

Supporting and involving carers

A guide for commissioners and providers



National Treatment Agency for Substance Misuse

September 2008

The National Treatment Agency for Substance Misuse

The National Treatment Agency for Substance Misuse (NTA) is a special health authority within the NHS, established by Government in 2001, to improve the availability, capacity and effectiveness of treatment for drug misuse in England.

Treatment can reduce the harm caused by drug misuse to individuals' well-being, to public health and to community safety. The Home Office estimates that there are approximately 250,000–300,000 problematic drug misusers in England who require treatment.

The overall purpose of the NTA is to:

- Double the number of people in effective, well-managed treatment between 1998 and 2008
- Increase the percentage of those successfully completing or appropriately continuing treatment year-on-year.

Reader information

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Executive summary

This guidance is relevant for all those involved in the planning, commissioning or delivery of services specifically for families and carers, and drug treatment services.

Having a relative or friend who is a drug misuser is an extremely stressful experience, which can affect individuals' physical health and psychological wellbeing, finances, social lives, and relationships with others. These impacts often mean that families, kinship carers and other carers need help in their own right, to enable them to cope better with what are usually ongoing, long-term issues.

Not only is it important to help family members, kinship carers and other carers deal with these challenges for their own wellbeing, but appropriately including family members and carers in the treatment process often allows them to better support drug users. There is a good deal of evidence that suggests supporting and involving family members and carers effectively can lead to improved outcomes for family members and carers, as well as drug users themselves – this is summarised at www.nta.nhs.uk/familycarer.

Effectively involving family members, kinship carers and other carers helps users increase their chances of:

- Entering treatment
- Reducing or stopping their drug misuse
- Engaging with treatment if they do enter
- Being retained in treatment
- Successfully concluding treatment.

Drug users are also less likely to suffer major relapses. This leads to better quality of service provision overall.

National policy and guidance increasingly highlights the benefits of health and social care services involving and supporting carers. In June 2008, the Government published *Carers at the Heart of 21st Century Families and Communities* (DH, 2008), which set out the vision and framework for developing support for carers as a progressive process of change over the next ten years. The 2008 Drug Strategy (Home Office, 2008a) places greater emphasis on families and carers' needs. *Drug Misuse and Dependence: UK Guidelines on Clinical Management* (DH *et al.*, 2007) also states the importance of providing services for families and carers as well as appropriately involving them in drug misusers' treatment.

Effective support for family members and carers in their own right, and involvement of families and carers in drug users treatment can be achieved by:

- Commissioning consistent, effective and quality services for family members and carers who are affected by someone else's drug use, either through generic mainstream carer services or through specialist substance misuse family member and carer services
- Ensuring services that treat drug users involve family members and carers in their treatment, as far as this is possible and appropriate
- Involving family members and carers effectively in the planning and commissioning of drug treatment, and family and carer services
- Embedding effective monitoring systems and practices relating to work with family members and carers within commissioned services
- Local commissioners tracking delivery of these services via robust delivery assurance systems

1 Introduction

This guide covers three areas in relation to services for families and carers:

- Commissioning themes
- Developing services specific to families and carers
- Involving families and carers in drug users' treatment.

This guide has been published to support the improvement in availability and quality of services for families and carers, as well as improving the involvement of families and carers in drug users' treatment. The guide provides information for substance misuse commissioners and providers on the evidence base and good practice in commissioning and providing services for families and carers, as well as for involving them in drug users' treatment. In addition to the main guidance, Appendix 1 (NTA, 2008) gives details of the evidence base for family and carer services and Appendix 2 (NTA, 2008) provides further information for specific groups. The guide is accompanied by a document providing examples of family and carer services, which both commissioners and providers may find helpful.

For the purposes of this guide, a family member is defined as any adult person who is significant in the life of the drug user, irrespective of his or her biological, social or legal status. A carer is defined as anyone who cares for or offers support on a regular and personal basis to an individual, whether or not he or she has formal carer responsibilities and status.

This guide applies to adult family members or carers of primary drug users. Although many young people do provide care, this guidance does not focus on young people and children; however,

some of the guidance, for example on developing family friendly services, may apply to young people and children. Nonetheless, the focus is on working with adult family members and carers, and this guidance should be read in conjunction with Hidden Harm (Home Office, 2003), The Children's Plan (DCSF, 2007) and the separate NTA guidance on child protection contained in Models of Care for Treatment of Adult Drug Misusers (NTA, 2002b; 2006b). The guidance in this document builds upon and extends the NTA commissioning guidance Supporting and Involving Carers (NTA, 2006c).

The NTA recognises the significant impact that substance misuse has on families and their important role in facilitating recovery. Estimates suggest there were 330,000 people using opiates, crack, or both, in England in 2005/06 (Hay *et al.*, 2005). Supporting families and carers can significantly improve their ability to deal with the impact and consequences of having a substance-misusing relative. Involving families and carers can also improve the engagement and outcomes of those who would benefit from drug treatment. The NTA is committed to improving services for families and carers within the drug treatment system and through improved links and pathways to generic family and carer services, and other sources of support.

Substance misuse commissioners have been encouraged to commission services for families and carers as part of an integrated drug treatment system for several years. In 2006, the NTA published Supporting and Involving Carers, which gave guidance on commissioning services. In 2005, Adfam – commissioned by the Home Office – published We Count Too, an invaluable guide to commissioning and delivering quality services for families and carers. Consequently, there has been good progress in a number of areas, with a national growth reported in the commissioning of services for families and carers (either through drug-specific routes or as part of an area's wider strategy to meet the needs of all families and carers). Since then, the National Institute for Health and Clinical Excellence has reviewed the evidence for the effectiveness of couples and family therapy for drug misusers (NICE, 2007b) and the Department of Health has issued further guidance on involving carers in drug misuse treatment as part of the new clinical guidelines (DH *et al.*, 2007).

