default mechanism for care provision.

The reasons we have for this are (in no particular order):

- We worry about the burden of administering self directed support and direct payments. Most of us have enough trouble dealing with our own often precarious day to day existence without having to manage and employ other people who will in turn help us manage our lives. This especially applies to direct payments. If we were to pass over responsibility for providing support to another agency then we see little
difference in concept to the present arrangements except, perhaps a privatisation of Social services.

- Having a mental illness is often intertwined with extreme stress and anxiety; self directed support could increase this.

- We worry that this is a way of Government passing responsibility direct to the individual. We live lives where our ability to take responsibility for our lives and sometimes our families is often extremely compromised. This is part of the nature of our impairment. We can need other people to take responsibility when we can’t.

- If our support worker goes off sick or leaves when we are responsible for managing them it will be our responsibility to make alternative arrangements, possibly at times of difficulty for us. We are not willing to be given this burden.

- When we are ill the majority of us would not be in a condition to manage our support or direct what we think it should be doing for us and yet this is the time when we most need support. It is possible that we would be in a position where we would lose the support at a time when we most need it because we could not manage or control the support we get.

- If we are to manage the support that is provided for us we think we should get a management fee for carrying this service out on behalf of the local council.

- We worry about the effect on benefits such as DLA if we get Direct Payments.

- We are aware of people with special needs who do get direct payments, they seem to benefit from the services that are provided to them but they can need to employ accountants to administer their service. Doing something like this would be beyond us.

- Many of us will at some point be sectioned, at which point we would lose the service at the very point we most need it. Being sectioned at different intervals means that we would have to go through the whole assessment process again and again and select our own support at times when least able to do this. People subject to section are likely to use council services the most and therefore be most likely to be eligible for self directed care when they are not under section.

- The type of support that we get from the council is often very different to that of those for people with physical disabilities. It is often of the sort that acts at a psychological or emotional level as well as helping us with daily tasks such as managing our finances and paying our bills. We are often in a position where we depend on our support workers for advice and direction and motivation. It would seem incongruous for us to then be put in a position where we direct our supporters in what
advice and support to offer us and even stranger where we may rely on a support worker to help us manage their payroll, conditions of service and management.

- We tend to have cyclical or episodic illnesses which means that the level of support we need will vary from week to week. Any support has to be flexible enough that it helps maintain us in the community when well and then increases in intensity when we are ill.

- We worry that passing over control to family and friends for self directed support may leave us more vulnerable than the present system of relying on statutory services for support.

- A lot of the support that the Council provides is through the voluntary sector which often provides group and communal activity that we value greatly. We often benefit hugely by socialising and mixing with our peers for instance in drop in centres or training units. We worry that the focus on the individual will have a negative impact on these services and will amount to a direct attack on our community which many of us place great store in.

- We worry that it would make it much easier for the Government to reduce costs, they will be able to reduce care on a person by person basis and these people are likely to be in a very difficult position to challenge funding and resource allocation decisions.

- We think many of us would have a great need for advocacy if we were to have to challenge any assessment of our care. Advocacy is limited in its provision across Scotland.

- Many of us also have alcohol and other substance addictions. We live unpredictable and at times, chaotic lives and would not be able to participate in these forms of support.

- Some of us have impairments that mean that we cannot manage money, for instance we may go manic and spend resources in ways that are not permitted.

- Those of us on procedures such as the care program approach may be those that use council services the most. The implementation of our care under these systems may be very directive for instance by putting pressure on us to take medication, have suitable relationships and generally act in more sensible and healthy ways than we may naturally be inclined to. Whilst we agree that we should have a say and some control in our care and can resent it when our autonomy is taken away we often, especially in retrospect, accept that these interventions are in our best interests at a time when we are less able to act in this fashion. This approach does not fit easily with the philosophy of self directed care.
• Our conditions are such that our needs change frequently we cannot anticipate the future or predict what level of care we need from month to month. If we are given a set amount of money to manage our care it will be at times too much and at other times far too little.

• Many of us who use Council services have frequent admissions to hospital at which point our self directed care would stop. This would mean that we would lose our support when we have a high need for it and would have to reinstate it on discharge when very vulnerable.

• The Government publication on self directed support produced in conjunction with VOX and the Mental Health Foundation repeatedly says that local mental health user groups would provide support advice and information and promotion for self directed support. As one of the leading local user groups we would like to state that we were never asked whether we would do this. We value our autonomy and having our own voice in these matters and, as a collective advocacy group (which is the case of most mental health users groups such as us) believe that this would compromise our role if we became a service provider in this fashion.

• Some of us would feel profoundly uncomfortable if were expected to instruct our support workers in what to do for us.

Further Comments

• For those people who would want to use self directed support and direct payments there should be better publicity and support to use and access them. We are aware of some people feeling that they were eligible to them and not being able to access them because by the time they applied the budget was used up.

• Some of us value our existing support agencies greatly and may be more inclined to use direct payments if we could get them directly from these existing trusted familiar and high quality service providers.

• We do like the idea of agencies that manage payroll functions, this might persuade some of us to use this service.

• We do want more say and control over our care and this care could be provided in a much more flexible way. We may do better to have a modernised service from the statutory sector than a brand new system of care provision.

• Some of the attractions of direct payments such as being able to buy a lap top, get alternative therapies, access the respite that we want are very appealing to us. To have access to a fund that would allow these things to happen could be great. We don’t think that having access to such possibilities should be available only to those able to take responsibility for the provision of their own care. If there were small
funds of money that would allow this to happen whilst still receiving council services we would be delighted. We imagine that this is very unlikely in the present financial climate.

- Using advance statements to help determine our care when ill may be very helpful.

- Direct payments may be very useful in rural areas where there is such a paucity of statutory services that commissioning our own services may bridge a service delivery gap.

- Whilst we have little knowledge of their effect on people with a mental illness we are aware that direct payments have transformed the lives of other people and have helped them back in to social networks and employment.

- Some of us think that we would like direct payments if we could find someone to administer and manage our care on our behalf but when we think of this as an option it seems to go against the whole point of direct payments.

- We do need the services that are provided for us to be as person centred as possible and genuinely needs led. This does not mean that they have to be arranged under the aegis of self directed support.

I hope that these comments from our members are useful in the development of the self directed support bill. I would emphasise again that we have little problem with people getting this service but we do have a great anxiety about it being provided universally. If it were we expect that many people with a mental health problem would suffer unnecessarily and be disadvantaged.

HUG Action for Mental Health
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