

# **East Midlands Family & Carer Strategy**

Published by the NTA on behalf of

**East Midlands Regional Family & Carer Forum**

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## Using this document

This document can act as a reference tool and good practice guide for partnerships across the East Midlands looking to improve family / carer involvement at all levels across a partnership area.

The definition of a carer in this document is adopted from the definition stated in the national strategy – *Carers at the heart of 21<sup>st</sup>- century families and communities* (2008).

‘A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems’

# Foreword by NTA and East Midlands Regional Family & Carer forum

Substance misuse is a complex issue. It affects not only individuals but also their families, friends and communities.

The job of the National Treatment Agency is to increase the availability of treatment for drug dependency, and to maximize the benefits treatment brings for individuals, their families and communities.

Treatment offers an individual the chance to manage their dependency and get on the road to recovery. It also gives society an immediate respite from the harm caused by drug misuse. Treatment is a gateway through which drug users can rebuild their lives, and reintegrate with their families and communities.

The East Midlands Family & Carer Forum have produced this strategy document to support the ongoing improvement agenda for drug treatment services across the region and promote the need for developments in family focused provision.

There is a crucial window of opportunity presented before us:

- *Drugs: Protecting Families and Communities. The 2008 Drug Strategy* states that we should involve families and carers in the planning and process of treatment
- The National Carers strategy (*Carers at the heart of 21<sup>st</sup> – century families and Communities, 2008*) has for the first time included mental health and substance misuse in the definition of a carer
- *Drug Misuse and Dependence - Guidelines on Clinical Management, 2007, Drug misuse: psychosocial interventions* (NICE clinical guideline 51) & *Drug misuse: opioid detoxification* (NICE clinical guideline 52) indicate the importance of supporting the families and carers of people who misuse drugs and other substances
- The Department for Children, Schools and Families “Think Family” approach further highlights that by taking a whole family approach and by working closely together, drug and alcohol services, dedicated young carer services and children, parenting and family services can meet the needs of parents whose substance misuse is adversely affecting the whole family

- Amongst all these drivers is the reality of an environment in which we need to demonstrate continually the effectiveness and efficiency and value for money. Our delivery focus is moving from less emphasis on process and more on outcomes – we need to demonstrate the outcomes delivered and carer involvement can underpin this

Once you engage families and carers in the process it is better for everyone – this is not without limitations and challenges but the evidence is stark and well worth the effort for the rewards it brings later.

This strategy represents an excellent platform from which to further develop and improve drug treatment services across the region with a particular focus on the role of family and carer services. I look forward to seeing the strategy recommendations translate in to partnership actions in the coming year.

**Sally Hughes**

**East Midlands Regional Manager, NTA**

For our family support services it has always been about working with **ALL** people affected by somebody else's using, whether or not the users are ready to seek help.

On many occasions, families and carers first contact with a specialist family / carer service will state that their drug user is not engaged with drug treatment services and the interventions delivered to these families by a trained specialist family worker often enables the user to enter treatment. The sessions available to the family / carer need to be educational around substance misuse, treatment options, the cycle of change, family dynamics and responses. Our data evidences that even treatment resistant drug users will enter treatment after interventions with their family / carer member. There is strong evidence to show that the user will engage in treatment, will be retained in treatment and that their outcome will be much more improved.

With the discussion of recovery being a key part of future drug treatment, the contribution of families to the recovery agenda has to be at the centre of development. Families need to recover too as they often become broken and damaged by drug use. Families have much to offer to the recovery agenda, but they need support to allow them to do so.

The cost benefit of support to families to allow them to effectively support their drug user is not known but if they are supported to maintain positive relationships to their user/ex user then we can establish stronger, safer and healthier communities.

**Dot Inger and Debbie Knowles**

**On behalf of East Midlands Regional Family and Carer Forum**

# **Support for the East Midlands Family & Carer Strategy**

Effective support for families and carers at all levels – in planning and commissioning services, by involving them in treatment and through supporting their own, unique needs – is vital and Adfam is extremely supportive of this new strategy.

Families have been increasingly recognised within government policy and practice guidance, however we would suggest that the real differences are made for families once these policies are put into practice at the local service delivery level – and this new Family and Carer Strategy should deliver just that.

The East Midlands is privileged to have a mix of experienced, knowledgeable and motivated individuals with the skills to move this agenda forward at a service delivery level. We hope that the excellent work going on in the East Midlands can be replicated elsewhere.

**Vivienne Evans OBE**  
**Chief Executive, Adfam**

The work that family members and other carers do is vital. They are a major unpaid resource, reducing to a significant extent the burden on health and social services that people with substance misuse problems would otherwise present.

Carers, then, as a major resource, need to be assisted and looked after, their motivation and energy needs to be maintained, and their ongoing commitment needs to be reinforced.

This is why it is vital that there is a strategy for carers, so that the work undertaken with them is not simply 'ad hoc' but is planned and delivered as part of the overall ongoing work with those who misuse substances and their families.

**Professor Richard Velleman**  
**Co-Author of *Supporting and involving carers. A guide for commissioners and providers***

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# 1. Introduction

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

The NTA works in partnership with national, regional and local agencies to:

- Ensure the efficient use of public funding to support effective, appropriate and accessible local services
- Promote evidence-based and co-ordinated practice, by distilling and disseminating best practice
- Improve performance by developing standards for treatment, **promoting user and carer involvement**, and expanding and developing the drug treatment workforce
- Monitor and develop the effectiveness of treatment.

