

# FLIPSIDE

The Association of Participating Service Users



## The Anniversary Edition

No. 41 Autumn/Winter 2016

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## Editorial

Fifteen years ago, in May 2001, APSU published the first issue of Flipside. APSU itself had been founded just a few months earlier.

Much has changed in the past fifteen years. The AOD sector has become much more familiar with the concepts of consumer participation and peer work, although the practice is still at a symbolic level. Some things haven't changed, like APSU's funding, which also remains at a symbolic level.

To mark this anniversary, we have included a few pieces of writing that have been published many Flipside's ago. We have also reflected on the past, present and future with three of the key figures in the fifteen years of APSU's activity. There are many more that we could not include, but we hope that our readers will agree that we chose well.

Karenza, who managed APSU from 2004-2005, went on to become CEO of ACSO, one of the biggest AOD services in Victoria. She gave us some insight into those early years when APSU was still a baby, but also a valuable perspective from her current position.

Damon, the former CEO of Harm Reduction Victoria, collaborated closely with APSU for many years. Damon's perspective is now additionally enriched by his experience in CoHealth, where he works with marginalised populations.

Regina managed APSU from 2006-2011. Her hard work at APSU played a major role in placing the topic of consumer participation on the AOD sector's agenda. Regina shared with us details about many challenges she faced whilst leading APSU, as well as her wisdom about the potentials for consumer participation and peer work in the AOD sector.

We thank our three guests for generously finding the time for us in their busy schedules. We also thank all the APSU members and Flipside readers for sticking with us all these years. And we particularly thank all those who, over the past fifteen years, have taken the time to dig into their soul, and write or make art for Flipside.

*Edita*

### Flipside No.41 Autumn/Winter 2016

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Interviews in this edition: Edita

#### **DISCLAIMER:**

*The views and opinions expressed within Flipside do not necessarily represent the views and opinions of APSU.*

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# My view as a service user

Originally published in Flipside 1, May 2001

At APSU we have a vision. We believe that one day drug treatment services will be able to really meet our needs. That we can be assisted to get some hope into our lives; that we can learn to deeply understand our fears, that we can be helped with the pain, and that we find others who care about our dreams and aspirations and help us realise them.

We need to identify our skills our insights and our experience. We need to learn to articulate our vast knowledge. We need to mobilise our resources. We need to express that no longer are we prepared to be passive recipients of treatment and we need to learn how to help each other. We need to trust in our capacity to walk in the direction of harmony and liberation. Of course we need professional helpers, but we need them on tap, not on top.

Remember if you treat a person the way they are, they will stay that way. If you treat a person as what he can become, he will become that.

We have lived through the incommunicable experience of addiction

We have felt; we still feel the passion of life to its top.

In our addiction our hearts were touched by fire.

*Gordon Storey*



*Gordon Storey, SHARC and APSU founder, during the march against stigma in June 2004*

# Karenza Louis-Smith: It's about the herbs and spices

*Karenza Louis-Smith managed APSU from 2004-2005. She is currently CEO of ACSO.*

**APSU: When did you start managing APSU?**

**Karenza:** I think it was 2004. Before that it was managed by Gordon Storey, SHARC CEO at the time.

**APSU: What was APSU like when you started working there?**

**Karenza:** I've always believed that APSU was brilliant and underfunded. At the time when I started we were doing some work with a group in America and consumers were helping us deliver and conduct a research. We were comparing drug use and people's journey of recovery between the United States and Australia, and understanding what were the different trigger points that helped people to get off and stay off drugs, which isn't an easy task. It was a major research piece and probably our biggest project when I came to APSU.

**APSU: What was the attitude of the AOD sector and was the sector familiar with the concept of consumer participation?**

**Karenza:** It probably wasn't as familiar in the sector at the time. People were supportive, but a little bit unsure. But then they were a bit unsure about SHARC too, because SHARC was all very much about consumers running services for consumers - experts by experience.

