

Substance Misuse Services in Wales

Are they meeting the needs of
service users and their families?

March 2012

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In writing:

**Communications and Facilities Manager
Healthcare Inspectorate Wales
Bevan House
Caerphilly Business Park
Van Road
CAERPHILLY
CF83 3ED**

Or via

Phone: 029 20 928850
Email: hiw@wales.gsi.gov.uk
Fax: 029 20 928877
Website: www.hiw.org.uk



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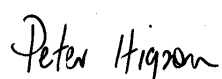
Foreword

It gives me great pleasure to introduce this report that looks at whether substance misuse services are meeting the needs of all service users and their families across Wales.

In undertaking this review we have been fortunate enough to have service users share their experiences with us openly and honestly. They have without exception shown great dignity and we have come to learn that there is no such person as a typical substance misuser - anyone of any age or walk of life could find themselves in this situation. We hope that all of those we spoke to will recognise their input to this report and see that their experiences have helped us to frame our findings and recommendations.

There are some excellent substance misuse services in place across Wales and a tireless and passionate workforce driving improvements forward but more needs to be done to make these services consistent and sustainable.

We hope that the information set out in this report will be of interest not only to those responsible for providing substance misuse services, but also to individuals and their families who are or could be in need of services in the future. As was clearly and passionately emphasised to us *'no one sets out to become an addict.'*



PETER HIGSON
Chief Executive
Healthcare Inspectorate Wales

Chapter 1: Introduction and background

1.1 Substance misuse refers to the harmful or hazardous use of psychoactive substances including alcohol and illicit drugs¹. It may also include the use of over the counter preparations and household products such as lighter fuel and other aerosols. The effects of substance misuse are far reaching and can have a damaging effect on individuals, their families and communities.

1.2 In recognition of the impact of substance misuse on Welsh communities the Welsh Government launched '*Working Together to Reduce Harm*' the new Substance Misuse Strategy for Wales (2008–2018) (*Working Together*) which builds on its earlier Strategy '*Tackling Substance Misuse in Wales: A Partnership Approach* (2000). *Working Together*' sets a clear national agenda for tackling and reducing the harm associated with substance misuse and identifies four priority action areas:

- Prevention.
- Supporting substance misusers.
- Supporting families.
- Tackling availability and protecting individuals and communities.

1.3 In tandem with the development of the new strategy the then Minister for Social Justice and Local Government commissioned Healthcare Inspectorate Wales (HIW) to develop and implement a programme of thematic reviews of substance misuse treatment services across Wales. The purpose of this programme is to assess whether the strategy is having the impact that was intended; evaluate the adequacy and quality of services provided across Wales; identify good practice and make recommendations for future improvement.

1.4 In year 1 of the programme (2009-10) we undertook a review of opiate substitute prescribing services '*The All Wales Review of Opiate Substitute Prescribing Services*' (August 2009). This review highlighted issues in relation to the

¹ World Health Organisation (WHO) is the directing and coordinating authority for health within the United Nations System.

pathway of care for substance misuse service users and in particular concerns about timely access to services.

1.5 We therefore decided in this our second year to look at the pathway of care and treatment of substance misusers across Wales in order to answer two fundamental questions:

'Are substance misuse services meeting the needs of all substance misusers?'

and

'Are families of substance misusers getting the support that they need?'

1.6 These questions align closely with two of the four priority action areas identified in '*Working Together*,' namely:

- **Action Area 2 – Support for substance misusers to improve their health and aid and maintain recovery:** thereby reducing the harm they cause themselves, their families and their communities.
- **Action Area 3 – Supporting and protecting families:** reducing the risk of harm to children and adults as a consequence of the substance misusing behaviour of a family member.

1.7 To enable us to answer the questions set out above we took forward a number of streams of work which included undertaking a desk top review of relevant literature and the findings of inspections undertaken of relevant areas, such as youth services and children and young people's services; visits to services across Wales; and interviews with service users, service commissioners and providers. We also conducted a series of regional workshops with providers, statutory bodies and commissioners to explore how agencies and services work together to support service users and their families. Further details of the scope and approach for our work are provided at **Appendix A**. A summary of the organisations who contributed to this review is set out at **Appendix B**.

1.8 To ensure that we kept a focus on service users and their families we developed a virtual family '*Dai's family*' to frame our discussions and workshop sessions with commissioners and providers. '*Dai's family*' is not unique and you may recognise or have come into contact with people in similar circumstances to a number of the characters. Pen pictures of the members of '*Dai's family*' are shown at [Appendix C](#).

1.9 Throughout the report we have highlighted the stories of real service users. We have changed their names to protect their privacy but what they told us was so powerful and heartfelt that their experiences needed to be retold and not forgotten. If we are really serious about tackling substance misuse and improving services we need to listen to what they have to say and take appropriate action.

Chapter 2: Awareness and attitudes - the impact on seeking help and receiving timely treatment and support

The impact of stigma

2.1 Sadly because of the links associated between substance misuse and crime and the stereotypical views of who substance misusers are; stigma and substance misuse are closely linked. To reduce the barriers to individuals coming forward to receive treatment and to drive improvement in the treatment that individuals receive we need to collectively tackle the attitudes of the general public and de-stigmatise substance misuse.

2.2 We collectively have to be honest and accept that a large number of people believe that individuals who misuse substances '*ask for what they get*' and that they have got themselves into the situation that they are in '*by choice*' and with an awareness of the consequences. Such stigma has undesirable consequences since it results in problems with drugs or alcohol being hidden, many of those we spoke to told us that they found it hard to admit to themselves that they had a problem and even harder to talk about it to others.

John's Story

John is in his forties and is warm and open, a typical valleys man who loves his rugby and going out with his mates to watch a match.

"I started to notice that I drank my pint much faster than all my mates and then I started to have a few in between rounds. My headaches and shakes got worse and then I just couldn't wait for the pub to open and would find myself stood outside waiting for it to open. I thought you had to drink shorts and not pints to become an alcoholic, then I started to realise I had a problem and so when my mates called for me to go down the pub I made excuses, they must think that I have got the best decorated house in the village."

2.3 Concerns about the reaction and attitudes of others are a real barrier to individuals who suspect that they have a problem contacting their GP, local drug and

alcohol team and others who could help them and so their situation often escalates to a point where they lose their job, family or home before they seek help.

Attitudes in health and social care

2.4 Unfortunately sometimes the beliefs and attitudes of society are also shared by health and social care practitioners and this can impact on the response that individuals get when they seek help.

2.5 Many of the service users we spoke to had as a first step approached their GP wanting to try to stop or reduce their substance misuse as they did not know where else to go to get help and support. While some service users told us of the excellent support they had received from their GP (these experiences are discussed in further detail in Chapter 3), the majority told us that despite clear evidence of biological, psychological and social factors contributing to substance misuse (drugs or alcohol), their GP had been unsympathetic and had not understood that:

‘You just can’t quit on your own.’

This attitude was particularly evident in relation to alcohol misuse, where across Wales there is generally a high level of acceptance of a drinking culture, which is unfortunately closely linked to our national sport of rugby.

2.6 Others told us of the great difficulties that they had experienced when trying to register with a GP once it was known that they had a substance misuse problem. Many of the experiences shared with us highlighted the prejudices that service users often have to deal with.

Ben's Story

Ben is tall and tattooed from head to toe with long dreadlocks. When he starts to relax and talk you can see his vulnerability and soft artistic nature,

"I know I look a bit scary with my tattoos and dreadlocks but it is all a facade because in reality I am so nervous and intimidated that I wouldn't even walk into a room where there were people on my own.

I had been a substance misuser and living on the street for some time when I decided that I needed to get help; I suddenly realised that I would be dead by the next winter if I didn't. I went to register with a GP but was turned down by nine separate GP practices. I was about to give up when someone from the drug support group came with me and spoke on my behalf, I was then accepted by a GP. I was at an all time low and the experience made me feel worthless."

2.7 Also, many service users felt that health and social care professionals sometimes put all their problems down to their substance misuse and didn't refer them for screening and testing for other illnesses that their symptoms may be due to.

David's Experience

David is in his mid-thirties, with a keen sense of humour. Very much like the friendly neighbour next door, or your brother that all your friends fancied. No one would guess he had a problem.

"It took me a long time to pluck up courage to go to my GP. Eventually I went but I have regretted it ever since. He told me to pull myself together and that it was a matter of will power. He said I needed to go away and just stop drinking. Now every time I go to see him whether it is due to a cough and cold or in-growing toenail he tells me it is because of my drinking. I don't feel as though he pays me the same level of attention as other patients and I am afraid that he is going to miss something and not refer me for tests because he puts the symptoms down to my substance misuse."