The NTA has achieved the Department of Health's targets to:

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

The NTA is now in the front line of a cross-government drive to reduce the harm caused by drugs. Its task is to improve the quality of treatment in order to maximise the benefit to individuals, families and communities.

The NTA recognises the significant impact that substance misuse has on families and their important role in facilitating recovery. 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.

The UK Drug Policy Commission published a report in November 2009 entitled *Supporting the Supporters - Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses* which estimates the price ordinary families are paying by caring for family members with drug problems – resulting in financial hardship - including debt - loss of employment, breakdown of family relationships and psychological stress.

This study has estimated that in the UK, at the very least:

- nearly 1.5 million adults will be significantly affected by a family member's drug use;
- the cost of the harms they experience as a result amounts to about £1.8 billion per year; and
- the support they provide would cost the NHS or Local Authorities about £750 million to provide if it was not available.

These figures are minimum estimates, but nevertheless demonstrate the enormous impact of drug use on adult family members and the value derived from the support they provide and highlights the importance of identifying and supporting this often unrecognised group. To build on the welcome increase in focus on families of drug users in national drug policies across the UK and the guidance that has been produced, action is required in the following areas to deliver the desired benefits to families:

- Improving the level and quality of direct support to help families in their own right
- Challenging the stigma associated with drug dependency
- Making the drug treatment system more supportive and inclusive of families
- Leadership – responsibility for driving forward an agenda to enhance support for families needs to be placed with an identified champion at national and local levels
- Information/knowledge development is essential for ensuring the adequacy and appropriateness of service provision – currently even the most basic data is lacking.

## **The role of the Regional Family & Carer Forum**

The Regional Family & Carer forum was established by the National Treatment Agency in 2003. It is a quarterly meeting of representatives from family and carer support services and DAAT partnerships from across the region. The group meets to share good practice and to work towards a common work plan in order to raise standards of carer support provision and involvement in all areas of the region.

The group advocates on behalf of the needs of their service users at a local, regional and national level to improve policy and practice around the needs of families, including kinship carers.

In July 2009, the East Midlands NTA hosted a conference on behalf of the group - entitled 'Families Matter'- to bring together key stakeholders in drug treatment across the region with the aim being to utilise the levers provided by the Governments recent Drug Strategy<sup>1</sup>, NICE guidance<sup>2</sup> and clinical guidelines<sup>3</sup> to improve and enhance family and carer support services so there is high quality provision of services consistently across the region. The conference included an action planning exercise for representatives from each partnership area to look at addressing gaps in provision for family and carers in their locality and there was the opportunity for delegates to comment on the draft version of this strategy.

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<sup>1</sup> *Drugs: Protecting Families and Communities. The 2008 Drug Strategy*

<sup>2</sup> *Drug misuse: psychosocial interventions* (NICE clinical guideline 51, 2007) and *Drug misuse: opioid detoxification* (NICE clinical guideline 52, 2007)

<sup>3</sup> *Drug Misuse and Dependence - Guidelines on Clinical Management* (2007)

Following consultation with various national, regional and local stakeholders, this strategy will focus on three key areas:

- Ensuring services that treat drug users involve family members and carers in their treatment
- Ensuring effective support is in place for family members and carers in their own right
- Involving family members and carers effectively in the planning and commissioning of drug treatment, and family / carer services to ensure that commissioning is consistent, effective and provides quality services.

## 2. Ensuring services that treat drug users involve family members and carers in their treatment

The provision of services for users and carers has historically been seen as separate entities. The fact that families and carers of drug users often provide round the clock support and can influence them entering and staying in treatment has previously been overlooked. Their contribution to the recovery of a client goes way beyond what a treatment service can provide. More importantly to partnerships, this can be a significant driver for treatment effectiveness, by which funding is now partly allocated.

Literature reviewed by Copello et al (2005) shows consistently that working directly with those concerned about someone else's substance use can lead to engagement of the user in treatment. Results from both controlled and uncontrolled studies are very consistent in supporting the influential role of family members in relation to treatment entry of the substance user. (Velleman, 2009)

The evidence base suggests that family involvement helps drug misusers at all stages of the treatment journey: it assists and encourages the users to **engage** in treatment, it helps **retention**, it speeds (successful) **throughput** and reduces treatment drop-out, and it is associated with more positive **outcomes**, both drug-related (ie: continued or returned to usage) and social (reductions in legal, family, employment and violence problems, and greater improvements in psychosocial functioning of children). (Velleman, 2009)

Several significant strategies and publications in recent years acknowledge the importance of involvement of family members / carers in a user's treatment. One of the key publications is the NICE clinical guidelines which detail the general and specific interventions that clinicians should offer to carers:

'Families and carers of drug misusers are both an important resource in treating the drug misuser and often in need of support for themselves. Depending upon the relationships between patients and their carers, and bearing in mind the patient's right to confidentiality, in as far as it is possible and practicable, information should be exchanged both ways between clinicians and carers, and carers should be active partners in drug misuse treatment.

Carers should be offered specific information and advice on:

- The risks from blood-borne viruses and overdose and, if appropriate, should be offered vaccination
- Safe storage of medicines.

It is recommended that clinicians:

- Make themselves accessible to family members and carers with the consent of the patient
- Assess and take account of the needs of family members and carers, including the welfare of dependent children, siblings and vulnerable adults
- Provide verbal and written information and advice on the impact of drug misuse and about treatment and the settings in which it may take place
- Provide information about self-help, group and individual support for families and carers
- Consider family or couples-based interventions.
- If families and carers have been offered but not benefited from guided self-help and/or support groups and continue to have significant family problems, consideration should be given to providing formal psychosocial interventions.'

