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Service user and carer participation toolkit

The term service user is used throughout this guidance, and refers to those people who have used or are using substance misuse services provided by health, social care and third sector organisations across Bridgend County Borough. This is a local determined term but other terms such as survivor, client, patient, or customers are equally as valid.

The term carer is also used throughout this guidance, as it is used to refer to people who look after family members or friends who need care, help or support. Carers can be of any age and support a wide range of needs. It does not however refer to carers who provide support as part of their voluntary organisation or that of paid care.

This guide recognises that the active participation of people who, because they have used services, or supported someone who has used services, brings a plethora of knowledge and experience to contribute to the design, planning, delivery and evaluation of services at a local, regional and national level.

The document is split into two sections. The first section explains the rationale for a user and carers participation and the second section outlines the charter itself for organisations and partnerships to sign up to its principles.



Background

Who the toolkit is aimed at

The primary audience for this toolkit is aimed at service providers and commissioners. It will also be of value to those service users and their supporters who wish to become more actively involved in the design, planning, delivery and evaluation of substance misuse services. This toolkit can be used as a guide for users and carers to refer to from time to time.

The toolkit is designed to be used by all services regardless of size, source of funding, structure or client group. It has, where possible, sought to provide guidance as to the suitability of different forms of user and carer participation for specific types of service. However, it is guidance and ultimately, the successful implementation of any particular form of user and carers participation is dependent on a clear, shared understanding of the aims of involvement and the ongoing enthusiasm and commitment of those involved.

The development of service user and carer toolkits and charters are not a new concept for Bridgend County Borough, with such guidance being in place for Children and Young Peoples Partnership, learning disabilities, older people and physical disability etc. However, it does demonstrate a strong commitment from partners to the true participation of users / carers within the substance misuse field.

User and carers participation is crucial as it is widely recognized and acknowledged that people experiencing substance misuse issues across Bridgend County Borough have the same rights and needs as the rest of society. As such, we aim to ensure that people who use services and their carers, are genuinely and constructively involved in all aspects of the service planning, design, delivery and evaluation.

Across Bridgend County Borough and the wider Abertawe Bro Morgannwg NHS Trust Community, there are a number service user and carer groups who are widely engaged in a range of service development and consultation. This guidance aims to solidify and renew this commitment to ensure that service users and carers are listened to and their contribution can lead to real and effective long term influence over how services are planned, developed and evaluated in years to come.

It's important to note, and this has been emphasised through consultation with user and carer groups, that service user and carer participation should not be seen as a one-off discrete piece of work, rather it should be seen far more broadly as a way to empower service users and carers to becoming an integral part of substance misuse service design and provision. As such, not only will commissioners and providers gain direct expertise but service users and carers will in turn be better equipped with skills, knowledge and confidence to make an active and informed choice about their level of participation in both substance misuse services and the wider community of which they live.

Why encourage service user and carer participation?

The concept of service user and carer participation emerged in the 1960s and 1970s through the disabled person's movement which called for greater user involvement. Its primary aims were to challenge the medical model of disability and for the inclusion of people living with disabilities in service design and delivery.

The principles of user and carer participation have continued to attract attention and greater importance has been afforded to involving members of the public, patients and service users in the design, delivery and evaluation of public services. Participation has become commonplace in the areas of disability, mental health and social care and more recently great progress has been seen in other areas such as substance misuse.

The benefits of true involvement are well documented and can be observed at a number of levels ranging from support groups, user and carer networks, consultation evaluation forms, face-to-face interviews, peer group forums, service management involvement and national strategy forums. Many other methods are also available and offer a range of benefits for both service users/carers and service providers.

Benefits to service users / carers

- It contributes to the development of open and transparent working relationships where individuals are valued and listened to;
- At an individual level, meaningful involvement allows active participation in treatment decisions and prevents individuals from becoming passive recipients of services;
- It provides individuals with opportunities to share their knowledge and expertise of what works and what does not work;
- It creates opportunities for users and carers to influence service delivery and service planning at local, regional and national levels;
- Where effective, user and carer involvement can increase and maintain self-esteem and self confidence and support their progression through recovery and rehabilitation.