2.8 We also found there to be little recognition of the fact that an older person may have a substance misuse problem. Older people often drink in private and alone; their symptoms of alcohol/drug abuse are often mistaken for confusion and frailty.

2.9 Innumerable television documentaries and *'fly on the wall'* programmes have highlighted the high level of hospital admissions and A&E attendances that occur due to substance misuse. However, rarely is the opportunity taken to assess individuals for substance misuse issues and to refer them to treatment services. While most A&E departments have posters and leaflets about substance misuse it was clear that most staff considered that it was for the individual to decide whether they needed help and that rarely would a referral be made by staff in generalist secondary care areas, unless there was a direct relationship between substance misuse and the illness they were being treated for. One circumstance where individuals may be eventually referred to substance misuse services as a result of an A&E attendance is where domestic or elderly abuse may be suspected, due to regular A&E attendances and bruising. The referral would be made after abuse had been ruled out and substance misuse highlighted as a possible cause of falls.

2.10 A particular area of concern in relation to awareness and attitude is the approach taken to individuals with a co-existing mental health problem (this is discussed further in Chapter 4). Service users told us of often feeling as though they were:

'Piggy in the middle'

They described to us circumstances when they have been told by mental health services that they have to go away and sort out their substance misuse issues before they can access treatment. They told us that they had felt helpless and confused because they considered their substance misuse issues to be due to their mental health problems and that they couldn't address one issue in isolation.

Chapter summary

2.11 As part of this review we have spoken to many service users from different walks of life who have ended up misusing substances due to many and varied circumstances and reasons; including bereavement, loneliness, mental health issues and just a gradual escalation of their drinking habits which went unnoticed until too late. Without exception those that we met were articulate, caring and honest about their experiences and what the consequences of their substance misuse have been on them and their families. None of them were looking for pity or sympathy; just help and support to get them on the road to recovery.

2.12 If we are to effectively tackle substance misuse we have to change the attitudes of society in general. The negative view of substance misuse has led to an under valuing of the importance of improving the quality of life of these individuals. Some of the attitudes evident in society are also there in health and social care with some primary care practitioners colluding with substance misusers particularly older people to underplay their problems and difficulties. It is important that primary care teams don't take a judgemental or zero tolerance approach which may result in them not registering a known substance misuser due to the possibility of them being difficult or causing trouble.

2.13 Such attitudes where present contribute to the perception and to the reality of stigmatisation of alcohol and drug misusers and can result in individuals not being accepted on to practice lists, and hence not being able to access care for issues not directly related to their addiction. While we acknowledge that some clients can be difficult and abusive the measures that practices and primary care services take must be on an individual basis and not a blanket negative approach, so that others for whom treatment would be positive and rewarding find it impossible to gain access to the care they need.

2.14 Our review identified a need for frontline staff working in the community, A&E, minor injury departments and ambulance staff to be provided with training and assessment tools to help them better identify and deal with substance misuse

particularly in older people. We also highlighted the need for training to focus on changing attitudes and beliefs. We are pleased to note that since our fieldwork work has been taken forward in this area. Training has been provided to staff working in A&E departments and there has been good engagement with paramedics. In addition, information wallets have been distributed to all A&E departments across Wales to assist staff to provide support and signpost individuals to the most appropriate service.

2.15 As noted, some primary care teams are already driving improvements to services for substance misusers and are with knowledge and enthusiasm providing the early intervention and support that service users' need. Their success needs to be built upon and their enthusiasm bottled.

Chapter 3: Information and access to services

3.1 Timely access to care and treatment is fundamentally important to all client groups but particularly to someone with a substance misuse problem. It takes a lot of courage to admit that you have an addiction and that you need help and so often delays in accessing services means that the *'window of opportunity is lost.'*

Information about services

3.2 Service users told us that they had not found it easy to find out what services there were and how to access them. This was a particular problem for those with alcohol issues. The majority of those we spoke to told us that they had found out about the services they accessed by word of mouth. They questioned why information wasn't more readily available and challenged whether information on websites was really the answer for everyone when some, particularly those who are homeless don't have access to computers.

3.3 As discussed in Chapter 2 service users also highlighted the variability in the knowledge and attitudes of primary care teams and GPs in particular. We are not going to repeat our findings here, but it suffices to say that we must not assume that all those in need of information, help and treatment will approach their GP in the first instance or that if they do go to their GP they will get the support and assistance they need.

3.4 Many service users told us that how they found *'drop in centres'* run by volunteers and recovering service users to be extremely helpful in terms of providing information and support.

Eric's Experience

Eric is middle aged and down to earth, very much part of the group and softly spoken.

"I had been putting off seeking help because I thought I would be judged. Then a friend told me about 'Number 7.' I walked past there several times but again kept on making excuses not to go in. Then one day one of the girls saw me and came out and started talking to me. I was so relieved she wasn't someone in a suit or a doctor or nurse she was just like me. We had the same issues and had similar experiences. I try to go to 'Number 7' as often as I can. The help and support I have received has put me firmly on the road to recovery."

3.5 'Number 7' in Pontypridd is one such example of a 'drop in centre' that offers peer support and signposting to other services and organisations that may be able to help. It was opened following requests from service users for a venue that allowed them to seek information and help others. Without exception service users talked about the invaluable impact that drop in centres have had on their recovery but concerns were raised in relation to the level and long term nature of funding. At the time of our review many drop in centres were not open seven days a week and in many cases funds only allowed them to open for the odd morning or afternoon.

3.6 Service providers and commissioners too had a mixed picture of the nature, type and availability of services. Whilst many had an impressive and extensive personal knowledge of what services were available based upon their own experiences of their local area or region, there was often no clear map of who did what and how so that the support and treatment plan for an individual could be developed and based on the best match of local services available.

3.7 For many service providers, the workshops we held themselves provided a valuable opportunity to learn from others about the services they provided and how they provided them; many told us that it had been the first opportunity offered to them to get together and discuss service provision and barriers and opportunities for provision.

3.8 We are pleased to note that since our fieldwork there has been much progress in this area. Many parts of Wales either have or are moving towards '*single point of contact*' arrangements which provide support to individuals to help them identify the services that can best assist them. In addition the DAN 24/7 website has been updated to make it more user friendly and information wallets have been distributed across Wales which provide advice about the services available and contact numbers.

Waiting times

3.9 The very nature of the problems facing service users means that their individual needs and circumstances are different, and their behaviour may be chaotic. The availability of treatment services therefore needs to be flexible enough to take account of changes in motivation and the unpredictability that accompanies substance misuse so that, as highlighted above, what might often be a small '*window of opportunity*' is not lost.

3.10 An audit carried out across Wales in 2006 revealed a mixed picture in terms of waiting times across Wales, and the identification of this, along with some extremes of performance led the Welsh Government to take concerted action. The good practice that had been identified in some parts of Wales, as part of the audit, was used to create national guidance for substance misuse services, and led to the introduction in 2007 of a range of key performance indicators. These together with the publication in 2008 of '*Working Together to Reduce Harm*' provide a clear and ongoing focus on the monitoring of waiting times to ensure improvement.

3.11 On-going monitoring, together with our own review of opiate substitute prescribing services in 2009² has identified that progress is being made. There is clear evidence that guidance is being put into practice and that where it is in place is leading to some significant reductions in waiting times. However, many areas of Wales are still some way off from achieving the standards set and the picture is still

² '*The All Wales Review of Opiate Substitute Prescribing Services*' (HIW, August 2009).

far from satisfactory. We will be following specific issues up with the Welsh Government.

3.12 Our workshops with service users, commissioners and service providers consistently raised concerns about waiting times. Illustrative examples were provided of significant variance between areas of Wales. In one instance service providers indicated waiting times in one city were around six weeks whereas in another the average waiting time for a comparable service was reported to be closer to 26 weeks. Service providers indicated that for some services, waiting times of up to 12 months or more were not uncommon.

3.13 Overall, long waiting lists and what was described as a 'postcode lottery' was highlighted as a key concern for service providers and users across the majority of the regional conferences held. This picture is not however borne out by the latest substance misuse statistics. '*Substance Misuse in Wales 2010-2011*³' includes statistics from the Welsh National Database for Substance Misuse and indicates that the percentage of clients:

- Assessed within 10 days of referral has increased to 66.5 %, with over 80% being assessed within four weeks.
- For which treatment started within 10 days of assessment has also increased to 90.2 % with 90% within four weeks.