**APSU: How did you decide about the focus of APSU's work?**

**Karenza:** We had established an APSU Steering Committee, which was made up of peer experts from various walks of life, and it was separate from the SHARC Board. We did quite a bit of advocacy work, with guidance and support from the Steering committee. One of the big things that we did was around the struggle that people were having in accessing thiamine injections. And we did a lot of work around stigma and discrimination. I remember we planned and led a march down Spring Street to Parliament House, carrying a coffin, and we stopped on the steps of the Parliament House. It was again about trying to raise, in quite a confronting way, the issue of stigma that's attached to people who have experienced drug and alcohol addiction in their lives. Certainly, in the work I do today it hasn't really changed and people are still terrified. People think drug use (ice today, back then it was heroin) equals evil, equals crime. When actually it's normal everyday people like you and me, it's families and people with children, and it's actually very, very real. So the whole idea of APSU was to try and change that perception and advocate for consumers. Certainly when I was there that was our focus. The research was all about saying people do recover from drug and alcohol addiction, they don't go on and commit crimes and go to prison for 50 years or die. Actually the vast majority gets well. Because it is a health issue - people are unwell and they need the help to get well. And people do it. That was really the message that

we were trying to promote.

**APSU:** Do you think that the perception has changed in the sector in the last 15 years?

**Karenza:** I think the sector gets it. I think the sector certainly is passionate that drug and alcohol addiction is a health issue and it's not a criminal justice issue. Policy makers are beginning to understand that. There is starting to be a shift, but there is still a long way to go with the public. Public is still really fearful.

**APSU:** Yes and the media play that card a lot, don't they?

**Karenza:** They can and they do. And when you have a drug like ice it's really easy to play that card, because you see a lot of violent crimes. So there are challenges. In my view the biggest challenge for APSU is that it never got a proper funding and it gets by with little. But I think what it does is phenomenal. Since I left APSU and went to Taskforce, and then came to ACSO, consumer participation is the major part of everything that we do. At ACSO we now employ peer workers across drug and alcohol and mental health programs. We send them all to APSU to do the training in peer work. And I'm a real believer in that, because what I gained and learned at SHARC and what I hopefully brought to my jobs since I've left SHARC and APSU has been that actually the concept of 'experts by experience' adds a whole another dimension to the way that you work and what you do. And we value having that in the workforce.

So for me APSU is an amazing organization. What it does is wonderful. It needs better support from the sector. It needs the sector to get behind it. I think the sector could do a lot more to support consumer participation.

**APSU:** Were there strong supporters of APSU in the government during your time?

**Karenza:** Probably not. It was very early days back then. We're talking about more than 10 years ago. And Gordon had done it all on his own when I joined. That was really hard, because he was running the youth residential program, Family Drug Help and APSU on his own.

**APSU:** He was quite a visionary, wasn't he?

**Karenza:** He was. I adored working with Gordon. And his death is a huge loss to the sector. I've never met somebody more passionate and fired up about what he wanted to do. He had a vision to change the world and change the way in which people with drug addiction were seen. He laid some incredible foundations around that. I was privileged



*Karenza at the SHARC march against stigma in June 2004*

to come in those years to work alongside him and drive some of that. We were able to get quite a few opinions published in journals. We worked on changing some of the rhetoric and the language around people not being passive recipients of care, but actually taking ownership and control of their own journey. And we were not advocating just for people with addiction, but for their families as well. We still have a long way to go, but we're making progress. I think that what we've got today is different from 12 years ago. I think if ACSO is helping in that journey by employing a peer workforce, and talking about the value and importance of it, that's a step forward in that change. But I think it would be wonderful to see more agencies do that and be proud of it.

Gordon always said "Recovery is a hero's journey" and I believe it is. So if you've got that, you should celebrate it in your workforce. Because then you have the best role models to inspire other people to say "I can do this too".

The question is how can you design a service for someone without their involvement in it, without knowing what their needs are and what they want? And how can you design a service that has a recovery foundation if you don't know what it means to recover or you don't know the secret herbs and spices to recover? Because 6 or 8 sessions of counselling alone aren't going to change my addiction overnight. It is about the herbs and spices, and about knowing what they are. I'm being blunt, but you don't get the best service design from a textbook or by employing only the workforce with formal qualification. I strongly believe that.

I hope that I have added the flavour of APSU, Family Drug Help and SHARC to ACSO. We have our Consumer Advisory Group. We have consumers on our board and they help us design various aspects of our service. And we have our peer workforce. I think that every provider should have something like that.

**APSU:** Indeed, more progressive thinkers in the sector are implementing consumer participation in all different forms. What developments would you like to see in consumer participation in AOD?

**Karenza:** 15 years later I would like to believe that the treatment sector could affiliate and become members of APSU, and actually support and fund those consumer voices. If I had a magic wand I would like for APSU to get more membership and support from the sector, and to find better ways to be funded and not necessarily rely on the Government. APSU needs more funding as a service for consumers, run by consumers, independent of treatment. Consumers need to have a place that they can call and say "I'm not doing well here, I'm not getting great treatment, this isn't helping me" and have someone who can actually advocate for them.

I would like to see APSU raise its voice and raise it loudly. Because it's a powerful voice. And I know that that was Gordon's vision. It's difficult because it's funded by government. If there was a way for APSU to become independent, it could really raise its voice. It would be wonderful to see. That would be my dream for APSU.

**APSU needs better support from the sector. I think the sector could do a lot more to support consumer participation.**

## Damon Brogan: Challenges for a collective movement

*Damon Brogan was the CEO of Harm Reduction Victoria from 2003-2011. He is currently working as the Community Health Worker in CoHealth.*

**APSU: How long have you been working in the AOD sector?**

**Damon:** In 1991 I started volunteering at a needle and syringe program in Canberra. Then I went back to my hometown Adelaide in 1992 and continued volunteering there. In 1994 I became manager of the drug users' program at the AIDS Council. So I have been around for a long time.

**APSU: And then you became CEO of Harm Reduction Victoria?**

**Damon:** Yes, it was still called VIVAIDS at the time. In 2003 I moved from South Australia to Melbourne and my first position was as the Pharmacotherapy Advocacy and Mediation (PAMS) officer. Then I became the VIVAIDS CEO in 2004 and was in that role until 2011.

**APSU: Did your collaboration with APSU start immediately in your VIVAIDS position?**

**Damon:** Pretty much. One of my first meetings in the AOD sector was with Gordon from SHARC. He was a great champion for recognition that service users have vital and unique insights and skills that need to be recognized. I think it's been a long journey to try to get that cemented into practice and culture in all organisations, but the advocacy for it certainly started then.

**APSU: How strong was that idea at the time? Was Gordon the main initiator or did the idea already exist in the AOD space?**

**Damon:** It existed in the harm reduction side of the AOD space, in that we were doing our own thing. And it existed in SHARC and APSU, in that you guys were doing your own thing. But it took time to get service providers and government to accept that people could have a role in all the different aspects of drug and alcohol services. Many of them said yes, it's a good idea, and obviously tried to take the argument forward, like Turning Point for example. Some of the people there supported it, but they had staff turnover and culture changes and... it's been a hard slog.

**APSU: The HIV epidemic in the 1980's brought this issue up for the harm reduction sector, but it would have been very different for the treatment sector, right?**

**Damon:** Yes. Everybody recognised with the HIV epidemic that it's only by working with people at risk, i.e. men who have sex with men, sex workers and injecting drug users, that you could bring about any kind of behaviour change, changes in norms, get the information out to empower people to be able to protect themselves from HIV and to support those who are affected by HIV. So the community involvement, and therefore recognition of the skills, expertise, passion and the ownership that the affected community had, was strong, but it's making the leap into AOD sector that's been a little more difficult. But I think in some ways the sector has changed a lot. We're still a little behind the mental health sector, but all of the big organisations now know that they have to have consumer involvement at every level. For instance, when I was interviewed for my job here at CoHealth, there was a consumer representative on the selection panel.

There are still very few paid positions in the sector that are open to lived experience, but there are some, so that is good.

**APSU: So you see that the idea of consumer involvement has grown and there is change?**

**Damon:** I think that idea was very scary for a lot of people, because people don't like change and they may have thought that having consumers involved would be very untidy. But I don't think that anybody is that scared by it any more. It's just not high on the priority list of all the organisations, as it should be. I personally don't think that the mental health sector does it particularly well, but it is very important to them that they have to at least tick the box. The box doesn't necessarily exist everywhere across the AOD sector, but it's not the scary idea like it once was. So hopefully we're on the verge of some cultural change that has been fought for very hard and for many years. There seems to me to be much more acknowledgment that people come with their own priorities and their own philosophies. We have to learn that in consumer representation and consumer empowerment we can't dictate to consumers which philosophy they take. And now I think that the sector is much more open. So in the way that it deals with service users it's much more acknowledged that it has to be more individual oriented, rather than pushing roads down people's throats. But when it comes to formalising the role of consumers in service provision organisations, that's still a bit of a patchwork.

I'm a bit perplexed that treatment agencies that say they want to get people through their dysfunctional drug use and get them to a place where they can live a completely normal life, then seem reluctant to employ or involve people who were their former service users. Because that person is the proof that they've done a good job, that they believe in what they're doing and that they have been a part in someone transforming their life. If you don't acknowledge the end product, it makes the process a bit suspect.

