‘Drug misuse and dependence: UK guidelines on clinical management’ – review proposal

Adfam submission September 2014

Introduction

Adfam welcomes this chance to offer feedback on the ‘orange book’ clinical guidelines. They are rightly seen by the treatment sector, alongside NICE guidance, as the cornerstone of evidence-based practice regards drug treatment. As such they offer an important change for informing practitioners regarding their work with the families of drug users. In the submission below Adfam details how families can be included in the clinical guidance; how their role can be harnessed to support drug users through their treatment journey; how practitioners can work competently to signpost families to their own sources of effective support; and how children can be effectively safeguarded from the proven risks presented by opioid substitution treatment medications.

This last issue is covered in detail in Adfam’s report *Medications in drug treatment: Tackling the risks to* children, a copy of which is included with this response. (Also available online: www.adfam.org.uk/cms/docs/adfam_ost_fullreport_web.pdf)

Chapter 3 - Essential elements of treatment provision

3.2.3.1 Assessment of risk

The guidance states that ‘risks to dependent children should be assessed as soon as possible after contact with services. This would normally include all clients being asked about their children, their ages (some service protocols may require date of birth), and the level of contact they have with them, as a minimum at initial assessment.’

This should be updated to reflect good practice in assessing whether drug-misusing adults have *contact with* children, even if they are not the biological parent. Risks – including those posed by the unsafe storage or inappropriate use of prescribed methadone – are the same whether the children are related to the adult or not. This may be particularly pertinent for assessment of males, whose contact with, and responsibility for, children is often insufficiently explored (DCSF (2009) Understanding Serious Case Reviews and their Impact). Men may also be more likely to have transient relationships in which their contact with children can change very quickly – being assessed as ‘safe’ one week, but beginning a relationship with a woman with two small children shortly afterwards.

3.2.3.2 Aims of full or comprehensive assessment

The guidance states that a comprehensive assessment for drug-misusing parents with dependent children should include 'obtaining information on the children and any drug-related risks to which they may be exposed', and that 'if risk of significant harm to a young person is found', clinicians should 'involve other professionals according to local child protection requirements'.

However, this process is possibly presented the wrong way around: in many cases, clinicians would only be able to find risk of significant harm *through* conversations with other professionals and the collection of contextual information from other agencies or workers involved with the family, such as social workers. It would be difficult for a single clinician to make accurate judgements of all the considerations listed in the guidance (including parents' emotional availability, family routines and contact with 'unsuitable characters') without structured input from other services and professionals.

The guidance should be amended to read: 'for drug-misusing parents with dependent children, obtaining information on the child and any drug-related risks to which they may be exposed, **including liaison with other professionals where possible and appropriate**.'

3.2.4 Care or treatment plan

Alongside 'childcare issues, including parenting, pregnancy [and] child protection' it should be made more explicit that the safety of prescribed medication is an important element of the care or treatment plan.

3.3.2 Content of keywork

The guidance states that keywork sessions with drug-misusing parents should include 'monitoring the family situation, supporting parenting, helping patients access resources, managing the interface with social services, antenatal services and other relevant professionals, and formally monitoring child protection risk.' Revisiting and reviewing the care plan should also include regular review of the patient's safety plan for any prescribed medication, in line with the wording from section 5.4.4.4 that 'the importance of safe storage must be emphasised at the first appointment and repeatedly thereafter'.

Chapter 4 – Psychosocial components of treatment

As well as recovery for the substance user Adfam believes it is essential to maintain a focus on the wider social, and 'whole-family' recovery of the people around them. Chapter 4 contains a number of opportunities for enlarging and strengthening the guidance on families and psychosocial components of treatment and ultimately encouraging this wider whole-family recovery.

4.3.1.3 Harm Reduction

Adfam suggests that this section include reference to families as appropriate targets for harm reduction advice.

Recommendations 1 and 2 of the ACMD's naloxone report clearly encourage the wider use of naloxone and the expansion of the pool of people to whom it is issued – stating 'Naloxone should be made more widely available, to tackle the high numbers of fatal opioid overdoses in the UK' and 'Government should ease the restrictions on who can be supplied with naloxone' respectively.

Whilst it's difficult to accurately state how many naloxone kits have been issued to family members in the UK (and significant barriers remain to the more widespread carrying out of this practice), Jane Ellison MP's letter to the chair of the ACMD suggest that the numbers should increase substantially. It states that the Medicines and Healthcare Products Regulatory Agency 'is drafting regulations to give effect to the [ACMD's] recommendation…it is planned that the new regulations will come into effect on the Common Commencement Date of 1 October 2015' (available at www.gov.uk/government/uploads/system/uploads/attachment_data/file/340711/IversonNaloxone.pdf).