3.14 However, the statistics also illustrate a significant increase in numbers for those appearing to wait over 12 months (from 1,015 in 2010 to 1,686 in 2011) although the report also notes this may be a reflection of the failure of some agencies to record the details of case closures rather than the figures being a reflection of actual waiting times.

³ <http://new.wales.gov.uk/topics/housingandcommunity/safety/substancemisuse/stats/?lang=en>

3.15 Such a disparity between the experiences described to us and the available statistics demands further investigation and we will be taking this forward with the Welsh Government.

3.16 As referred to above service users' circumstances and needs differ widely, and their behaviour can be chaotic and unpredictable. This can lead to them experiencing difficulties attending appointments which have been set for a specific time and date. Therefore, if services are to be effective, they must be designed and delivered in a way that accommodates these complex behaviours and does not expect service users to conform to a rigid system. Services must be flexible enough to take account of changes in motivation and the unpredictability that accompanies substance misuse. This is particularly important in relation to appointment arrangements for assessment and treatment. Non attendance for appointments not only affects the chances of an effective recovery for the individual concerned, but it also impacts on the waiting times for others as resources are being wasted.

3.17 An audit⁴ looking into the high rates of non attendance in Wales identified a range of factors contributing to this. These included inflexible opening times; long travel distances; childcare problems; personal crises; and a lack of family/social support. Problems were also identified around staff attitudes and poor inter-agency working. Overall, it was noted that services acknowledge the chaotic behaviour and lifestyles of those with substance misuse issues and many have introduced more flexible arrangements that offer services in a range of venues as well as texting reminders to clients. It is important that services continue to work flexibly and are not constrained by having to comply with generic appointment procedures.

3.18 These findings were mirrored in our conversations with service users who talked about how they found services that they could just drop into or call when they needed help and support to be more helpful. They raised particular concerns about some NHS services where non attendance at two appointments had led to them being taking off treatment lists and having to go back to the end of the waiting times

⁴ *'Waiting times and prescribing: the service user experience'* a presentation to the All Wales Substance Misuse Service User Conference *'Breaking the chains of addiction,'* 10 June 2010.

queue again. In Chapter 4 we provide some illustrative examples of practice worth sharing where services in rural areas have been developed to *'take the services to the service user'* particularly when they have not been in contact with services for some time.

Chapter summary

3.19 Getting timely access to care and treatment is fundamentally important to someone with a substance misuse problem and to ensure that *'windows of opportunity'* are not lost. Information about services is out there but we have to question whether it is being shared in the right way, in the right places and in a manner that is joined up.

3.20 We asked service users a very simple question: *'How did you find out about services?'* Most told us that it was through word of mouth and that often this had happened by chance and sometime after they had first realised that they needed help.

3.21 We need to start thinking *'outside of the box'* and not treat substance misuse services like another healthcare service. We need to ensure that information is available in the right places. One service user questioned *'why off licences are not required to have posters of the contact details of local service providers detailed?'* Others were not aware of the *'one stop'* telephone number for Wales provided by DAN 247⁵ that can signpost to and provide advice about services. Instead, they referred to the *'Ask Frank'* call line and wondered whether this could be further developed.

3.22 Too often we apply the medical model to services that equally require a social response. Like those suffering from a mental health issue, substance misusers need long term support and care if abstinence is to be maintained and long term recovery assured. This is not a service that can have orderly appointments and a culture of

⁵ DAN 247 is a free and bilingual telephone drugs helpline providing a single point of contact for anyone in Wales wanting further information or help relating to drugs or alcohol.

'one strike and you are out.' It needs to be flexible, responsive and assertive in its approach; taking services to those who need them rather than waiting to be called upon. It is only by changing our approach that we will avoid non attendance and the waiting times dilemma; we cannot forget that those misusing substances have to have sustained access to services before they can change their behaviour and approach.

3.23 Service users have highlighted the importance of *'drop in centres'* that provide peer support and empower service users to take a hold of their addiction. They can provide a non-judgemental environment in which those struggling with decisions in relation to their next step to recovery can feel safe to share their thoughts and experiences. We need to listen to what they have said and ensure that such centres are mainstreamed into service provision and hence made more sustainable through long term funding.

Chapter 4: Level and adequacy of service provision

The views of service providers and commissioners

4.1 As part of this review we met with service providers and commissioners. Between January and March 2011 we held seven regional workshops to draw up a contextualised, summative account of the nature of current practice and service provision across Wales in order to identify good practice and any gaps in provision.

4.2 To maintain a strong and consistent focus to workshop discussions we used '*Dai's family*,' a virtual family, to:

- Explore care pathways.
- Identify barriers to treatment.
- Identify gaps in provision.

4.3 There are eight members of '*Dai's family*,' each with their own issues and concerns. A description of each member is provided at **Appendix C**; this should be used for reference when reading this chapter.

4.4 Discussions with service providers and commissioners in relation to the availability and quality of services were organised around the individual family members and their needs, although the findings around services available to individual family members often equally applied to the other members of '*Dai's family*.' Some of the key findings from our discussions are set out below. Many of the issues raised in these discussions have already been referred to in more detail in other chapters of this report. Where this is the case, although we may make reference to the issues below, we have sought to avoid a detailed repetition here.

Identifying substance misuse problems

4.5 Many service providers felt that the chances of an individual's substance misuse issues being identified and tackled early enough to maximise their chances

of a successful recovery was fundamentally influenced by the individuals age, gender and family circumstances, and the stigma and stereotyping that may be associated with substance misuse.

4.6 Our discussions centring around Mair for example concluded that generally, as an older lady she would need to be strongly motivated and engaged with accessing help herself. This is because commissioners and service providers considered that the services she would be likely to present to, particularly through Accident and Emergency, were not seen as being geared up to identifying Mair's holistic needs. In particular, providers questioned whether staff working in such services would have the time or expertise to tease out her issues.

4.7 Discussions noted that in Mair's circumstances, a '*Protection of Vulnerable Adults*' (POVA)⁶ referral may be made, but providers were not confident that this would be consistently applied or actioned.

4.8 However, once identified, commissioners and providers noted that a number of third sector organisations were available to provide key advice and support to someone in Mair's position. Providers referred to one such organisation working across Wales:

Women's Aid: The Wales Domestic Abuse Helpline provides free, confidential, 24-hour information and signposting services to anyone experiencing domestic abuse, along with available services. Access to refuge for women who are escaping domestic abuse can be coordinated through the helpline.

Information gathering and sharing across agencies

4.9 Across Wales, commissioners and providers referred to an increasingly joined up approach to information gathering and sharing across agencies. The

⁶ Guidance for healthcare staff on how to report a concern that a vulnerable adult may have been subject to neglect or abuse is set out at:
<http://www.nhswalesgovernance.com/display/Home.aspx?a=455&s=2&m=156&d=0&p=158>

development and use of common referral and assessment tools; the agreement of information sharing protocols between agencies and the introduction of regular, often weekly single point of entry meetings and multi-agency risk assessments were seen as key in helping to create a better, more rounded picture of an individual's needs and, where appropriate, the needs of the whole family unit.

4.10 However, participants considered that more work was needed to build on the progress made so far. For example, although common referral forms often have been introduced, they are not yet used consistently and the quality and volume of information received by service providers varies considerably.

4.11 A more consistent and sustainable approach is needed within and between regions in order to avoid arrangements that were still described as being '*a little hit and miss.*'

A family based approach

4.12 In 2010, the Welsh Government introduced the Integrated Family Support Services (IFSS) model in response to concerns that existing services were not sufficiently meeting the needs of some children and families with complex problems. The collaborative IFSS model aims to reform services provided to vulnerable children and families in Wales by supporting families to stay together by empowering them to take positive steps to improve their lives. Integrated Family Support Teams (IFSTs) are being established to provide targeted support and better connect children and adult services with a focus on the family as a unit. IFSS is being implemented across Wales using a phased approach, with three services established in September 2010:

- Newport IFSS.
- Wrexham IFSS.
- Merthyr Tydfil/Rhondda Cynon Taff (Consortium).

4.13 Although these new arrangements were still in their infancy, our workshop discussions in those areas where IFSTs had been established were optimistic about the opportunities and potential for the new arrangements to really drive a more joined up, family based approach to tackling substance misuse problems where parental substance misuse coexists with concerns about the welfare of the child or where children themselves are involved in misuse.

4.14 However, we consider it essential that in introducing these innovative approaches, care is taken to avoid a resulting disparity in the focus and attention given to those substance misusers who may fall outside the boundaries of the services provided by such targeted services. In our discussions around '*Dai's family*' for example, consideration of Gareth's circumstances and needs often focused around limiting his influence on the wider family and the risks he was seen as presenting to the children rather than also helping Gareth to access the help and support he needed to address his own complex circumstances.