**National Institute for Health and Clinical Excellence (NICE) guidelines on detoxification (NICE, 2007a) and on the psychosocial management of drug misuse (NICE, 2007b) (see section 5.7 and chapter 4)**

At the NTA Families Matter event held on 10<sup>th</sup> July 2009, Professor Richard Velleman delivered a presentation on 'Why do families matter? The evidence base'. Within the presentation, Professor Velleman addressed two questions:

1. Why do services not address the need to involve, when appropriate, family members or other people who care into users' care planning?
2. What are the benefits of involving families or other people who care?

In response to question 1, Professor Velleman described that research conducted suggests that there are 3 reasons why services do not involve family members or other people who care into users care / treatment planning:

- Model (individual / internal causes)
- Prejudice (we blame families)
- Ignorance (we do not know the evidence of how useful they can be)

Other theories include that there is a possible lack of confidence amongst the workforce in working with families and the importance of ensuring that there is sufficient capacity and training available to services in order to engage effectively with carers and families.

In response to question 2, Professor Velleman quoted the following:

- Because drug misuse is a SOCIAL phenomenon, work with people's social context seems to help
- Involving a family member means that it is more likely that alcohol or drug misusers will then engage in treatment.
- Basically, the family member can influence the person with the alcohol or drug problem by helping them to decide to seek or accept help for the problem.

In essence, the approach aims to create change in the behaviour of those concerned in order to achieve treatment entry for the person with the drug or alcohol problem.

For example, Barber and Crisp (1995) developed the 'pressures to change' approach, which starts by engaging the family member: work with them is then focused on:

- education;
- discussion of their responses to drinking / drug-taking situations;
- setting up activities incompatible with drinking / drug-taking; and
- and preparing the family member to confront the person with the drink / drug problem and request that he/she approaches services to seek help.

Research consistently shows that working directly with those concerned about someone else's substance use can lead to engagement of the user in treatment which challenges the powerful myth, widely held within the substance misuse problems and therapy field: that family members concerned about a relative's substance misuse cannot influence someone with a substance misuse problems to change. It is true that family members cannot make an individual stop drinking or using drugs, but they can change their own behaviour in ways that will help the misuser recognise that the substance use is problematic, and that change is desirable.

We can use family members to get resistant substance misusers into treatment and to engage them there, and if we then involve family members in their treatment, both the family members and the users have better outcomes.

### **3. Ensuring effective support is in place for family members and carers in their own right**

*Supporting and Involving Carers; A guide for commissioners and providers* (NTA, 2006 & 2008) states:

‘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.’

‘We Count Too’ (Adfam, 2009) documented the enormous and devastating impact of drug misuse on family members and carers. The feelings and experiences encompass all areas of the carer and family member’s life and include:

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

These feelings are borne out in the growing body of research and consultation in this field, together with the significant negative impact on the mental and physical health and wellbeing of family members and carers. Families and carers express clear and consistent needs for the following:

- Information
- Support, in the short and long term
- Contact with others with similar experiences
- Understanding and a non-judgemental approach
- Respite
- Practical help.

There is good evidence that these family members benefit from help in their own right, and that if they get this help, their own outcomes (reduced symptoms, better coping mechanisms, better quality of life, etc) are greatly improved. These better 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 and other problems in turn (Velleman and Templeton, 2007; Rutter, 2006). It is also the case that there is good evidence that, if family members get help in their own right, there are considerable knock-on effects on users too (in terms of their engagement, retention etc).

Research and evaluation demonstrates a range of positive benefits from the provision of dedicated support services for family members and carers. Partnerships have a responsibility to reduce the harm caused by drug misuse to communities as a whole, including the families and carers of drug users, whether or not the users are accessing treatment.

Families and carers have separate and distinct needs from users. Carers and family members tend to focus their attention on the individual's mis-using behaviour and this approach is reinforced by combining work with carers with work with users. At times, the interests and needs of the two groups coincide, but they are often in conflict. The provision of dedicated family and carer support services focusing on their needs will enable them to function more effectively and provide the opportunity for users to take responsibility for their own actions. Systems and processes designed for user involvement may well not work for families and carers – they need systems and processes that work for them. While there are specific circumstances when joint working with users and carers can be appropriate and useful, these are exceptions to this rule and should not overtake the need to separate most work with families and carers and users.

Family and carer support services cannot be fitted simply into Models of Care for drug treatment services. While Models of Care offers a broad structure that has some relevance to work with families and carers, it is designed to provide a framework for the treatment of drug misuse. Family and carer support services should be designed and commissioned with the primary aim of improving the health and wellbeing of individual family members and family functioning as a whole. This is a long-term task, requiring different and more flexible interventions than drug treatment and therefore requiring relevant and different service specifications and monitoring systems.

Carer and family support services need to reflect and draw on carers and family members' own experience. The majority of services for carers and family members in this country have developed out of self-help initiatives. This is one of their strengths and needs to be valued and built on by commissioners. While personal experience is not a guarantee of quality service provision, it needs to be integrated into services commissioned for carers and family members, as without it, services will have difficulty understanding and responding appropriately to the needs and experience of their clients.

It is acknowledged that further work is required at national, regional and local levels, to fully identify and meet the particular needs of different Black and minority ethnic communities, and those of other groups who are less likely to gain access to mainstream services, including lesbian and gay carers and carers with disabilities.