In addition to naloxone, more general harm reduction advice should be provided to family members on, for instance, safer injecting practices and awareness of decreased opioid tolerance following release from prison, as well as accompanying emergency healthcare guidance covering overdose.

4.3.1.7 Other non-treatment interventions

Similarly, families should be mentioned in this section as the ideal source of support and partnership for both the service user and the practitioner in encouraging the drug user to take part in non-treatment interventions. Non-treatment interventions offer a valuable chance for the service user to further their recovery by taking part in processes in 'normal' territory outside the confines of treatment, and also to continue to build or re-establish relationship with family members, some of which may have been seriously damaged during the period of drug use.

The family is one of the most valuable elements of recovery capital that a service user can call upon, both during treatment (emotional and practical support in engagement and coping with any arising difficulties) and after it (housing, encouragement towards employment and/or other meaningful activities, and support in adjusting to life post-treatment). By carrying out non-treatment interventions, which may include taking a course together, going to classes or volunteering, the bonds with family members are strengthened and later access to the family as recovery capital is safeguarded.

4.3.2.4 Family therapy

This section stresses the importance of ensuring families have access to support, including therapy, in the statement that families 'may also benefit from self-help or support groups specifically focused on addressing carer needs.'

Adfam welcomes this statement but suggests that it is expanded to make clear the twin motivation for getting support for families, whether through self-help and mutual aid type groups or joint structured interventions with the substance user: that adequately supported families are a vital source of recovery capital and can do a better job of keeping the service user engaged in treatment than if highly stressed or depressed themselves; and that families affected by substance use need and deserve support in their own right.

4.3.2.5 Mutual aid (self-help) approaches

This section, with its statement that 'these interventions can be of benefit to a wide range of people at different levels of the care and treatment system' should also include reference to the usefulness of mutual aid groups for families affected by drug use. There is a large network of groups which includes the 12-step based Famanon and Al-Anon for families affected by drug and alcohol use respectively, as well as a wide selection of grass-roots organisations which adhere to no particular

formal model of support but nonetheless provide a great deal of valuable practical and emotional support.

4.5 Competencies to deliver psychosocial interventions

Given the complexities of psychosocial intervention models and the skills needed to deliver them, Adfam wholly endorses the presence of a sub-section of the guidance dedicated to competency. In addition to the current content, families should be specifically mentioned as a core group that practitioners delivering psychosocial interventions to substance users should be competent in working with.

Large amounts of anecdotal evidence and personal testimony gathered throughout Adfam's work indicate that there is a real variation in the skills and attitudes of practitioners relating to family members, with some clearly seeing the service user as a person who exists in, and impacts upon, a wider familial and societal context, and other focussing very much on the individual's needs as medical and self-contained. A specific mention in this section specifying work with families as an area that *all* drug practitioners need to be familiar with (although not necessarily expert in) would be welcome. Some treatment services do embrace work with families but recruit or nominate a single practitioner to be a family lead; Adfam believes that working with families is *everybody's* business, and this should be a core competency for all practitioners.

Chapter 5 – Pharmacological interventions

5.1 Key points

It should be made clearer in this section that risks to children should be a primary consideration in deciding which drug to prescribe, and whether to permit take-home dispensing.

The current statement 'patients must be made fully aware of…the importance of protecting children from accidental ingestion' should be strengthened in light of evidence that a number of young children have died or been seriously harmed by parents *deliberately* administering methadone to them as an inappropriate pacifier (Adfam, 2014). The toxicity of methadone should be stressed in updated guidance with the message that, in line with the wording from NICE Technology Appraisal 114, **'patients must be made aware of the high mortality risk of methadone in opioid-naïve individuals and children'**, with the added information that this is true **even in very small doses.**

The guidance also states that 'prescribing arrangements should aim to reduce risks to children', but this point is insufficiently explained, even as a brief 'key point'. The logic underlying this message is that for those clients with children, a) prescribing methadone (which has a high overdose risk compared with buprenorphine) and b) allowing it to be taken home should both only be done with caution, subject to satisfactory and detailed risk assessment. This is a key point, and there should be a separate bulletpoint which states that '**Prescribing arrangements, both in the choice of opiate substitute and the permission for take-home doses, should aim to reduce risks to children'.**

5.2.4 Communication between prescriber and dispensing pharmacist

It should be recommended that ensuring medication is stored and used safely is a key element of communication between the prescriber and dispensing pharmacist. Pharmacists should be encouraged to 'share information with prescribers and other healthcare professionals and agencies

in line with locally determined confidentiality agreements **when there are concerns over the safety of children in the household, or unsafe or inappropriate use of medication'**.