4.15 The importance of safeguarding those who may be in vulnerable situations, particularly children, must not be underestimated. However, we simply cannot afford to allow either the strategic development of our services or their front line implementation to concentrate on the needs of one particular type of service user at the expense of others, and we must be alert to any such unintended consequences.

A postcode lottery?

4.16 Perhaps one of the strongest themes across all the workshops we held was that of the mixed picture of service provision across Wales. Service providers and commissioners invariably concluded that the accessibility, availability, quality and sustainability of the services that may be offered to a substance misuser or their family was dependent upon '*where and when you turn up*' (both in terms of geographical location and the type of service you were seeking to access); who you happen to see; what their view is on substance misusers; and what they happen to know about the services in their area.

4.17 The examples provided of this were many and varied, covering both over provision, often in city areas where we heard about duplication of many services, to significant under provision in some rural areas where service providers referred to substance misusers having to travel for hours to get to a service that may only be available for a short time once every few weeks. Conversely, others told us about the creative and innovative approaches being developed to tackle the challenges of providing services in rural areas, and particularly focusing on *'taking services to those who need them; when they need them; and how they need them.'* An example of such an innovative approach was the appointment of *'home workers'* in rural areas who make home visits to clients for whom travelling proved difficult. However, we were told that in some areas due to financial pressures such home visits have stopped.

4.18 Overall, many service providers considered that across Wales, services for those with alcohol misuse were often given a lower priority than those focusing on drug use which were thought to be given a much higher profile. This was particularly noticeable in discussions around older members of the family where, as identified earlier, providers noted that such misuse may not always be noticed or actively considered as a factor that may be affecting an individual's behaviour, health or well being. For older people, even if alcohol were to be identified as a factor, it is often seen as being more socially acceptable and therefore much less likely to lead to active support or intervention.

4.19 We also identified a view amongst some service commissioners and providers that substance misuse in the more affluent areas of Wales is often unrecognised, and even where problems may be identified, there was considered to be a more limited service provision than in other, more deprived areas.

4.20 Many service providers and commissioners made a very clear link between the value placed by some statutory bodies on substance misuse services and the individuals accessing them and the adequacy of the physical locations from which such services were being delivered. Despite there being considerable investment in the improvement of facilities since 2006 we heard that substance misuse services in some areas of Wales are still being delivered from what was described as badly

designed; poorly located, ‘*Cinderella*’ buildings which were maintained only to the minimum levels of comfort and decoration.

Substance misuse and mental health services

4.21 Across Wales, the links between substance misuse services and mental health services were considered to be significantly under developed, with participants noting poor communication and often even poorer understanding across both services. This is a matter of considerable concern, given that for many substance misusers there is also often a mental health need. The Royal College of Psychiatrists⁷ share this view, themselves identifying that mental health services frequently fail to identify patients who also have drug use problem and noting that a third of substance misuse patients with mental health needs do not receive any interventions.

4.22 As consistently identified throughout our review, and mirrored in our virtual family, most individuals needs are complex, and the response and support needed to address those needs rarely centre around a single service. Services must therefore be equipped to deal effectively with a dual or multiple diagnosis by working together with other agencies and providers so that a holistic response may be developed; the responsibilities of individual service providers is clearly defined and substance users may follow a fully integrated care pathway.

The transition from children’s to adult services

4.23 Our workshop discussions around services available to Siân, Lucy and Tom identified a number of challenges around the provision of support services. In particular, the transition from child to adult services was seen to be a problem area. Service commissioners and providers were often themselves unclear about when and how individuals would be required to move between services, and were

⁷ The Royal College of Psychiatrists is the professional and educational body for psychiatrists in the United Kingdom.

concerned that young people could very easily become *'lost'* to services and *'fall between the gaps'* during this transition.

4.24 Education services were also often described as the *'weaker link'* both in terms of the education providers' knowledge and understanding of the issues facing some children and young people and the adequacy of the communication and links through to other agencies and services.

4.25 Once again, although statutory services were described as being patchy, the work of the Third Sector in providing support was consistently recognised. One example of a valued service is:

Barnardo's Seraf Service provides long term support to young people aged under eighteen who are having difficulties like missing school, running away, may be in relationships they're unhappy with or doing sexual things they don't really want to do.

These things can lead to abuse and sexual exploitation.

The Seraf Service aims to support young people to help keep them safe and happy. Each young person has a one to one worker who will support them around problems they might be having where they live or at school. They can look at things like low self esteem, understanding healthy relationships, body image, personal safety, drugs, alcohol, self harm, sexual health and difficulties with family or friends or whatever a young people feels is important for them.

The *'Carousel'* effect and the stop and start nature of services

4.26 Our discussions around service provision for Gareth, our *'virtual'* long term substance misuser and offender perhaps revealed the clearest example of the effects of stigma, stereotyping and the short term nature of many services on the chances of a sustainable recovery. Gareth was seen by service providers and

commissioners as being very likely to suffer from the effects of negative attitudes and a lack of understanding by statutory services, particularly GPs and their staff.

4.27 What was described as the short term or strict time limited nature of services was also considered to be a problem, even where those services were considered to be very helpful overall, such as the Drug Intervention Programme.

The Drug Intervention Programme (DIP) is a crime reduction initiative, which provides a much needed support structure to encourage offenders out of crime and into treatment.

It aims to break the cycle of drug misuse, offending behaviour and custody by intervening at every stage of the criminal justice system to engage offenders in treatment and provide aftercare support.

The Home Office funds the initiative however the Welsh Government implements it in Wales. A multi-agency National Implementation Working Group (NIWG) consulted with key stakeholders and decided that to maximise the benefits and cost effectiveness it should be delivered regionally.

To support regional delivery, four Regional Management Boards run the programme in their local areas. They have developed Local Implementation Plans as the starting point from which to commission services delivered by Criminal Justice Intervention Teams (CJITs).

4.28 For services provided by the Third Sector, the sustainability of these programmes and therefore their longer term value was considered to be inherently compromised because they continue to rely on short term funding arrangements.

4.29 Overall, these factors contributed to what may be described as '*carousel services*,' where substance misusers were seen as moving between services '*getting*

off and on again' without ever really making the consistent, sustainable journey through to recovery.

Diversiónary activities and aftercare

4.30 Diversiónary services are designed to promote greater awareness of life without alcohol and drugs, allowing service users to overcome feelings of boredom and isolation which can lead to relapse. Whilst service providers and commissioners were able to describe a range of service providers offering such diversionary programmes across Wales, like so many of the substance misuse programmes currently available, access to such services was found to be patchy. Where they were available, these services were described as being invaluable.

The DOMINO (Development Of Motivation In New Outlooks) project aims to provide service users, regardless of whether they have requested abstinence or harm reduction, with the opportunity to participate in a worthwhile and productive learning experience.

The project provides a range of diversionary activities, allowing service users to overcome feelings of boredom and isolation which can lead to relapse. They also provide an opportunity for service users to socialise within a structured environment and become part of a supportive, non-judgmental group irrespective of their circumstances.

The DOMINO project currently involves a wide range of activities: gardening, nature walks, art and crafts, local history, cookery and hygiene, basic literacy and numeracy skills, IT and guitar/music classes.

4.31 Overall, the awareness, understanding and availability of aftercare services was considered to be an issue. Many service providers and commissioners were unclear what services were available and how they operated to support clients once they are clean to stay clean. Many felt there should be open access to long term relapse prevention for substance misusers across Wales.

4.32 The ‘constant’ factor across all our discussions with statutory service providers and commissioners was the value and impact the Third Sector has in providing creative, innovative and non judgemental services for substance misusers. They were often described to us as ‘*being designed for substance misusers by those who understood substance misusers.*’

The views of service users

4.33 Our discussions with service users highlighted a number of services that they have found to be of benefit to their recovery. We are pleased to say that there were many examples and experiences we could have shared with you in this section; we have provided a few to give a flavour of the types of services and approach to service provision that substance misusers told us works for them.

Ann's Story

Ann is an attractive young woman with the most beautiful small baby, who she clearly dotes upon. Ann explained that she has been clean for over a year now and that her beautiful son was her key motivation.

"I couldn't have done it without the help I received from Kaleidoscope I have no doubt that my baby would have gone into care. I can come here and get the help and support I need, they even arranged for me to have a specialist midwife. I have tried to come off the stuff before but always ended back on it, it was the dark moments when I needed support most that I found it difficult to get hold of someone and so slipped back into my old ways. I know that I will always be in danger of slipping but I now know where to come if I need help and that help is always there."

