pRogReSsioN

NewS & InformatioN for CADS Clients from CADS ConsumeR TeaM

Issue 59

Dec 2018—March 2019

Greetings all

It's hard to believe another year is coming to an end. It seems to have happened so quickly that we got caught out and did not get this issue printed and distributed to pharmacies in time for Xmas—so big apologies from the Consumer Team. We will aim to do better next year!

This year I had the very good (tho highly unusual) fortune to attend 3 conferences—all different but similar. They were:

- Cutting Edge, the national addiction conference in Rotorua
- 30 years of Harm Reduction: the first national harm reduction conference held in Christchurch
- APSAD/ the Australasian Professional Society on Alcohol and other Drugs

Although this takes me away from work here there are many upsides to attending conferences—I get to hear a range of speakers which increases my knowledge on some things and reminds me of some stuff I already knew but had kinda forgotten.

Conferences also provide opportunities to meet other people working in the addictions sector and to develop some great contacts. Some of the inspiring speakers are discussed on p3.

So what else have we been up to this year?

- The year's work started with a focus on SACAT/ Substance Addiction Compulsory Assessment and Treatment which came into effect in Feb. The team was involved in developing info for clients and their whanau and in helping develop the policies for CADS staff
- Continuing from 2017 Andrew held focus groups with AOTS clients at each of the units to find out more about people's experience of the opioid treatment service. See pp.6-7 for results of this year's Treatment and Service Perceptions Questionnaire
- Astrid and I got involved in the City Mission rebuild where it is proposed that medical detox be situated. This is still in the early planning stages so we don't have much to tell you as yet but will keep you informed
- Marc organised the annual Group Evaluations process in CADS Counselling Service. Over 400 clients took part (thank u!) and the group facilitators have received a summary of your feedback
- Throughout the year we have been responsible for public health campaigns within CADS including world hepatitis day; Support. Don't Punish; mental health awareness week; and international overdose awareness day.
  It has been encouraging to see people photographing or taking the info we have provided in reception areas about recognising and responding to overdose on different drugs. Having this knowledge means you might just save a life
- I was invited to join the national hep C advisory group which organised a symposium in late July. Since then the group has developed a Green Paper and met with the Minister of Health and we are hopefully on our way to developing a national hep C action plan. I realise that might not sound exciting but an action plan is a commitment from govt to get things happening.

This is just the tip of the iceberg in terms of the myriad of activities we have been involved in this year and next year looks like being another big one.

A major change will be that CADS will get a new regional manager as Robert Steenhuisen is retiring after 14 years. I've known Robert since the mid-'80s when he was at 393 so it will be weird not having him around. But change is a constant here at CADS so bring it on. Til next time, play safe out there!

Sheridan (CADS Consumer Advisor)

MARC (Counselling Services Consumer Liaison) talks ConFidentiality

Here at Waitemata DHB the Specialist Mental Health and Addictions Services are looking at the communication that happens (or doesn't) when clients move from one service to another. This is part of a national project to look at improving communication. (There's more info about this on p XX)

As part of this project I was asked to get feedback from people who use our services about the CADS transition letters; these are the letters that CADS might send to a client and/or to the client's GP when the client leaves CADS.

This seldom happens for most CADS Counselling clients whereas it is normal practice for some parts of CADS – like the Medical Detox Services who have a responsibility to inform GPs when one of their patients has undergone a medically assisted withdrawal as it could affect someone's medical care and the decisions that a GP might make.

Doing this made me increasingly aware that CADS clients have varying understandings of what confidentiality means.

Some people think CADS is a closed loop e.g. what happens here stays here. Others recalled the discussion at their assessment and were aware some information could be passed on to other services.

I'm not really surprised at the confusion. For many people the first assessment is at a time that is already very difficult; few people come when everything is fine, and why would they? It can be stressful for people and it is easy to be distracted during an assessment.

During the assessment the clinicians are trying to explain how the services work and to give people important information including info about the

limits to confidentiality.

I'm also aware that the information CADS collects has changed somewhat in the last couple of years.

Once CADS was mostly an information island meaning information came into the service but rarely left except when the appropriate legal hoops had been jumped through; agencies like Police and ACC had to prove that they had a right to this information and the client would usually have been made aware of this disclosure. The process was time consuming and involved lots of red tape – and this is still the case.

Where things have changed is that now with the new Oranga Tamariki (OT) there are more questions about children, their dates of birth and whose care they are in.

I think we all want to keep children safe and have them grow up to be healthy happy adults. Sometimes there can be different understandings of what this means and how that should happen. Throw drug and alcohol use in the mix and it creates questions:

- how does addiction affect parenting?
- Will CADS inform Oranga Tamariki if I've got kids and am using drugs?
- What will they tell them?
- And would I hear about it before Oranga Tamariki are at my door?

Making a notification to Oranga Tamariki is not something that most CADS clinicians do as part of their daily work.

When they do happen there will have been a lot of consultation within the team and with the clinical team leader and supervisors who are senior members of the team guiding the staff's clinical work.

So this doesn't mean that clinicians will be notifying OT because someone relapsed, although if they were a danger to their children when intoxicated that would be a significant risk.

It is a difficult balancing act keeping children safe. Government has made it clear that it is everybody's responsibility to keep children safe and that includes services like CADS.

Do you feel you were well informed about your confidentiality by CADS? Is there anything we could do better?

It would be good to hear from people who use CADS services about this so we can be confident that people are aware of the limits to confidentiality and are not so surprised when information may be shared.

It is clear that the government expects services to be working more closely together and while this could offer some great opportunities for CADS clients we need to keep out eyes and ears open for any strings attached.

So let's keep talking about this. I would like to know what you think.

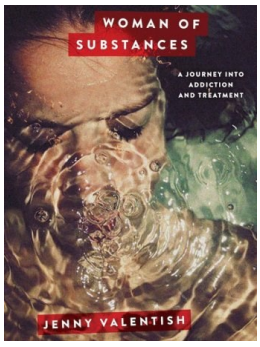
How about giving me a call on 815 5830. Thanks.

Speakers at Cutting Edge 2018 and the First NZ Harm Reduction Conference

Amongst the interesting guest speakers at this year's Cutting Edge conference were Johann Hari author of 'Chasing the Scream: The First and Last Days of the War on Drugs' and Jenny Valentish author of 'Woman of Substances: A Journey into Addiction and Treatment' in which she combines her own lived experience with research into problematic drug and alcohol use. (Both books are definitely worth reading.)

Johann Hari commented that NZ seemed well covered when it came to 12 step fellowships and treatment options but that the 12-step model isn't for everyone.

It is important for people to find a community and long-term support as they change their drug and alcohol use however the non-12 step options in NZ seemed to him to be few and far between.



Jenny Valentish spoke about the short-comings of the medical and addiction treatment industries which she believes have failed to understand and communicate how substance use affects women. So many studies and clinical trials (especially of medications) omit women that you have to wonder if the results have any meaning for women at all.

Gender is significant in so many different ways: while substance use is often linked to childhood trauma, women are far more likely to be pathologised and treated for mental health disorders than men are.

And while women with severe eating disorders also often have problems with substances there are few places that will treat both at once.

She says that Alcoholics Anonymous – which was originally designed for men – focuses heavily on the idea of handing yourself over to a "higher power" when, in her experience, what women need at that point is autonomy.

It was great to listen to people examine the status quo and challenge the sector to think differently.

At both Cutting Edge and the Harm Reduction conference (and APSAD) was someone who is doing something very different: Dr Marianne Jauncey the medical director of Sydney's supervised injecting facility.

(Australia now has 2 MSIC/ Medically Supervised Injecting Centres: the Sydney one has been going for 18 years whereas the injecting space in Melbourne only opened 5 months ago.)

The aims of the Centre are to:

- reduce the illnesses and deaths associated with injecting drug use
- reduce transmission of HIV and hep C
- Reduce public injecting and discarded equipment
- Support people who inject drugs to access other health and social supports.

Since it began the Sydney MSIC has:

- supervised more than 1.1 million injections
- managed 8000 overdoses without a single death
- Made over 13,000 referrals to other services.

Other positive outcomes are:

- A reduction in ambulance callouts
- An increase in the number of people entering detox and addiction treatment
- A reduction in transmission and risky behaviour associated with HIV and Hep C
- No negative impact on crime
- No increase in rates of drug use

Marianne is involved in a campaign to bring about a 'rethink' on drugs, including the removal of criminal sanctions for use.

It was great to see this as a recommendation in the mental health and addictions inquiry report He Ara Oranga.

Sir Mason Durie who was on the Inquiry advisory group gave a historical perspective beginning in 1903 when the Maori Councils first met through to the 2018 mental health and addictions inquiry.

He gave an overview of the messages and requests the advisory group heard from people around NZ:

- to be treated with mana and dignity,
- to involve whanau more actively,
- that health systems work better together,
- that mental health and addictions are not the same thing (agree!),
- that the focus needs to be on recovery not illness

For more info on the Inquiry report see p7. And you can Google these people if you want to know more. Each one has important things to say.

Andrew (Auckland Opioid Treatment Service Consumer Liaison) and the Consumer Team Mobile Phone

Greetings and salutations to all readers of pRogReSsioN.

First of all a useful item of news: we now have a Consumer Team dedicated mobile phone that CADS clients can phone or text

021 562 289

This phone is for all CADS clients and all CADS services.

So if, for example, you are a client of the Inpatient Unit (IPU or Detox) and you want to contact Astrid the Consumer Liaison for that service, you can text or call her on that number.

You may not get hold of her first try, so will need to leave a voice message. Your text or voice message will be promptly returned. You can also contact Marc, Consumer Liaison for CADS Counselling on this number.

I (AOTS Consumer Liaison, Andrew) will hold the phone and manage the

calls. This is because AOTS is the service that gets the highest number of client calls.

I will also be using this phone to contact clients. Especially by text to proceed with the Continuing Care project which is an effort to gather feedback from former AOTS clients who have left the service. Some of these are clients who have 'jumped' - an unplanned voluntary withdrawal.

Talking to clients who have recently left treatment in this manner to and discussing the reasons why is really helpful for the service. We may find there are things AOTS could do differently to help people stay in treatment (if that's what they want).

So if you have recently left the service please don't be taken back if you receive a text or call from me via the CADS Consumer Team phone.

BTW: Contacting AOTS clients can be an ongoing headache for service key workers. Often dozens of unanswered calls can go by which leads to endless time-wasting for service staff.

The service cannot continue to provide treatment if it cannot contact clients. Eventually it ends with the service withholding doses or worse in an effort to force clients to get in contact. The truth is that treatment will always be smoother if clients are easy to contact.

For info about the Managing Mood group held at Pitman House see the back page

Andrew outlines AOTS Client Feedback This Year

Since 2018 is coming to an end I will mention a few of the issues that the consumer team has been hearing in AOTS client feedback.

First of all a big thank you to all who have provided such feedback. It comes through phone calls to the consumer team, notes in the suggestion box, the complaints process and in-person chats with clients.

If something has happened in your experience with AOTS that you are not happy about, please let us know.

The top 5 themes we have heard this year would probably go like this:

- benzo script reductions (mainly from clients at AOTS West and North)
- Communication. i.e. Takeaways stop but the client only finds out about it at the chemist on the day of dispensing with no prior warning via a call or word from AOTS.
- AOTS reacting to unfavourable third party information.
- Difference of opinion or practice between AOTS and clients' GPs. People feel AOTS has interfered with scripts that originated from their GP.
- Staff attitudes.

All these issues and more are things the service is working on.

It's a matter of finding the correct balance between the needs of clients to live a normal life and the needs of the service to comply with the guidelines and regulations governing the provision of Opioid Substitution Treatment.

Not always easy to achieve.

Update re Hepatitis C Treatment

In the last issue of pRogReSsioN I reported that the new non-genotype specific anti-viral medication for hep C was scheduled to become available on October 1st 2018. Well, after a delay it is finally here!

From 1 February PHARMAC is funding Maviret (glecaprevir and pibrentasvir) for people with hepatitis C regardless of the type of hepatitis C virus they have.

Since 2016 around 3000 people have received treatment with Harvoni an Viekira Pak since PHARMAC started funding them. It's estimated that 50,000 people could benefit from this new medication.

Below is information from the national Hep C advisory group:

Elimination of hepatitis C in NZ by 2030 is feasible. However, it will require:

- Implementation of a National Action Plan
- Political will to enable implementation of all requirements ('pillars') of a National Action Plan
- Destigmatisation ('normalisation') of hepatitis C to remove barriers to prevention, diagnosis, and treatment

Starting now and diagnosing and treating nearly all people with hepatitis C by 2030 will:*

- Reduce total HCV infections by **83%**
- Prevent **2,300** deaths
- Prevent **1,200** cases of decompensated cirrhosis
- Prevent **1,600** cases of hepatocellular carcinoma

*Polaris Observatory 2018

The main barriers to achieving this goal for NZ are:

1. Lack of awareness and education
2. Stigma and discrimination
3. Gaps in the coordination of care and services
4. Lack of patient and HCP support
5. Absence of a national elimination strategy

EIGHT PILLARS OF NEW ZEALAND'S NATIONAL ACTION PLAN TO ELIMINATE HEPATITIS C

Political will

1. **Increase awareness & understanding of hepatitis C** — Implement national & targeted awareness campaigns.
2. **Improve prevention & harm reduction strategies** — Reduce transmission & reinfection. Upscale harm reduction programmes & peer support.
3. **A national registry** — To track screening, diagnosis & treatment & enable an effective national programme that address ethics & privacy issues.
4. **A national screening programme for hepatitis C** — Identify & enable all NZ people with hepatitis C the opportunity for a curative treatment.
5. **Targeted screening programme for hepatitis C** — Develop culturally responsive strategies to improve access to testing & care for populations at risk.
6. **Improve access to care** — Provide access to pan-genotypic treatment with no restrictions & broaden the prescriber base to include nurses & pharmacists.
7. **A national monitoring & evaluation system** — Include national targets with well-defined indicators, i.e. treatment rate > 7% of the HCV infected population per year to meet the 2030 target.
8. **Adequate resourcing & funding for the duration of the elimination programme** — Secure funding for 20 years.

Destigmatisation

Key message: To eliminate hepatitis C in NZ by 2030, a national action plan must be developed, financed, and implemented as soon as possible.

What AOTS Clients Told Us About Their Perceptions of Auckland Opioid Treatment Service (AOTS)

A big thank you to the 186 people who took part in this year's Treatment and Service Perceptions Questionnaire which ran for 12 weeks (June – August). The info you provide is invaluable.

The survey asks people to rate sentences depending on how strongly they agree or disagree with them or they can indicate 'don't know'. The overall results were:

- 82% strongly agree or agree that their key worker has understood the kind of help they want
- 23% agreed that they and their key worker had different ideas about the client's treatment goals
- 69% had been able to speak to another key worker if their key worker was unavailable
- 76% feel they have had support to sort out their problems
- 85% feel respected and treated as an individual by staff
- 74% felt involved in decision-making about their treatment
- 86% believe methadone or Suboxone® is helping them
- 77% had left doctor's appointments happy and satisfied over the past 12 months
- 81% had seen their key worker as often as they would like over the last year
- 73% find most of the service's rules or policies reasonable and understandable
- 64% knew they were able to contact AOTS by texting 4769
- 43% find texting makes communication with AOTS easier
- 81% would recommend AOTS to others they think might benefit from OST and 10% would not. Those who would not recommend AOTS referred to both the service and the medication as liquid handcuffs; they feel they are not included in decisions about their treatment and do not feel respected by the staff.

  6 people indicated they would recommend AOTS simply because there are no other effective treatment options or no alternative OST clinics for people dependent on opioids and 7 people said they would recommend AOTS though added a caveat like "*it all depends on getting a good doctor and key worker*".

Most of the people who indicated they would recommend the service to others said they would do so because it has helped them:

- *It's free, it's access to knowledge and allows people to have a chance to make better decisions. I believe in harm reduction*
- *To get some type of stability in their lives, stay out of jail and not have to do crime to support their addiction*
- *It's a structured drug intake for the benefit of the user. Great source of information. Relieving mental pressure is the best for talking to key worker/ getting things off your chest. A great service full of positive enthusiasm from key workers*
- *... if you and your case worker are on the same page as each other. I know that being with CADS and having a good support worker you keep in contact with each other regularly keeps me and I'm sure others on track especially if you are both on the same track*
- *it's a good programme that substitutes harmful substances for similar non-harmful ones so the dependency is still there but is manageable*
- *There are so many benefits. You do not feel alone and helpless. People at CADS are there with you, supporting and advising you and you can get to the place you want to be healthwise and mentally*

(Contd. on next page)

What Consumers Told Us of Their 2017 Experience of AOTS contd.

Perceptions of treatment

Most people have experienced benefits of OST (stability, improved relationships etc) and several said that without OST they and/or their friends would be doing drugs, in prison or dead. However many also added caveats to their support for the treatment saying things like *Methadone is often used as the stick with which to beat us over the head …*

Only two people spoke about the hassle of collecting their scripts from the service however it is clear that the constraints of OST are lessening the attractiveness of treatment for some people who want the opportunities to live like people not on OST: to go away for weekends when asked, to not be late for work several days a week etc. Surely that's not too much to ask?

Perceptions of the service

Client comments point to the significance of positive and mutually respectful relationships with staff who were described by many as non-judgemental, caring, supportive, easy to talk to, kind and compassionate.

Not everyone was so complimentary and several people spoke of the different experiences t hey have had with different key workers with one person commenting "some care more than others".

Texting the service

It seems there is still work to be done on communication as less than 2/3 of clients know they can text AOTS and less than half (43%) felt that texting makes communication with AOTS easier. This seems weird as texting is such a common communication tool now so we need to find out why people aren't aware of it or find it helpful.

Recommendations

Over the years the survey has shown how important it is that key workers find out what clients want from treatment—not just at the start of treatment but all the way through because people's goals change over time.

One of the ways key workers will do this is by inviting clients to develop their own recovery plan; this is an easy way to ensure key workers and clients are on the same page.

The survey has shown that some clients would like more contact while others would prefer less so it's really important that staff and clients discuss and negotiate how often they need to have contact.

Huge thanks to all the people who took part in this year's survey. We'll do it all again in 2019 ...

He Ara Oranga: Report of the Govt Inquiry into Mental health and Addiction

You are probably aware that the Labour/Greens/NZ First coalition government opened an inquiry after widespread concern about mental health services. The purpose of the inquiry was to:

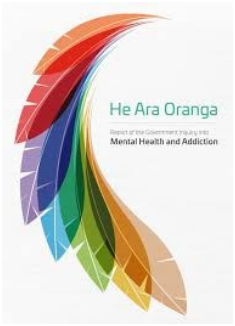
- Hear the voices of the community
- Report on how NZ is preventing mental health and addiction problems and responding to the needs of people with those problems
- Recommend changes to improve NZ's approach to mental health with a focus on equity of access, community confidence in the system and better outcomes esp for Maori and other groups with disproportionately poorer outcomes.

The report is 219 pages, ten of which focus on Action on Alcohol and Other Drugs.

The report acknowledges the significant widespread impacts that the harmful use of AOD has on individuals, whanau and communities and recommends a bolder approach be taken to minimise these harms.

It says *Addiction should be viewed as a health and social use that requires care and support (including more addiction treatment services) for effective management…*

The criminalisation of illicit drugs pose a barrier to seeking help and convictions for personal drug use have far-reaching consequences on people's lives. Criminal sanctions for the possession for personal use of controlled drugs should be replaced with civil responses such as fines or treatment programmes.



Both of these recommendations were made in the previous Law Commission's review of Alcohol In Our Lives in 2009 and the review of the Misuse of Drugs Act in 2010 .

Will this government be bold and take on these recommendations? We certainly hope so.

There is a video available on YouTube which explains the report and you can download your own copy at https://mentalhealth.inquiry.govt.nz/inquiry-report/he-ara-oranga/

The Pitman House Managing Mood Group

The group has been running for two years and has been very popular.

Managing Mood is a CADS group but because it is facilitated by two AOTS key workers (Jenny and Rebecca) it is mostly filled with AOTS clients.

It is a 10 week programme and is a skills based, educational group that incorporates a lot of discussion and reflection.

People learn skills to help with emotional challenges, relationship issues and they discuss topics like guilt, shame and anger and everyone gets a workbook they can use at home.

The programme is based in mindfulness practice and Dialectical Behavioural Therapy (DBT).

If you are interested please speak with your CADS key worker to discuss a possible referral. The next group starts on 31st January.

We're All (Well, Most of Us) Going on a Summer Holiday .....

Astrid will be here holding the fort while the rest of the Consumer Team takes a break over Xmas-New Year.

- Sheridan returns to work on Tuesday 15 Jan
- Marc will return on Monday 7th January
- Andrew's back Monday 14 Jan

In the New Year Andrew and Astrid are changing their days of work so after mid-January our hours will be:

- Andrew (AOTS Consumer Liaison) Tues, Wed, Thur and Fri 9am—4pm
- Astrid is at Pitman House Detox Services: CHDS/ Community & Home Detox Mon and Wed morning; IPU/ detox in-patient unit Tues and Wed afternoon and CADS South each Friday 9am—3.30pm
- Marc (Counselling Service) is available Mon, Tues, Wed and Fri 9am—3pm
- Sheridan (all CADS services) works 8.30-5pm Mon—Fri

If you need to speak with one of us phone 815 5830 & reception will connect you to someone from the Consumer Team or you can call or text us on 021 562 289

Tell Us What You Think

Providing feedback to CADS is easy: you can phone us, use the suggestion boxes, the complaints process or you can email us by going to www.cads.org.nz and clicking on Email Us Now

This opens another page where you can give feedback about...

- a Group »
- the service »
- the website »

You can also make a complaint on-line. Although all online complaints come to the Consumer Advisor they are managed and investigated by the manager of the service not by the consumer team).

You can email the Consumer Team via the Consumer Advisor at (it's a long email address sorry)

cadsconsumeradvisor@waitematadhb.govt.nz

All of the Consumer Team can be contacted on 815-5830 or the Consumer Advisor can be called direct on 845-7520

Do leave a message if there's no-one there as we regularly clear our voicemail

Or you can text us on 021 562 289

We need to hear from you if we are to accurately present consumer opinions and experiences so please feel free to get in touch. We look forward to hearing from you.