

CQC Consultation: Regulation of Substance Misuse Services

Adfam is the national umbrella organisation working to improve support for families affected by drug and alcohol use. As well as providing support materials and training specifically for families and the professionals with whom they work, we inform policy development and campaign both locally and nationally for improved family support services. Our final goal is that no family member in need of support should go without.

In response to this consultation, Adfam has commented on those points to which it felt it could contribute valuable opinion. Questions which Adfam considered to be outside their remit of expertise or to which it could add no value have been omitted.

(Q.1) Do you feel confident that the key lines of enquiry and the list of prompts will help our inspectors judge how safe, effective, caring, responsive and well-led specialist substance misuse service providers are?

Broadly, yes; the KLOEs provide a comprehensive list of prompts and should be an effective tool in determining the quality of a service if applied appropriately by inspectors. However, there are several further points Adfam would like to highlight:

- When looking at whether lessons are learnt and improvements made when something goes wrong, it is important to involve family members in any investigations conducted. Families can often provide valuable insight professionals do not have: the Carer's Trust's '*Triangle of Care*¹' guide (2013) found that in a number of inquiries into serious incidents, failure to communicate with and listen to carers was a significant contributory factor. For example, family members often have vital information, relevant to the safe and effective treatment of the service user, and are best placed to notice any changes in the behaviour of their relative – thus being more likely to pick up on risks of relapse. In the same way, families can make an important contribution to the assessment of risk and in monitoring and maintaining the safety of those in treatment. As such, it is important that a service provides a procedure whereby families and others with information pertaining to the client are able to report any concerns they may have, or discuss any issues they consider relevant to the client's treatment. The provision of such a mechanism should be included in the list of safety prompts. (**Safety**)

¹ Available at: www.rcn.org.uk/__data/assets/pdf_file/0009/549063/Triangle_of_Care_-_Carers_Included_Sept_2013.pdf

- With regards to the safe management of medicines (including prescribing, recording, handling, storage, safe administration and disposal), it is worth considering risks posed by take-home prescriptions, especially in relation to opioid substitution treatment (OST). Adfam has published a research paper, '*Medications in Drug Treatment: Tackling the Risks to Children*²,' which examined risks posed to children when their parents, guardians or other adult care-givers are prescribed OST; following a number of high profile reports of children dying or coming to serious harm after ingesting OST medication, usually prescribed to one or both parents. Amongst other things, the report found that parents and professionals were often insufficiently aware of the dangers of OST to children; and consequently, that necessary safety precautions, including safe storage of OST, were not adhered to. In addition, we found that despite guidance from National Institute for Health and Care Excellence (NICE) Technology Appraisal 114 and the Department of Health's '*Drug Misuse and Dependence: UK Guidelines on Clinical Management*,' - which acknowledge the possible dangers to children and proscribe safety measures - prescribers were failing to adequately consider children's safeguarding as a primary factor, both when deciding which drug to prescribe and whether to permit take-home doses. It is therefore advised that an additional prompt question be included to gather evidence of the service's policies and procedures with regards to OST and safeguarding. **(Safety)**
- The focus on providing a 'holistic' approach is welcomed. Holistic working requires an understanding of the complexity of the client's situation and issues, the environment in which they exist and the effects these have on the client in various aspects of their lives. Adfam would therefore propose that family involvement and consultation are key components of holistic working, in terms of truly understanding the issues and situations facing the individual client and the repercussions, or possible repercussions, of these. In ensuring that a service is effective, it is important to highlight that individuals in treatment attain better outcomes when families are closely involved in their care. The '*Triangle of Care*' (Carers Trust, 2013) promotes the inclusion and recognition of carers as 'partners in care,' given that successful long term outcomes are most likely when staff accept the benefits of carer involvement, and collectively promote the concept of a therapeutic triangle formed by themselves, the service user and carer. According to the '*Forgotten Carers*³ report (UK Drug Policy Commission, 2012), there is considerable variation in the extent to which services involve family members in the treatment of their loved one, despite overwhelming evidence that family involvement contributes to effective outcomes for the user: helping to prevent relapse and aid long-term recovery. Research by Copello (2008) found that interventions that work with both the user and their family either match or improve outcomes when compared to interventions focused solely on the user. As is recognised in the list of prompts, the engagement and involvement of those who use the services and those close to them is further evidence that a service is well-led, delivering person-centred care. **(Effective and Responsive)**

² Available at: www.adfam.org.uk/cms/docs/adfam_ost_fullreport_web.pdf

³ Available at: www.ukdpc.org.uk/wp-content/uploads/the-forgotten-carers-support-for-adult-family-members-affected-by-a-relatives-drug-problems-.pdf