Joe's Experience

Joe has been a substance misuser since a teenager and as co-existing mental health issues; he is warm, funny and really open about his experiences because he wants to ensure improvements that will help others.

"I have been receiving help and support for some time. Some months ago I got the opportunity to attend gardening and exercise classes which I found relaxed me and made me feel useful. Unfortunately the funding was only available for six months and so I couldn't continue. I sometimes think that those in charge see it has a jolly but for me it was a lifeline, my family saw a real difference in my confidence when I was attending classes and it got me out of the house. I have got a tendency to lock myself away and isolate myself."

4.34 As referred earlier, whilst we came across a range of services offering such diversionary programmes across Wales, like so many of the substance misuse programmes currently available, access to such services is patchy, and even where they are available, this is often only on a short term basis.

Mark's Plea

Mark is a smart, articulate young man who was a bit sceptical about our review. He's honest though saying that he is happy to talk but is unconvinced that our discussions with service users aren't just tokenistic.

"I am frustrated and don't feel that statutory bodies listen. We know what works well and it's not being locked away on a rehab ward. It's organisations like TEDS that work, where we are helped to achieve our goals without people looking down their nose at us. If there is one message I want you to take away today it is look at the work that TEDS and other organisations like this do and share it as good practice."

4.35 Treatment and Education Drug Services (TEDS) is a voluntary agency offering free and confidential services to users of drugs or alcohol throughout the Rhondda Cynon Taff area. TEDS aims to provide high quality services to anyone

affected by substance misuse by working within a harm reduction framework on a client led basis. It also provides services for families and friends. TEDS works with service users to help them achieve their goals, whether that's stopping use or offering advice and help about safe practices that reduce the risk of harm. The service also helps service users to get appropriate help and advice about other problems resulting from drug or alcohol use e.g. housing, debt, legal issues etc.

Lucy's View

Lucy is in her 50s. She lives alone and started drinking the odd glass of wine in the evening. Before she knew it her drinking had escalated and she was asked to leave her job - escalating her loneliness and drinking problem.

"For me the Peer Mentoring Programme has been fantastic. I have a peer mentor who has been there with me every step of the way; I can call her any time of day or night. She's been through similar problems as I have and so she understands my highs and my lows. I am going on the Peer mentor training myself next week so that I can help others, but my mentor will always be there for me."

4.36 The [Peer Mentoring Scheme](#), (PMS) is a [Welsh Government](#) pan-Wales initiative funded by the [European Social Fund](#)⁸. The overall purpose of the PMS is to encourage, support and enable current and ex drug and alcohol users to achieve economic independence by gaining sustainable employment.

4.37 A team of Peer Mentors has been employed to offer individual, intensive support to people referred to the scheme. The scheme also uses volunteer Peer Mentors. All mentors are provided with extensive training and development to extend and consolidate their knowledge, skills and expertise, and the majority of Peer Mentors are themselves ex service users.

⁸ The European Social Fund (ESF) aims to help people fulfil their potential by giving them better skills and better job prospects. Further details of the operation of the ESF in Wales may be accessed at: <http://wales.gov.uk/topics/educationandskills/allsectorpolicies/europeansocialfund/?lang=en>

Chapter summary

4.38 We sought in this chapter to determine the level and adequacy of substance misuse services across Wales. Through our discussions with commissioners, service providers and substance misusers themselves, the answer was clear:

“It all depends.....”

4.39 If you are a substance misuser, the chances of you accessing the services you need, when you need them, in the way that you need them depends upon a variety of factors. It depends upon your individual circumstances; your age and gender; where you live; how actively you seek help yourself; where and when you seek to access services for the first time; who you happen to see; what they happen to know about the services available; who else is seeking to access the same services; and how those services are funded.

4.40 The strategic vision of holistic, joined up and coherent services across Wales all working together in a *‘whole system approach’* is clear. However, whilst we saw clear evidence that services are developing in the right direction to achieve this vision, the execution is still very patchy.

4.41 Despite the considerable efforts being made to tackle the circumstances leading to substance misuse, too often services are only able to deal with an individuals or families immediate presenting symptoms rather than dealing with the underlying causes holistically and sustainably.

4.42 We heard about some inspirational services being delivered across Wales, demonstrating high levels of creativity and innovation, particularly from the Third Sector. The difficulty is that these are often pockets of excellence operating at a very local level. The kind of creativity and innovation that leads to the design and delivery of such services needs to be harnessed and replicated across Wales and not just by commissioners and service providers locally and regionally. At an all Wales level, policy makers too need to ensure the strategic development of

substance misuse services is as creative, innovative, flexible and responsive as that being delivered locally.

4.43 What definitely isn't patchy across Wales is the passion and commitment of policy makers, commissioners and services providers from across the statutory and third sectors. We were privileged to hear an open and honest reflection from commissioners and service providers across Wales about what they were good at and where they needed to do better.

4.44 Wales has the opportunity to be an exemplar in terms of the provision of substance misuse services. Service users; commissioners and providers know what needs to be done to improve services, and there was no shortage of ideas and suggestions to address the challenges facing them. However, there needs to be a level of bravery from politicians particularly at the local level to drive forward the social aspects of the '*holistic approach*' that is needed. The conclusions and next steps we set out in Chapter 6 have therefore been developed with these groups so that they focus on what they themselves have identified as needed and reflect what can and should be done practically to achieve this.

Chapter 5: Housing and wrap around services - the impact on access to services and recovery

5.1 *'Working Together'* recognises the important role that housing and support from wrap around services play in helping people to tackle their substance misuse, and that a lack of housing and support can provide a barrier to treatment and impact on the effectiveness of treatment. However, this review and the findings from our work in relation to homicides where the perpetrator was a mental health service user have highlighted many shortcomings in the provision of housing and wrap around services for these client groups.

5.2 From our discussions with service users it was clear that they see housing as being key to their recovery and future abstinence. Their views echoed the findings of a survey of substance misusers undertaken by Addaction⁹ in 2005 which found that 83% of individuals surveyed felt that stable housing was one of the most important support services required to help them stay clean.

5.3 In recognition of the important role that housing plays in recovery, the Welsh Government went out to consultation on its *'Supporting People - Housing Related Support Strategy'* in February 2009. The draft strategy made explicit reference to the fact that the Government wanted to see the continued development of a spectrum of services for people with substance misuse issues. It also recognised that the provision of housing and support was vital in helping people to manage or break their drug or alcohol habit, and that those working in the area of housing needed to be supported to understand the issues around substance misuse to a level where they are able to address its causes and refer individuals to appropriate services such as detoxification or counselling.

5.4 However, the resulting *'National Housing Strategy – Improving Lives and Communities – Homes in Wales'* launched in April 2010 only makes fleeting reference to this client group *'Support for people in and around their homes, such as avoiding debt problems, preventing domestic violence, and help to overcome drug and alcohol*

⁹ Drainey S (2005) Aftercare Consultation 2005: the service user perspective Addaction, London.

problems, all of which tackle significant causes of physical and mental health problems.'

5.5 Discussions with commissioners and providers highlighted that housing issues are still a key concern and that for adults particularly males over the age of eighteen and without dependent children the likelihood of getting permanent housing is slim. Homeless substance misusers without dependents will only normally be considered homeless by statutory bodies if they can prove some form of vulnerability beyond drug use; for example mental health or physical health issues which makes them more vulnerable as a result of homelessness than the general population.

5.6 Our discussions with service users further emphasised the problems that adults with a substance misuse issue face in this regard. Many of those we spoke to had lost their job, home and family due to their substance misuse; almost overnight their circumstances had changed dramatically and they were left alone and vulnerable.

Sarah's Story

Sarah is an attractive, articulate and intelligent woman in her early thirties, who is clearly on the road to recovery and is helping others to find their way.

"I lost everything due to my drinking, my home and my family. I ended up homeless and sleeping in doorways. I couldn't get a house I wasn't a priority so I decided to sleep in the doorway of my local council offices, hoping someone would help me. Instead the office staff just stepped over me every morning and evening; it was like they didn't even see me. After several weeks I suffered a stroke and was taken to hospital where I spent six weeks recovering only to be discharged to the doorstep of the council offices. I was so miserable and cold I started drinking again."

5.7 A number of reports have highlighted the relationship between substance misuse and housing and support. Specifically '*Where do they go? Housing, Mental Health and Leaving Prison, Revolving Doors 2002*' highlighted that individuals with a

mental illness, criminal record and substance addiction are deemed ineligible for 99% of the social housing and 95% of the hostels in one London borough.