5.3.4.4 Provision of information

As a point of emphasis, the text should be amended to read 'risks to children of ingesting prescribed medication and the importance of safe storage must be emphasised at the first appointment and repeatedly thereafter. Assessment of compliance with these safety measures should form ***a primary*** part of the decision-making concerning dispensing and supervision arrangements'.

Even so, based on the current wording it is not sufficiently clear *how* the 'assessment of compliance' with safety measures is to be undertaken. This has been shown to be a crucial flaw in practice when tragedies have occurred involving child ingestions, with prescribers being unaware of risks in the home environment (Derbyshire LSCB (2013), Serious Case Review BDS12; Staffordshire LSCB (2010), Serious Case Review C1 and C2). The guidance should be clearer that in order to properly assess compliance, the input of other professionals – especially those who visit the home – is likely to be necessary, including health visitors, (other) drug treatment workers and/or social workers.

Evidence shows that simply providing information on safe storage is not sufficient to prevent the unsafe storage or misuse of medicines (Bloor 2005; Derbyshire LSCB 2013). To strengthen the guidance, prescribers should be encouraged to agree a safety plan with the service user, which is available to, and shared with, other professionals working with the family and visiting the family home, including drug treatment staff, health visitors or social workers. This would ensure a greater level of awareness around safety needs.

5.3.5 Choosing an appropriate opiate substitute

The guidance states that 'safety, for example likelihood of diversion and overdose risk' should be taken into account when choosing an appropriate opiate substitute. This should be more explicit in referencing the overdose risk of methadone *to children specifically.* Again, this has already been recognised in NICE Technology Appraisal 114.

The current statement that 'if both [methadone and buprenorphine] are equally suitable, methadone should be prescribed as the first choice' has potentially led to methadone being viewed by clinicians as the 'default' option. Again, given the high mortality risk associated with methadone as referenced by NICE, both drugs may *not* be *'*equally suitable' for clients who could pose a risk to children by storing or using their medication inappropriately. This point should be reflected in updated guidance.

5.4.2 Stopping supervision

The guidance states that 'take-home doses should not normally be prescribed where…there are concerns about the safety of medicines stored in the home and possible risks to children'. Whilst this is true, a single bulletpoint gives insufficient priority to a key issue – the safety of children – and does not provide any guidance on how 'concerns' about safety would be detected or investigated by the clinician. This should be rectified: clinicians should be advised to undertake or organise home visits, challenge any inconsistencies in the service user's reports of safety, and pursue effective liaison with other local services in contact with the family.

The guidance also states that even when there are concerns about the safety of medicines stored in the home and possible risk to children, 'take-home doses might be permitted but the dose taken

home limited by frequent dispensing'. This statement should be removed, as it potentially devalues the importance of safety around children. Single incidents of children ingesting small amounts of methadone can be fatal, and if there are *any* documented risks about the safety of medications in the home then supervised consumption should be compulsory. The safety of children is paramount.

Guidance on the progression from supervised consumption to take-home medication is also lacking detail in its current format. It should made clear that any move to take-home medication should be accompanied by the provision of a lockable storage box, safety information, and the agreement of a safety plan which is shared with other organisations visiting the home in order to ensure that compliance can be monitored. Following any move from supervised consumption to take-home, there should be clear processes in place to review this situation at regular intervals, with a return to supervised consumption always considered in response to any identified risks to children.

5.6.4 NICE technology appraisal

Regarding the choice of medication, the guidance uses a statement from NICE Technology appraisal 114 that the decision about whether to use methadone or buprenorphine 'should be made on a case by case basis, taking into account a number of factors, including the person's history of opioid dependence, their commitment to a particular long-term management strategy, and an estimate of the risks and benefits of each treatment made by the responsible clinician in consultation with the person'. However, this misses a potentially crucial point about the protection of children, which is addressed elsewhere in the same Technology appraisal:

'The responsible clinician, in consultation with the person, should estimate the risks and benefits of prescribing methadone or buprenorphine, taking account of the person's lifestyle and family situation (for example, **whether they are considered chaotic and might put children and other opioid-naïve individuals living with them at risk**).' (Emphasis added). The guidance also notes the 'high mortality risk associated with methadone in children and other opioid-naïve people'. This particular point should be included in the updated guidance to reflect the importance of children's safety more clearly.