Health and social care legislation and guidance, including that on carers, give carers of drug users, along with other carer's legal entitlements to assessment and support. All organisations with a responsibility for caring for users are required to focus on carers' needs as well.

Partnerships are required to involve family members and carers actively in their planning processes. Without the provision of dedicated support services for them, this remains a difficult aspiration to achieve. When family members and carers receive effective, good-quality support, this is likely to enable them to contribute objectively and consistently.

## **4. Involving family members and carers effectively in the planning and commissioning of drug treatment, and family and carer services**

The rationale behind the involvement of users, ex users and carers is well documented.

Families and carers are 'experts by experience'. Family members / carers provide a valuable resource as potential volunteers and paid workers in the substance misuse field, drawing on the experience and expertise gained from living with a drug user. They have direct experience of the current issues for substance users and family members / carers and they are the ones who are engaged with the services provided, or equally are not engaged with those services and can say why they are not. Where involvement is successful, it can break down barriers, improve relations between staff and clients, help improve services and lead to better treatment outcomes. In short it is good common sense to consult with the people who we are providing services for. It is also a requirement of numerous guidelines - most importantly, section 11 of the *Health and Social Care Act 2001* (now Section 242 of the *NHS ACT 2006*), which places a duty on NHS organisations to make arrangements to involve and consult patients, and applies equally to non NHS service providers, who provide services to patients through contract to a commissioning organisation or a commissioning partnership where the NHS is one of the partners.

The *NTA Guidance for local partnerships on user and carer involvement* (2006) defines clear partnership commissioning standards for the involvement as:

'Involve and consult patients and the public in:

- Planning services that they are responsible for
- Developing and considering proposals for changes in the way those services are provided
- Decisions to be made that affect how those services operate'

The guidance also states that:

‘Involving users and carers is not an end in itself but a way of achieving three fundamental objectives:

- Strengthened accountability to all stakeholders
- Services that genuinely respond to the needs of users and carers
- A sense of ownership and trust

And in addition the National Drug Strategy – *Drugs: protecting families and communities* (Home Office, 2008) states that:

‘On treatment, we will....involve families and carers in the planning and process of treatment.’

Family members / carers have expert knowledge of drug use and drug users from first hand experience, and the change made to treatment provision has a direct impact on them. So naturally, family members / carers have a vested interest in the work of the commissioning partnerships and the type of treatment and support that they provide. Conversely, improvements to family member / carer support can improve outcomes for service users. In this very real way there is a direct link between the involvement of service users and carers. The key difference is that whilst service users are usually only too happy to take the opportunity to talk about themselves, the involvement of carers requires a completely different, and more sensitive approach.

Carers often find it very difficult to even accept that they may have very specific needs themselves, over and above the needs of their user, and that they are entitled to support in their own right. Carer involvement is best facilitated in cooperation with a specific carer support service for this client group, which should be commissioned in every area.

‘Commissioning dedicated family support services needs to be linked into DAT Joint Commissioning structures for treatment services and DAT work on Communities and on Young People. It is helpful to identify a lead staff member with allocated time to work on this and to consider links to other strategies, such as Crime and Disorder, Carers and Children and Young People. Families also need to know how to feed into the consultative and strategic planning processes and family representation (with appropriate support) is advisable within relevant

meetings. They can not only be advocates for users, but also provide a voice for family members' own needs.'

We Count Too (Adfam, 2009)

Involvement should be meaningful and have a clear purpose. Service users and families / carers who agree to attend meetings should be offered support before, during and after the event. This includes briefings about what to expect and what will be discussed during the meeting, training if necessary and emotional support, especially where people are sharing their personal experience. Appreciation has to be made of the fact that reliving aspects of often troubled lives can be very upsetting and emotional.

Timings of meetings are another issue where efforts need to be made to accommodate as many people as possible. Whilst professionals tend to work from nine till five it is often the case that the lives of users and carers do not conveniently fit into that routine. Carers in particular are often excluded from daytime meetings due to work or childcare commitments. If we expect people to be involved, every effort needs to be made to schedule events that are convenient to them and their lives wherever possible.

Partnerships should recognise that the nature of involvement invariably means that individuals have the opportunity to complain about service provision and practice, and welcome the opportunity to seek ways of improving the experience of clients. However, participants are discouraged from making reference to individual workers in open forums and meetings. Complaints procedures are in place in all services and this is the appropriate mechanism to make individual complaints. Professionals should also take care to protect the identities of clients when citing examples in presentations or discussions.

## **Reimbursement**

The process of consultation with the people that we are providing services for is of immense value. Therefore, it is only right that those who are willing to give their time and expert knowledge are adequately reimbursed. Service users often receive cash reimbursement for attending forum meetings and vouchers for involvement with specific pieces of work. Childcare expenses can be claimed in line with NTA guidelines. Travelling expenses in the form of cash reimbursement should be provided for any event where cash payments have not been made. For carers the same rules apply, where specific consultation is involved. In line with guidelines, carers can also claim for adult care in order to attend events. Whilst reimbursement may vary for specific work or events the guiding principle is that nobody involved in consultation should be “out of pocket” and that we should always make the arrangements clear before people agree to be involved. There are separate arrangements for individuals engaging in consultations with the NTA (*NTA policy on involvement of users and family members, 2008*)

## **COMPACT**

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. Local outcome measures need to take account of the size and nature of the service.