5.8 *'Home and Dry? Homelessness and substance misuse, Crisis, 2002'* highlighted that 54% of those who had used heroin had first used it after becoming homeless, 73% had first used other opiates, and 72% had first used crack. While 36% of those surveyed considered their drug use to have increased in the last year, and both this and the use of alcohol correlated with a worsening accommodation situation. (Sample of 389 homeless people in London who had slept rough for at least six nights in the previous six months.)

5.9 Further, *'Keys to Change, a study of the role of local authority housing in the care and rehabilitation of drug and alcohol users in the London Borough of Lambeth (Drugs Prevention Initiative, 1994), Tackling drug use in rented housing'* emphasised the importance of housing in enabling individuals to sustain abstinence. It highlighted that many local authorities do not accept that individuals were vulnerable and in priority need because of substance misuse problems, and recommended that care should be taken, when considering vulnerability, not to ignore the difficulties which individuals with a substance misuse issue have finding and keeping settled accommodation.

5.10 There needs to be a shift in the thinking of statutory agencies in relation to the care and treatment of those with a substance misuse issue. They need to start seeing substance misuse as a chronic condition that needs to be treated *'holistically'* as to enable full recovery biological, psychological and social factors need to be addressed together. We cannot expect an individual to stop misusing substances if we expect them to continue to live in conditions from which substance misuse gives them an escape.

The impact of zero tolerance

5.11 Service users told us than when they are fortunate to access accommodation, whether it is a hostel or rented accommodation they often find that

there is zero tolerance to the use of drugs and alcohol. They described such restrictions as being unrealistic when they are in the early stages of accessing treatment and felt that there was a complete lack of understanding of their situation and what it meant to be a recovering substance misuser. They described living in fear of losing their accommodation and the extra stresses that this placed on them.

Chapter summary

5.12 Despite *Working Together* recognising the important role that housing and support from wrap around services play in helping people to tackle their substance misuse, issues of homelessness and substance misuse are not well integrated at the local authority level. More needs to be done to ensure the proper co-ordination of housing and substance misuse services.

5.13 However, any housing strategy will be ineffective unless a range of related support services are also put in place to sustain service users in their tenancies. Such wrap around services may include anything from practical help with cooking and paying bills to mental health services.

5.14 Substance misusers present with a variety of complex issues and these issues and their needs will also change with time. At different stages of treatment and recovery service users may need different services, and housing and related support services must be flexible enough to meet these needs. A comprehensive package of services is needed that includes entry level shelters where alcohol and drug use is permitted; transitional housing supported housing as well as permanent housing.

5.15 Housing needs to be considered as part of the holistic care package but again often the stigma of substance misuse impacts on funding and decisions made at the local level as to who should be a housing priority. Other groups of people are seen to be more deserving and often people don't want a substance misuser living in the same street as them. Sadly as evidence of this in *Working Together* the Welsh Government reported that it *'had put in place a dedicated funding stream within the*

Social Housing Grant (SHG) programme for schemes to add to and address accommodation for substance misusers. However, partners have experienced difficulties in identifying suitable locations for schemes and in obtaining local community support, particularly where a planning consent is required.'

5.16 More needs to be done to encourage local authorities and other statutory agencies to invest in the development of housing and wrap around services for this client group; particularly, education, training and employment, which are key to reducing the harm caused to individuals by substance misuse and to their ability to abstain and re-establish themselves in the community.

Chapter 6: Conclusions and Next Steps

6.1 We have to accept that substance misuse is a growing problem and that drugs such as cocaine are becoming more available to a wider group of people and age groups. In 2008-09, an estimated 168,000 adults (9.9 per cent)¹⁰ in Wales reported having used controlled drugs. In 2010-11 there were 13,354 drug seizures made by Welsh police forces¹¹.

6.2 The most recent figures relating to the extent of substance misuse in England and Wales estimates that almost 2.9 million people (8.8%)¹² of adults had used some form of illicit drugs within the last year. Around one million adults reported using Class A¹³ drugs within the last year. Class A drug use was more prevalent amongst those aged 20-24, whereas the use of any illicit drug was highest amongst 16-19 year olds. The highest incidence of drug use was found to be amongst men, both Class A drugs (men 4.2%, women 1.8%), and any illicit drug (men 12%, women 5.7%) (Smith and Flatley 2011).

6.3 If we are to properly tackle the issue of substance misuse we have to change attitudes and raise awareness so that individuals with a problem feel empowered to seek help and supported to find the right help. To do this we need to raise awareness generally, train health, social services and housing staff appropriately and offer services in a flexible, responsive way.

6.4 As highlighted in Chapter 3 there are a lot of good services in place across Wales and a large number of substance misuse workers who are doing a wonderful job with compassion and enthusiasm. However, the picture of services is patchy and complex with a lack of clarity and bureaucracy often in place at a local service delivery level. Currently Substance Misuse Action Fund (SMAF) money is devolved

¹⁰ Figures taken from Welsh Government Statistical Bulletin.

¹¹ Figures taken from Home Office Statistical bulletin - Seizures of drugs in England and Wales 2010-2011.

¹² Annual national statistics compiled from the 2010-11 British Crime Survey.

¹³ Class A drugs include: heroin, powder cocaine, crack cocaine, LSD, magic mushrooms, methadone, methamphetamine and ecstasy.

to Community Safety partnerships and Health Boards; we are not convinced that this is the best way of managing these monies as we saw evidence of duplication and overlap of services as well as a disparity and gaps in services when we looked at them as part of this review. We consider that careful consideration should be given to managing SMAF funds at a regional level so that a more strategic and collegiate approach to the commissioning, funding and monitoring of the quality of services can be put in place.

6.5 Whatever commissioning and monitoring arrangements are in place in the future there needs to be greater engagement with service users. They know what worked for them and what is important to those on the journey to recovery. Also those managing SMAF funds need to be empowered to tackle the wider social issues that are linked to substance misuse such as housing and related wrap around services. We cannot perpetuate the myth that substance misusers deserve all they get and therefore they shouldn't be considered a priority for housing. Such a blanket approach means that we are not supporting individuals who are vulnerable and not giving them a chance to recover. Commissioners and providers must not let the stigma attached to substance use by society in general influence their funding decisions.

6.6 We set out below a series of recommendations for the Welsh Government, commissioners and providers to take forward. We will be following up on progress with their implementation as part of our rolling review programme:

Recommendation 1: The Welsh Government should look to devolve all SMAF funds (including those currently included in health board budgets) to a regional level body/committee that is best able to commission at a strategic level.

Recommendation 2: The Welsh Government should strengthen the arrangements that are currently in place to ensure that service users are at the centre of commissioning and decision making.

Recommendation 3: Statutory bodies should ensure that awareness training for staff who may come into contact with someone with a substance misuse issue is in place and that it is integrated and embedded into training strategies and plans.

Recommendation 4: There needs to be greater investment in the provision of information about local substance misuse services and statutory bodies need to work with local businesses to consider how this information could be best disseminated.

Recommendation 5: Drop in information centres need to be seen as an integral part of substance misuse services.

Recommendation 6: Mechanisms should be put in place to share noteworthy practice at a regional level.

Recommendation 7: The Welsh Government should review existing common assessment and referral tools to ensure that they are user friendly and used consistently across Wales.

Recommendation 8: Commissioners and providers should put mechanisms in place to ensure that screening tools are properly used and individuals are assessed appropriately.

Recommendation 9: Substance misuse service providers and commissioners must work with other services such as mental health services to ensure a holistic response to the needs of individuals.

Recommendation 10: Clear pathways should be developed to manage the transition from children's services to adult services.

Recommendation 11: Local commissioners should work with providers and other partners to ensure that services are joined up and work together to provide holistic care throughout the recovery pathway. Substance misuse must be seen as

a chronic condition and hence services need to be configured to support individuals throughout their life.

Recommendation 12: The Welsh Government should develop a housing strategy for those with substance misuse issues that ensure that wrap round services are provided to help those with a substance misuse issue maintain their home. In this respect Local Authorities need to recognise that the onus is on them as part of the local substance misuse commissioning arrangements to ensure that suitable housing arrangements and wrap around services are in place at the local level.

Recommendation 13: Third sector provider organisations need to work with local commissioners when applying for funding through grants, the lottery fund or charitable organisations for new services so that agreement can be reached as to how these services will be funded (or not) over the longer term.

Recommendation 14: Local commissioners need to work with the Prison Service to ensure that accommodation and wrap round services are available for prisoners with substance misuse issues upon them leaving prison.