- Whilst family involvement is undoubtedly beneficial for the client in treatment, it is also conducive to addressing the needs of the families themselves: 1.5million people are affected by a relative's drug use and their needs often go unmet and un-assessed (UK Drug Policy Commission, 2012). Families report negative impacts on their physical and mental health and wellbeing, financial circumstances and social relationships. They are more likely to be diagnosed with their own medical condition than other families, and often suffer stress-related physical and psychological symptoms, which can be severe and long lasting, and are associated with high use of primary care services (Copello et.al., 2010). In addition, the care and support that families provide to relatives with a *drug* problem saves the state an estimated £747million a year (UKDPC, 2012). When families are supported, family health, self-esteem and functioning improves. It further helps break down stigma and prejudice in local communities. As a result, the UKDPC noted, *'Increasing and improving the support available for families, both in their own right and to assist their contribution to their relative's recovery, is imperative both from a moral duty and from a simple economic standpoint.'* It is recommended that the recognition of these benefits and the incorporation of such support within a service be taken into account during inspection and rating. **(Caring)**

(Q.2) We have provided examples of evidence we may collect to inspect substance misuse services. Do you agree that this is the right kind of evidence for us to look at?

The consultation of those close to the person in treatment, including families, through the collection of ongoing local information, pre-inspection information and on-site inspection is extremely welcome. It is Adfam's view that family members are too infrequently consulted, despite their familiarity with treatment services. To illustrate this point; findings from Adfam's ongoing Outcomes Measurement project show that only 44% of family members agreed with the statement that they were aware of how their relative's treatment was progressing and only 36% felt involved in important decisions made around their relative's treatment, whilst 62% felt respected by treatment staff. Firstly, it would be useful to collect evidence such as this through questionnaires or interviews with family members of clients. Secondly, it seems reasonable to suggest that a possible indicator of a good treatment service is one which makes those with whom they come into contact, be it a client or their family, feel respected, communicated with and not excluded.

(Q.4) What are your views on how we should rate specialist substance misuse services?

The rating system used is appropriate. However, more information on the frequency of inspections and the follow-up procedures for services failing to attain 'good' or 'outstanding' ratings would be welcome.

(Q.5) What are your views on the characteristics outlined (in appendix B)? Are these what you would expect to see in a specialist substance misuse service that was outstanding, good, required improvement or was inadequate?

- It is encouraging to see that a service rated 'outstanding' in safety requires staff take a proactive approach in anticipating and managing risks to people, whilst involving users and

their families in managing their own risks. However, the risks posed by take-home prescribed medication (in particular OST) is one Adfam is keen to see gain recognition and be accorded appropriate prioritisation by treatment services. The number of cases where children have died after ingesting their parents' medication, and the increasing regularity with which they arise, demands that this issue be tackled effectively. As such, it is considered that a service cannot be rated as 'outstanding' on safety indicators without robust policies and procedures in place, which recognise and prioritise these risks. Conversely, where insufficient procedures or policies are in place, the service should be rated 'inadequate.' Furthermore, a service with 'outstanding' safety measures should have in place a mechanism whereby families or others close to the client are able to report concerns and other issues of which they believe the service should be informed. **(Safety)**

- Adfam would support the view that a service should not be rated 'outstanding' unless it recognises the value of family involvement in treatment, with policies in place to facilitate such involvement. Treatment is most likely to be effective (that is, achieving long-term positive outcomes for both the user and those close to them) when they are closely involved in the care and support of the person in treatment. **(Effective)**
- Given the range and severity of negative impacts suffered by the families of drug and alcohol users – including to their physical and mental health and wellbeing, finances and social relationships - Adfam would suggest that the provision of support services for families as well as the user is an indication of 'outstanding' service provision: ensuring a person-centred culture, that people are treated with compassion, kindness, dignity and respect and that services are responsive to local needs. When families receive support, they are better placed to be able to support the person in treatment and are a crucial source of recovery capital. The assertion that people's emotional and social needs are highly valued in a service – an indicator for 'outstanding' practice under the 'caring' heading – would be weakened without a level of engagement with those close to the individual in treatment. Where a service does not offer formal family support or mutual aid services, Adfam believes that 'outstanding' services should sign-post families on to appropriate forms of support as a minimum offer. **(Caring and Responsive)**
- Similarly, a strategic drive, led by management, towards the recognition of the needs of families themselves and the benefits of family involvement in treatment should be expected of a service considered to be 'outstanding.' **(Well-led)**

Whilst it is essential that families are consulted throughout the treatment stages – this being well-recognised in the list of prompts – it is suggested that a service worthy of 'outstanding' status goes one step further: involving and supporting families as 'partners in care', in service design and delivery. The extent to which services recognise and promote these principles and engage successfully with families is important in evaluating the overall effectiveness of a drug and alcohol treatment service, and is an indication that the service is providing strong, evidence-based, holistic care and support.