To build on this progress, the NTA is issuing this guidance to help further develop provision – and encourage areas that have not yet put in place robust provision – to consider how they may take this agenda forward. Commissioning partnerships that already provide a minimum level of service can focus on the development of an increasing range of services and better service quality. It is not intended that partnerships disinvest from one aspect of family and carer provision to invest in another as a consequence of this guidance.

1.1 Key messages

- Providing services to meet the needs of families and carers leads to improvements for families, carers, children and drug misusers
- Areas without provision, or with limited provision, can benefit from developing or expanding services for families and carers
- Developing a family-friendly focus will assist providers to achieve the best outcomes for users and carers
- Involving families and carers can improve engagement, retention and outcomes for drug users in treatment
- Involving families and carers in the planning and commissioning of services improves the effectiveness of services and the drug treatment system.

1.2 The national context

National policy and guidance increasingly requires that health and social services involve and support families and carers. The national strategy (DH, 2008) sets out a clear vision for the development of support for carers. Since the publication of Supporting and Involving Carers (NTA, 2006), further national strategies and guidance have demonstrated the need for improved services for and involvement of families and carers.

The 2008 Drug Strategy sets out the Government's aims for the next ten years in drug treatment and prevention, which include objectives for meeting families and carers' needs (Home Office, 2008). The strategy aims to address the needs of parents and children as individuals, as well as working with families to prevent drug use, reduce risk and get people in to treatment. Among its aims, the strategy intends to provide interventions for families, involve families and carers in the planning of services and encourage the provision of family-friendly drug treatment services.

In 2007, Drug Misuse and Dependence: UK Guidelines on Clinical Management was published. The guidelines follow current evidence and professional consensus, and provide guidance on the treatment of drug misuse in the UK. The guidelines address the importance of meeting carers' needs and involving carers in drug misusers' treatment, and recognise that families and carers are an important resource in treating drug misusers with their own support needs. They advise that where practical and possible, carers should be active partners in drug misusers care, and also provide specific information on the range of services that should be offered to carers to meet their own needs.

1.3 Clinical guidelines

Drug Misuse and Dependence: UK Guidelines on Clinical Management (DH *et al.*, 2007) reflects some of the considerable changes that have occurred in drug treatment over the past eight years and gives up-to-date guidance on good practice in the

treatment of drug misuse. It stresses the importance of specific services for families and carers, as participants in drug misusers' treatment.

The National Institute for Health and Clinical Excellence (NICE) issued two sets of guidance in 2007, on opioid detoxification (NICE, 2007a) and psychosocial interventions (NICE, 2007b). Both include recommendations on supporting families and carers, and give specific guidance on how families and carers may be able to support people with drug problems and get help for themselves.

The guidance states that staff should ask families and carers about, and discuss concerns regarding, the impact of drug misuse on themselves and other family members, including children. They should also:

- Offer family members and carers an assessment of their personal, social and mental health needs
- Provide verbal and written information and advice on the impact of drug misuse on service users, families and carers
- Provide information about detoxification and the settings in which it may take place
- Provide information about self-help and support groups for families and carers.

Where the needs of families and carers of people who misuse drugs have been identified, staff should:

- Offer guided self-help, typically consisting of a single session with accompanying written material
- Provide information and facilitate contact with support groups, such as self-help groups specifically focused on addressing families and carers' needs.

Where the families of people who misuse drugs have not benefited, or are not likely to benefit, from guided self-help and support groups, and continue to have significant problems, staff should consider offering individual family meetings. These should:

- Provide information and education about drug misuse
- Help to identify sources of stress related to drug misuse
- Explore and promote effective coping behaviours
- Normally consist of at least five weekly sessions.

The guidance on psychosocial interventions also makes specific recommendations on the involvement of partners in the treatment of drug misusers. NICE recommends behavioural couples therapy, which should be considered for people who are in close contact with a non-drug-misusing partner and who present for treatment of stimulant or opioid misuse (including those who continue to use illicit drugs while receiving opioid maintenance treatment or after completing opioid detoxification). The intervention should:

- Focus on the service user's drug misuse

- Consist of at least 12 weekly sessions.

The NTA is currently producing a toolkit on behavioural couples therapy, which will be published during 2008/09.

1.4 Who is the guide for?

The primary audiences for the guide are the substance misuse commissioning managers and joint commissioning group members within partnerships. The guide will also be of value to:

- Drug action team partnerships
- Carers' leads within primary care trusts and local authorities
- Family and carer support services
- Drug treatment services
- Service user and family and carer groups
- Regional Government Offices.

2 Commissioning themes

2.1 Benefits and barriers to family and carer services

There are a growing number of areas across England where family members and carers of people with drug problems are actively helped and supported. There are also some services for drug users that actively welcome family members and carers, as participants and supporters of the treatment process.

However, in many areas, there is potential to improve the availability and capacity of services for families and carers. There are areas where no services exist to help family members and carers deal with the negative impact of a relative or friend who has developed a serious drug problem. Families and carers can also feel marginalised within the drug treatment system and where a family focus is absent, they can feel discouraged from participating.