The scope and objectives of the review

The aim of the review will be to assess:

'What is it like for people using substance misuse services in different parts of Wales?'

The scope of the review will be:

To follow service user journeys from the point of entry to the point of maintenance or 'moving on.' This will encompass the availability of information, referral, access and 'signposting' through to shared care and support services. It will identify 'bumps' in the system in terms of how people journey across different tiers of substance misuse service provision. Finally it will consider how well risk factors are managed throughout the journey including child protection, protection of vulnerable adults, co-existing mental health problems, older people, younger people, transition and drop out.

The review will:

- Involve services users to gain their perspective on how well services are delivered.
- Include commissioners and service providers across statutory and non-statutory sectors.
- Encompass areas not currently covered in any existing performance monitoring and management arrangements.
- Aim to evaluate the experiences of service users.
- Assess the quality of services provided against existing standards and guidance.

We will do this by:

Using 'virtual service user profiles' to test service commissioning and provision across the four regions.

Organisations visited by region

Dyfed Powys

Ceredigion Community Safety Partnership (CSP)
Carmarthen Community Safety Partnership (CSP)
Carmarthen Substance Misuse Action Team (SMAT)
Ceredigion Community Safety Partnership (CSP)
Ceredigion Substance Misuse Action Team (SMAT)
Chooselife Llanelli
Cyswllt Contact Aberystwyth
Kaleidoscope Carmarthen
Kaleidoscope Llanelli
Pembrokeshire Community Safety Partnership (CSP)
Powys Community Safety Partnership (CSP)
Powys Drug and Alcohol Centre (PDAC) Llandrindod Wells
Powys Health Board
Prism Alcohol and Drug Advisory Service Haverfordwest
Prism Alcohol and Drug Advisory Service Llanelli
Prism Alcohol and Drug Advisory Service Carmarthen
Prism Alcohol and Drug Advisory Service Lampeter
Rhosercan Ceredigion
Social Care Substance Misuse Team
Turning Point Llanelli
West Wales Substance Misuse Service (WWSMS) Milford Haven
West Wales Substance Misuse Service (WWSMS) Carmarthen

North Wales

Anglesey Substance Misuse Action Team (SMAT)
Arch Initiatives Colwyn Bay
Arch Initiatives Bangor

Arch Initiatives Wrexham
Betsi Cadwaladr University Health Board
CAIS Drug and Alcohol Agency Colwyn Bay
CAIS Drug and Alcohol Agency Conwy
CAIS Drug and Alcohol Agency Bangor
CAIS Drug and Alcohol Agency Wrexham
CAIS Drug and Alcohol Agency Hafan Wen
Conwy Community Safety Partnership
Conwy Substance Misuse Action Team
Flintshire Community Safety Partnership (CSP)
Touchstones12 Colwyn Bay
Wrexham Community Safety Partnership
Wrexham Substance Misuse Action Team (SMAT)

Gwent

Aneurin Bevan SMS Lead
Blaenau Gwent Substance Misuse Action Team (SMAT)
Caerphilly Community Safety Partnership (CSP)
Caerphilly Substance Misuse Action Team (SMAT)
Crime Reduction Initiative (CRI) Newport
Drug and Alcohol Family Support (DAFS) Blaenau Gwent
Drug Intervention Programme (DIP) Blackwood
Drugaid Caerphilly
GP Shared Care Blaenau Gwent
Gwent Alcohol Project (GAP) Caerphilly
Gwent Alcohol Project (GAP) Newport
Gwent Drug Intervention Programme (DIP)
Gwent Specialist Substance Misuse Service (GSSMS) Newport
In2Change Newport
Kaleidoscope Newport
Kaleidoscope Monmouthshire/Torfaen
Monmouthshire and Torfaen Substance Misuse Action Team (SMAT)

Neath Port Talbot Substance Misuse Action Team (SMAT)
Newport Community Safety Partnership
Newport Substance Misuse Action Team (SMAT)
Turnaround Caerphilly

South Wales

Adfer Unit Whitchurch Hospital Cardiff
Ashcroft House
AMBU Community Drug and Alcohol Team (CDAT)
Bridgend Community Safety Partnership (CSP)
Bridgend Substance Misuse Action Team (SMAT)
Cardiff Addictions Unit (CAU)
Cardiff Community Drug and Alcohol Team (CDAT)
Cardiff Community Safety Partnership (CSP)
Cardiff and Vale Health Board
Community Addictions Unit Barry
Crime Reductions Initiative Cardiff
Cwm Taf Health Board
Drug Intervention Programme (DIP) Barry
Drug Intervention Programme (DIP) Cardiff
Inroads Barry
Inroads Cardiff
Ogwr Dash Bridgend
Primary Care Substance Abuse Liaison Team (PSALT) Swansea
Rhondda Cynon Taff Community Drug and Alcohol Team (CDAT) Pontypridd
Rhondda Cynon Taff Community Safety Partnership (CSP)
Rhondda Integrated Substance Misuse Service (RISMS)
Salvation Army Cardiff
Swansea Community Drug and Alcohol Team (CDAT)
Swansea Community Safety Partnership (CSP)
Swansea Drugs Project
Treatment and Education Drugs Service (TEDS) Aberdare

Merthyr Community Safety Partnership (CSP)
Merthyr Community Drug and Alcohol Team (CDAT)
Merthyr Integrated Drug and Alcohol Service (MIDAS)
Wallich Clifford Cardiff
West Glamorgan Council on Alcohol and Drug Abuse (WGCADA) Swansea
West Glamorgan Council on Alcohol and Drug Abuse (WGCADA) Bridgend
Vale of Glamorgan Substance Misuse Action Team (SMAT)

Organisations involved in workshops – by area where workshop held

Swansea

ABMU Health Board
Drugaid
Drug Intervention Programme (DIP)
Kaleidoscope
Neath Port Talbot Youth Offending Team (YOT)
North Port Talbot Council for Voluntary Service
Ogwr Dash
Primary Care Substance Abuse Liaison Team (PSALT)
Safer Wales
South Wales Police Western BCU
Swansea Substance Misuse Action Team (SMAT)
West Glamorgan Council on Alcohol and Drug Abuse (WGCADA)
Young People's Drug and Alcohol Service

Cardiff

Ahscroft House
Cardiff Addictions Unit
Cardiff County Council
Child and Adolescent Mental Health Services (CAMHS)

Inroads
Job Centre Plus
Kaleidoscope
MIND Cymru
Pen Yr Enfys
Penarth Youth Project
Probation – Vale of Glamorgan
Safer Vale Partnership
Salvation Army
Wales Probation Trust

Carmarthen

All Wales Probation Trust
Ceredigion Domestic Abuse Forum
Chooselife
Cyswllt Contact Ceredigion
Hywel Dda Health Board
Kaleidoscope
Pembrokeshire County Council
Prism
Powys Domestic Abuse Forum/Powys CC
Powys Drug and Alcohol Centres
Powys Teaching Health Board
Radnorshire Women's Aid
Rhosercan
Turning Point Cymru
Wales Probation Trust
West Wales Action for Mental Health
West Wales Substance Misuse Service (WWSMS)
Youth Offending and Prevention Service (YOPS)

Gwent

Aneurin Bevan Health Board -Mental Health Specialist Services

Barnardos Cymru

Caerphilly County Council - POVA

Caerphilly County Council Directorate of Social Services – Social Work Drug and Alcohol Team

Caerphilly County Council Directorate of Social Services – Mental Health and Crime Reductions Initiative (CRI)

Domestic Abuse Monmouthshire County Council

Drugaid

Gwalia Care and Support

Gwent Drug Intervention Programme

Gwent Council on Alcohol and Drug Misuse

Integrated Family Support Team (IFST)

Kaleidoscope

Learning Disabilities Team

Monmouthshire County Council – Domestic Abuse

Monmouthshire County Council – Safeguarding Children

Monmouthshire County Council – Commissioning (Mental Health and Substance Misuse)

Monmouthshire County Council - POVA

Newport West Community Midwife

Newport Community Safety Partnership (CSP)

Safeguarding Children Board Newport Council

Substance Misuse Action Team Newport Council

Turnaround

Youth Offending Team Caerphilly/Blaenau Gwent

Youth Offending Service Monmouthshire and Torfaen

Merthyr

Barnardos Cymru

Child and Adolescent Mental Health Services (CAMHS)

Community Drug and Alcohol Team (CDAT)