Partnerships have a lead role to play in commissioning services for family members/ carers. Carer and family support services require adequate funding to enable them to deliver consistent quality services. While partnerships are not the only potential source for this, their focus on addressing the impact of drug misuse on individuals and communities gives them a responsibility to take the lead in identifying such funding and commissioning services. It is recognised that, in the short term, it is not realistic for all partnerships to fully fund services. However, the long-term goal should be to work towards a situation where every area has carer and family support services which are fully and recurrently funded, though a combination of partnership budgets, generic carers' funding and other sources.

## 5. Summary

Much can be written in this strategy about the issue of family and carer involvement, however most of the required information is included in the document *Supporting and involving carers: A guide for commissioners and providers* (NTA, 2008). This includes the rationale, evidence base and the practical recommendations on how to move the agenda forward and develop local provision. The scale and depth of the information, evidence base and guidance is impressive and provides compelling reasons for the involvement of families and carers in a drug user's treatment, inclusion of families and carers in the planning and commissioning of drug treatment and the importance of providing services to meet the needs of families and carers.

Over the years there have been some inspiring examples of family and carer support services being established, often by carers themselves. However, the most striking feature of the region has been the wide variation in provision for carer support. This varies from fully funded independent services to other areas where services struggle to provide even limited support. What is clear is that there is not a variation in need. Even conservative estimates would give us a figure of 8000 plus carers of drug users in most partnership areas. If we add in alcohol, then we are looking at tens of thousands of potential clients.

With the weight of legislation and guidance it now seems that the time is right to approach the issue on a regional basis, in terms of our aspirations for family and carer support and involvement. Clinical Guidelines have reinforced the issue of family / carer involvement in the treatment of clients, where appropriate. Legislation has recognised this group of individuals as 'carers' in the same definition as all carers. From years of practice, our carer support services know that this group have very distinct and separate needs from users, including harm reduction, mental health, criminal justice and often their own substance misuse, both prescribed and illicit.

Carer involvement is best facilitated in partnership with carer support services and the dedicated professionals that work in them. In many cases the effectiveness of treatment for drug users is enhanced by, and in some cases dependent upon the support and aftercare that is provided by family, friends and significant others.

## **6. Useful Resources**

### **Appendix A – Family and Carer activity in the East Midlands**

#### **Examples forwarded by members of the East Midlands Family and Carer Forum**

##### **Derby City**

###### **Laurens Link**

Lauren's Link was founded and set up in November 2000 with the support and guidance from Derby DAAT (now Derby CSP) and Derby CVS. The organisation gained charitable status in 2004. Lauren's Link offers support to anyone affected by someone else's drug/alcohol misuse over the age of 18 years old.

The organisation is funded through various trusts from Derby City Community Safety Partnership Drug Strategy Team, PCT, local Trusts, Derbyshire Constabulary and Lloyds TSB. The service users also take part in fund raising, ie: Annual Golf Day, Sponsored Walks, Raffles etc.

Lauren's Link has recently opened a Charity Shop, called Lauren's. The money earned from the shop sustains its upkeep and we have recently employed a part time Supervisor. Service users of Lauren's Link are volunteers in the shop along with service users of the Building Bridges sub-project. This project supports persons being released from either custody or prison back into Derby City. It is very much a hand holding service and is very careful not to duplicate the work of Probation & DIP but works alongside partnership agencies. The service users of the Building Bridges project who have volunteered so far in Lauren's have all done so with great enthusiasm and some have even moved on to full time posts within the retail trade.

Another sub-project of Lauren's Link is called Angels. This project supports anyone bereaved specific to drug/alcohol related death over the age of 18 years. The service users accessing Angels meet monthly and spend the day together. This self-help group can talk openly and in graphic detail about their loved one's death without fear of upsetting or shocking anyone.

Lauren's Link prides itself on partnership working and has an excellent relationship with Treatment Services in Derby City, namely, Phoenix Futures and the Bradshaw Clinic. Educational sessions have been delivered at the self help group on Drug awareness, Methadone – it's effects and use, Harm Reduction, Overdose, Hep C and HIV. Recovering drug users also come and talk to the group. The group particularly enjoy this talk as they can ask the questions they have always wanted to ask their own user. These are all going to be regular talks as and when required.

Lauren's Link is very much a client led support service and like all other Carer organisations already established is governed and monitored by a Board of Trustees who all have the necessary skills relevant to the delivery and development of the service.

## Derbyshire

### **SPODA**

In Derbyshire, SPODA started as a self help group in 1997 and have since become a registered charity and a company Ltd by guarantee, delivering support to any one aged 18 yrs and over that is affected by another's substance use. In 2006 SPODA were awarded the East Midlands Drug team of the year.

SPODA is funded through variable charitable trust funding Derbyshire DAAT, and Derbyshire County Council through the carers budget and the LAA. The DAAT have been great supporters of the project since its infancy and have assisted the project to become the effective and award winning service that it is today.

SPODA's governance is set and monitored by their board of trustees their skills are varied and relevant to the delivery of a service that meets all recommendations and quality standards set by the NTA and Piquaso.

The service delivers specialist support to grandparents and kin-carers with a dedicated worker that has been delivering effective interventions to this client group for the past five years.

SPODA have a unique partnership with Derbyshire Constabulary and local coroners to provide family liaison support to families bereaved by a drug related death. This work is valuable not only to the families and friends of the deceased but sensitive information is taken to the multi agency drug related death review group to learn and implement change to prevent future drug related deaths.

As part of the NTA's harm reduction agenda, SPODA train carers and families on overdose management to equip them on how to respond effectively should they ever have to deal with an overdose situation.

