

Health & Social Services Committee

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Venue: Committee Rooms 3 & 4, National Assembly

Title: The National Service Framework for Mental Health: Standard 2 – User and Carer Participation:
Response from Hafal

Hafal empowers people with severe mental illness and their families to achieve a better quality of life, to fulfil their ambitions for recovery, to fight discrimination, and to enjoy equal access to health and social care, housing, income, education and employment

Hafal's Mission Statement

1. What does "full" and "genuine" participation mean to you/ your organisation?

Hafal is a client (patient) led organisation which is managed by trustees who are themselves mainly users and carers; these individuals are elected from the organisation's membership which also comprises people who experience severe mental illness and their family members/ carers. The themes of equality, empowerment and recovery run through all that Hafal does. Hafal has taken an innovative approach to ensuring these values are put into practice by Hafal's stakeholders. This has been achieved by the establishment of a Programme led by the Empowerment/ Recovery Co-ordinator who works with clients, volunteers, staff and trustees in identifying practical ways to achieve a better quality of life by having greater opportunities for self-determination.

At Hafal we encourage clients fully and genuinely to participate in all aspects of the organisation, and also to get involved with activities externally. This includes the devising of individual action plans, the running and management of their local Hafal service and of the wider organisation through membership. Externally we promote and support individuals (clients or carers) to participate in planning, evaluating, etc., of statutory services through local groups. We also encourage clients and carers to voice their opinions on major mental health issues such as the draft Mental Health Bill.

We have recently produced a report titled "You're the Expert" which is based on research questionnaires returned by over 300 clients and carers living in Wales. The questions covered a range of areas including priorities for treatment and therapies, attitudes to the new Mental Health Bill and views on Hafal's

values, particularly those on empowerment. The findings of the research were very positive with two-thirds of people recognising that contact with Hafal has resulted in increased feelings of empowerment and that they believed they had a say in what the organisation does generally.

We believe that "full" and "genuine" participation suggests an all-round approach not an add-on or a marginal activity; it is not one dimensional but multi-faceted, and is integral to all aspects of a service.

2. What are the barriers to full and genuine user and carer participation in:

a) The development of individual care plans?

There are a number of factors which could be considered barriers to participation in the development of care plans, these include:-

Professional attitude – does the keyworker/ care co-ordinator truly reflect in their practice that clients are individuals who are equal to others in their community/ society, and treat them with the respect and dignity they deserve?

Clients'/ carers' attitudes – does the individual feel equal to other people in society or do they feel "second-class" because of the stigma and discrimination they experience?

Clients who lack self-belief and self-confidence have a tendency to think that the expert knows what is best for them and so passively receive care. Mental health professionals must demonstrate an awareness of this and work in a way that gently challenges these perceptions.

Time – does the keyworker/care co-ordinator have the time to build up a relationship and rapport with their client and have time to explore how the client wants to improve their life?

Ownership – who owns the care plan? Clients cannot feel a sense of ownership or commitment to their care plan unless they have genuinely been involved in drawing the plan up in partnership with the keyworker.

b) In the planning, design, commissioning, delivery, monitoring and evaluation of mental health services?

The major barrier to engaging clients' and carers' in consultation on wider mental health services is clients' and carers' lack of awareness of the opportunities for involvement. Having listened to the experience of our clients on this issue it is apparent that there is willingness to be involved and to share views, but few individuals know about the process. There must also be a genuine commitment on the part of mental health services to involve clients and carers; this involvement should be at the core of all aspects of consultation on planning, design, commissioning, delivery, monitoring and evaluation.

3. How can these barriers be overcome and by whom?

Everyone who works with clients and carers should do so in a fair, equal and non-judgmental way. Communication with clients and carers should be "adult-to-adult", leading to honest relationships built on mutual respect and trust. This is central to care planning and wider involvement. In terms of care planning mental health professionals and others may need to reflect on what their role is in relation to supporting clients. Professional staff need to have appropriate skills and time to build a unique therapeutic partnership with the individual.

Practical suggestions to overcome barriers:-

Care plans

- Staff having more time – small case loads
- Time for reflection on practice
- Training
- Information materials for clients and carers which clearly explain what the care plan process is about
- Training for clients, self awareness, confidence building
- Support and commitment at all levels within the organisation for client participation

Wider Participation

- Far reaching advertising to flag up opportunities for participation with as many clients/ carers as possible
- "Job descriptions" for clients/carers' representatives; realistic expectations of clients/ carers
- Practical support such as expenses for clients/ carer representatives.
- Having the time and means for the client/ carer representatives to feedback/ gather information from other stakeholders (via contact with other organisations, e.g. voluntary sector)
- Client/ carers being considered and treated equally with other team members (joint training)
- Receiving the same information as other team members

4. What should be the role of:

i. The LHB

ii. The NHS Trust

iii. The primary care team

iv. The voluntary sector

v. The service user/ carer

There should be consistency within all organisations in how they work with clients and carers in an "equal" manner. Organisations should individually consider how they can include client and carer participation realistically in all aspects of their work. How can participation be included in the core values alongside anti-discriminatory practice, for example?

- i. Local Health Boards should ensure active client and carer participation in commissioning and evaluating services. In addition they should insist that all services under their remit must demonstrate a commitment to client and carer involvement.
- ii. The NHS Trust – should reflect the practice suggested in 1-3 above.
- iii. Primary care teams - should reflect the practice suggested in 1-3 above.
- iv. The voluntary sector has a key role in supporting clients and carers in representation. Organisations should have systems which not only provide opportunities for participation within the organisation but also encourage individuals to further develop interests, knowledge and skills which can be used outside the organisation. Voluntary organisations also have a role in educating clients about the systems of participation in addition to their function of linking clients and carers to groups who have vacancies for representatives.
- v. The service users and carers have a vital function in sharing their expertise, knowledge, and "lived experience" with staff of statutory and voluntary services to ensure that these agencies can provide the best match to the needs of people who experience severe mental illness and their families and carers. It should be made clear to representatives when they are approached to provide comments whether it is their individual views which are sought or whether they are there to voice the views of other clients or carers. If the individual is representing the views of others they should gather opinions and provide feedback to the people they are representing. Other organisations should set up systems to support clients and carer representatives to do this.

5. Please identify examples of good practice in encouraging full and genuine participation by users and carers in all aspects of mental health services.

We believe that Hafal's Recovery/ Empowerment Programme and our Partnership Compact are examples of good practice. Both initiatives are integral to the daily work Hafal does at service and strategic level. At Hafal we encourage and support clients to be central in making decisions about their lives and recovery, to play a part along with fellow clients, volunteers and staff in the running and management of the local Hafal service, to engage with local consultation either by becoming client/ carer representatives or feeding information into the systems, to have a say in the Wales-wide charity through membership and finally to campaign and explore ways of responding to major mental health issues such as the draft Mental Health Bill.

6. In addition, the Committee would be interested to have evidence on whether people with mental health problems feel stigmatized and if so what should be done to eliminate it.

Being stigmatized is the experience of many of the people (clients and carers) with whom we have daily contact. Stigma and discrimination are evident at many levels, from name-calling to employment barriers. Hafal's approach to combating stigma and discrimination has a number of strands. These include working with each individual so that they feel empowered and view themselves as "equal" to others in their community, running projects and carers groups that work in partnership with non-mental health organisations and agencies, and educating the public by using positive stories in media and campaign work.

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Further evidence to be made available: "You're the Expert" survey and The Recovery Programme Document.