Cwm Taf Health Board – Child Protection & Vulnerable Children

Cwm Taf Health Board – Mental Health

Cwm Taf Health Board – Public Health

Drugaid

Drug Intervention Programme

Include Turnaround

Integrated Family Support Team RCT

Kaleidoscope

Merthyr Chief Inspector of Police

Merthyr CBC Adult Protection

Merthyr CBC – Housing and Community Safety

RCT CBC – Mental Health and Substance Misuse

RCT Community Drug and Alcohol Team

RCT Community Safety Partnership (CSP)

RCT Domestic Abuse

Rhondda Integrated Substance Misuse Service (RISMS)

South Wales Probation

Social Work Team RCT CBC

Supporting People Team RCT CBC

Treatment and Education Drugs Service (TEDS)

Youth Offending Team Merthyr CBC

Youth Offending Service RCT

North Wales

Adult Social Services Denbighshire County Council

Anglesey County Council

Cais Ltd

Child and Adolescent Mental Health Services (CAMHS) - BCUHB
Children and Families Services – Denbighshire County Council
Conwy and Denbighshire Substance Misuse Action Team (SMAT)
Conwy County Borough Council – POVA
Drug & Alcohol rapid Response Team (DARRT)
Drug and Alcohol Family Support
Drug Intervention Programme (DIP)
Flintshire Community Safety Partnership
Gwynedd County Council
In2Change/Youth Justice Service
Specialist Midwife Liaison Service – Betsi Cadwaladr University Health Board
Touchstones12
Wales Probation
Wrexham Youth Justice Service
Youth Justice Service - Flintshire County Council

'Dai's family'

Background

In the world of computers, Virtual Reality allows interaction and learning through a simulated environment, whether that environment is a simulation of the real world or an imaginary world. In the same way, Virtual Profiles of people can be used to explore and learn about real systems and processes, de-sensitise sensitive situations or topics and promote dialogue about specific issues in a 'safe' environment.

Dai's Virtual Family has been developed for use during the Substance Misuse review. Dai is the central character linked to a suite of family and friend profiles. These are intended to provide a consistent framework for interviews and other forms of evidence gathering as part of the fieldwork with the aim of being able to answer the review question:

'What is it like for people using substance misuse services in different parts of Wales?'

The family members of *'Dai's family'* range in age from four years old to 57 years. The individual profiles have been developed by HIW's team of Substance Misuse peer reviewers using professional experience and knowledge. They have been consulted on through workshops with service commissioners and providers across Wales.

'Dai's family' is based on a concept initially developed by Denbighshire Local Authority for use during the engagement/ consultation phase of the Health, Social Care and Well Being Strategy *'Healthy Denbighshire'* 2008-11.

Members of 'Dai's family'

Dai and Anne Jones live in a private rented house. They both have a history of dependence and are both struggling with the consequences of this.

Dai

Dai started using drugs at an early age. As with many adolescents, he struggled with school and family pressures turning to cannabis and alcohol to cope with boredom and failure to achieve. This quickly progressed through the drug using spectrum and for a time he was injecting.

Dai has been in and out of treatment with varying degrees of success and during the last episode of inpatient treatment he met Anne, who he now lives with, and they have two children. Since then Dai has engaged with community services locally.

Dai is currently engaged in methadone maintenance treatment receiving 80mgs a day. There is suspicion that Dai is not using all of this methadone and is selling a proportion of it. Dai occasionally uses cocaine. This was a big problem for him previously but he has managed to bring his use down considerably. During the period when he was using both opiates and cocaine chaotically, Dai was arrested many times for acquisitive crime related offences and has a significant conviction history. During this time he became Hepatitis C positive. Dai is a likeable man, who is bright and occasionally ambitious. He is currently undertaking an access to learning course as he feels that his way out of his current situation is to become clean and get a job. Dai does drink heavily at weekends but doesn't see this as a problem.

Anne

Anne is of African Caribbean origin and met Dai when in a treatment unit seven years ago. She is originally from London. Anne and Dai have two children, six year old Tom and four year old Lucy.

Tom is in school and Lucy is due to start in reception in September. They are looked after by Dai's mother who lives around the corner when Anne is at work.

Anne started using when she met an older drug using man whilst she was in school and had a daughter, Siân who is now 15. Before that she was doing well and achieving normally. Anne has managed to maintain abstinence since she left treatment seven years ago, however she smokes cannabis every day.

She is volunteering for the local Tier 2 agency and would like to progress with this into paid work. Anne struggles with the fact that Dai is still using but is pleased that he is now on a '*script*' and not using illicitly. She feels she can cope as long as this remains the case because previously Dai used all the money available to them to fund his habit. They have a number of debts as a result of this and are currently in rent arrears.

Anne suffered a significant episode of post natal depression following the birth of both Tom and Lucy. She suffers from low mood from time to time and this affects her ability to care for the children.

Siân

Siân is Anne's 15 year old daughter. She dropped out of school last year stating that it was boring and she wasn't getting on with her teachers. Siân had a challenging upbringing living with her mother Anne during her childhood, whilst she was using. Siân was often left alone for long periods of time whilst Anne was out either earning money or scoring. Anne often had friends around the house who were also using and it was during this time that Siân was sexually abused at an early age.

Whilst Siân has a reasonable relationship with Anne and Dai, she doesn't like living at home as she feels that she has to justify her behaviour and actions so she often stays away with friends sleeping on sofas. She has an older boyfriend who is using drugs and she has just found out she is pregnant. Siân has been arrested a few times recently for both shop lifting and soliciting and has recently engaged with the Youth Offending Team.

Anne and Dai are not aware of the boyfriend, the extent of Siân's drinking and drug use or the sex work and at times use her to baby sit Tom and Lucy when the need arises. During one of these occasions Lucy was said to have fallen down the stairs and broken her right arm.

Mair

Mair is Dai's mother and lives in the same town. She is a 58 year old widow. It has recently come to light that she was sexually abused by a female perpetrator as a child, Mair has refused to say who that was, stating she cannot remember.

Mair has problems with her memory and this is becoming increasingly obvious. Most days Mair drinks at least a couple of bottles of wine, saying that it helps calm her nerves.

Dai is becoming concerned about this as his mother has been to hospital quite a few times recently having fallen at home and a couple of times whilst out shopping. She is covered in bruises and says this is because of the falls.

Mair has a significant amount of money as a result of a compensation claim involving an accident in which her husband died. She lives off this money but has recently become anxious about money saying it won't last her until she dies and asking who will care for her then.

Mair looks after Tom and Lucy from time to time and has a good relationship with Siân who spends time with her.

Tom and Lucy

Tom and Lucy are six and four and are mixed race children. Tom sometimes comes home from school having been in a fight as other children tease him about his heritage. The school say it's not a problem – just children being children.

Lucy is recovering from a broken arm having fallen down the stairs at home when being looked after by Siân. She has become withdrawn since this and wants to be with her mother, becoming upset when Anne goes to work.

Gareth

Gareth is Dai's best friend since childhood. They both dropped out of school at the same time and were both using together. Gareth is currently homeless and asks to stay at Dai's house from time to time. Anne does not like this as Gareth can become aggressive when he has been drinking heavily which is becoming most of the time. Gareth's drug use is escalating and he has begun injecting again recently. His situation appears to be worsening further as often he cannot afford the bags he wants, his increasing use of benzodiazepines appears to be adding to his aggression. He has also confided in Dai that he is also injecting steroids in an attempt to counter weight-loss. Dai has confided none of this to Anne.

Gareth currently has a number of infected injecting sites a couple of which have become abscesses. Gareth's mood swings are becoming increasingly unpredictable. Gareth has a significant criminal history and was on a 14 week Drug Intervention Programme (DIP) programme a year ago. He is currently not engaged in treatment. Dai and Anne have had an increasing number of arguments recently about Gareth coming round to the house. Dai understands Anne's concerns but has said *"I have no choice, he is my friend."*

Angharad

Angharad is Anne and Dai's neighbour, the only one they really have a close relationship with. Angharad is ten years older than Anne and they have become reasonably close over the past two years.

Angharad lives alone having divorced her husband fifteen years ago after a long period of suffering violence and abuse due to his drunken rages after he was laid off work. Angharad is teetotal and tends to disapprove of drinking in any form. She has one son Ieuan, he occasionally visits at Christmas out of a sense of duty but views

his mother as being at fault for abandoning his father, and for his later death due to liver failure.

Angharad has been taking a keen interest in Anne's wellbeing of late and is particularly concerned about Siân. Her loyalties are feeling tested as she thinks Siân is *'out of control'* and believes that something must be done. She is also becoming increasingly frustrated at Dai's reluctance (in her eyes) to do the right thing by his family. Anne has become increasingly dependent on Angharad's advice.