(Q.6) What are your views on our equality and human rights duties impact analysis?

A system of regulation that places human rights and equality at its centre is commended. Drug and alcohol users and their families are often marginalised, stigmatised and discriminated against, whilst also facing a number of other challenges brought about by the substance use. Last year, Adfam ran an anti-stigma campaign during which we sought families' views and experiences of stigma: this consultation (much like reports received from other projects and communication with family members) showed that experiences of stigma and discriminatory attitudes were plentiful, and that they were serious barriers to people accessing all forms of support. An awareness and knowledge of human rights and equality in services is therefore paramount. It is also essential that services are familiar with the information contained in the 'what we know' section of the impact analysis. In order for inspectors to be able to judge how safe, effective, caring, responsive and well-led specialist substance misuse service providers are, inspections must be highly conscious of human rights principles.

One further point on which to pick up would be:

- **Carers:** It is suggested that this section (under the 'what we know' heading) include a reference to the Carers Act 2014, which expanded and concretised the rights of carers, including those of drug and alcohol users. Under the Carers Act 2014, any adult '*who provides, or intends to provide, care for another adult*' is entitled to a needs assessment and access to support. Carers of individuals with a drug or alcohol problem are thus entitled to the same assessment and support as, for example, carers for people with mental illness; regardless of their needs for support or their financial resources. Under this new legislation, carers are not discriminated against based on the needs of the person for whom they are providing care.

(Q.7) Are there any additional organisations that we should develop relationships with to understand people's experiences of care and identify examples of good practice in substance misuse organisations?

Building relationships with local community groups is key. Adfam would suggest that local family support services, in particular, are a valuable source of information and feedback. Families are, like most 'experts by experience', often very keen to share their experiences and opinions.

As well as local family support services, national umbrella organisations would be able to provide valuable insight, having a wide network of contacts in the sector, including local grassroots services. Through their networks, such organisations would be well placed to provide both national and local accounts of the state and standard of specialist treatment service delivery. The Substance Misuse Skills Consortium – a cross-sector initiative and alliance intended to maximise the skills and capacity of the treatment workforce and share good practice – could additionally provide valuable insight into the sector and guidance on good practice.

(Q.8) How confident are you that the sources of information we plan to look at will identify risks of poor quality care and good practice in specialist substance misuse services? What other indicators would you suggest?

The sources listed provide sufficient scope to be able to identify risks and good practice in substance misuse services. Again, however, we would press the point that the collection of information from families and those close to the person in treatment is vital. In gathering information from patients and the public, it is advisable to heavily target family support services and family members themselves to gather their experiences of care and treatment.

When collecting complaints submitted to the service, it is also worth inquiring whether family members are afforded the ability to lodge complaints and, if so, these should also be indicators in the overall analysis of the service and the KLOEs.

(Q.9) Is there other information we should be asking for from providers about the specialist substance misuse services they deliver before an inspection?

When looking at medicine management, safety and a service's effectiveness, it is important that inspectors gather evidence of the service's policies and procedures around take-home medication, in particular OST, and the safeguarding policies in place to protect children or vulnerable adults who may be at risk. The extent to which services value holistic working and their modes of achieving this are also key indicators of the quality of a service; and evidence should be gathered to this end, including the level of involvement of families and carers in care planning and treatment.

(Q.10) We recognise the difficulties sometimes experienced in engaging with people who use specialist substance misuse services. Have we proposed appropriate methods to ensure that we are able to gather the views of people who use different types of substance misuse services before and during inspections?

The inclusion of an 'expert by experience' in the inspection team is an excellent measure in seeking to gather the views of people using the service, given that we know people often feel more comfortable in confiding and sharing opinions when they share similar experiences.

In Adfam's experience, families are eager to share their opinions and offer feedback and also have a valuable insight into the safety, effectiveness, responsiveness, compassion and management of a service - from a unique perspective. In order to capture the experiences and opinions of families, the same methods can be used: drop-in sessions or discussion groups, speaking to families individually, using comment cards, posters, questionnaires and online forms designed for families.

(Q.14) How do you think we should seek the views of families, carers or people close to people who use specialist substance misuse services to help inform our inspections and assessments?

Adfam's beliefs as regards to seeking the views of families, carers and those close to people engaging with specialist substance misuse specialists have been expressed throughout. Seeking the views of families, friends, carers and other close to the person in treatment is highly advisable. However, as well as consulting the views of families and those close to **current** clients, consultation with independent local family support services would be of additional value; since it would also provide a window into the experiences of families, carers and people close to those who **aren't** presently in treatment, and further broadens the evidence base. Families and others who are members of these groups are both familiar and in contact with local treatment services: they are a valuable and independent voice on families' and carers' experiences of the whole local treatment environment.

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