SPODA's service delivery is to use the Stress Strain Coping Support Model to enable those affected to identify strategies to minimise the negative effects on their lives and to address issues such as drug education, responses, family dynamics and how a family member or carer can effectively support a drug user. All of these interventions can

improve family functioning and to provide a structure by which SPODA's service users can support their substance users to make positive life changes.

Carers are also given days out to take a break from their caring roles and have weekly access to complimentary therapies. Many are assessed for their suitability for a full carer's assessment through the Local Authority.

SPODA have contributed in the development of many national policies and UK research by providing a family member to assist in the process of consultation.

SPODA assist through their partnership with the DAAT, the PCT and the community safety partnership to ensure that carer and family involvement is included for all aspects of commissioning, service redesign and delivery of the NTA and community safety agenda. Carers and families views and ideas are listened to and they assist to deliver all aspects of planning local service delivery with the partnerships, this work is valuable to create a healthier and safer Derbyshire and to assist to achieve local and national targets.

## **Leicestershire and Rutland**

### **Snowdrops**

Snowdrops Family Drug Support is a Constituted Voluntary Agency that has been providing support throughout Leicestershire since 2006 to anyone affected by someone else's drug use.

The unique service offered by Snowdrops is the only one of its kind in the Leicestershire area and is provided solely by volunteers, many of whom are also carers of family members with drug problems.

Snowdrops were initially supported by Leicester, Leicestershire and Rutland DAATS who provided a small set up grant to help pay for office furniture, computers etc. Snowdrops currently rely upon fundraising and donations in order to provide the service.

The project provides Support Groups, Practical Support, Befriending, Telephone support, Training events, Respite/relaxation, Advocacy support, Information – library and a website.

Snowdrops volunteers are passionate about the much needed service they provide, and their aim is to secure core funding in order to become a registered charity with a project manager and paid staff.

### **Leicestershire and Rutland DAATs**

Leicestershire and Rutland have recently set up a bi-monthly 'Families and Carers Forum', hosted by the local DAATs. The Forum, in its early stages, is now putting together a 'Terms of Reference' and in the future hopes to become a strong and influential voice in promoting the need to support families and carers within their own right; and to encourage treatment providers to involve and engage families and carers in the service user's treatment journey.

The Leicestershire and Rutland DAATs are also currently undertaking work with generic mainstream carer services throughout the counties, to raise the profile and needs of families and carers of drug and alcohol users, and ensure that these services are able to offer support to such families and carers.

## **Lincolnshire**

### **Oasis**

In 2010 The Oasis Project will have been supporting families, carers and friends of substance misusers for a decade. Services for families at present are provided by a small number of permanent staff which means county cover is stretched but it is envisioned that additional recruitment will take place in the spring of 2010.

Oasis provides support on a one-to-one basis, self help groups or through a 24-hour Helpline. Our main focus is to educate families about substance misuse with particular emphasis on the Hidden Harm agenda of care for children. Oasis is the Tier 1 crisis management service for families.

### **Family Resilience Worker Role**

In the past twelve months, front line emergency work was augmented and extended through a Family Resilience Worker who has provided longer term advice and coping strategy for the East Lindsey and Boston areas of the county. This post has evolved during its inception to provide a Tier 2 level of support for families once the initial crisis has been stabilised by our Tier 1 Project Workers.

The Family Resilience Worker post was funded as a pilot scheme for one year from June 2009 by the PCT through the Lincolnshire DAAT. A Lincoln University Feasibility Study has been commissioned by The Oasis Project to investigate and endorse this pilot scheme: the Study report will be published in January 2010.

## **Northamptonshire**

### **Family Support Link**

Family Support Link is a registered charity, originally set up in January 2003 as a self help support function, achieving registered charity status in May 2007, since then, Family Support Link has been governed and monitored by a Board of Trustees. The charity aims to reduce the physical, psychological and emotional harm caused to families living with, or caring for someone who is addicted to drugs and/or alcohol, empowering them to improve their lives. Particular emphasis is placed on those we have traditionally found difficult to engage with, by encouraging a pro-active not re-active approach.

The service provides effective support, counselling, education and early intervention for those families, educates the community in relation to the stigma, social exclusion, isolation and discrimination faced daily, by these families by means of a telephone help line, one to one support, outreach and drop in support, with out of hours appointments by arrangement. In addition, it offers awareness and training for professionals. All services provision is Northamptonshire based and our offices are based at Wellingborough, with a further satellite office at Corby.

Often forgotten, grandparents are also supported, particularly those who may be left looking after children at a time in their lives when they are less able to cope both physically and emotionally with the impact this may have on them. This improves the likelihood of a positive outcome to keep the family unit intact. Family Support Link also recognises the problems faced by siblings who are living in the same household as a problematic drug or alcohol user.

Family Support Link also recognises the value of working with offenders in the prison system to strengthen and support family/carer relationships during these stressful times, to assist offender reintegration on release. To date, we have commenced work in HMP Wellingborough and are forming links with HMP Peterborough.

The families that we support are diverse, of both genders and all age ranges. In addition they come from all social, economic and ethnic backgrounds.

These interventions will empower families, increase knowledge and understanding, change attitudes, support community cohesion and promote engagement with children and young people.

As with many small charities and voluntary sector organisations, Family Support Link rely on the help support, expert knowledge and time given by our dedicated volunteers. Family Support Link is currently commissioned by the DAAT and part funded by the Criminal Justice DIP to deliver services countywide. The charity also actively seeks additional funding from other sources and secured additional two year funding from Lloyds TSB for England and Wales in 2008. Small funding secured from Wellingborough and East Northants Councils enabled the development and production of a Blood Borne Virus leaflet aimed specifically at family members.