Chapter 7 – Specific treatment situations and populations

Adfam suggests that this chapter should see 'families' added as a separate population. Although the families of those using drugs are not engaged in treatment in their own right, they can be *involved* in treatment in some ways – as seen in the statement 'families and carers of drug misusers are both an important resource in treating drug misusers…Carers of adults can be involved in patients' treatment' and 'carers should be active partners in drug misuse treatment'.

7.1 Key points

The guidance should include a key point covering the importance of engaging families through the treatment journey. Having families involved in and supportive of treatment is very useful. NTA guidance states that 'involving families and carers can improve engagement, retention and outcomes for drug users in treatment" ("Supporting and Involving Carers: A Guide for Commissioners and Providers." National Treatment Agency for Substance Misuse 2008), and '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 (NTA 2008).

As well as families supporting their loved one through the treatment intervention of their recovery journey, research indicates that interventions which work with both the family and service user together either matched or improved outcomes when compared with interventions focusing solely on the service user (Copello et al (2008) The relative efficacy of two levels of a primary care intervention for family members affected by the addiction problem of a close relative: a randomized trial. 104 Addiction 49-58). This type of joint intervention should therefore be mentioned as both a possible method of effective substance use treatment and a help to families.

7.3.3.5 Working with patients and their carers

Confidentiality is a commonly reported issue in the engagement of family members in treatment. Anecdotal evidence indicates that parents and other family members who wish to kept informed about their loved one's treatment journey often find that treatment services cite the need to respect the loved one's right to confidentiality as a barrier to disclosing information, sometimes of the most basic kind. Whilst the confidentiality of the person entering treatment is of course of paramount importance, it must be balanced against the understandable wish of family members to be positively involved and play a supportive role. To discourage it being used as a blanket rule which prevents the sharing of all information, a section in this chapter should be included explaining how rules around confidentiality should be best adopted.

Adfam believes that guidance should be provided here on how families can be signposted to their own sources of support. The effectiveness of family support groups (which may either be standalone, voluntary organisations, part of an integrated treatment system or part of a larger carers' service) has been well documented through many Adfam research projects and consultations, with family members typically citing both the practical and emotional support provided, often by peers in a mutual aid setting, as crucial to their own recovery. This section provides an ideal opportunity for encouraging practitioners to promote these sources of support as well as the idea that family members encountered during the treatment journey are legitimate recipients of support in their own right.

7.3.4.1 Continuing care

This section should contain a specific mention of mutual aid and peer support networks. This type of support constitutes a set of potentially highly effective parallel processes and relationships to more formally delivered treatment. Mutual aid and peer support offer a credible peer voice offering support, advice, encouragement and empathy. It is cheap to fund and there is a great deal of anecdotal evidence and personal testimony as to its effectiveness. For these reasons a specific mention should be made here of it.

7.3.4 Preparing for release

Families play a key role in supporting people with substance use issues who leave prison. As the guidelines note, this is a time of great risk for drug users whose opioid tolerance has decreased in prison. It is also a time when service users will need support to continue to engage in treatment and for the non-treatment elements of recovery. Engaging families around both of these areas is essential.

Adfam suggests, regarding the first issue, that the guidance state that families should be routinely briefed on the overdose risks and given appropriate harm reduction and emergency healthcare advice. The section above on naloxone covers this in more detail (4.3.1.3).

Regarding the second issue Adfam suggests that families are mentioned as a prime asset in recovery capital terms, with a job to do post-release in supporting their loved on to engage socially with friends and peers and with a meaningful activity of some kind, whether volunteering, employment or education.

7.5.1 (Mental health) Introduction

The treatment of dual diagnosis is an area of anguish for many family members. Too often they feel they are passed from pillar to post by services providing substance use and mental health treatment when they wish to feel informed and empowered to support their family member. The section '7.5.3 Mental health policy' identifies the key areas of policy response to the issue of dual diagnosis – shared definitions, closer local working, clearer and more effective communication between individuals and services.

Adfam suggests that families are mentioned here as sources of specific support. Concerned others play an essential part in bridging the two sets of services and keeping the drug user motivated to continue engagement with both mental health and substance use services. They make sense of a potentially complex situation – two services, (at least) two keyworkers, and different sets of job titles, terminology and priorities. Guidance should cover how family members or carers should be involved, kept informed, sought as a source of information and, where appropriate, consulted in the development of care plans.

If you would like to discuss any part of this submission please contact policy@adfam.org.uk.