There are compelling reasons for supporting families and carers; for their benefit and the benefit of drug users and treatment services (Copello *et al.*, 2005; Liddle, 2004). The research is discussed in more detail in Appendix 1 (NTA, 2008). Key points include:

- Family members and carers need help in their own right. They are very often significantly affected by the drug misuse and frequently experience high levels of physical and psychological problems as a result
- Family members and carers need support to make informed choices about whether to continue caring for drug users and how to care for them in the most effective way, if they decide to continue

- Family members and carers are a good means to reach people who are not in treatment. The people who are most influential in getting them into treatment are often family members and carers. Engaging with family members leads to a significant rise in the numbers of drug users entering and engaging with treatment
- Some drug users never access formal treatment and recover or attempt recovery with only the support of family and friends. Reaching and supporting these family members and carers has the potential to aid the recovery of people in groups that are hard to engage through traditional services
- Supporting family members and carers improves support for drug users. If family members and carers receive help and support in their own right, they will be far more able to effectively help and support drug users. Moreover, if drug users do enter treatment, they are much more likely to stay in treatment themselves, more likely to re-engage if they drop out, and more likely to have a successful outcome if their family members and carers receive help themselves.

In this way, supporting carers not only helps carers themselves, but also improves treatment take-up, retention and outcomes for drug users, while bolstering the support they may receive outside of formal treatment. There are, however, barriers to commissioning services for families and carers. These can include:

- Concern over confidentiality, information sharing and record keeping
- Professional concerns about skills in relation to working with families and carers or concerns about an increase in workload and effects on service performance.

These can be overcome through effective commissioning, clear information-sharing protocols and staff development strategies to improve competencies at a partnership and provider level.

2.2 Models of service delivery

Partnerships currently adopt a number of models for commissioning family and carer services. Whichever model is used, it is important that families and carers can access the substance misuse expertise they need and the mainstream carer assessments and funding they may be entitled to, through establishing appropriate services and pathways. Family members and carers need support over a wide range of issues, including dealing with the criminal justice system, users entering or leaving prison, bereavement, harassment, domestic violence and alcohol use. Models of delivery for families and carers need to take account of these wide-ranging needs and ensure pathways to services that can meet them are part of the local framework.

Current models for delivery include:

- Substance misuse specific family and carer services commissioned as an integral part of the local drug treatment system. These are often standalone services with links to local drug treatment and other services. Where they are provided by the local drug treatment provider, it is important that they offer a discrete service for families and carers in terms of content of the service and the space it operates from. Families and carers may not want to share space with drug treatment users when accessing services to meet their own support needs
- Services for substance misuse carers commissioned as part of local authority carer services

There is a risk that mainstream generic carer centres do not have the specific substance misuse expertise required to provide relevant services for substance misuse families and carers. This can be addressed through training for mainstream carer staff or by commissioning substance misuse specific services. There is also a risk that specialist substance misuse services are not equipped to ensure families and carers access mainstream carer entitlements they may be eligible for. This can be addressed through staff training or by commissioning these services from a mainstream generic carer centre.

Many partnerships choose to commission a range of services, including substance misuse and generic provision, to ensure all aspects of need are met. Commissioning partnerships may wish to commission jointly for some components of a comprehensive range of services for families and carers. Whichever model is adopted, there will be a need for joint working across local areas including treatment services, substance misuse specific family and carer services, local authority carer services, the criminal justice system and other agencies that are potential sources of support.

2.3 Planning, commissioning and consultation

The needs of families and carers will best be met through cross-cutting solutions that are the responsibility of a range of partnerships including drug action teams, crime and disorder reduction partnerships and local safeguarding children boards. When planning and commissioning family and carer services it is useful to take into account where this agenda overlaps with other local priorities, and how they can contribute to the aspirations of the local strategic partnership or targets contained within local area agreements.

The NTA guidance Supporting and Involving Carers (NTA, 2006c), the NTA's Commissioner's Resource Pack (NTA, 2002) and Adfam's We Count Too (Adfam, 2005) provide support for commissioners and providers on setting up family and carer services and embedding quality standards within services. Services are commissioned most effectively when families and carers are actively involved in their planning, commissioning and consultation. Partnerships and providers will also benefit from

establishing a named lead for family and carer issues within their commissioning teams or organisations. The NTA's commissioners resource pack (NTA, 2002a) suggests the commissioning cycle includes:

- Assessment of needs and auditing of current provision
- Strategic planning – determining priorities and agreeing commissioning aims through a consultative and partnership approach
- Operational planning, including building provider capacity and preferred quality assurance systems
- Purchasing activities, including specifying services, identifying funding and contracting via service level agreements
- Monitoring, evaluating and reviewing contracts and performance.

2.3.1 Needs assessment and auditing current provision

The Needs Assessment Guidance for Partnerships (NTA, 2007) states that family members and carers are an important element in the delivery of treatment and should be fully included in the needs assessment process. The guidance outlines a range of methods for assessing needs, which apply to drug misusers and their family members and carers.

In order to assess needs, estimates are developed to clarify the size and range of needs among the local family and carer population, and it is important to also identify hidden need. Working with the drug treatment agencies to identify the number of users who are being supported by a family member or carer and consulting them about their needs will help this process. It is also useful to build partnerships with local community organisations where family members and carers, particularly from black and minority ethnic communities, may be receiving informal support.