## **Nottingham City**

### **Nottingham City CDP**

Nottingham City has a specifically commissioned carer support service that facilitates carer consultations and forums in cooperation with the Crime and Drugs Partnership to make sure that our carers are involved as much as possible, whilst at the same time protecting them from unnecessary exposure. At a strategic level, we have also seen great strides in developments of carers' needs assessment and specific work since the setting up of a Carers Strategy Group, made up of key partners and stakeholders who oversee local developments in policy and practice, and specifically compile and performance manage the Carers Grid of the Adult Drug Treatment Plan. This sets out the strategic objectives for the key partners and acts as the work plan, both for the Carers Strategy Group and the Nottingham Service User and Carer Involvement Strategy.

### **Hidden Harm training**

Nottingham has ensured that Hidden Harm training for all drug workers is mandatory. Safer Nottinghamshire DAAT lead on the Safeguarding Strategic Steering group where various agencies from across treatment, health, criminal justice, families and children's services and social care meet quarterly to discuss priorities and ways forward with regards to Safeguarding children. Recommendations/actions are then included within adult and young people treatment plans and also fed into the Safeguarding Board.

Nottingham City recognises the importance of meeting the needs of children and families affected by parental substance use and have commissioned a specific post to support adult and children's services to meet their legal safeguarding requirements and implement the recommendations of the Hidden Harm Report. This post is jointly funded by the Nottingham Crime and Drug Partnership and Children's Services. This commitment to joint working is further reflected in the Adult and Children and Young Peoples Treatment Plan sharing the same Hidden Harm action planning grids. The implementation of these actions is overseen by a multiagency Hidden Harm Strategic Steering Group.

There is the expectation that drug treatment services will recognise and respond to the needs of children and families. This expectation is embedded within drug treatment SLA's, reviews and quality standards.

## Nottinghamshire

### Hettys

For the last 13 years Nottinghamshire DAAT (now the Safer Nottinghamshire Board) has supported, directed and commissioned Hettys to deliver a needs led holistic carer support service for families affected by someone else's drug or alcohol misuse.

Hettys was initially started by a group of volunteers in 1996 and is now sustained through DAAT and PCT Service Level Agreements to deliver its service across the County of Nottinghamshire. DAAT commissioning and guidance means that Hettys has evolved and now employs a part time Senior Manager, a part time Team Manager, two part time Criminal Justice Workers, 5 part time support workers and a full time Kinship Care Worker. Nottinghamshire acknowledge that involving family / carer Services at a strategic Level can add quality and improvements within the treatment systems as well as giving families support within their own right. It is crucial that carer services do not work in isolation, but are part of the wider partnership approach. Through effective referral pathways we can ensure that both families and substance mis-users receive the best care and support possible.

The charitable status that this service has achieved means that it still relies heavily on experienced and fully trained volunteers, to help to keep up with the ever increasing demand on the service. It is also a huge asset when it comes to piloting new projects to plug any gaps within service provision, until we can prove there is a demand that requires mainstream funding – for example: complementary therapies.

The Safer Nottinghamshire DAAT through their Criminal Justice funding also provides structured sessions within local prisons to enable recovering drug and alcohol users to explore their relationships and acknowledge their responsibility in the breakdown of such relationships. They are encouraged to discuss realistic ways forward for both prisoner and family and understand their own families need for specialised support. Working with local DIP workers, Hetty's can provide long term rehabilitation through positive family functioning which will benefit both drug / alcohol user and family and help to prevent reoffending. Feedback from prisoners and prison officers provides positive evidence for the continuation of these sessions.

Nottinghamshire use local consultation with families who have accessed the carer/family service to see if there are any improvements that can be made to the way we deliver our service provision, the accessibility to the service and knowledge and skills of our workforce. This happens when families have not contacted us for two months, we write as a matter of courtesy and include a consultation questionnaire, and this also helps to gain clarity to the outcomes to their situation.

Consultation with Kinship Carers has been a key issue over the last couple of years; Nottinghamshire has been proactive in addressing issues and concerns at a national level in the House of Lords. Locally we have helped to host conferences with Grandparents Plus, inviting Grandparents and key partnership agencies (Social Care) to come together and listen to each other. These conferences are now being run nationally by Grandparents Plus in the hope that their voices and the voices of extended family members who have had to take parental responsibility for a child will not only be heard but listened to and acted upon.

If you would be interested in contacting any of the services or partnerships mentioned in this appendix, please contact the regional NTA office on 0115 971 2738 who will provide you with the relevant details.

## Appendix B – Wider context

There is not scope within this strategy to go into great details around all of the other strategic areas and issues that overlap with our involvement work. It is still an evolving field, that seems to spread ever further, and often faster than practitioners can keep up with. However, some key areas of development that need to be looked at further include:

