



“Taking the Wheel”



*a campaign by people with a serious
mental illness to drive their own recovery*

What Users Want!

Feedback from the “Taking the Wheel” campaign

About the “Taking the Wheel” campaign

The “Taking the Wheel” campaign has inspired users of secondary mental health service across Wales to take more control of their lives and the services they receive. The campaign is being run by people with a serious mental illness, and service-user led organisations Hafal and MDF the Bipolar Organisation Cymru have worked in partnership with the Mental Health Foundation to support the campaign.



“Taking the Wheel” was launched at a user-led Seminar in May 2011 and has featured a rally around Wales in a VW microbus with 22 weekly events in every county and national events at the National Eisteddfod and Royal Welsh Show. The events have generated a huge amount of interest among the public – particularly the fully-renovated 1964 samba VW microbus and the accompanying campaign rally ‘simulator’ – a giant-screen, surround-sound driving experience! More importantly, the events have engaged hundreds of service users across Wales who have discussed how they can be empowered to take control of their lives and the services they receive. As part of our approach we have conducted a study at each event asking service users for feedback on their experiences – and suggestions for empowerment – in each area of their lives. We also asked service users to comment on their expectations and aspirations for mental health services.

Key messages from the campaign

1. Care Planning

The clear message emerging from the “Taking the Wheel” campaign is that service users want help across a wide range of areas, as these sample comments show:

- Speaking about **Physical Health** a service user from Powys said: “We should get health checks from GPs. My medication puts me at risk of heart disease.” Another service user from Merthyr said: “Free gym membership would help a lot of people keep their weight down.”
- Speaking about **Training and Education** a service user commented: “No-one has ever spoken to me about any training.” One service user from Wrexham said: “I’ve taken part in training which has helped build my confidence and enabled me to become a trainer.”
- Speaking about **Medication** a service user commented: “I don’t take my medication because I don’t know what it’s meant to do.” A service user from Denbighshire commented: “Finding the right medication has been the greatest help for me.” Another service user said: “We shouldn’t just get given the cheapest one.”
- Speaking about **Other Treatments and Therapies** a service user said: “All I get given is medication. That’s it, nothing else.” A service user from Merthyr said: “I have used CBT, ‘talk therapy’ and a computer-based therapy. However, the problem was they were all time-limited and didn’t continue long enough to achieve a real effect.”
- Speaking about **Work and Occupation** comments included: “What support is there to help me to start working again?” One service user suggested: “When someone is diagnosed their job should be held open.”

- Speaking about **Finance and Money** a service user said: “People in banks should be trained to help people with mental illness. We need specialist help.”
- Speaking about **Social, Cultural and Spiritual** issues a service user from Caerphilly said: “I play guitar and have really enjoyed becoming involved in a music group, we’ve performed to the local arts group and it’s helped me build my confidence up.” Another service user commented: “Peer support schemes are what we need. You need someone who has been through something similar. They can give you advice.”
- Speaking about **Parenting and Caring Relationships** a service user from Pembrokeshire said: “It would be good if there was a group for parents in the same situation.”

The overarching message emerging from the campaign is that all of the above areas need to be addressed in a holistic Care and Treatment Plan. Comments on Care and Treatment Plans have included the following:

“What is a Care Plan – I’ve never heard of that or been told about that?”

“I think I’ve got one but I’ve not been involved in putting it together.”

“I have one but after being on a workshop I now realise how badly it was done. I’m going to ask to go through it again and have it redone.”

“When it comes to writing a care plan it’s OK writing things down but in your mind you think: ‘I can’t possibly do that!’ But before you know it you have a review of your goals and you can see the progress you’ve made.”

“The areas I’ve concentrated on in my plan have been housing, finance and training. My care plan has a very structured approach which has made my targets achievable.”

The Welsh Government has already responded to the need for effective and holistic care planning: its Interim Policy Implementation Guidance for delivering CPA in Wales (July 2010) states that the Care and Treatment Plan should proportionately address each of the key life areas. These are now set out in the Mental Health Measure as follows:

- Medical treatment (medication, etc.) and other forms of treatment, including access to appropriate psychological and other treatments
- Personal care and physical well-being
- Accommodation, including housing
- Work and occupation
- Training and education
- Finance and money
- Social (including leisure), cultural and spiritual
- Parenting or caring.



Furthermore, the Interim Guidance emphasises the need to record goals in all areas of life, stating: “Service users with relatively straightforward needs may be able to take any necessary action alone in relation to several of the areas but it is important that this is still recorded: for example, if a service user has rented accommodation that is satisfactory and well managed by them, then it is sufficient simply to state that they will continue to maintain their tenancy. By contrast a service user with complex needs may need more detailed action recorded against several or indeed all of the areas. This methodical approach is important in order to sustain a holistic focus on recovery.”

However, the overwhelming experience of service users participating on the campaign is that while they may have a Plan, they do not have one which conforms to this guidance. The Interim Guidance promotes three guiding principles which will make CPA the key driver for a recovery-based approach:

- Care and treatment will be holistic
- Care and treatment will be coordinated and integrated
- Individuals will be involved and engaged.

But service users have said that their plans are not holistic and that they were not fully involved in writing them. As one service user commented: *“It’s news to me that we have to cover all these things in a Care Plan. Mine’s about my meds.”*

Service users responding to “Taking the Wheel” recognise that there is policy in place to support holistic care planning. The issue seems to be that the policy is not being put into practice. One service user from Porthcawl said: *“Service users want to have a comprehensive Care and Treatment Plan which they are in control of. This is the best way that they can make decisions about their recovery. But we need to make sure that these Plans are actually delivered.”*

The consensus among service users is that the only way to ensure that all areas of life are covered in the Care and Treatment Plan is if the Regulations for the Measure specify the format of the Plan and provide sections for all the eight areas of life to be covered. They also agree that this message should be reinforced in the Measure's Code of Practice which, like the Interim Guidance, should specify that goals are recorded for all areas of life.