Benefits to service providers

- They can learn more about the experiences of users and carers and encourage the development of closer working relationships between service users and staff;
- They can use these experiences to change current provision or develop additional services to meet the needs identified by its service users and carers;
- They can encourage service users and carers to express their views and use their energy and experience to make long-term improvements to service;
- They are able to use the information from service users and carers to evidence outcome measures and report to stakeholders;
- It enables the development of transparent and open services and decision making processes;
- Effective service user and carer involvement creates a working environment where both staff and service users /carers feel comfortable about expressing personal opinion – both positive and negative;
- Service user / carer involvement should be used to inform training and reflection on practice.

Benefits to service commissioners

- They will be able to ensure that service provision meets the needs of the local population;
- Information from user and carer involvement aids the identification of gaps in service delivery;
- Effective involvement informs and contributes to service reviews to drive up quality;
- It improves commissioners' abilities to influence the national debate by having better local information.



Common barriers to participation

Challenges of service user / carers participation

For service users / carers

- Definitions and understanding of service user /carer participation involvement can vary and this can lead to confusion about what it is and how people can become involved;
- Research indicates that some service users / carer often evaluate their relationship with their key worker rather than the service that they receive;
- Some service users /carers may be cynical about the value of service user involvement because their previous experience has been of a tokenistic nature;
- Service users / carers may be worried about expressing their view for fear of reprisal especially if they are dependent on services;
- Some service users / carers may not feel confident enough to participate in groups and must be given the opportunity to contribute at a pace and in a manner that meets their needs;
- Service users /carers can lose faith in the involvement process if they are not kept informed of what has or has not been done because of their involvement, or if there is no improvement to the service;
- Literacy issues can preclude some service users / carers from participating;
- Any cynicism expressed by service providers can affect service users/carers participation, either positively or negatively.



For service providers

- The variety of definitions of service user / carer involvement can lead to confusion for staff about what is being asked of them;
- Services can have difficulties changing where the culture of user / carer involvement has not been the norm;
- Staff may feel threatened by perceived criticism;
- Resource implications can create challenges for services to involve service users / carers;
- Services may need to try different models of involvement before finding the best model;
- Services may use a variety of models at any one time to engage service user / carers;
- The needs and abilities of service users / carers vary within services therefore different methods may have to be used at the same time;
- Services can, at times, find it difficult to establish a consensus with service users about the best way(s) to work together.

For service commissioners

- It will be necessary for service commissioners to improve their knowledge of user involvement and to include a clear description in the service specification of exactly what they want service providers to do and how that activity should be evidenced.



Currently activity

Where are people currently involved?

Local, regional and national best practice guidance recognises that the effective and efficient participation of service users and carers requires the active engagement in the design, planning and evaluative processes of services. Locally a variety of methods are used to formalise opportunities. This toolkit is being developed to further strengthen the expectations of the local Substance Misuse Action Team.

Locally, service users and carers are welcomed and sit around the same table as strategic service planners and as such have the opportunity to represent retrospective forums. Further commitment is required and has been provided locally in relation to ensuring service users and carers are able to participate by obtaining training around skills development and confidence.

Great investment has been provided across Substance Misuse Services in Bridgend County in relation to service user and carer engagement.

- BIG – Bridgend Involvement Group
- DIP users group
- Service user and carer Participation Officer
- Service user and carer engagement on strategic planning teams
- CARAT – prison based service
- DASH users forum
- WGCADA users forum.



Methods of engaging service users and carers

It is clear that this is no blueprint for service user and carer participation but a range of opportunities that if used effectively, could promote positive interaction between services and their users and carers. Equal to the importance of service user/carer participation is ensuring the right level of engagement is used – as different types of participation work for different people. Clearly however, the resulting effectiveness depends on how they are implemented. It is important to note that there is a specific safe guarding issue considering the vulnerability of clients both young and old and as such the differing levels of engagement should be matched and used appropriately to the individual.