- 1. A patient led NHS:** The statutory responsibility for involvement lies with the NHS, and there is a need to do further work to co-ordinate involvement work so that duplication in some areas can be avoided and some major gaps can be addressed in others. When the duty to report comes in later in 2009 there will be an increased need to resolve this issue. With the increasing emphasis on the criminal justice agenda, it is easy to forget that people in treatment are primarily NHS patients, and should be afforded the same rights as anyone else.
- 2. Local Involvement Networks (LINKs):** These are a relatively new development but very important for involvement. Local Involvement Networks (LINKs) aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported - the role of LINKs is to find out what people want, monitor local services and to use their powers to hold them to account. LINK membership is open to individuals and groups in each Local Authority Area.
- 3. Health Care Commission Core Standards. Patient focus** – HCC inspections have included drug treatment for a while now, and work needs to be done to see where this can be something that our clients can have a bigger say in. Specifically around the core standards that include: “Does it organise its services around the needs and preferences of patients?” And “The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving health care services”
- 4. Every Child Matters:** ‘Every Child Matters: Change for Children’ sets out the national framework for local change programmes to build services around the needs of children and young people so that we maximise opportunity and minimise risk. The services that reach every child and young person have a crucial role to play in shifting the focus from dealing with the consequences of difficulties in children’s lives to preventing things from going wrong in the first place. The transformation that we need can only be delivered through local leaders working together in strong partnership with local communities on a programme of change. That is why this document sets out what action needs to be taken

locally and how Government will work with and support Local Authorities and their partners.

- 5. Local Area Agreements:** All single and two tier authorities have strategic partnerships mandated to deliver on joint outcomes agreed around their sustainable community plans. Across the UK these priorities include improved mental and emotional wellbeing of children and adults, improved access to drug and alcohol treatment and reduction in alcohol presentations in hospital admissions. These joint targets have a direct link with providing family support services as the outcomes of improved wellbeing of the family, keeping families together and increasing access to treatment is demonstrated in the provision of bespoke family support services.
- 6. Hidden Harm:** In 2003 the advisory council on the Misuse of Drugs (ACMD) published its report Hidden Harm – responding to the needs of children of problematic drug users. This 3 year inquiry by ACMD revealed a disturbing picture about the nature and extent of actual and potential harm to babies and children living with parental drug misuse. The report captured 6 key messages and 48 recommendations which cut across drugs, children, health and criminals justice sectors and addressed a broad range of policies and practices. As well as working together, joint planning and commissioning one of the recommendations within this report was “Dedicated services for children affected and their families”
- 7. Around arrest, beyond release 2 - moving forward** (2009) is a follow-up study to the ‘Around Arrest, Beyond Release’ report originally published in August 2007. It was undertaken by the Drugs Interventions Programme (DIP) to help services (both mainstream and specialist) consider practically the issues that affect families around the time of a drug user’s arrest and beyond their release from prison or treatment. “The three-year action plan (2008-2011) in **Drugs: protecting families and communities** – the 2008 drug strategy also made a commitment to publish the report. The report identifies and recommends practice that can assist the planning, development, and delivery of family and family-focused support. It is aimed at those involved in commissioning, planning and delivering services provided to address issues (including drugs, health, community safety, housing and safeguarding) within the local community. It should be of interest to those who are likely to come into contact with other vulnerable adults, children and families.

## **Appendix C – NTA needs assessment guidance in relation to families and carers**

In July 2009, the NTA published supplementary needs assessment guidance 'Undertaking needs assessment – drug treatment, recovery and reintegration in the community and prisons – July 2009. Supplementary advice in relation to families and carers.

A copy of this document is included in this appendix for reference purposes – please double click on the page below to access the document.

If you are having problems with accessing this, the document is also available in the Treatment Planning section on the NTA website:

[http://www.nta.nhs.uk/areas/treatment\\_planning/treatment\\_plans\\_2010\\_11/treatment\\_planning\\_in\\_the\\_community\\_prisons\\_2010\\_11\\_templates\\_and\\_guidance.aspx](http://www.nta.nhs.uk/areas/treatment_planning/treatment_plans_2010_11/treatment_planning_in_the_community_prisons_2010_11_templates_and_guidance.aspx)



***National Treatment Agency  
for Substance Misuse***

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**Undertaking needs assessment**

**Drug treatment**

Recovery and reintegration in the community and prisons

**Supplementary advice in relation to families and carers**

Publication date: July 2009

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## Appendix D - Regional Family and Carer Forum recommendations

Reference to the following key drivers should be included in any strategic planning documentation looking at family and carers needs:

- Reference to Drug Strategy 2008 and commitment to implement recommendations around involvement of family and carers, including kinship carers and significant others.
- Acknowledgment of the inclusion of substance misuse carers in the new definition of “carer” as set out in the new Carer Strategy - *Carers at the heart of 21<sup>st</sup>- century families and communities*. (HM Government, 2008)
- Reference to the recommendations in *Supporting and involving carers- A guide for commissioners and providers* (NTA, 2008).
- Reference to the two sets of NICE Guidelines in 2007 and a commitment to implement recommendations.
- Reference to Clinical Guidelines and commitment to implement recommendations around involvement.
- Reference to Sec 242 of the *NHS Act 2006* (formerly Section 11 of the *Health and Social Care Act 2001*) and commitment to implement legal requirements of the Act, but not necessarily direct reference.
- A separate grid in the plan for family and carer Involvement detailing commitment to involvement at all levels, from individuals care to the commissioning cycle, with clear objectives that can be performance assured by Partnerships and the NTA.
- Evidence that family / carer Involvement is a driver for change and not just a consultation exercise after change decisions have been made.

- Commitment to ongoing funding of carer involvement, including a partnership post with responsibility in this area.
  
- Consideration of family and carer needs in relation to the following service areas:
  - Harm Reduction training, safer drinking etc. (Naloxone pilots are currently being set up in some areas in the UK).
  
  - Housing and debt
  
  - Social activities and social integration for users and carers
  
  - Mental Health / Dual Diagnosis

## **Appendix D – Guidelines, references and sources of information**

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