In many areas, some form of provision for carers and family members already exists, although partnerships are not always aware of this. These can include self-help groups, community groups, support offered through generic carer centres, mental health groups and social services departments. In auditing current provision, it is important to make contact with these services as well as more established ones. It is also useful to audit existing provision against the menu of services in We Count Too (Adfam, 2005). Even in areas with well-established and resourced family and carer support services there may be gaps in relation to certain aspects of provision.

2.3.2 Strategic planning

Having developed a comprehensive needs assessment, local partnerships can move on to determine their commissioning priorities and aims. These may contribute to local strategic plans as and when partnerships develop and continue to update them.

Developing such a plan would be likely to involve actively consulting family members and carers as well as generic carer centres and treatment providers. A local plan may identify local needs, gaps in provision and options for service delivery development to meet identified need. Where there is little provision, a partnership may decide to undertake capacity building work. Where there is a competing range of provision, service specifications may need clarifying or services remodelled. Where generic carer provision is well developed but substance misuse support is limited, it may be the best option to develop services within the local carer centre. Partnerships may also wish to commission jointly where they have similar needs and common priorities.

2.3.3 Operational planning

Implementing the strategic plan will involve identifying local services and pathways to meet identified need. Where there is limited provision, services may best be developed through local capacity building. This can include developing self-help groups and projects, commissioning pilot initiatives, commissioning targeted initiatives aimed at specific groups, and developing partnerships with local community groups, including black and minority ethnic groups and women's groups. It is also useful to encourage partnerships between local family and carer services and community groups.

Before proceeding to purchasing specific services, partnerships need to decide the preferred quality assurance systems. There are suggested quality standards for family and carer services in We Count Too. Partnerships may also wish to require services to comply with more detailed organisational standards including systems for self-assessment and the relevant staff competencies included in the Drug and Alcohol National Occupational Standards (DANOS) standards (Skills for Health, 2008).

2.3.4 Purchasing, funding and contracting

Once commissioning moves beyond the stage of funding small or pilot initiatives, service specifications underpin the development of family and carer services. Service specifications include clear aims and objectives, realistic and measurable targets, quality standards, joint working expectations and staff competencies. These are reflected in more detail in service level agreements, which include these relevant conditions together with the contractual framework and reference to legal requirements, policies and procedures.

When contracting services it is essential that providers are able to demonstrate comprehensive understanding and experience of the impact of drug use on families, carers and local communities. It is also important for providers to demonstrate how they will ensure clear separation between provision for family members and carers, and provision for drug users. This is particularly relevant

where services for families and carers are delivered by the drug treatment service.

Currently, family and carer services are funded by a variety of sources, ranging from one-off charitable donations to sustained funding from statutory sources. It may be possible for partnerships to access a range of funding from local and national sources, particularly where strategic plans have made links with other local priorities or agendas. It is important that funding and contracting processes meet quality commissioning standards, including those in the voluntary sector compact, particularly where small voluntary groups are providing services.

2.3.5 Monitoring, evaluation and review

Effective service delivery is supported by regular monitoring and review of relevant service performance information. Providers are assisted by clear aims and objectives, reflecting local outcome measures agreed with local commissioners and set out in service level agreements. Local outcome measures need to take account of the size and nature of the service. Those designed for treatment services are, on the whole, inappropriate for family and carer support services. Areas where providers can usefully collect data and where aspirations for delivery can be set include; numbers in contact with services, repeat contacts and levels of service provided, self-reported measures of progress and data and targets relating to specific under-supported groups.

Partnerships will also want to establish compliance with governance standards, staff management and development and partnership working. Commissioners and providers can make use of service audits as a tool for establishing compliance against a range of quality standards. Robust performance management structures, including relevant outcome measures written into service specifications, may enable commissioners and providers to ensure that family member and carer services in their areas meet the needs identified.

2.4 Diversity issues

It is important to bear in mind the needs of specific groups when commissioning services for families and carers in their own right (see Appendix 2 (NTA, 2008)). A comprehensive needs assessment will assist with this process as will a mapping of existing services. There are particular groups known to find it difficult to access support, including black and minority ethnic communities, people with disabilities, partners, men, grandparents, and lesbian, gay, bisexual and transgender people. People in rural communities can also find it difficult to access services. Targeted approaches to ensure services reach these groups can be effective and can include outreach services as well as developing partnerships with diverse groups, community groups and faith groups. Established family and carer services can also build effective links and partnerships with those who

provide services for these under-supported groups. Substance misuse family and carer services are – for the most part – run by and used by women, and services can consider approaches for involving men, including setting up men-only support groups, using computer-based communication and developing roles for men as volunteers. Issues for and responses to particular groups are discussed in more detail in Appendix 2 (NTA, 2008).

2.5 Support when there is co-existing domestic violence

Domestic violence and aggression accompany many instances of drug misuse. It is important not to make assumptions about violence and aggression. For example, most is directed from men to women, but sometimes the reverse occurs, or there is violence and aggression in both directions. Sometimes the drug misuse is a consequence of previous or concurrent violent abuse. The key point is that services are aware of domestic violence and are able to identify a family member or carer for appropriate support or have had training to enable workers to work with the issue themselves. The Stella Project has undertaken considerable work on drug and alcohol-related domestic violence, including best practice in delivering services to those affected, including families and children (see section 6.3).