Levels of engagement

As a basic commitment to genuine engagement and participation, SMAT and its partners commitment to:

Building confidence

Service users and carers have unique skills and abilities and more importantly are experts in their own illness and therefore experts by experience. This should be recognised by all partners and as such service users and carers should be equal partners around any table. However, it is vitally important to provide support and training to enable service users and carers to understand and analyse the information provided and on which their views are sought. Building of confidence is central to empower users and carers to articulate views into the planning and commissioning process.

Provision of relevant and timely information / papers

To effectively enable service users and carers the opportunity to formulate a view, adequate time via early delivery of papers so that service users and carers can digest papers / consult with forums prior to meetings is of crucial importance.

Suitability of time and dates of meeting

Where service user and carers engagement is required, appropriate through should be provided time of day meeting are being held. For example, early in the morning may not be suitable for sufferers with dual diagnosis or before 11am may not be suitable for carers. Further consideration should be given to decentralisation of meetings away from official statutory buildings to make meetings more accessible. Pro-actively attending areas where service users convene could also mean the removal of other barriers to participation.

Reacting to feedback provided by service users and carers

Service users and carers often react to engagement opportunities as being tokenistic as often, little feedback is provided to those engaged within service shaping. Feedback should be given demonstrating how user and carer views have been acted upon and being transparent with explanation when they haven't. Honesty is a highly valued quality which is respected by all service users and carers across the county borough.

Relinquish of power

Often when given the opportunity to engage, service users and carers can feel intimidated by professionals and as a result feel less able to have their voices heard. As such, to empower service users and carers to engage more effectively, partnership members who are on boards in a professional paid basis should relinquish a degree of their own power to build the confidence and esteem of others. Simple actions such as dropping job titles during introductions at meetings would be effective. For example, Mike Smith, Bridgend County Borough Council would be less intimidating than Mike Smith, Head of Service Bridgend County Borough Council.

There are a wide range of opportunities to engage with service users and carers and it's important to recognise that the standard public meeting / consultation events are not always suitable for all types of engagement. It's important to recognise a range of methods should be used when engaging effectively with those service users and carers within the substance misuse field so that all abilities and disabilities can be catered for. These can be used when looking at strategic or treatment planning.

- Involvement in assessment process;
- Involvement in treatment decisions;
- Suggestion boxes;
- User/carer written questionnaires;
 - one to one;
 - anonymous self completion;
 - independent one to one;
 - one to one working with current / ex service user or carer.
- Service users and carer representative forums;
- Consultation events;
- Direct contribution to planning teams and subgroups;
- Membership to committee and boards;
- Service user groups;
- Peer mentoring;
- Facilitation of training;
- Recruitment of staff;
- Appraisal of staff;
- Development of newsletters;
- Marketing and publicity of services;
- Involvement in tendering process for services;
- Facilitation of workshops;
- Scrutiny and evaluation of services.

Charter for user and carers participation

Working in partnership to achieve equality

We believe that all people should be treated with dignity and respect and have a voice that will be heard at all levels of local planning and partnership working. As such overriding principles are critical.

The Substance Misuse Action Team states that each partner organisation across the county borough should sign up to a local charter, which states the rights of people with experience of substance misuse and their carers to be involved in all aspects of service provision

The charter aims to ensure:

- That service users' and carers' involvement becomes an integral part of all activities that are concerned with mental health agencies and services.
- That a range of types of involvement are encouraged relating to individuals participating in decisions which affect their own lives and collective involvement in planning, development and monitoring.
- That things are organised (structures) and done (processes) in ways that make user participation both possible and a positive experience.
- That the development of independent organisations of service users and carers is actively encouraged and supported.
- That there are clear mechanisms developed for service user and carer involvement activities to influence decisions making.
- That service user and carer involvement has an identifiable impact on how substance misuse services are organised and delivered.
- That service-users and carers who are involved should always receive feedback on what happens to their contribution and what effect it has had.

