C10

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

Ymateb gan Hafal

Response from Hafal

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dros adferiad
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hafal

for recovery
from serious
mental illness

www.hafal.org

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Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

Evidence from Hafal

1. About us

Hafal is Wales' principal organisation run by people with serious mental illness and their carers. In the last two years Hafal has extended its services to a broader range of clients with other disabilities but this evidence is based primarily on discussion with carers of people with a mental illness.

All Hafal's services stem from our unique Recovery Programme which empowers clients to make a step-by-step recovery plan, to look at all aspects of their life and set goals, and to take control of their lives: carers are of course key supporters of the people they care for as they work towards recovery.

Hafal provides a range of services and support specifically for carers. These include:

- **Family support:** working closely with carers and family members to provide the best support for clients
- **Advocacy:** supporting carers by representing their interests
- **Breaks for carers:** engaging a person being cared for in an activity so that carers can take a break
- **Accessible information and advice:** providing carers with the latest news and information relevant to them
- **Mutual support:** enabling carers to support each other through carers' groups
- **Giving carers a voice:** especially in the planning of local services
- **Awareness raising:** highlighting carers' rights, such as the right to an assessment

2. Who we represent

This response is based on our experience as a mass membership, client-led organisation representing many carers as well as service users. In addition during August and September 2018 we talked to informal groups of carers in Conwy, Gwynedd, Swansea, and Pembrokeshire about the specific issues under scrutiny by the Health, Social Care and Sport Committee.

3. Our conversations with carers

Wider context

It is impossible to separate carers' experience of the Act from the wider issue of their experience of mental health services since 2016. Although we specifically asked about the Act the wider issues were far more important to carers:

One group said their local authority was ***doing its best despite a 40% reduction in budget***.

Individuals told us:

There are no staff to give support

There is no social worker since 2016 for the person I care for or for me

Less is being offered at the moment

Assessment achieves nothing – all support services have been discontinued

Attitudes to carers

One group commented that ***carers are not kept informed of events (e.g. when patients have been transferred from one unit to another)***; and ***their concerns about a lack of activities/recovery programmes on wards are ignored.***

Some carers feel that they are ***perceived as a "problem" rather than part of the solution***.

Others felt that [one inpatient unit] ***would prefer carers not to come to the ward.***

Access to information

One group said: ***professionals frequently feel unable to provide information that may be beneficial to the carer or the cared-for.***

This lack of easily-accessed information means that: ***carers and service users need insider knowledge to access services/resources to which they have a right or entitlement.***

Other points:

A major problem is that carers often don't know what to ask for i.e. unless you know that a service or resource exists, professionals don't provide signposting.

Not supported well enough, especially from a communicative point of view when dealing with families and relatives

Respite support

A typical comment was: ***I used to get respite support but it has not been offered or discussed at all in the last year***

And: ***no respite support at all!***

General comments

We are all at the back of the queue

People don't listen to us enough

Carers are left to support each other

We are lonely and need the help and support

Crisis support at [one inpatient unit] ***was superb***

The Local Mental Health Team offered me no support and lacked all understanding of the mentally ill person and myself as carer

Not included in the care and treatment of my daughter

Shocking turnover of staff

Support was zero

Not enough staff

Ideas for improvement

Reduce the amount of jargon and social care "corporate speak" so that information/advice given to carers is succinct and practical

Carers need more respite to be made available

Services that would improve carers' well-being include a befriending service, carer training (e.g. resilience, etc), carer advocacy, talking therapies, rural transport service, home help (maintenance and gardening service)

Carers should be provided with a "carers pack" which provides information about generic services/resources with an element tailored to the specific condition of the "cared for"

Carers should be kept informed about decisions made about the cared-for (some carers feel that professionals hide behind confidentiality rules).

More staff and reinstating support workers

More funding

A lot more understanding is needed

Offer more advice and help

Listen carefully, please, to carers' concerns

Free bus pass for carers

Help with ways to give more help to the person with the problem

Better information on facilities available

Helpful to have a point of contact when we are concerned

4. Our Response

Most carers have not noticed any improvement since the introduction of the Act because:

- The legal right to assessment predates the Act and the strengthening of that legal right is relatively marginal compared with other factors affecting carers' experience
- Reduced resources have affected the capacity of services to undertake good quality assessments and to deliver on needs identified in assessments, including respite care
- Reduced resources have also impoverished services for the people whom the carers support – a far greater concern for carers than carer-specific rights and services
- Services have not built on the Act to create a new culture of respect for and cooperation with carers

But in our view this does not reflect badly on either the wider intention or the detail of the Act as it affects carers: it is rather a reminder that legislation has a limited role and provides little unless it is combined with both resources and also a matching policy and delivery response by service providers.

Resources, especially for adult social care, have been under intense pressure since the Act to the point where for some carers the right to assessment has little meaning: if there are no carer-specific services available, including respite care, then a major part of the point of the assessment is removed; if in addition there is little or no service being delivered to the person they care for, then much of the *rest* of the purpose of an assessment (namely to agree cooperation between the carer and services in providing care) is also lost.

Unfortunately this is not an untypical situation: many carers of adults with a serious mental illness have no access to any carer-specific services including respite care; further, the person they care for may receive no service beyond prescription of medication and access to inpatient care when a major crisis occurs. In these circumstances a carer could be forgiven for questioning the point of doing an assessment although we would always encourage them to do so.

So the wider issue of resources cannot be avoided in responding to this enquiry and it will remain the highest priority for carers, for those they care for, and therefore for Hafal.

But there are other issues, perhaps more tractable because they are not so dependent on resources - and might indeed lead to better use of those resources…

The Act provides a useful platform on which a new relationship could be developed between services and carers but this has not happened. There are examples of course of excellent practitioners who engage well with carers *to everybody's advantage* but this is exceptional and not the prevailing culture within services. Why is this?

Services routinely perceive carers as:

- Making unreasonable demands on services both for themselves and those who they care for
- "Part of the problem" – causing or exacerbating the problems of those they care for. In the case of mental illness this can take the form of professional prejudice concerning the alleged role of families in causing some illnesses

This can result in:

- Contact with carers being avoided or made difficult
- Ignoring carers' suggestions about provision of care
- Justifying exclusion of carers from planning or delivering support because of their alleged anti-therapeutic behaviour
- Hiding behind confidentiality considerations to exclude carers
- Grudging carer-specific services including respite care

In practice:

- Many carers do indeed advocate vigorously for those they care for, not least because many people with a serious mental illness (and many other vulnerable people) have low self-esteem and therefore low expectations for services. Without such advocacy by carers many vulnerable people would live miserable lives without complaint – hardly a satisfactory outcome
- Carers typically have the best insights into what is needed and what works in terms of support for those they care for – and therefore how resources can best be used
- A very few carers may cause problems but if they do then this should be raised candidly with them: avoiding or excluding them will only make matters worse
- Carers understand the principles of confidentiality and, where exceptionally the person they care for wishes to keep matters confidential from them, then services should explain this clearly to carers

But the key to improvement and making best use of the Act is not just to change the response of services to these specific issues but to encourage them to see carers in a wholly new light, namely as equal partners in making the best of shared resources.

Those who plan and provide services should have regard to three key resources: what the person can do for themselves; what the carer/family can do; and what services can do.

To do this effectively they need to start their dialogue and cooperation with both the client and their carer before concluding what they need to provide themselves.

Services need to be candid with clients and carers about what resources they bring to the table: better to be clear about the constraints they are operating under than let clients and carers find out the hard way that services are limited. If this leads to the client or carer complaining then that complaint will be directed at those who decide on and deploy resources rather than at front-line practitioners – which is how things should be in order to sustain cooperation and good relationships where it matters.

Carers' assessments are also a good place for candour about what services can be provided to carers: carers want to know what is possible and they can then operate on that basis. Of course services should deliver what they promise but if they promise realistically and then deliver they will benefit from a cooperative relationship in everybody's interest.

Of course front-line practitioners cannot deliver such a change of culture without the support of their agencies and managers.

In addition we make four specific recommendations:

- Welsh Government should provide guidance to Local Authorities on meeting the specialist information, advice, and support needs of mental health carers, for example in relation to Nearest Relative rights under the Mental Health Act. "One-size-fits-all" generic carer services are not able to cover these specialist areas adequately and specialist services should be recruited or commissioned.
- In Conwy Hafal provides (mental health) carer assessments with funding from the local authority and Health Board. Carers report a good experience of this approach, receiving good quality assessments from a specialist agency separate from the main service providers. The cost of this approach is demonstrably less than in-house provision of assessments.
- There would be great advantage in services linking closely development of individual Care and Treatment Plans for people with a mental illness (required under the Mental Health Measure) with their carers' Assessments (under the Social Services and Wellbeing Act): in most cases this would be welcomed by carers and cared-for and would effectively create a complete and linked package setting out what each party will do to support the recovery of the cared-for and the well-being of the carer.
- More advice and help should be given to enable carers to obtain Direct Payments for their own needs and to support their cared-for to take control of their own care through Direct Payments. In practice Direct Payments for people with a serious

mental illness are usually dependent on carer involvement and this represents a key means of extending choice.

5. Conclusion

The provisions for carers in the Social Services and Wellbeing (Wales) Act 2014 provide a platform on which a new relationship could be established with carers to the benefit of carers, cared-for, and service-providers. But this will not happen until resources for social care are sufficient and services change their view of carers to one of respect and cooperation.

Meanwhile carers are vastly more worried about the current pressure on services for those they care for than on the impact of the Act on carers.

6. Contact details

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