2.6 Considerations for staff in specialist services

Family members and carers may need information and training on specific topics, to enable them to adequately and safely care for the drug user and themselves. If services are to effectively identify, assess and intervene with family members and carers and involve them in the treatment plans of drug users, their staff will also require training, ongoing supervision and support. There are a variety of potential challenges for staff as drug treatment services become more family and carer focused, which training and ongoing supervision and support can address. These can include:

- Negative perception of families and carers – staff within drugs services viewing family members as over-involved and interfering
- Differences of opinion between family members or carers and treatment staff over treatment regimes
- Worries over workload – staff concerns that carers' needs will overwhelm their capacity
- Lack of training in holistic approaches – staff within drugs services only having skills to work with single individuals, or with groups of individuals who all have the same problems, rather than families
- A lack of knowledge of entitlements to benefits and mainstream support for families and carers.

These concerns can be addressed by a measured pace of well-communicated, planned change within services, as well as

specific training for staff. Where many professionals have accessed some training in relation to the effects of substance misuse on the user, few have undergone specific training on the impact of substance misuse on family members. Many staff will benefit from awareness-raising training about carers' experiences and challenges when looking after a drug user. Partnerships and commissioners can address these issues so that generic and specialist substance misuse professionals:

- Challenge their own perceptions and negative attitudes to families and carers of drug users
- Feel better equipped to identify family members and carers
- Feel better equipped to respond to their needs
- Know how to involve others and refer on, as appropriate.

Partnerships and providers can raise this level of family and carer awareness and competence within staff teams by setting ongoing goals for services such as:

- Ensuring that regular and competent supervision is provided for all staff, and that ongoing family and carer training is provided
- Induction into the team or service reflects this treatment philosophy
- Services that provide support for family members and carers map the job descriptions of each of their staff (paid and unpaid) against the relevant DANOS (Drug and Alcohol National Occupational Standards) standard.

3 Providing specific services for families and carers

3.1 The impact of substance misuse on families and carers

It is hard to accurately estimate how many people may be affected by the substance misuse of someone else. UK reports have estimated that as many as 17 per cent of the population are likely to be family members affected in this way. Included within this figure is an estimate that between 8–12 per cent of all children are affected by parental drug and alcohol misuse (Velleman and Templeton, 2005a, b). This guide does not specifically address children's issues; however, children will inevitably benefit from work with adult carers.

Substance misuse can have a negative impact on the nuclear family, the wider family and the social networks and communities within which substance misuse occurs, with children and young people particularly affected. As well as affecting their physical and psychological health in acute ways, family members, as children and adults, are also at risk themselves of developing more chronic problems, including misusing substances themselves, and are at

risk of becoming involved in a range of antisocial and criminal behaviours. Substance misuse rarely occurs in isolation and other co-existing problems – such as mental health problems, isolation, deprivation, unemployment and domestic abuse – are often present. The anger, shame and embarrassment family members can experience often means that help is not sought and the problem remains hidden from those able to offer help and support (Copello *et al.*, 2005).

However, studies show that although family members experience these types of serious problems, there is a range of resilience factors and processes that can positively influence an individual or family response to substance misuse. These include planning and coping strategies, problem solving skills, ability to deal with change and building confidence and self esteem. Services commissioned for family members and carers, or those that involve them, will want to incorporate measures to increase resilience (Velleman and Templeton, 2007).

There is good evidence that, if family members get help themselves, there are considerable positive effects on users. There is also some evidence that the intervention can, in some cases, lead to a change in the problem alcohol or drug consumption of the relative and that this in turn can lead to improved family relationships. There are a variety of interventions aimed at assisting family members, many of which show significant improvements in a wide range of family and individual functioning, and although aimed at assisting family members, often have considerable impact on substance-misusing relatives (Copello *et al.*, 2005).

3.1.1 Improvements for families and carers

We know that family members and carers frequently have problems associated with having a relative or friend with a serious substance misuse problem. There is good evidence that family members benefit from such help, with outcomes such as reduced symptoms, better coping mechanisms and better quality of life. These improved outcomes are not confined to single family members, but can often be seen across the family unit as a whole, where positive outcomes include greater resilience on the part of children within the family, which in turn reduces the chances of them going on to develop substance misuse and other problems (Copello *et al.*, 2005).

3.2 Key principles in providing family and carer services

When providing family and carers services, the following principles are important:

- Families and carers have separate and distinct needs from users, which may conflict with them
- Families and carers may or may not be in contact with the drug user

- Family and carer support services need to reflect and draw on family members and carers' own experiences and expertise
- Partnerships have a lead role to play in commissioning services for family members and carers
- Staff in services have a lead role to play in encouraging users to work with family members and carers
- Family and carer involvement in existing drug treatment services works most effectively when dedicated services for families and carers are also in place.

3.3 What would a family and carers service look like?

When providing services for families and carers, there are a number of key components. A comprehensive family and carer support service would provide a variety of interventions for the range of challenges families and carers face when looking after drug users. These could include:

- Information and advice specific to drugs and addiction, via written publications, drop-in sessions and helplines
- Practical support, advice and information not specific to drugs, in areas such as housing, benefits, education and employment
- Support groups that are accessible to a range of carers and family members, for example partners, parents, grandparents, children and siblings
- One-to-one support, provided ideally via both outreach and centre-based provision
- Services which are available to whole family groups (as opposed to individual family members), to enable them to work through issues as a family
- Respite provision and personal learning opportunities.

In addition, it is helpful if services develop:

- Specific support in partnership with criminal justice focused services
- Specific support relating to bereavement.

There are also a number of areas where family members and carers may need training, to protect their own wellbeing as well as that of their loved ones. These include:

- Understanding substance use
- Setting and keeping boundaries
- Overdose training
- Harm reduction training concerning blood-borne viruses, including the necessity for agencies to promote the need for (and develop procedures to enable) family members to be inoculated against hepatitis A and B.