All SMAT stakeholders believe that service user and carer involvement activity across Bridgend county borough should reflect and operate from the following set of principles and values:

- ✓ *That all service user and carer involvement activity is based and founded on anti-discriminatory practice.*
- ✓ *The development of service user and carer groups and service user and carer involvement are distinct activities, each needing resourcing. Each local agency should actively promote the development of service user and carer involvement forums within each service.*
- ✓ *Encourage and actively support the participation and involvement of service users and carers from diverse cultures and communities within each locality in a way that is acceptable and relevant to them.*
- ✓ *That such activity should recognise the intrinsic value of people regardless of circumstances by acknowledging their uniqueness, their personal needs and by treating them with dignity and respect at all times.*
- ✓ *That service user and carer involvement activity or involvement in a local service user or carer group should not be seen or used by substance misuse professionals as therapy or a part of an individuals treatment plan.*
- ✓ *That individuals who give their views and suggestions about substance misuse services do not have the threat of treatment or support withdrawn because of involvement.*
- ✓ *That all service user and carer involvement activity must defend the right of confidentiality for service users and carers who wish to make individual comments, observations or suggestions about local services provision.*
- ✓ *That individual service users, carers and representatives from user or carer managed projects can expect a non-threatening and safe environment where they can find a voice, express their ideas, observations and concerns.*
- ✓ *That all service user and carer involvement, participation and development projects in each locality should be subject to regular evaluation and review by service users and carers.*
- ✓ *That a diversity of methods should be used that enables service users and carers to participate in such a way that is appropriate to their needs and circumstances.*
- ✓ *Service users and carers require to be compensated for their own out of pocket expenses, e.g. travel and subsistence costs etc.*
- ✓ *Service users and carers should be seen as consultants within their field, due to their real life experiences and expertise, thus being paid a consulting fee for service.*

By agreeing to this charter, partners are agreed to ensuring active participation of service users and carers where:

- ✓ *Each service user and carer will be encouraged to ask questions and obtain a clear understanding of decisions making processes.*
- ✓ *Each service user and carer will be treated as an equal partner whose input is as important and paid staff.*
- ✓ *Each service user and carer will be treated with respect and courtesy by all staff, who will make expectations very clear.*
- ✓ *Professionals are trained on service user and carer involvement across the board.*
- ✓ *Services will aim at all times to consult in ways that best enable the service user and carer voice to be spoken freely and with confidence, and to be heard carefully and to good effect.*
- ✓ *Services agree that on issues which professionals wish users and carers engagement, existing user/carer groups should only be approached. It is not acceptable that individual users or carers who are not user or carer group members should be approached or co-opted.*
- ✓ *Services agree that consultation should be made formally to user and carer groups, by letter or by phone with adequate time and resource to formulate a response. Engagement in meetings should also reflect best practice.*
- ✓ *That individual service users, carers and representatives from user or carer managed projects can expect a non-threatening and safe environment where they can find a voice, express their ideas, observations and concerns.*
- ✓ *Involvement provides the opportunity to influence real changes. Professionals should only invite service users and carers to get involved if there is an opportunity to have real influence to shade away from possible tokenistic feeling of engagement.*
- ✓ *To encourage effective user and carer engagement – at times, professionals must be prepared to go to groups/forums rather than expect representatives to go to professional meetings.*
- ✓ *Resources are provided so that representatives are encouraged within forums and networks where they are able to access training and opportunities which will develop skills and experience.*

By agreeing to this service users and carers will expect:

- ✓ *To be full partners in the planning of their own services.*
- ✓ *To be supported to engage during meetings when required.*
- ✓ *To have meetings held in an appropriate format, at appropriate times and venues.*
- ✓ *To be involved in formal process for gathering views.*
- ✓ *To have support to communicate to forums/networks.*
- ✓ *To receive reasonable reimbursement of expenses incurred*
- ✓ *To receive good quality and accessible information in good time prior to meetings.*
- ✓ *To obtain good quality and appropriate training.*
- ✓ *To have agreed roles and responsibilities.*
- ✓ *To be kept informed about how their contributions have influenced planning.*
- ✓ *To be part of monitoring and evaluating services.*
- ✓ *To be actively part in the development of roles and recruitment where appropriate.*

Signature:

Organisation: Date: