

**Substance Misuse Treatment Framework  
Carers and Families of Substance Misusers  
A Framework for the Provision of Support  
and Involvement**

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## **Aim**

This document seeks to promote the benefits of involving adult carers and adult family members of substance misusers in the development of policy, and in the design, planning and evaluation of services for these carers. It also seeks to promote the involvement of them in the planning of their individual care plans.

It is aimed at adult carers and adult family members of substance misusers, service providers and commissioners within the statutory, voluntary and independent sectors and within the Criminal Justice System as appropriate.

## Definition

The term 'carer' is applied to people who are unpaid and look after family members or friends who are in need of care, help or support (Welsh Assembly Government). There is not a typical carer, and carers may often not recognise or describe themselves as such but see themselves for example primarily as parent, friend or partner.

To ensure an inclusive approach throughout this document the term 'carer' will be used in addition to family member and refers to anyone affected directly by someone else's substance misuse and whose aim is to provide support and help to them.

This document is targeted at adults carers and family members. However, it is recognised that substance misuse can have significant impact on children and young carers as identified in Hidden Harm (DH 2003). Agencies involved with adult service users should be alert to the possibility that there are young carers in the household, and involve the children's commissioning and provider bodies where this is appropriate.

## Background

Carers' issues form an integral part of the National health and social care agenda in Wales. In recent years there has been a growing recognition of the impact that an individual's substance misuse can have on family and friends. The evidence suggests that this impact can be both on physical and mental health as well as financial and social. (EIU)

The devastating impact that substance misuse can have on the family and carers is well documented. Adfam in *We Count Too* identified the following four key areas:

- Fear and loss of control
- Anger and betrayal
- Guilt and responsibility
- Shame and isolation

The precise number of family members and carers that are affected by someone else's substance misuse is not known. It is clear however, that the impact that any one individual can have can be widespread. Velleman (2002) suggest that for 'every substance misuser will negatively affect at least two close family members' to the extent that they will require primary healthcare service.

Substance misuse can have a major impact on carers and families as well as to the user. However, it must be recognised that carers and families have distinctly different needs and requirements for support than the person that they are providing support for.

Carers and family members of substance misusers are a diverse group and the stresses or problems that they may experience will be influenced by a number of factors which may include for example their own coping skills and mechanisms, culture and other stresses that they may be experiencing at that time in their life.

There are examples of good practice for both carer and family involvement and service provision but no single blueprint or service model which could be defined as the ideal or most effective. For services and developments to be effective they must be adapted to local need and circumstances (Department of Health) and consist of a range of co-ordinated services to meet carers' support needs and offer choice.

## Underpinning Principles

The following principles should be considered to underpin service developments or initiatives:

- Co-ordinated and quality services
  - Avoid duplication
  - Best use of resource
  - Effective
  - Evidence based
- Consultation and partnership
  - Involvement and active participation in all levels of policy, planning and reviews.
- Choice
- Equity
  - Of access to services and support regardless of age, gender, race, disability, sexual orientation, religion, culture
- Information
- Financial security
- Practical help
- Recognition
  - Individuals with own rights , expertise and need.

## Strategy & Policy Drivers

Carers are already recognised as key partners in the delivery of health and social wellbeing agenda in Wales. Both health and social care legislation and guidance, gives carers legal entitlements to assessment and support, which includes carers of substance misuse users.

Key Strategic and Policy Documents include:

- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- National Health Service Reform and Health Care Professions Act 2002
- Carers (Equal Opportunities) Act 2004
- Creating a Unified and Fair System for Assessing and Managing Care [“unified assessment”]
- Care programme approach
- Work and Families Act 2006
- Hidden Harm
- Fulfilled Lives
- Designed for Life
- Carers’ Strategy for Wales.

The key priority areas identified for action in the 2000 Carer Strategy in Wales are:

- Health and social care
- Information
- Support
- Young carers
- Carers and employment.

The Carers Strategy consultation (WAG 2006) recommends that the following are seen as key objectives for carers:

- are not disadvantaged as a consequence of fulfilling their caring responsibilities
- are listened to treated with respect and receive recognition for the important contribution they make in supporting people to sustain their independence
- are able to maintain as normal a life as possible outside of their caring role
- have timely access to an assessment of their own needs
- have access to services that will enable them to be properly supported
- are able to access employment, education and leisure opportunities.



Welsh Assembly Government identify that the refocused Carers Strategy will seek to ensure:

- better constructive engagement with carers as key partners in the planning and delivery of both health and social services
- better assessment and care management arrangements to ensure that people receive timely and appropriate services to meet their needs.

## Organisational Responsibility

All organisations with a responsibility for providing services for substance misusers are additionally required to consider carers' needs. Community Safety Partnerships have a lead role in the development and commissioning of services for carers and family members. Community safety partnerships have an overarching responsibility to reduce the harm caused by substance misuse to not just individuals but communities as a whole which includes the families and carers of substance misusers, whether or not the users are accessing treatment.

There is a growing body of research and evidence which identifies the positive benefits that the provision of dedicated support services for carers and family members can bring to the carer, family member and user. Carers provide invaluable support to those that they care for and this needs to be acknowledged by commissioners and providers to ensure that they can continue in their caring role and that their own needs are not forgotten.

When considering the development of support services for families and carers the key aims should be:

- the health and wellbeing of individual carers
- the health and wellbeing of family members
- family functioning as a whole.

To develop and maintain effective family and carer support services partnerships need to consider potential funding sources. Joint agency and cross boundary working is necessary to ensure a consistent approach and to avoid duplication. A range of support services will be required and these may be from open access to specialist.

Any developments should be based on local need assessments and will require the development of appropriate service specification and monitoring and evaluation systems. The following key messages should be considered:

Key messages:

- the needs of carers and families are separate and distinct needs from users
- local partnerships have a duty to actively involve carers in their planning processes, without dedicated support this is difficult to achieve
- for effective carer involvement support services need to be in place for carers and family. Support services should be reflective and use family and carer experience
- carers and family cannot simply be fitted into established models of care for substance misuse treatment and there needs to be a clear distinction between support for family/carers and the user.

## Carer Involvement

### Effective Carer and Family Involvement in Strategic Planning, Consultation and Joint Working

Partnerships and service providers will need to review their current systems to examine how carers can be meaningfully engaged in these systems.

They need to consider:

- How carers can be involved at all stages
- The use of jargon free language
- Development a systematic approach to involvement and engagement
- Identify information leaflets etc that carers can both contribute to and benefit from
- Identify a range of options to actively engage carers
- Sections of the community may be hard to reach and engage. The following documents containing useful information on how to engage carers
  - “We count too” (ADFAM 2005)
  - Challenging the Myth “They look after their own” (WAG 2003)
  - We Care too, a good practice guide for working with black carers (Afiya Trust 2002)
- Identify opportunities to consult and involve carers on specific issues which they may have a specific interest or expertise
- Provide feedback on consultations and involvement
- Link and ensure feedback between national, regional and local meetings.

### Supporting carers and families to actively engage at this level

- Consider carer advocates
- Focus groups
- Training opportunities
- Reimbursement of expenses (needs to reflect national and local policy)
- Buddy system
- Offer regular feedback about input and involvement
- Involvement in setting of the agenda and also venue and location for the meeting, and times
- Set up carer forums to gather collective information rather than the other way around and agencies go out to these groups
- Have pre meetings or discuss agenda or consultation questions etc so that questions can be considered and formulated in advance
- Models of Carer and Family Support.

## Rationale for commissioning and service provision for carers and family members

Although not specific to carers and families of substance misusers it has long been recognised that carer's health is in general less good than non-carers. A survey carried out in 2001 shows that nearly one in five - 21% of carers in the UK providing substantial care are not in good health compared to 11% of those who do not have caring responsibilities. The survey also showed that the more care a carer provides, the more likely it is that they will be in poor health, particularly if the care provided is over 50 hours a week.

In Wales, nearly 15% of all carers suffer from ill-health with 23.74% - nearly one in four of those caring for over 50 hours a week - counting themselves as being in poor health. Merthyr Tydfil has the highest percentage of all carers suffering from ill-health (18.72%), followed by Blaenau Gwent (18.08%), Rhondda Cynon Taff (17.74%), Caerphilly (17.55%) and Neath Port Talbot (17.45%). For those providing over 50 hours of care per week, over one in four (28.29%) in Merthyr Tydfil, Blaenau Gwent (28.14%) and Torfaen (26.82%) suffer from ill-health. (In Poor Health - The Impact of Caring on Health - Carers UK refers)

Carers and family members of people who abuse substances may be difficult to identify and support. Their role may be less visible to those outside of the family or local community and together with issues such as stigma they can fail to or not be aware of services that may be available to support them.

Research and evaluation identifies a number of positive benefits from the provision of dedicated carer support services for both the carer and user. The benefits for carers are:

- Reduces isolation
- Increases support for the substance misuser
- Working towards a shared goal
- Increased awareness of substance misuse issues
- Identification and recognition of family and carers own needs
- Improved communication (EIU).

Carer and family support can have positive impact on the service users:

- engagement in treatment
- retention in treatment
- attainment of successful outcomes.

## Developing Models of Service

### Identifying Need

Local needs assessment and service mapping should underpin any developments and identify priority areas for development. Prior to determining which option makes most sense for the local area, it is important to ensure that full consultation has taken place with key stakeholders.

A range and choice of support services need to be provided from open access to specialist provision. Access to these services will be set by locally agreed protocols.

Service mapping of current provision will provide a useful baseline and identify local services strengths and weaknesses, gaps and possible duplication. Partnerships may be aware of some of the provision but maybe unaware of many local initiatives which may not necessarily be seen as core substance misuse services or have been developed by carers and families for example.

Carers and families have separate and distinct needs from users. Focusing on these through the provision of dedicated support services will enable them to function more effectively and provide the opportunity for users to take responsibility for their own actions. (NTA) Research and consultation has consistently identified the following as being the underlying support that carers require (NTA):

- Information
- Respite
- Practical help
- Contact with other with similar experiences
- Short and long term support.

This may then inform next steps, examples are:

- Where limited provision exists capacity building may be considered
- Service specifications should be developed to ensure there is no overprovision or duplication
- Where the need for service provision is limited then consideration should be given to commissioning across CSPs
- Some areas will have well structured generic carer provision and working through this media may offer a way to develop specialist support
- Engagement with difficult to reach carers and families should be considered. Identify who they are and how can they be reached.

(adapted from NTA 2006)

### Service Provision

Effective carer and family support models are characterised by being flexible and responsive to a range and diversity of need and recognise that the need for intervention and support will not necessarily be time limited. Successful care and

family support services are those that identify and focus on the health and well being of their 'service user'.

A comprehensive menu for carer and family support services which offer a range and choice of interventions is set out in Chapter six of "We Count Too" (Adfam)

It is suggested that this should include:

- Supporting and advising carers
- Providing Information and advice
- Respite provision
- Support groups
- Bereavement support
- Engagement with criminal justice services.

Consideration must be given on how to work with and engage particular groups who are known to find it more difficult to access support e.g. men, black and minority ethnic, travellers. Targeted initiatives maybe an option for specific groups.

## **Levels of Support**

There is a statutory duty to inform carers of their right to a carer's assessment. Carers who provide 'regular and substantial care' are entitled under current legislation to receive a carers assessment, which should lead to a care plan and possibly access to relevant support and funding, e.g. for respite, as long as their needs meet the fair access to care criteria set by the local authority. The local authority has a statutory responsibility to carry out these assessments. This responsibility can be devolved to substance misuse providers by the local authority.

Open access services could include:

- Signposting by mainstream services to the appropriate substance misuse services
- Advice, information and education about substance misuse and treatment
- Drop in facilities which may offer 1 to 1 support and advice
- Harm reduction training
- Helplines
- Support groups
- Structured community based support and interventions. (An assessment of need can be carried out and a care plan produced by the organisation who will be providing these services).

Structured community based support and interventions can include:

- Structured psychosocial interventions (i.e. counselling), which may be time limited, depending on service capacity
- Telephone or outreach based structured counselling

- Respite and alternative therapies, where this forms part of the support plan.

Liaison with other specialist agencies, for example social services (in relation to child protection and criminal justice services).

Specialist service provision may include:

- Short stay residential provision
- respite and structured programmes of therapeutic intervention designed to relieve stress, raise self-esteem and identify coping strategies.
- group and one-to-one support therapy.

Structured services will be provided by fully trained staff, accredited by the relevant national bodies, e.g. BACCP for counsellors. (adapted from NTA 2006).

An assessment will be undertaken and a care plan produced and agreed with the carer by the Local Authority in accordance with the Unified and Fair Assessment system.

# Quality Standards

## Five Essential Requirements

The organisational processes that are necessary in order to deliver quality services:

**1. Family members affected by drug use are actively involved in the organisation.**

- Family members with personal experience have an effective voice in the service/group design, management, delivery, monitoring and review processes.

**2. The service works in partnership with other relevant local organisations and services:**

- The service has access to other services and good networks, which they use to contribute to making sure that families get co-ordinated support
- The service works jointly with other drugs services and family support services to maximise choice and opportunity.

**3. The service is clear about its principles, aims and focus and how these will be achieved and monitored.**

- The service is clear about its purpose and aims, eg whether it is focused on support and/or on campaigning.
- The service is clear about its target group(s), eg parents, grandparents, partners, children and young people
- The service has clear monitoring and review processes in place
- The service is clear about who it is accountable to and has a clear management structure
- The service has an agreed development or business plan
- The service has in place sufficient funding to deliver its aims in a sustainable manner.

**4. The service has in place policies, procedures and protocols covering confidentiality and its legal responsibilities. These include:**

- Confidentiality
- Data protection and record-keeping
- Health and Safety
- Insurance
- Complaints
- Equal Opportunities
- Legal and medical advice
- Child protection
- Drugs and alcohol in the workplace



- Volunteers
- Service specific protocols (depending on type of service provided).

**5. All service staff are appropriately trained and supported.**

- All staff (paid and unpaid) and management committee members/trustees receive the training they need to enable them to carry out their roles
- All staff (paid and unpaid) have clear roles and responsibilities
- All staff (paid and unpaid) receive regular support and supervision, including around how their personal experience impacts on their work.

('We Count Too' - ADFAM refers)