- Giving out safe-sex packs to any family member or carer who requires them.

In particular, when working with and supporting families and carers, it is vital to understand the impact of the caring role on the family member and carers and to take a needs-led view when working with them. Depending upon their circumstances, while some families and carers simply require information on the person's condition and treatment, others will need focused emotional, practical and advocacy support. This can ensure both family members and carers, and drug users receive adequate services and support. Once again, it is vital to understand that family member and carers' needs are distinct from users' needs (NTA, 2006c).

3.3.1 Local authority carer assessments and benefits

Under the Carers and Disabled Children Act 2000, all carers who provide "regular and substantial care" are entitled to receive a local authority carer assessment, which should lead to a care plan and possibly access to relevant support and funding where carers meet the Fair Access to Care criteria (DH, 2002). As the disabled person neither needs to have been assessed nor receiving services, some carers of people who have refused help will be eligible for an assessment. Carers also do not have to ask for an assessment; they have the right to be offered it by local services under the Carers (Equal Opportunities) Act 2004 and the Carers Recognition and Services Act 1995. Guidelines on eligibility are available from the Department of Health (DH, 2002).

Carer's Allowance is the only statutory national benefit available solely to carers. To be eligible carers must be over-16, not earning above a certain threshold and spend at least 35 hours a week caring for a person in receipt of Attendance Allowance or Disability Living Allowance. Carers may be entitled to a local authority Carer Assessment and may be entitled to services paid for by Carer's Grant, whether or not they are receiving Carer's Allowance.

Although there may be a minority of substance misuse affected family members and carers who qualify for these statutory services and benefits, it is important that partnerships establish a local pathway to these services for those who may be eligible. This could be through substance misuse specific family and carer services that are commissioned to provide this service or through generic carer services or social services that provide the service locally.

3.3.2 Assessing family members and carers

This guidance recommends that services providing structured interventions for family members and carers should carry out a simple assessment of their needs, leading to an agreed support plan. This process need not be as detailed as assessment and care planning for drug treatment; however, there is useful material

to refer to in the NTA's Care Planning Practice Guide (NTA, 2006a).

The depth of the assessment should be considered and should be in line with the capacity of the service to meet identified needs. Clients of family and carer support services often start by focusing on the drug user – the purpose of an assessment is to focus on families and carers' own needs, so information and discussions around the user should be kept to a minimum in the assessment process. The assessment should be carried out by a staff member who is competent to carry out an assessment of need.

A family member and carer assessment would include personal and contact details, including any information required for monitoring purposes, as well as the following areas:

- What the family member or carer wants to know about, for example substance use, relevant harm reduction measures (such as safe sex for partners), treatment services and the criminal justice system
- The family member or carer's relationship with the user, including whether the user is living with them and how well they communicate
- Impact of drug use and the user's behaviour on the family member or carer's feelings and personal functioning, including physical and mental health, and social and professional life
- Impact of drug use and the user's behaviour on relationships with other members of the family and close friends
- Whether there are domestic violence or harassment issues
- Whether the family and carer has been involved with the criminal justice system
- Any child protection issues
- How the family member or carer copes or deals with the drug use and the user's behaviour, and the effects of that coping
- How much and what type of social support the family member or carer receives, as well as what they feel they would need to continue caring
- Discussion of the family member or carer's goals for the next six months in terms of the issues identified through the above assessment.

Once clients are aware of the range of services they can access, it is important to agree which of these will be helpful in terms of achieving their goals.

3.3.3 Developing a support plan

A simple support plan can be developed from the family member and carer assessment, which sets out what services they will receive. The family member and carer's support plan will include a date when progress is to be reviewed (normally every 3–6

months). It will also include realistic, agreed goals for the carer, around areas such as:

Self-care

- Risks, and family and carer safety; for example learning how to minimise harm, changing the locks and only allowing users in the house when they are calm
- Improving the family member or carer's emotional and physical wellbeing, for example anger management, fewer arguments with other family members and reducing self-medication
- Using other sources of support, information and advocacy, such as going out to meet friends more often (or at all)
- Identifying own interests and exercising choices, for example education (attending a further education or training course), work (going back to full-time work, or taking up part-time employment) and leisure (taking breaks and having a respite from caring).

Supporting caring responsibilities for drug users

- Being informed about substance misuse problems, the effects of drugs on the user, harm reduction and treatment approaches
- Learning how best to help and assist their drug misusing relative, for example not paying for the user's drugs and overdose management skills.

Supporting caring responsibilities for the wider family

- Recognising the impact of the relative's substance misuse, for example minimising the implications of a parent's substance misuse on his or her caring role on children in the family

Support plan review meetings assess progress toward current goals, assess any changing circumstances and set new goals. Feedback from clients and workers on the support plan process can assist service development by providing information on the usefulness of different aspects of the service.

4 Involving family members and carers in treatment services

This section identifies the key principles for appropriately involving families and carers in drug users' treatment. There may be instances where it is not appropriate and their involvement will have a negative impact. Taking into account the family context in all assessments will determine whether and when family and carer involvement is appropriate in drug users' treatment. This section then outlines ways of increasing levels of family and carer involvement where it is appropriate, and how these are supported through needs assessment, care planning and information sharing. Finally, the approaches agencies can take to facilitate

more effective involvement of families and carers within treatment services are discussed.