Significantly, service users also view the Care and Treatment Plan as the means of ensuring that mental health services are shaped by patients' needs. Expert Patient Trainer Dave Smith explained: *"I've spoken to a lot of fellow service users during the campaign and the consensus is that we don't expect vast new resources for mental health services. We know that this isn't going to happen anyway. But we do want client-centred services. And we're agreed that this can be done concretely by using Part 2 of the Measure which concerns care planning."*

"Service users want individual Care and Treatment Plans which meet the three principles set out in the Interim CPA Guidance. But it's not good enough to make these Plans fit the services provided. It should be the other way around. When all clients have a quality Care and Treatment Plan, planners of mental health services should move towards a position where Plans are analysed collectively and all commissioning of secondary mental health services is based on the needs identified. In other words, all services should be based on what's in the Plans, not the other way round. And there should be enough flexibility in the provision of services so that they can meet every individual's needs."

Additionally, service users were interested in how the eight areas of life covered in a holistic Care and Treatment Plan could be used to demonstrate outcomes and measure performance. Users agree that outcome measures for secondary mental health services should be specifically concerned with individuals' progress with their Care and Treatment Plans (rather than ticking boxes to confirm that services are "in place"). Measures could include, for example:

- service users supported into employment
- reduction in hospital admissions
- user scoring of progress in their recovery
- reduction in side-effects of medication
- rates of weight loss and smoking cessation
- progression down the housing continuum from high-level support to independent living.



2. Extending choice

One service user from Cardiff commented: *"In an ideal world I would like to pick and choose. I could have a therapist, be in a spa."* Another said: *"I've just been told what to do for my whole life."*

These statements reflected a number of comments from service users who want to be given the ability to exercise choice and have a much greater say about the care and treatment they receive – and who provides it. By making choices, service users feel that they can become more empowered and receive the best service possible. As one service user attending a North Wales event explained: *"I'm really interested in this idea of taking control of resources so I can purchase my own care package. This sounds really good to me because it not only means I would get a choice, but it would also keep services on their toes because they would have to convince me to choose what they have on offer. This could make all the difference because at the moment services often have a take-it-or-leave-it approach and they aren't really incentivised to provide what we want."*

Some service users were very interested in learning more about Direct Payments and some suggested that personal health budgets had the potential to increase patient choice. There were also suggestions for immediate ways in which choice could be promoted. One participant asked: *"Why can't there be a fund for us to pay for talking therapies beyond what's available through the usual services?"* Another asked: *"Why can't we choose the hospital we go to? I don't want to go to our local one."*

Dave Smith explains: *"The issue of choosing an in-patient service generated a lot of discussion. Some users will prefer to use a local service; others will prefer to choose public or independent in-patient facilities which are further away but which provide a service suited to their needs or which have a better reputation. Service users need more information and guidance on how they can exercise choice within the current system either at the point of admission or through Advance Directives. We are aware that the Welsh Government is looking for more cost-effective procurement of beds on a national basis. But having established who the preferred providers are, why not give the choice of where to go to service users wherever practicable?"*

3. Developing and managing services

Service users have been vocal about developing and managing services themselves. One service user from North Wales pointed out that: *"We run our project and it's run really well. It's a good service and it gives us what we want. We should run the NHS!"*

Peer-led services are proven to be effective because service users can identify with those delivering the services. The campaign has shown that service users are becoming more ambitious about developing and managing services themselves, and that there is a need for more opportunities to empower service users to manage services. Hafal and MDF the Bipolar Organisations are examples of large national organisations which are governed by service users and deliver mental health services, and there are also many successful local organisations run in this way. Service users want to be empowered to manage services at every level – even at a micro level. One service user from Gwynedd suggested: *“Tenants should be able to live together and manage their house collectively. With some support from outside, groups of four or five tenants should have control over who joins them as new tenants and how daily living within the house is organised.”*

4. Planning and commissioning mental health services

One service user taking part in the campaign said: *“I’d like to sit on the board of my local hospital. I’d make the right decisions.”* Another asked: *“How can I be involved in this Measure? We should be the ones leading it. It’s about us.”*

During the campaign it has become clear that in addition to taking control of their own recovery, **service users want to engage with the providers of mental health services so that they can get more involved in planning and commissioning those services.** Participants of “Taking the Wheel” are determined to make their voices heard and participate in the running of local services. The consensus among service users is that consumers of services know best how services should be delivered, and service users want to take full advantage of opportunities to get involved.

With the coming of the new Measure and proposed Local Authority collaboratives the mental health landscape in Wales is changing. Service users recognise that there is an opportunity and need for new mechanisms to involve service users collectively and ensure that they are involved at national level in planning and commissioning, and not just in a tokenistic way. Service users agreed that the Government needs to engage representative service users both from mass-membership organisations such as Hafal and MDF the Bipolar Organisation as well as from local user groups.

The Way Ahead

“Taking the Wheel” has shown that service users want recovery-focused services based on effective and holistic Care and Treatment Plans which they write themselves. Service users have also indicated very clearly that they want the whole process of providing secondary mental health services to be based upon the delivery of individual Care Plans.

Service users now urge the Welsh Government to make this goal the central theme of the revised mental health strategy which they are currently writing. Service users also believe that there is a need for an independently-chaired national board (including service user and carer experts) through which the Welsh Government can develop policy and performance-manage delivery of the strategy.



For more information on the campaign please go to: www.hafal.org

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