NADA
network of alcohol & other drugs agencies

The newsletter of the Network of Alcohol and other Drug Agencies

Issue 3: September 2014

advocate

In this edition we ask a number of guest writers to respond to:

Consumer participation: we're doing it to improve the way we deliver services.

Read features from:

- Consumer Health Forum of Australia
- NSW Users and AIDS Association
- NSW Consumer Advisory Group Mental Health
- Centre for Social Research in Health

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The Hon Jillian Skinner MP

Minister for Health
Minister for Medical Research

NSW Health has a long history of partnering with NGOs to deliver key health services that keep our communities healthy and out of hospital. We remain committed to strengthening and continuing this partnership.

NGOs work closely with the most vulnerable members of society, providing services where the public system may not have the expertise or experience. NGOs put clients at the heart of service delivery, combining clinical care with the social support that really gets people back on their feet.

Partnerships for Health is our response to the recommendations of the Grants Management Improvement Taskforce report 2013. This work emphasises the value NSW Health places on the NGO sector and signals an intention to improve the governance, transparency and efficiency of this partnership.

This will begin with new contract arrangements in 2014/15, which provide clearer definitions of services and improved performance management. Following this, a new purchasing framework will be phased in from 2015/16, which will deliver greater consistency in the way NSW Health purchases services from NGOs.

We will be introducing new purchasing arrangements using a range of procurement methods, including open-tenders, panels of pre-approved providers and sole-source contracts. The funding approach will depend on the type of services required to meet client needs, and the number of providers in the market that could deliver those services to specified standards. The timing of procurement will depend on the readiness of NSW Health and the NGO sector.

These reforms will support future purchasing of drug and alcohol services over the course of 2015/16 and are expected to result in an expanded role for the NGO sector in delivering health services overall.

Client needs remain at the centre of all that we do, and NSW Health will enable sufficient time for the sector to prepare itself for any changes. We are listening closely to advice from peak bodies about phasing and timing, and the Ministry of Health is also working with peaks on preparing the sector for the transition from grants to purchasing.

As a member of the NGO Advisory Committee, NADA is actively involved in the implementation of Partnerships for Health, and is seen as an important and valued partner in this journey. NSW Health has a dedicated email address (partnerships@doh.health.nsw.gov.au) for referring any questions, and monthly news updates are being published on the Ministry's website at:

http://www.health.nsw.gov.au/business/partners/Pages/latest-news.aspx

Many of NSW Health's NGO partnerships go back over 20 years, and I am excited to be working with the sector on building a sustainable framework for partnership that helps us keep people healthy and out of hospital, particularly our most vulnerable populations.

The Hon Jillian Skinner MP
Minister for Health
Minister for Medical Research

Consumer participation:

We're doing it to improve the way we deliver services

Adam Stankevicius, Chief Executive Officer, Consumers Health Forum of Australia (CHF)

The title of this edition highlights what is self-evident in providing good health care that may be so obvious, it is sometimes overlooked.

The CHF believes that consumer-centred health care is central to the delivery of the best and most appropriate health care. Health care works best when the person receiving it is taking an active role in participating in the process, whether it be by having a good understanding of their condition, maximising the benefits of their treatment or by ensuring they are doing what's best for their health.

We believe the principles of consumer-centred health care apply as much to participants in alcohol and other drugs (AOD) services as to consumers in other parts of the health system.

Consider the six principles of consumer-centred care that CHF advocates.

Accessible and affordable care – it should be timely, well-organised and sustainable

Whole of person care - seeing to a person's emotional, physical, social and support needs

Coordinated and comprehensive care – joined up, integrated and available

Appropriate care – meets individual needs, is safe, competent and seeks consumer understanding

Trust and respect – doctor, nurse and health worker understands and is responsive to a person's needs, are transparent and accountable

Informed decision making – consumers are told treatment options, costs and their consent is sought.

Is it not reasonable to ensure that all of these principles also apply to those participants in treatment for alcohol and other drugs dependency?

A virtue of the consumer-centred approach in administering services is its inherent simplicity. We as health care providers all want to have a say in our own health care, regardless of the treatment we seek.

While for some providers, not least in the AOD, a consumer-centred approach may seem revolutionary, placing the consumer at the centre of your care is hardly difficult to understand.

Similar to the mental health sector, there has been a history in the AOD sector where 'you do things to the consumer, rather than with them'. Added complications can include whether a consumer is perceived 'well enough' (due to being in treatment) to contribute and the stigma and discrimination around illicit drug use which pervades many parts of our community (even health professionals).

CHF supports NADA's ambition to break down barriers to consumer-centred care and build the capacity of organisations to increase their consumer participation practices.

There is well-based evidence to support this drive.

The Australian Commission on Safety and Quality in Healthcare in its report on patient-centred care three years ago, showed research demonstrated that patient-centred care "improves patient care experience and creates public value for services. When health professionals, managers, patients, families and carers work in partnership, the quality and safety of health care rises, costs decrease, provider satisfaction increases and patient care experience improves."

The report indicates that Australian healthcare organisations were becoming increasingly interested in patient-centred care. Although organisations can readily put patient charters and informed consent policies in place, "many find it hard to actively change the way care is delivered, and may struggle to involve patients, families, carers, and consumers and to learn from their experiences".

Traditionalists in the AOD sector may argue that consumer-centredness is not appropriate in our sector. However, national policy and quality standards supports this much needed move.

Consideration should be given to the key strategies of the report on safety and quality that suggested for building patient-centred care:

- Regular monitoring and reporting patient feedback data
- Engaging patients and families as partners
- Demonstrating committed senior leadership
- Building staff capacity and a supportive work environment
- Establishing performance accountability
- Supporting a learning culture

So to improve services through a consumer-centred approach, service delivery can move from being 'right' (correct and following a guideline) to the 'right thing' for the person that meets their needs and preferences.

As with most significant change for the better, the challenge is not so much in the complexity of the change itself, but in accepting the benefits of that change and working with patience and leadership towards the goal.

That's the hard part, but it is achievable … and it's in the best interests of our consumers, the AOD sector and our health system.

Consumers Health Forum of Australia

Consumer Participation and People Who Inject Drugs

Fiona Poeder, Director, Programs & Services, NSW Users & AIDS Association (NUAA)

NUAA is an independent peer-based drug user organisation that has been the voice of the drug using community in NSW since 1989. Its peak body, AVIL, has been demonstrating that consumer participation has tangible benefits for both people who inject drugs (PWID) and service providers since 2008. When PWID become meaningfully engaged with the services they use, barriers are reduced, trust can develop, and access to services can increase.

NUAA has actively followed AIVL's work on consumer participation. We have largely focused on illicit drug treatment service and developed the Treatment Services Users (TSU) Project I and 2. It became apparent through TSU 1 and 2, there are a number of myths associated with consumer participation in relation to PWID. These include:

- Treatment service users are not capable of full consumer participation;
- Confidentiality concerns preclude consumer participation (other than at an non identifiable, less meaningful level, such as the anonymity of suggestion boxes in organisations for instance);
- Treatment service users just want to get on with their recovery and do not want to participate in activities such as program and staff reviews.

The projects found that there was an awareness, understanding and interest in consumer participation by treatment consumers. When the principles of true consumer participation were explained to consumers, consumers indicated it was a valued concept.

Staff opposition appeared strongest when more meaningful forms of consumer participation are discussed or introduced (for instance consumer participation in recruitment or appraisals).

Other findings included the debate regarding who is or isn't a consumer. For example the debate around can 'ex-drug' user represent consumers.

That training and capacity building should be core training for both staff and clients to ensure misunderstandings are minimised, and planning, implementation and management of consumer participation projects are maximised.

That issues of power and risk must be considered prior to implementing consumer participation projects.

That existing cultures in some drug treatment settings (including power dynamics between staff and clients) must be carefully considered and addressed when planning and undertaking consumer participation initiatives.

In 2011 the Mental Health and Drug and Alcohol Office of the Ministry of Health, funded NUAA to develop and roll out a two year consumer participation pilot project aimed to increase the level of consumer participation within services. NUAA incorporated the learnings from TSU 1 and 2 to develop the CHANGE Project. CHANGE is not an acronym but an aspiration. Three project sites, a Sydney metropolitan pharmacotherapy clinic, a Sydney residential treatment service and a regional pharmacotherapy clinic were approached and agreed to participate.

Consumers and staff in each of the three sites undertook separate and combined training developed and delivered by NUAA. After the training was completed, services were supported to run their own consumer participation projects and activities. The project rolled out differently at each site, but the common outcome was that consumer participation activity increased, and services improved for both consumers and staff.

It is imperative that consumer participation initiatives are not tokenistic. When we consider the concept, it should always be meaningful and not merely to tick the consumer participation box.

This can be somewhat of a dilemma. On one hand we are increasingly observing consumer participation being linked to quality improvement directives from funding bodies, while on the other, there may be reluctance from staff/services to participate in activities they perceive may put their employment and/or power within the service at risk. This dilemma is compounded when there is a lack of understanding, education, and training and resources supporting consumer participation initiatives in the sector.

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The model of consumer participation that the CHANGE project is founded on, views consumer participation as a ladder of low to high end consumer participation initiatives. Lower end initiatives involve surveys and consumer consultation, with higher end initiatives meaningfully involving consumers in activities such as participation in the development of organisational policies and procedures and having consumers sit on employment panels and staff appraisals. Regardless of the initiatives undertaken by services, it is imperative that consumers are fed back information about, or results of, consumer participation activities. This action demonstrates in a tangible way that consumers' input has been heard and is valued.

NUAA also run a Peer Participation Program (PPP). Like most of the work NUUA undertakes around consumer participation, PPP is unfunded. Members of the PPP largely become involved with NUAA because they want to give something back to the community. Members learn skills and gain experience while assisting NUAA in providing the drug users' voice in NSW – a win/win situation. NUAA 'practice what we preach', we have peers participate on appropriate employment panels, consult on our strategic plan and provide advice on resources.

Apart from the PPP, NUAA supports consumer participation activities throughout the sector in a number of ways: through supporting peers to attend advisory groups and consultation initiatives, supporting peers to represent PWID in all number of forum and through the provision of advice and training on consumer participation.

For more about NUAA see page 9 for their member profile or contact NUAA on (02) 8354 7300.

Consumer participation:

Climbing the ladder towards Citizen Power

Dr Peri O'Shea, Chief Executive Officer, NSW CAG

I was asked to write an article entitled 'Consumer participation: we're doing it to improve the way we deliver services'. I changed this to the title above as I assert at the outset that consumer participation is much more than a tool to improve service delivery. Consumer participation also leads to the development of more effective public policy and facilitates individual recovery. Meaningful, effective consumer participation also shifts the power imbalance and marginalisation of many of the people we work with experience – its life changing!

"..citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future." (Sherry Arnstein 1969).

Participation is a fundamental human right as enshrined in Article 25 of the International Covenant on Civil and Political Rights and the disability consumer catch cry 'nothing about us without us' is equally relevant to people with a lived experience of mental illness and, I daresay, consumers in the alcohol and other drugs sector.

Consumer participation should occur at all levels. At the individual level - in all decisions regarding a person's treatment and care; at the service level - in service planning, governance and service quality improvement processes; and at the systemic level - in processes that inform social policy and legislative systems change.

To be meaningful and effective, consumer participation needs to be understood and supported but, most importantly, the consumer participant must have the power to change the outcome. If the consumer participant does not have this power; does not know they have this power; is prevented from using this power (intentionally or not) or does not know how to use this power; this is tokenism. Tokenism can be more harmful than no participation as it can result in frustration, feelings of powerlessness, and hopelessness due to unmet expectations. Sherry Arnstein's Ladder of Citizen Participation, (see Figure 1 below) illustrates this well.

"There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process. … participation without redistribution of power is an empty and frustrating process for the powerless. It allows the power holders to claim that all sides were considered, but makes it possible for only some of those sides to benefit. It maintains the status quo."

The mental health sector has moved some way up the ladder with significant achievements toward citizen power being supported by federal and state policies and processes. These include: the establishment of several Mental Health Commissions (MHC) both federally and in many states and territories including NSW; federal and state standards that require consumer partnership and a move away from clinical to a whole of person approach. For example the National MHC's Contributing Life Project and the MHC of NSW's whole of government Strategic Plan for Mental Health. Actual implementation on the ground at service and practice levels however, is often ad hoc and inconsistent. While there are some shining examples of consumer participation, most remain halfway up the ladder hovering between tokenism and effective participation.

Halfway up the ladder can be a dangerous place for consumers (as discussed above). The good news is, in the mental health sector at least, the middle rungs have also become an uncomfortable resting place for policy makers, service providers and administrators as well as others who at least theoretically understand the benefits of real consumer participation, and want to know how they can progress up to the higher rungs.

At NSW CAG, we work with consumers to achieve and support systemic change through participation. While we are an independent non government organisation, we work with consumers to assist government and other service providers to reach the higher rungs of consumer participation at all levels.

For information on how we do this please visit www.nswcag.org.au.

NSW CAG was originally established as a ministerial committee in 1992 in response to the First National Mental Health Plan which stated that each state or territory:

Establish or maintain a mental health consumer advisory committee which is representative of the range of mental health consumers and carers. Such an Advisory Committee shall provide advice, including to both the relevant Minister and Chief Executive Officer of the agency. (First National Mental Health Plan, 1992).

In 1994, NSW CAG was incorporated. A few years after establishment, it became clear that one organisation could not properly represent both consumers and carers, as their interests are not always aligned. We have found that when establishing participation processes it is important not to assume that carers can participate or speak on behalf of consumers or vice versa.

The history of the consumer movement predates NSW CAG involvement. Recognition of the importance of consumer participation is part of a broader historical and social context which was moving towards more liberal, humanistic, less paternalistic approaches to mental illness. This move was further empowered by the 1993 National Inquiry into the Human Rights of People with Mental Illness (Burdekin Report). Just over 20 years after the Burdekin Report and more than 40 years since Arnstein first introduced the 'Ladder of Participation', we are still not at the top of the ladder. But we are heading in the right direction and sometimes we even get a glimpse of the top rung. And I know the view will be good when we get there.

Sherry R. Arnstein (1969) A Ladder Of Citizen Participation, Journal of the American Institute of Planners, 35:4, 216-224

CEO report

Larry Pierce

This edition of the *Advocate* focuses on consumers in the drug and alcohol sector, in particular from the NGO perspective. I wouldn't be the first in our sector to identify that it is incredibly important to get consumer representation and direct meaningful involvement right to shape the future of drug and alcohol service delivery, while acknowledging that it is also a challenging outcome to achieve.

Having come from a treatment background in the mid 1980's, I remember well the feelings of drug and alcohol workers, be they doctors, nurses or AOD counsellors that our clients were a despised and stigmatised lot, and that it was part of our job to provide them with dignified and appropriate service and defend them within the context of the wider health system. But this wasn't promoting the rights of clients as consumers with rights and fully integrated involvement in treatment service delivery, this was us saying to the external world, leave them alone – only we have the right to treat them badly if we feel we need to for their own good!

And I believe this is still at the core in drug and alcohol service delivery - we advocate for our clients as consumers, while retaining our 'right' to provide treatment under a vast array of rules and regulations that mostly have not been informed by the needs of those that receive that treatment. We know best because we are the treatment experts and our clients are not able to make certain consumer choices until they are 'ready' in our expert view. Also there are so many consumers' in our sector - alcohol clients are different to heroin clients and these again are different to younger clients who are using amphetamines and new emerging psychoactive substances - how do you pick a consumer from this lot?

This may be difficult for some staff in the sector to accept, as many of us don't believe that we hold the judgements imposed by society generally. However stigma and discrimination in healthcare, even within our sector, remains one of the biggest barriers we face in improving consumer involvement in policy and service provision.

I hope we can continue to reflect and learn from these issues and engage with our clients as consumers and ensure there is consumer representation at the very top of the decision making chain in the health system in NSW.

(This has been a long term goal of mine.) I think we are making some slow, but well considered moves in this direction, and I hope that this issue of the *Advocate* helps us in the sector to move the agenda forward and continue to engage and support consumers to improve our services.

NADA is committed to supporting and advocating for greater consumer representation at the policy and planning level of the drug and alcohol system in NSW, as well building our sectors capacity for meaningful and appropriate consumer participation.

> *... stigma and discrimination in healthcare, even within our sector, remains one of the biggest barriers we face in improving consumer involvement in policy and service provision.*

NADA Sector Watch

Over the next twelve months the drug and alcohol non government sector will be involved in a number of changes both at a state level through Partnerships for Health, and at a federal level with the outcomes of the national review of drug and alcohol prevention and treatment services. NADA will keep the sector informed through regular updates for you, your staff, management committee and board.

Click here for the latest update.

NADA events

Do you have something you would like included in the next NADA *Advocate*?

NADA encourages members and stakeholders to contribute to the NADA *Advocate*. You could promote new services and projects, innovative partnerships, awards and achievements, research activity or upcoming events.

Email final content to **Clarissa**

The next issue's content deadline is 24 November 2014 for distribution mid-December.

Benchmarking Workshop

25 February 2014
Venue TBA, Sydney NSW

For more information, please click here.

NADA events

FREE Psychopharmacology Workshop

23 October 2014

Focusing on psychotropic medications used in Australia, prescribing patterns, therapeutic effects, side effects and potential complications. Drugs of abuse and addiction will also be considered. Participants will be assisted in anticipating or identifying possible adverse effects in their clients who are on medication. Case studies and vignettes will be discussed in group sessions. For more information, click here.

NADA Forum: NGO Program Reform Reengineering our Sector

17 November 2014 Parkroyal Darling Harbour, Sydney, NSW
The purpose of this year's forum is to inform and engage the sector in discussion about how we shape the future of our services and the questions: Where is the sector heading, following reviews at the state and commonwealth level? Should we be exploring different partnership and governance models? How do we plan for the future in a time of uncertainty? For more information click here.

NADA AGM

17 November 2014 Parkroyal Darling Harbour, Sydney. For more information, click here.

Program Evaluation Workshop

27-28 November 2014

The Canberra Room, The Menzies, Sydney NSW. For more information, click here.

Congratulations to Waverly Drug and Alcohol Centre

The winner of the iPad Mini for completing the annual NADA member survey is **Waverley Drug and Alcohol Centre**. We hope that the iPad can be used to enhance the services provided in their community.

Feedback from our members in an important mechanism to inform the work we do on your behalf. Thank you to all NADA members for taking time to complete the annual survey.

Supporting regional networks

NADA North Coast Consultation

Ciara Donaghy, NADA Program Manager

NADA hosted a regional network consultation in July with members and stakeholders on the NSW North Coast. The aim of the consultation was to explore the needs of service providers in the area to reduce drug and alcohol related harms, particularly the networks and partnerships required to support this.

The consultation raised a number of challenges for members, including the uncertainty of the current funding environment and the challenge that presents in the recruitment and retention of staff. Participants identified a key goal for the future is to have a continued focus on client empowerment and improvement, and to maintain a positive atmosphere for staff and clients in an uncertain environment.

The need to improve referral pathways and create stronger partnerships was raised, noting that some providers didn't know what services are available, there were inappropriate referrals, and that the need often exceeds the capacity of those services that are available. A range of resources were discussed to assist in identifying and developing referral pathways including The Partnerships in Prevention Toolkit (Community Solutions QLD), the Women's AOD Services Directory, the Mental Health Professionals' Network and the National Health Services Directory.

These suggestions have been forwarded to the Local Health District on behalf of NADA North Coast members. NADA hope to work with the Northern NSW Local Health District and North Coast members to improve local networks.

NADA has supported members to establish networks for specialist youth services and women's services and is exploring network activities in other geographical areas over the coming months. If you have any suggestions or want to get involved, please contact Ciara.

Three key strategies were identified by the group as possible ways in which to develop and enhance local partnerships.

1. Local Service Mapping and Needs Analysis. A local service mapping and needs analysis exercise would assist in identifying the services that are currently funded, what services are operational, what they offer and how long they are funded for.
2. Partnerships to promote primary healthcare pathways. Increasing access to primary health care while in treatment will help reduce chronic health issues and impact on reducing emergency department presentations.
3. Interagency meetings at a service provider level. An interagency meeting between local health district and drug and alcohol NGOs, mental health and allied health services in the North Coast area could assist in building effective partnerships, linkages and referral pathways in the region.

"NADA has supported members to establish networks for specialist youth services and women's services and is exploring network activities in other geographical areas over the coming months."

NSW Users & AIDS Association (NUAA)

NADA Member Profile

NUAA is an independent peer-based drug user organisation that has been the voice of the NSW drug using community since 1989.

Underpinning NUAA's programs and services are national and state strategies and plans relating to blood borne viruses (BBVs) and public health. NUAA represents the health, rights and advocacy needs of potentially the most marginalised community in NSW – people who inject drugs (PWID). This is achieved through a range of programs and services including peer education, BBV prevention, policy initiatives, training, resource production, representing issues of concern in both the government and non-government sector, community participation and the provision of sterile injecting equipment through the only peer-run needle and syringe program (NSP) in NSW.

NUAA was an integral part of the early unofficial movement to provide sterile injecting equipment to PWID in direct response to the emerging impact of Acquired Immune Deficiency Syndrome (AIDS). At that time, the practice of sharing injecting paraphernalia – particularly needles and syringes – was acknowledged as a major vector for the newly emerging virus. Some twenty five years later (and while we have aided in maintaining low rates of HIV/AIDS among the injecting drug using community) Hepatitis C transmission prevention continues to present inimitable challenges.

Covers of past NUAA publications of Users News.

NUAA's unique peer-driven NSP utilises a self-service model in a fixed primary site, in Crown Street, Surry Hills. This service is supported by members of our Peer Participation Project (PPP). Additionally, NUAA provides an outreach service which has been recently extended to the South-Western area of Sydney.

Peer education has been core to our work since our inception and falls under the banner of PeerLink at NUAA. PeerLink utilises existing NUAA networks, research and other information sources to scout locations for peer education projects. Peer education occurs in drug use networks and contexts all the time and is integral to how peers communicate; learning from, and with each other. Utilising community development and health promotion principles, PeerLink provides efficacy, education and resources on peer education and works with peers and in partnership with services to address localised issues.

Users News, NUAA's flagship publication, has recently gone digital. Each year we will develop two electronic and two hard copy editions (also available online). The digital editions will be interactive and include audio and video materials. To reach those who do not have internet access, NUAA will be distributing a limited print run of the digital editions of Users' News for inmates and isolated communities.

Our recently redeveloped website contains links to other drug user organisations' resources, recently developed harm reduction and Hepatitis C-related videos, educational resources, a variety of project related forums and a calendar of up coming NUAA events, workshops and training opportunities. You can check this out at www.nuaa.org.au.

NUAA continues to lead the way in peer support in opioid substitute treatment (OST) settings. In partnership with the Kirby Institute, we have a dedicated peer support worker (PSW) established in OST sites in the Hunter and Sydney, as well as playing a similar role at NUAA's NSP. The PSW supports PWID and those with a

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history of injecting drug use through the hepatitis C treatment journey – providing support, referrals and understanding only a peer can. Our Enhanced Treatment of Hepatitis in Opioid Settings (ETHOS) project, demonstrated that peer support not only aids people through the treatment journey, it increases uptake of treatment and treatment adherence. In addition, the PSW continues their support role for people who have achieved clearance and for those who have not - one of the issues largely overlooked through the post-treatment journey.

NUAA has developed and is implementing is the 'Liver Mate Peer Based Peer Support Kit'. This is an all-encompassing DIY kit for peers to set up treatment support groups independently. The groups are supported by NUAA via a forum on the NUAA website that includes information, resources and a place for group members to ask questions.

NUAA leads the way in tackling the stigma and discrimination targeted toward PWID. We have adapted resources developed by the Australian Injecting and Illicit Drug Users League (AIVL) and now have a suite of tools to utilise in our challenge to target the stigma and discrimination directed toward PWID. The importance of this cannot be underestimated: the very real stigma and discrimination faced by PWID undermines access to a wide range of health services. The uniqueness of NUAA's program is that it is provided by PWID who have the benefit of life experience to support resources delivered.

Anyone interested in learning more about any of NUAA's projects can contact NUAA directly: email nuaa@nuaa.org.au visit us at www.nuaa.org.au or call (02) 8354 7300.

Gerard Byrne

The Salvation Army Recovery Services, Clinical Director

NADA Board Member profile

How long have you been with NADA?

I first connected with NADA in the early 1990s through attending forums and conferences. I was elected onto the Board for the first time in 1998 and served as President for three years from 2001. I served on the Board continuously 2011. I was re-elected onto the Board in 2013. So I have been connected with NADA is some form for over 20 years.

What experiences do you bring to NADA?

I have had 25 years' experience in AOD work in the non government, government and private sectors; however the majority of that time has been spent with The Salvation Army. I am also on the Boards of the ATCA, QNADA and ATODA, so I can bring an understanding of the sector issues in other jurisdictions. Prior to working in the NGO AOD sector, I worked in the banking and finance industry and have also owned and operated my own business in the entertainment and promotions industry. So I bring a mixed bag of experience, but mainly I bring a solid history in AOD work.

What NADA activities are you working on at the moment?

Like the rest of the NADA Board and staff and most NGOs in NSW (and other jurisdictions) I am concentrating on keeping up to date with the various review processes that are occurring at both the state and federal levels. I am contributing to the NADA response through the activities the Board is involved in as it supports the excellent work of Larry and the team.

What is the most interesting part of your role with NADA?

The people I have had the privilege of meeting over the years is the singular most interesting part of my involvement with NADA. I am also interested in the mechanisations of government and in looking for ways to make sure that government policy and funding priorities support the non government community services sector.

What else are you currently involved in?

I am involved in training staff to work in the AOD sector through The Salvation Army's registered training organisation. I am currently involved in training staff at Stanmore and am training seven Aboriginal and Torres Strait Islander staff at Mt Isa and will shortly commence training staff at Normanton in the Lower Gulf region of Queensland. Away from the workplace (and the numerous reviews) I am involved in junior football (rugby league that is) through my son's team. My main role is fund raising, every Saturday I dutifully line up to purchase an egg and bacon roll from the BBQ – it's for the children so I am committed. I enjoy motorbikes, spending lots of years on dirt bikes, but converted to a road bike last year.

A day in the life of...

Sara Adey

NUAA Peer Participation Project (PPP) member, NSW Users & AIDS Association (NUAA)

Sector worker profile

Sara has been with NUAA's Peer Participation Project (PPP) NUAA for nearly two years and participates regularly in a number of NUAA services and forums.

How did you get to this place and time in your career and what have been the benefits?

I came into this [NUAA's PPP] because I felt like I wanted to give back to society. I continue to be encouraged to learn – it's an educational exchange and it's ongoing. I've benefitted by getting skills that I can use at NUAA and in my life; it's a win-win for both me and my community. For instance, I've completed 'Save A Mate' and Narcain/Overdose training and I've saved people's lives – three over the last six months.

What does an average work day involve for you in the role of a PPP member in NUAA's needle and syringe program (NSP)?

First up we do a walk around – looking for used injecting equipment, communicating with the local community on who NUAA is, the role that PPPs play and the importance of picking up used injecting equipment. We record the feedback the community relate to us, it's always positive. It's also about broadening people's minds and getting a better understanding of the whole situation.

Then it's a matter of stacking shelves, greeting clients, helping with their injecting equipment needs; at the bottom of all this is peer education. We talk about extended distribution of injecting equipment, we give referrals and conduct brief interventions. This is all supported through the phone and internet. We also have monthly health promotion initiatives; on Hepatitis C, overdose, vein care, and all the time we're encouraging clients to participate in their own health decisions and to become members of NUAA.

When I'm not at the NSP I assist on the Users News Editorial Board by giving input and looking at overall strategies. Other things I've been involved in as a consumer participant include feeding into NUAA's Strategic Plan, I've been asked to give a peer perspective at the launch of the Viral Hepatitis Strategies, as well as doing this sort of thing; talking about consumer participation and its benefits. PPPs also work with other organisations - I have been interviewed for articles, we work with other organisations and on other projects, we provide advice for agencies: Haymarket, KRC, MSIC for example. We provide for people who inject drugs, people with lived experience. We're out there and our opinions matter, we're making our presence felt our voices heard.

What is the best thing about your job?

That's hard say, but it comes to two equally important things: empowerment of yourself and other PWID – and what I get from working with PWID. It's almost social, working with peers on all levels and the personal connections of course.

What is one thing you would like to see different in the non government drug and alcohol sector? What needs to change to get there?

What I would like to see differently would be government organisations being better able to understand and listen, they have to understand the needs of the non-government sector. That takes more money and more resources of course.

If you could be a superhero, what would your superpowers be?

The world would take off its judgemental hat around people who have had difficult or different backgrounds and everyone would realise that people who take drugs are just people. On top of that, drugs would be decriminalised.

NSW Drug and Alcohol Health Services Library

NSW GOVERNMENT Health
Sydney Local Health District

The Drug and Alcohol Health Services Library is a great resource for all professionals in NSW who work with clients impacted by drug and alcohol issues, including the non government sector.

We provide access to Australian and international journal titles; books, reports, conference papers, and other miscellaneous print publications; as well as audio visual materials. We also have access to any material held in libraries across Australia.

For those requiring subject-specific research, we provide comprehensive literature searches tailored to a client's specific requirements. We can also train clients in the use of electronic databases, the Internet and other online resources.

Many drug and alcohol professionals across NSW already receive the library's monthly electronic Journal Contents Bulletin. Subscribers have access to the latest in clinical management and research information.

Whether you chose to visit the library at RPA Hospital, or prefer the convenience of email or telephone, library manager Mira Branezac and her colleague Neil Ford will make it their priority to provide you with the information you need, when you need it.

More information

You can visit the library at:

Level 3,
Kerry Packer Education Centre
Royal Prince Alfred Hospital
Camperdown

Or you can contact us on:

Ph: (02) 9515 7430
Fax: (02) 9515 7244
Email: mira.branezac@sswahs.nsw.gov.au

The library is open 9am-5pm, Monday, Tuesday, Thursday and Friday. It is CLOSED Wednesdays. We can negotiate with clients if they need to see us outside these business hours.

Welcome new NADA member

RAINBOW LODGE

The Judge Rainbow Memorial Fund Inc. was formed in 1964 in honour of Judge Alfred Ernest Rainbow Q.C., M.A., LL.B; a former judge of the Judicial Court, who worked tirelessly to assist individuals who had experience with the criminal justice system.

The first residential service was at Bass Hill. This was too far from the city, so the service moved to Dulwich Hill. The final move was made to Wigram Road, Glebe in April 1971. The main purpose of the Rainbow Lodge Program is to give men, who are newly released from correctional facilities, an opportunity to re-engage with the community in a safe and supportive environment.

The program includes:

- Affordable supported accommodation for three months
- Assertive case management - which uses best practice principles and is client centred and strength based
- Access to an activities program designed to enhance and develop pro-social skills
- Generic counselling provided in-house on a fortnightly basis by an independent professional counsellor
- Alcohol and other drug counselling provided in-house on a fortnightly basis by an independent professional counsellor
- Referral and advocacy.

Translating research into practice

Consumer Participation in Drug Treatment Services

Professor Carla Treloar, Deputy Director, Centre for Social Research in Health

CSRH
Centre for Social Research in Health

The National Drug Strategy, 2010-2015, highlights the need for consumer participation in governance and states that treatment services should incorporate the principle of consumer involvement in planning and operations. It also supports moves towards a nationally consistent approach for treatment services, including quality frameworks and reporting requirements.

Consumer participation is broadly defined as: 'the process of involving health consumers in decision making about health service planning, policy development, setting priorities and quality issues in the delivery of health services'(Commonwealth Department of Health and Aged Care, 2001). Consumer participation has been well developed in some health sectors, particularly in the field of mental health (Plunkett, 2008; Whiteford & Buckingham, 2005). However, there is limited literature on which to draw when developing consumer participation frameworks in the drug and alcohol sector.

Consumer participation occurs at a number of levels. At the individual service level, it involves consumers being consulted and having a say in decisions about service delivery that affect them as consumers. At the systems and policy level, it involves consumers or their representatives having a voice in policy making, service planning, delivery and evaluation and on access and equity issues. Australian research has shown that while consumer participation activities in drug and alcohol services were not uncommon, the activities were largely concerned with 'low-level' involvement, such as providing or receiving information from consumers (Bryant, Saxton, Madden, Bath, & Robinson, 2008).

Despite recognition of the benefits of consumer involvement in their own treatment, there remains a dearth of research of consumer participation in drug and alcohol treatment (Brener, Resnick, Ellard, Treloar, & Bryant, 2009; Bryant, Saxton, Madden, Bath, & Robinson, 2008; King, 2001; Treloar, Rance, Madden, & Liebelt, 2011). A range of factors potentially effecting consumer participation projects in drug and alcohol treatment settings have been described, including:

1. Stigma and discrimination, and attitudes of health workers

Discrimination (or fear of discrimination) that consumers face in treatment episodes has the potential to effect their healthcare and treatment uptake (Ahern, Stuber, & Galea, 2007; Brener, Von Hippel, Kippax, & Preacher, 2010; Luoma et al., 2007). Negative stereotypes about drug and alcohol clients (Australian Injecting & Illicit Drug Users League, 2011; King, 2001; Radcliffe & Stevens, 2008) and discriminatory attitudes have the potential to obscure the outcomes of consumer participation (Paterson, Backmund, Hirsch, & Yim, 2007). For example, any failings on the part of the consumers involved are perceived to reinforce the stereotype that people who use drugs are unable to perform effectively in such settings (Patterson, Weaver, & Crawford, 2010).

2. Power and empowerment

People who access drug treatment services often enter such services at a time when they are extremely vulnerable and may have other issues to manage (Treloar et al., 2004) which may create challenges for articulating and asserting their needs and rights. If consumers perceive their access to treatment as fragile, fear punitive responses or being perceived as a 'difficult client' (Treloar, Fraser, & valentine, 2007), they may find it difficult to assert rights and feel comfortable participating in higher level planning and decision-making (Australian Injecting and Illicit Drug Users League (AIVL), 2008; Hinton, 2010; Patterson et al., 2008).

3. Organisational barriers to consumer participation

Delays in implementing consumer participation are to be expected in a field characterised by a lack of resources in already overstretched services (Treloar et al., 2011) and when the amount of work involved in implementing the projects is underestimated (AIVL). Some services have been described as lacking the stability (such as in staffing turnover) required to effectively instigate and manage a meaningful and sustained consumer involvement strategy (Treloar et al., 2011).

4. Consumer-situated barriers to consumer participation

It is important to note that consumers of drug and alcohol treatment, as in any health context, have pre-existing issues which have the potential to divert energy and motivation away from consumer participation projects. Reported barriers include the potentially stressful and demanding nature of drug and alcohol treatment, chronic illness and the loss of community members through relapse or death (Foster, Tyrell, Cropper, & Hunt, 2007; Meyer, 2004). Other health barriers include the patients' desire to focus on treatment, the quality of the relationship with service providers, and personal characteristics (Thompson, 2007).

> *Australian research has shown that while consumer participation activities in D&A services were not uncommon, the activities were largely concerned with 'low-level' involvement.*

The CHANGE Project

WHOS RTOD participation in a pilot project across multiple OTP sites

Carolyn Stubley, WHOS, Nurse Manager

In late 2011, WHOS Residential Treatment of Opioid Dependence (RTOD) program was approached by NUAA and the Centre for Social Research in Health (CSRH) to participate in a multi site consumer participation pilot project. The project was funded by the NSW Ministry of Health and aimed to increase understanding of consumer participation and its benefit amongst both service staff and service users. The following is an observation of the pilot project and the outcomes achieved.

The pilot commenced in early 2012 with a designated project worker from NUAA, RTOD clients and key staff. The pilot targeted clients that were on maintenance Opioid Substitution Treatment (OST) in community based Opioid Treatment Program (OTP) clinics in Sydney and regional NSW. WHOS RTOD was the only non-government organisation to participate and the only residential program. WHOS RTOD was chosen as a participant due to the client group being on maintenance OST.

Activities varied across the multiple sites depending on the service setting, needs and capacity of both the service and the service users. Any project activities during the two year pilot were undertaken by the clients of the service, with input from key staff and guidance from the NUAA project officer.

The project had two components to promote consumer participation:

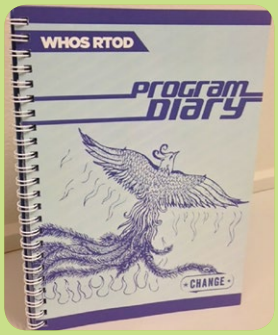
1. To introduce a more formal suggestion box feedback process
2. To identify a specific project that the client's felt would benefit both current and future consumers of the service and was developed solely by clients for clients.

As a manager I have worked in both a community OTP and the WHOS RTOD program therefore I could envisage the differences in the way the pilot program would be implemented in these very different environments. In the public clinics, clients consistently attend the service daily, sometimes over a lengthy timeframe. Comparatively, the residential program has clients progressing through various stages with a core 90 day program; therefore the project had to be tailored to the changing population.

Being a residential Therapeutic Community (TC) program, WHOS RTOD had a challenge in determining the type of project that could be continued with a changing population. Clients are involved in the day to day running of their environment being based on peer dynamics with staff essentially being part of that community so the project needed to enhance the experience of consumer participation.

The first part of the project was very achievable with NUAA providing a very sturdy suggestion box (much better than our cardboard box already in existence). In the beginning the clients kept track of the suggestions. Staff would give feedback to clients on suggestions and how they would be addressed.

The second part of the project took time to determine what clients felt would benefit them and others coming through the service. Many ideas floated around for some months until there was agreement from all clients around the concept of a diary that covered the WHOS 90 day program written by clients for clients. When asked what the clients thought a good name for the pilot project would be, the name "The CHANGE project" came up and this name was adopted for the entire pilot.



Fortunately during the pilot there were several WHOS RTOD clients that continued through to the various stages (i.e. transition and exit) of the program who from their time in RTOD were involved in the project. The now senior clients supported the changing RTOD population to continue work on the diary.

The RTOD diary designed by the clients of WHOS RTOD includes sections on;

- What is consumer participation?
- Don't leave before the miracle happens
- The stages of the program
- The first three months
- Client stories and client illustrations
- Rules and anything else they felt was relevant for a new client to know upon entering the program
- 90 days of journal entry pages with a 'today's tip' section on every page.

NUAA kindly printed the diary for us and provided 100 copies to be given to every new client that enters the WHOS RTOD program. This has been so successful in RTOD that we hope to develop a diary for every WHOS service.

Another great outcome from the project is having a consumer representative attend all WHOS services staff meetings to read out the client suggestions and then feedback to their peers on the progress to meet these suggestions.

Participation in this project was a worthwhile exercise yielding good results in the area of consumer participation and was certainly an interesting process to witness its development. An evaluation was conducted by the CSRH and a journal article written for the International Journal of Drug Policy (Rance, J & Treloar, C, 2014) with the outcomes of that evaluation.

Reference;

Rance & Treloar. "We are people too": Consumer participation and the potential transformation of therapeutic relations within drug treatment. International Journal of Drug Policy (2014)

WHOS
helping people help themselves

Rekindling the Spirit:

Developing a Consumer Advisory Group

Rekindling the Spirit (RTS) is a community based organisation in Lismore within the Bundjalung Nation area of New South Wales. They provide a family-based approach to supporting Aboriginal men and women to find their own path of empowerment through spiritual, emotional, sexual and physical healing and mixes traditional healing with contemporary group and counselling practices.

RTS's vision is to promote and support a world where Aboriginal communities are free from social injustice, substance misuse, family violence and child abuse.

RTS work closely with community and government organisations to support the local community and have recently initiated a consumer advisory group with the Lismore Aboriginal Health Service (LAHS). Both RTS and LAHS recognise the benefits of developing partnerships with service providers, consumers and the community in working towards improved social and emotional wellbeing for the people in the local area. The consumer advisory group was established to engage and act as a consultative forum for consumers.

Over the past six months RTS and LAHS, have been supporting a group of men and women who use these services to develop skills in managing and facilitating the consumer advisory group. The group have held two meetings in the past four months, and have been looking at the services delivery models and providing feedback to the Rekindling the Spirit Board any issues or discrepancies. The group also provide idea's that could be incorporated into service delivery models to improve service delivery and outcomes for clients.

Rekindling the Spirit Managing Director, Greg Telford, stated it has been a pleasure to watch the participants involved in the development and ongoing facilitation of the consumer advisory group grow and gain a sense of empowerment. He indicated the establishment of the group has supported consumers to recognise that they have knowledge, skills and a voice to contribute to improved service delivery.

The group continues to develop and become embedded in RTS over the coming year with a view to becoming a permanent component of the Rekindling the Spirit service model.

Women Want to Know about alcohol consumption and pregnancy

***Women Want to Know* is a new public health campaign that encourages health professionals to have conversations with women who are pregnant, or planning a pregnancy, about the risks of alcohol consumption during pregnancy.**

Alcohol is linked to adverse consequences in pregnancy including miscarriage, premature birth, low birth weight and Fetal Alcohol Spectrum Disorders (FASD). FASD has lifelong consequences for the child including physical and behavioural deficits. For these reasons the National Health and Medical Research Council recommends that for women who are pregnant or planning pregnancy, not drinking alcohol is the safest option.

Research shows that 97% women want to receive information about alcohol from their health professional during pregnancy[1].

Women Want to Know provides FREE resources and online CPD accredited training for health professionals on how to approach conversations about alcohol and pregnancy.

Women Want to Know has been developed by the Foundation for Alcohol Research and Education (FARE) in collaboration with leading health bodies and funded by the Australian Government.

For more information visit **www.alcohol.gov.au**

fare
Foundation for Alcohol Research & Education

women want to know
discuss pregnancy & alcohol

1. Peadon E, Payne J, Henley N, O'Leary C, D'Antoine H, Bartu A, Bower C, Elliott E. (2011). How do women want to be informed about alcohol use in pregnancy? In: Book of Abstracts. 4th International Conference on Fetal Alcohol Spectrum Disorders 2011. The Power of Knowledge. Integrating Research, Policy, and Promoting Practice Around the World. March 2-5, 2011, Vancouver, Canada.

Would you recommend this service to family or friends?

Supporting NADA members improve consumer participation

Robert Stirling, Director Planning and Strategy, NADA

How many of us have completed a survey that asks the question 'would you recommend this service to family or friends?' Reflecting on our own services, effective consumer participation has the potential for consumers of your service to say 'yes'.

For many it does represent a change to how we go about our business, and another area to develop among a range of other competing priorities. However the benefits could mean longer retention in your program and improved health and social outcomes. And isn't that really why our services exist?

NADA sees building our sector's capacity for meaningful and appropriate consumer participation as an important part of our sector development program. Not only as tool to support continuous quality improvement for our members, but acknowledging that everybody deserves the right to inform the health services that they receive.

To date, NADA's sector capacity activities to support consumer participation include:

- Involvement in a number of committees and advisory groups at government and service levels. Including NUAA's Change Project, and the review of the NSW Health Consumer Participation Guidelines.
- Advocating for consumer representatives on NSW Health drug and alcohol committees.
- Including consumer participation as a priority area in NADA's Sector Development Plan.
- Service User Participation Scoping Report (2011)

NADA commissioned LMS Consulting to undertake the above scoping report. The recommendations included in the report have been guiding NADA's work in this area.

- **NUAA Workshop: What do services need to do to undertake effective consumer participation?** (2011)

The workshop highlighted the findings from AIVL's Treatment Service Users reports, NUAA's role and consumer participation activities, and strategies to support members.

- **Community (re)Integration Forum** (2013)

This forum provided the views of nine consumers in delivering services to meet broader health and social needs.

- **Putting together the puzzle: Stigma, discrimination and injecting drug use** (2014)

Delivered by NUAA, members learnt about the impact stigma and discrimination has on people who inject drugs and the health outcomes for this population.

- **Consumer Participation Forum** (2014)

NADA, in partnership with The Lyndon Community and NUAA, the forum provided an opportunity for members to hear about different experiences and challenges in implementing strategies, and provide recommendations to further this area.

What people got from the forum:

"Strategies to implement consumer participation in the workplace to improve service outcomes and learning how other services currently undertake consumer participation"

- The development of a consumer participation policy template and workplace audit tool for members.
- CMHDARN's program supports the development of consumer participation in research (see page 18 for more information).

"NADA is committed to supporting the consumer participation practices of its members, further developing how NADA engages consumers in its own work, and advocating for high level consumer representation in policy and planning."

Would you like support with consumer participation?

NADA have developed a Consumer Participation Workplace Audit Tool to support members reflect on their engagement with consumers, and develop actions into practice. Also look out for the consumer participation policy template in the revised NADA Policy Toolkit coming soon.

NUAA have generously provided NADA with a number of their Consumer Participation Kits to be made available to NADA members. If you're interested in receiving a copy, please contact Robert or Ciara.

See page 17 for more consumer participation resources.

Workforce planning: Don't we already do that?

Mark Buckingham, NADA President

Yes I would say we do. But how well are we doing it and what level of importance are we giving it? Based on organisational size and capacity, I would think some of us are doing it well, others not so well, and others not at all. There is an increasing need to formalise what we do and how we do it, and in my view the current environment demands it now more than ever.

Workforce planning is an ongoing process used to align the needs and aims of an organisation with those of its workforce, ensuring it can meet legislative, regulatory, service and contractual requirements as well as organisational objectives. As a sector, we are currently in an environment where all the above are actively shifting and demand responsive planning at a both an organisational and sector level.

The NSW non government drug and alcohol sector is preparing for significant change in the way that funders will determine, firstly the need for services, but ultimately the business attributes that it contracts with. These reforms present opportunities to strengthen our sector, but come with challenges in terms of the impact on our workforce.

The need to reflect on our workforce as we transition is critical. Workforce planning requires increased assessment and review and will most certainly be a cornerstone upon which organisations will qualify its capacity to meet and adapt to the needs of clients in NSW across the continuum of care.

For many of us this will require re-shaping service delivery models to reflect the direct integration of new/re-shaped services via partnerships, or the direct demonstration of organisational capability to respond with a workforce that's capable of meeting the expectation of clients. This will require considering how we meet broader health and social needs, including physical and mental health. Reflecting on the theme of this issue of the *Advocate*, what are the structures and competencies we need to support a peer workforce in the drug and alcohol sector?

As a business that is contracted to deliver services on behalf of the public sector, we will require operational support that includes financial management, continuous quality improvement, as well as meeting reporting and compliance obligations.

Identifying the required workforce to deliver future services would be an easier process if as a sector, had a clearer understanding of the possible frameworks or purchase plans that will inform our services.

This would address critical matters like continuity of staff capability as well as measures to address capacity and take into account possible new functions and roles that outline detailed workforce characteristics and capabilities required now and into the future.

NADA plan to work with the NSW Ministry of Health to support effective workforce planning, including ensuring workforce is a priority area in the development of the drug and alcohol strategic plan.

"Workforce planning requires increased assessment and review, and will most certainly be a cornerstone upon which organisations will qualify its capacity to meet and adapt to the needs of clients in NSW across the continuum of care."

Resources to support consumer participation

Guidelines

A Guide to Consumer Participation in NSW Drug and Alcohol Services

This NSW Ministry of Health guide from 2005, provides a set of principles to assist staff in facilitating consumer access to drug and alcohol services in NSW. The guide contains background information and guiding principles as well as information around planning for consumer participation and possible strategies that could be implemented. These guidelines are currently under review.

Reports

Treatment Service Users Project (TSU) Phase One Report

Treatment Service Users Project (TSU) Phase Two Final Report

Voices on choices: working towards consumer-led alcohol and drug treatment

Nothing About Us Without Us Report

Organisations

Australian Injecting and Illicit Drug Users League (AIVL)

www.aivl.org.au

AIVL is the national peak organisation representing the state and territory drug user organisations and issues of national significance for people who use or have used illicit drugs.

New South Wales Users and AIDS Association Inc (NUAA)

www.nuaa.org.au

NUAA advances the rights and dignity of people who use drugs illicitly in NSW.

Association of Participating Service Users (APSU)

www.apsuonline.org.au

The Association of Participating Service Users is a Victorian organisation which represents consumers of drug and alcohol services.

NSW Consumer Advisory Group Mental Health Inc (NSW CAG)

www.nswcag.org.au

NSW CAG is a state wide organisation that provides an ongoing opportunity for mental health consumers to participate in policy and service development, implementation and evaluation.

Local and international resources

Straight from the Source: A Practical Guide to Consumer Participation in the Victorian Alcohol and Other Drug Sector.

The Peer Model Manual: The manual contains three modules - Peer Helper Training; Experts by Experience and Speakers Bureau. Each module addresses a specific way in which consumers can be involved in the sector.

Consumer Participation Resource Kit

The Consumer Participation Resource Kit from Victoria contains information on ways to engage with service users, to listen to their views and to develop strategies based on their advice with the aim of improving service provision.

Consumer and Peer Roles in the Addiction Sector (NZ)

This document creates discussion around the roles and activities of the consumer and peer workforce in New Zealand.

Consumers Contribute to the Addiction Sector in More Ways Than One (NZ)

A factsheet to introduce the addiction sector, and other allied sectors, to existing and newly emerging consumer and peer roles within addiction treatment.

Involving Service Users Toolkit (UK)

Drug User Involvement in Treatment Decisions (UK)

This report discusses the involvement of drug users in making decisions about their treatment.

CMHDARN Update

Focus on consumer engagement in research

Join CMHDARN today!

CMHDARN has the long term goal of improving service delivery to people with mental health and/or drug and alcohol (MHDA) issues. It aims to build research evidence into the policy and practice of front line drug and alcohol and mental health services.

One key approach to attaining this goal is to offer a range of activities and resources through which the community managed MHDA sectors can engage and enhance research-related activities and research skills and knowledge. With the combined memberships of NADA and MHCC, CMHDARN has the potential to increase research capacity of over 300 services across NSW. This is borne out by the large number of people across the MHDA sectors who have already engaged with CMHDARN. For example, during August 2010-Dec 2013, there were eleven research events - 572 registrations; four reflective practice webinars (92 participants); CMHDARN website (launched September 2012) - 2464 unique visitors; 4,539 visits and 20,000 page views.

CMHDARN has demonstrated a strong commitment to the participation and active involvement of consumers and carers. Since inception, the CMHDARN steering and project reference groups have had representation of carers and consumers and consumer organisations in the role of planning, management and guidance of CMHDARN activities.

Particular Activities which have addressed consumer participation in research as well as broader issues impacting on consumers include:

- **A research forum** specifically focussed on consumer participation and representation in research: *'Nothing About us, Without Us- We are the Evidence': Consumer Participation and Representation in Research Forum* (see **this link** and scroll down to August 2012)
- A reflective practice webinar on stigma and discrimination of people affected by MHDA, *Stigma and discrimination towards people with drug and alcohol and mental health issues*
- **Research Seeding Grants Program.** Consumer involvement was one of the selection criteria for the research seeding grants program and applications were assessed based on this. Successful applicant organisations were encouraged to incorporate consumers into their projects, and were provided with specific resources about consumer participation in research and discussions were held at the workshop. The external evaluation of the Research Seeding Grants Program (2013) found that the project enhanced organisational capacity to deliver services to consumers (90%), and that they had additional insight into consumers as a result of participation in the project, as one respondent commented:
- **Resources and integration of issues.** Issues relating to people living with MHDA are raised in all CMHDARN activities, and links to relevant resources are provided on **the website**.

Into the Future

In order to further support organisations to improve the nature and extent of their involvement of consumers and carers in their research, CMHDARN is calling for Expressions of Interest from consultants to develop an online best practice guide, *Improving organisational approaches to consumer and carer participation in research and evaluation activity*. For further information on this project, please contact **Deb Tipper**.

community mental health drug and alcohol RESEARCH NETWORK CMHDARN

Comments from Research Forum participants

"The main thing I get is the very different focus on issues of consumers and workers. It's those different viewpoints that can inform a collaborative process"

"The lived experience is often the best teacher. Bradley's presentation was wonderful, the passion and honesty that he shares is priceless".

"Importance of consumers' voices and how it can influence future research and heighten the benefits of evidence-based research."

NADA farewells

Kay Elson, CEO of the Haymarket Foundation retires

Kay Elson's contribution to the non government alcohol and other drugs, and homelessness sector in NSW is inspiring.

Starting out in the industry as a volunteer with Mission Beat ion 1980, Kay went on to work as the manager of the Fairlight Centre in Manly – one of the first proclaimed places under the Intoxicated Persons Act 1979.

In 1985 Kay went on to become the Manager of Swanton Lodge, a crisis accommodation service for men and women in the inner city. Kay's experience in working at the coalface of complex need service provision paved the way for establishing A Women's Place in Kings Cross and setting up the Inner City Housing Project for People with complex mental health and drug and alcohol issues.

Kay's ability to map out wrap-around service provision for those in crisis, while addressing the discrimination they experienced is apparent through the achievements of the services she established.

Initiatives such as Lou's Place, the remodelling of Campbell House, and in 2006 as the CEO of the Haymarket Foundation, Kay was an integral part of the improvements in service provision implemented at the Bourke Street Project and the transition of the Albion Street lodge to the Haymarket Centre.

The announcement of Kay's retirement from our sector is bittersweet news. NADA staff on behalf of the sector wish her all the very best in more relaxing future pursuits and she can be contented in the knowledge that the varied tapestry of her work endeavours will stand the test of time.

Farewell to Barry Evans

Long term NADA Board member and CEO of The Buttery, Barry Evans, retired from the sector last month.

Barry has been a long standing member of NADA and the ATCA and has been involved in a central way in many of the key developments for our sector both at state and national level. The NADA Board of Directors and NADA staff wish Barry a warm farewell and all the best for his retirement.

We sincerely hope Barry will continue to make valuable contributions to the non government drug and alcohol sector, and in particular with the Therapeutic Community movement.

"I personally want to take this opportunity to thank Barry for the assistance he has given me as NADA CEO and for his valuable contribution to the governance of the NADA Board over the past two decades."

Larry Pierce, CEO NADA

New NADA Resource

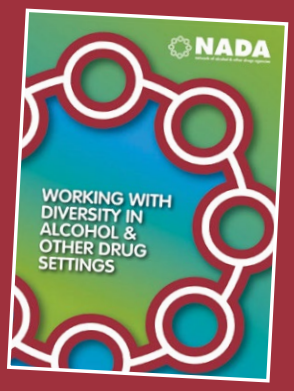
Working with diversity in alcohol and other drug settings

The *Working with Diversity in Alcohol and Other Drug Settings* resource has been developed by NADA to support non government drug and alcohol organisations in their work with the diversity of clients that access our services and represent the NSW population. It contains examples of best practice approaches, as well as a range of useful resources for services providers.

The following populations have been included in the resource:

- Aboriginal and Torres Strait Islander peoples
- Culturally and Linguistically Diverse communities
- Lesbian, Gay, Bisexual, Transgender and Intersex people
- Older People

Click here to download the resource.



How to engage people with and affected by Hepatitis C

Ruth Bearpark (Project officer, Education and development, above), David Pieper (Project Coordinator, Community Engagement) Fungi Siggins (Project Officer, Community Support)

Over 231,000 people in Australia are living with Hepatitis C, with 82.3% contracting the virus as a result of shared injecting equipment (HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2013).

While we all know how vital it is that communities directly affected by Hepatitis C be at the centre of any national response, it's also essential that services supporting those communities are equipped to facilitate that active participation.

Hepatitis NSW (HNSW) work actively in partnership with other organisations and with the affected communities themselves to bring about improvements in quality of life, information, support and treatment, and to prevent HCV transmission.

This article discusses three HNSW projects that encourage consumer participation using strategies such as: capacity development, advocacy and peer support.

Capacity Development

Workshops are held four times a year to build on the capacity in the sector. These workshops aim to increase worker confidence to engage their consumers more deeply on issues around hepatitis and health promotion and to talk about the choices people make around risks and consequences. The idea is the one day interactive forum delivers information and knowledge around viral hepatitis through the development of practical skills in Hepatitis C health promotion. By engaging in activities, participants learn the information while also learning activities that can be modified and implemented in their own services. Activities that can be used with consumers of a range of services including alcohol and other drug services, to promote harm reduction and reduce stigma. Facilitated exercises explore how to talk about choices people make around risks and consequences. The workshop includes a free kit packed with activities and tools for the organisation or group. Ongoing support is offered to services with free membership to HepLink, a capacity building online forum for professionals responding to viral hepatitis in a range of settings.

The next workshop will be held on October 15th 2014 at our Surry Hills office.

These workshops can also be tailored and delivered at any AOD service or any other setting across NSW who are working with priority populations affected by hepatitis.

Peer Support

One of the most significant and effective tools used in HNSW workshops to address stigma associated with Hepatitis C is the C-een & Heard program - a powerful speaker program which offers a chance to share first hand in someone's personal account of living with Hepatitis C.

The HNSW's C-een & Heard program enables people who are affected by Hepatitis C to talk about the psychosocial or medical and treatment related aspects of their experience of living with Hepatitis C to the healthcare workforce and the broader community. This approach brings many benefits to audiences including 'humanising' or 'giving a face' to the experience of living with Hepatitis C. Additionally, providing this service can empower the speakers themselves, and benefit the broader Hepatitis C affected community.

HepConnect is a peer phone service aiming to reduce isolation and ease treatment difficulties often associated with Hepatitis C. HepConnect provides a phone based peer support service for people living with Hepatitis C, their partners and carers, and particularly for people who are considering or are currently undergoing Hepatitis C combination treatment.

HNSW also provides one-to-one peer support through the HepConnect program which enables people who are affected by Hepatitis C to receive support and discuss their concerns and experiences with trained peer workers who have experiences of living with the virus and undergoing treatment. Programs like this recognise and value the unique significance of the lived experience and strengthens a sense of community while reducing isolation.

C me Community Advocacy

People living with Hepatitis C are often socially excluded or isolated because of stigma and discrimination. This limits the capacity for community advocacy for, and by people with Hepatitis C.

Hepatitis NSW's C me Project recruits and trains community advocates from the affected community to act as local advocates in campaigning. Supporting and training volunteers to use their life experience to advocate for change provides a voice for communities affected by Hepatitis C and enhances the capacity of Hepatitis NSW to interact with every Local Health District in NSW. Personal stories and the involvement of people with lived experience is a powerful tool in effecting change. Involving community advocates in the development of the campaign message helps ensure the relevance of the message. Providing a range of campaign tools enables people to participate in campaign activities at a variety of levels.

Community advocates put a human face to our campaigns and have been active in advocating for change on a range for issues from access to treatments to stigma and discrimination and blood borne virus education on the school curriculum. As a result communities of people living with Hepatitis C are stronger with more active participants working together to tackle Hepatitis C and enact change. People with Hepatitis C are able to lead more active, healthier lives.

For more information on Hepatitis NSW and there programs:

Visit: www.hep.org.au
Email: hnsw@hep.org.au
Call: 02 9332 1853

Hepatitis NSW

NADA Snapshot

Policy and submissions

- NADA sent correspondence to the Minister for Health, the Hon Peter Dutton, MP, recommending that the establishment of Primary Health Networks in NSW align with Local Health Districts to enable joint population health planning, joint referral and care pathways, and collaborative service provision leading to more effective systems integration.

Advocacy and representation

- NADA met with the NSW Minister for Health to discuss the outcomes of the sector mapping exercise and future funding approaches.
- NADA continues working with the NSW Ministry of Health's Integrated Care Branch and MHDAO on future funding models, performance monitoring and contractual and administrative arrangements.
- NADA and representatives from the network of state and territory alcohol and other drug peaks met with Senator Nash.
- NADA and the MHCC met with the NSW Mental Health Commission about our ongoing partnership project, the Community Mental Health Drug and Alcohol Research Network.
- NADA attended the quarterly MHDAO Drug and Alcohol Program Council meeting and quarterly MHDAO Drug and Alcohol Quality in Treatment meeting.
- NADA host the peaks consultation for the NSW Ministry of Health Older People's Drug & Alcohol Project Expert Advisory Group.
- NADA attended the Community Engagement and Action Program Advisory Group with the NSW Ministry of Health and the Australian Drug Foundation.
- NADA and MHCC signed a joint memorandum of understanding with the NHMRC Centre for of Research Excellence in Mental Health and Substance Use.
- Continues to consult with the Community Services and Industry Skills Council (CS&HISC) on the review of the format and content of the Community Services Cert IV and Diploma in AOD and combined AOD and Mental Health training packages.
- NADA met with a range of services in New Zealand to discuss sector and workforce development, and look at different partnership models in the NGO mental health and addiction sectors.
- NADA attended the National Drug Research Institute's Social Concepts of Addiction Forum to discuss sector research priorities.
- NADA continues to work closely and meet fortnightly with InforMH in relation to client data management and reporting on behalf of its members using NADAbase
- NADA is involved in the revision of the National Comorbidity Guidelines as part of an expert panel and attended the first consultation meeting in September.

Sector development activity

- NADA hosted a forum on consumer participation in partnership with The Lyndon Community and NUAA.
- NADA hosted a consultation with North Coast members and stakeholders to explore the needs of service providers in the area in reducing drug and alcohol related harms, particularly the networks and partnerships required to support this. For more information on this consultation see page 8.
- CMHDARN hosted a forum on Understanding Best Practice Research when working with Aboriginal and Torres Strait Islander organisations and people, and a webinar on Improving organisational capacity and demonstrating efficacy.

Contact NADA

Phone: **02 9698 8669**
Post: **PO Box 2345**
Strawberry Hills
NSW 2012

Larry Pierce
Chief Executive Officer
(02) 8113 1311

Robert Stirling
Director Planning and Strategy
(02) 8113 1320

Heidi Becker
Manager, Programs and Services
(02) 8113 1317

Suzie Hudson
Program Manager
(02) 8113 1309

Ciara Donaghy
Program Manager
(02) 8113 1306

Chelsie Hughes
Project Officer
(02) 8113 1312

Edith Olivares *Maternity Leave*
Project Officer
(02) 8113 1308

Craig Bulley
Administration Officer
(02) 8113 1305

Deb Tipper
CMHDARN Project Officer
(02) 9555 8388

Clarissa Cole
Publications Coordinator

Feedback

Training Grants