4.1 Family and carer involvement with drug misusers' treatment

The evidence base suggests that family and carer involvement helps drug misusers at all stages of the treatment journey: it assists and encourages the users to engage in treatment, it helps retention, and it can speed successful throughput and reduce treatment dropout (Copello *et al.*, 2005). It is associated with more positive outcomes, both drug-related (reduced illicit drug use and progression to abstinence) and social (reductions in legal, family, employment and violence problems, and greater improvements in psychosocial functioning of children). Family-based engagement strategies have also been shown to make a significant difference in the treatment engagement rates of young people (Liddle, 2004). There is a growing evidence base for behavioural, community-reinforcement and family approaches, showing that involvement of concerned others can lead to improved outcomes in treatment for drug and alcohol users (Stanton *et al.*, 1983; Stanton and Shadish, 1999).

4.2 Key principles in involving families and carers

Key principles for effectively involving families and carers when commissioning services include:

- Building in family and carer involvement in care planning and care plan reviews into treatment service specifications, when commissioning or reviewing services
- Developing care pathways defining how families and carers can access help, advice, and support, both for themselves and in conjunction with their drug-using relative.

Key principles for effectively involving families and carers when providing services include:

- Taking a holistic, whole family approach, in relation to the impact of drug misuse on others, and families and carers' contributions to addressing it
- Including standard questions in drug user assessments about whether the user has a family member or carer, and what support they may require, followed up by the offer of a family member or carers assessment to any of those identified
- Offer all family members and carers information (such as on the specific addiction, treatment and how to look after themselves as carers) and a referral to family and carer support services
- Training treatment service staff on the impact on families and carers of drug use, and on support offered by family and carer support services. Enabling specialist staff to develop the

competencies to offer psychosocial interventions to families and carers where these are indicated

- Joint working between treatment services, family and carer services and other local agencies who may be a source of support.

4.3 Levels of work with family members and carers

As these principles become embedded in treatment services, services become more family and carer focused. Services will move through four different levels of working with families and carers as a result of this process. This can be assisted by having a named lead for families and carers within the team to champion and support the work. This model was developed during discussions of the NTA Carer Advisory Group, which led the development of this guidance. General principles can be found in Copello *et al.* (2005).

1. The first level is simply to be family-friendly, which includes welcoming family members and carers into the service. This can be demonstrated in many ways, such as giving family members and carers plenty of information about drugs and their effects, inviting them to assessment sessions, providing friendly waiting environments and making sure the service is sensitive to families' varying circumstances and backgrounds (BME families, single parents, stepfamilies and grandparents). Services can also consider childcare arrangements and making links with other local services, which may assist with family issues that enable the family member or carer to attend the treatment service if they wish. Family members and carers are probably starting a new journey in their lives at the same time as drug users. When substance users engage, it represents an opportunity for family members and carers to engage for the first time too – this can be capitalised on for the benefit of all concerned. Information can be provided to the service user to give to family members and carers as appropriate
2. The second level is offering the opportunity for carers and other family members to see someone to discuss their own situation, and to offer support and specific interventions to assist the family member or carer
3. The third level is offering to see users and family or carers together, and involving the family member or carer in the user's treatment, and ensuring that the course of action pursued by the user and the agency is understood and shared with the family member or carer. This can be relevant at all stages of the drug user's treatment journey, including during aftercare. Clear agreements need to be drawn up with the user and family member or carer about confidentiality and information sharing. In all circumstances, family members and

carers need information about drugs, addiction, treatment, and local services. Beyond this level, information-sharing agreements will necessarily be a balance between the user's wishes, and the need to enable families and carers to make informed choices about the amount of care they can safely and effectively provide. Protocols need to be established that clarify how and when information will be shared and with whom, including any circumstances in which confidentiality may be breached. Service information-sharing protocols need to be established and regularly reviewed between all parties.

Further guidance on information sharing with carers is contained in *Carers and Confidentiality in Mental Health* (RCPsych, 2004). It is good practice for the drug user and family member or carer to have different keyworkers if having separate sessions. Relevant confidentiality and information sharing agreements need to be understood and adhered to

4. The fourth level is offering specific, evidence-based interventions developed for work with either families and carers, or users and family members and carers together.

The subsequent sections outline a path to increasing levels of family and carer involvement within treatment services.

4.4 Including family members and carers in the assessment of drug users

Information can be routinely gathered from drug users about their family members and carers as part of their own assessment. The information can be used to help assess the families and carers' needs and can be achieved in a number of ways, including:

- Asking drug users during their own assessment about their opinions on the needs of their carers and family
- Asking drug users whether they are happy for the service to send information about drugs and drug services to their families and carers directly
- Asking drug users for consent for families and carers to participate in their treatment and assessment sessions
- Enquiring about young people affected by the adult's drug misuse
- Undertaking an appropriate assessment (for example, via the drug-misusing parent who is currently being assessed) of the needs of these young people
- Referring any young people to appropriate local services.

Clearly, a key element of the assessment of family members and carers, and drug users is their own willingness to be involved in this way, which remains their decision. However, to encourage both users and families or carers to be jointly involved, staff can stress that:

- The involvement of members of the drug user's social networks who are able to encourage change is an important step in reducing or stopping drug misuse
- Family members are among those most likely to encourage and support that change.

However, users and family members or carers' expectations in the care planning process need to be handled carefully, to ensure that users themselves, not carers, take primary responsibility for treatment engagement and outcomes.

4.5 Family member and carer assessments and support plans

Family members and carers will need to have a full assessment of their own needs, offered separately from the needs assessment of the drug user. It is helpful if the local model of service delivery can offer the family member or carer a choice about where the assessment takes place depending on their preferences and needs. When undertaking an assessment, staff should bear in mind that carers will often be focused on the needs of the drug user. Instead, the purpose of a family member and carer assessment is to focus on their own needs, so discussion about the user should be kept to a minimum in the family member and carers' assessment process. Assessments are carried out by a member of staff who is trained and confident in undertaking this responsibility. The family members and carers assessment and support plan is covered in more detail in sections 3.3.2 and 3.3.3.

4.6 Confidentiality and information sharing

It is clear that joint working between drug misusers and family members or carers is only appropriate if all parties are willing participants. Where joint working is appropriate it is supported by clear confidentiality and information sharing protocols which are understood by all parties. Organisational confidentiality procedures should be explained to clients, family members and carers when they first engage with a service. This will cover what information is confidential and to whom and when the agency has a legal obligation to breach confidentiality.

Where clients and family members or carers agree to joint working, it is useful to also have information sharing agreements which describe what information will be shared, by whom and when it will be shared.

Where family members or carers and drug users are working with different services, there will need to be agreed information sharing protocols and policies across the agencies that are clear and understood by all participants.

4.6.1 Levels of information sharing

Level 1: To provide information about drugs and services on offer.

Level 2: At a first session with a drug misuser, a basic confidentiality and information-sharing agreement is introduced, explaining that it is often helpful for family members and carers to be reassured that the person is seeking treatment but that no other information will be shared. If clients consent, the agency can inform family members and carers that clients are being seen, how frequently, their next appointment and if they miss an appointment, but no detail of what is happening in their sessions.

Level 3: A more extensive agreement where clients consent to agencies informing family members or carers of what is happening in the sessions. If appropriate, they may agree to invite them to participate in sessions.

Whichever type of confidentiality or information sharing agreement is agreed upon, it is vital that both users and family members and carers know that they can ask to revisit the agreement at any time, and also that the agency regularly reviews these arrangements with all parties.

4.7 Involvement of family members and carers at discharge

Family members and carers can be involved throughout a drug user's treatment journey, where appropriate. However, exits from treatment can present particular challenges for families and carers as well as for the drug user. It is good practice for services to develop clear protocols on how to involve family members, what procedures to follow and what information to share during exits from treatment, both planned and unplanned, and when crises occur.

If clients drop out of treatment, family members and carers may be able to assist in re-engaging them in treatment. If there is an unplanned exit, there are risks of overdose, and it is very useful for family members to have some overdose prevention training. Similarly, if users are being discharged prematurely from residential drug treatment, or from hospitals, there is a need to inform family members and attempt to arrange some form of family support, and to inform the family members of the dangers that their user will face, such as relapse and overdose. All services will want to have emergency contact details for carers and family members, and provide information to carers about who to contact in an emergency.

4.8 Flexible approaches to involving family members and carers

A service may need to work flexibly with both carers and users, so that the needs of all those involved are best met. The needs of family members, carers and users will change over time and the services they receive need to reflect these changes. Holistic, family-focused work may be realised in different ways:

- Both the family member or carer and drug user may need help and support on their own in order to facilitate holistic family working
- In the initial stages, unilateral family work may be more effective – working only with the family member or carer in order to (better) engage the drug user
- Continuing work with the family member or carer when the drug user (temporarily) drops out of treatment may allow the drug user to return to the service more quickly and smoothly.

4.9 Being proactive in involving family members and carers

There are many ways that services can take proactive steps to ensure that they are becoming more carer friendly and family focused. These include:

- Actively seeking to engage family members and carers as partners in the treatment plan, as opposed to waiting for family members or carers to contact the team
- Ensuring family and carer work is regularly examined at team meetings
- Undertaking regular audits of cases and case notes to review the extent of family and carer work
- Ensuring questions about family and carer work are included in client satisfaction questionnaires.

5 Resources

5.1 Further reading

Around Arrest, Beyond Release (Home Office, 2007), from work undertaken by Karen Whitehouse.

The Home Office Drug Interventions Programme has completed a series of field work visits to local partnerships and projects which have identified examples of good practice. Two seminars were held in March 2008 and practice report are scheduled to be available later in 2008, Details of the seminars are available at the Home Office website (Home Office, 2008b).

5.2 Setting up services for family members and carers

Working With the Children and Families of Problem Drinkers: A Toolkit (Templeton *et al.*, 2006) lays out a wide range of issues relating to developing and delivering services to affected family members. Although the guidance is oriented to setting up services for family members of people with alcohol problems, almost all of the issues it raises are equally as appropriate to setting up services for carers and family members of drug users. The toolkit contains information on planning the service, getting it

up and running, maintaining the service and other useful resources.

We Count Too (Adfam, 2005) lists good practice guidelines and quality standards for work with family members affected by a relative's drug use. The menu is designed for groups and services to use as a checklist against which progress can be measured and new ideas generated.

5.3 Involving families and carers when there is co-existing domestic violence

Domestic violence and aggression accompany many instances of drug or alcohol misuse.

The Stella Project is a source of expert guidance on this subject. It project advocates that it is unsafe to offer couples counselling or family based network therapies where domestic violence is occurring, in that whatever the abused person says in the safety of the session may be used against them in future violent confrontations (see www.gldvp.org.uk).

Relate has been developing policy in this area for the past five years and has procedures in place to ensure safe working with couples (such as seeing all couples separately to ask about domestic violence regardless of whether it has been disclosed in a joint session).

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