**APSU: It is now widely accepted that AOD treatment needs to focus on the individual, but consumer participation is a collective movement. What is your view on how to deal with the tension that exists between these two aspects?**

**Damon:** I've become aware of how diverse our "population" is. Here at CoHealth, where I'm working now, we are dealing with a lot of people who are homeless and facing criminal charges. On average the socio-economic challenges that our clients face are far greater than what I thought were normal across the injecting drug user population. Because we are dealing with the poor and the dispossessed in a way. I had a different view when I was working at an AIDS council or at Harm Reduction Victoria, where we saw a very diverse range of people and a lot of them were knowledgeable, passionate and had the time to prioritise things like a collective movement. Here they are dealing with how to get

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through the day, so it's much harder with people who worry about where they're going to sleep tonight, where they're going to get to eat, their safety from sexual assault, bashings, the police... it's much harder to get some kind of collective involvement. It's always a challenge too, because we might get one or two people who want to get involved and somehow they are meant to represent the community where there isn't that cohesion. There is not necessarily a mechanism for them to be endorsed or to report back to the people. That's why I think of some of the things that APSU, Harm Reduction Victoria and AIVL were doing a few years ago where there was a little bit of funding to try out different models of involving people, these initiatives were important. And some of the problems that hit me straight away: how are people selected, how do they select themselves, how can they be truly representative so that it is a collective thing? And that's a practical difficulty. In a more philosophical sense, the service providers are used to deal with the individual. Now they might extend it to affected family members

as well, because the government has said that's a priority, but it's very much about the individual and I think it's harder for them to accept individuals as voices for or conduits to a broader community or population. It's different in health promotion. We do a whole range of health promotion campaigns here about various topics and clients have a say about that, because we survey them about what they would like the campaigns to be about. In that way we can involve clients into the design. But treatment agencies have always been individually focused. So maybe you've identified one of the things we have to overcome.

Do they have any of our people with our lived experience on ethics committees? We'd know what the ethical issues are. They affect us every day.

**APSU: What developments would you like to see in consumer participation?**

**Damon:** There are few developments that I would like to see immediately. When there are independent ethics committees for research involving human beings, and I'm talking about research that involves people with history of alcohol and drug use, do they have any of us? Do they have any of our people with our lived experience on those ethics committees? We'd know what the ethical issues are. They affect us every day. Despite many researchers and advocates from our side of the table saying that for years, any issue in research design is still justified as having been through an ethics committee. The information from research eventually influences what programs government funds or what interventions are used. But when it comes to how that research is done, ethics committee is a very easy place to put people who have been educated and trained on how to articulate the voice of lived experience. There's no way in. We're shut out from that. So I think that would be a symbolic, but also a very pragmatic thing.

It's great that the government has a policy that says consumer involvement has to be there, but until there are some parameters around that and some money... If you think that it's important to improve the health of the community and empower people to transform their lives, to become contributing, participating members of the community... If you think that it's important, you have to put some funding into it. Those are the changes I'd like to see.



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Self Help Addiction Resource Centre

APSU believes that people who use alcohol and other drug treatment services are the reason the system exists; their needs, strengths and expertise should drive the system. APSU is run by service users for service users and has an active member base. We invite you to join us in having a say. APSU membership is free, confidential and open to anyone interested in voicing their opinions and ideas on the issues facing service users today. We need your help to give us all a fair go. To become a member please fill out the form below and post to: **140 Grange Road, Carnegie VIC 3163** or fax to: **03 9572 3498** or go to: [www.apsuonline.org.au](http://www.apsuonline.org.au) to register online.

## MEMBERSHIP APPLICATION

I wish to become a member of APSU and I would like to:

- Receive the quarterly APSU FLIPSIDE magazine
- Be sent information on how to become involved

I am a:     Service user     Service provider     Family member     Other

How did you find out about APSU? \_\_\_\_\_

Language spoken at home: \_\_\_\_\_

Cultural identity: \_\_\_\_\_

Age:     16-25     25-35     36-45     46-65     over 65

Other issues:     Physical disability     Mental health     Visual     Hearing  
 Speech     Acquired brain injury

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/Suburb: \_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

Email: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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## The Stolen Generations

*Originally published in Flipside 24 Winter 2009*

We are the stolen children from the land of broken dreams  
Broken hearts for promises, white skin that only gleams.  
Now here and there a whisper in the depths of those below  
The high voice of opinion swinging to and fro.  
To the left and to the right, and the optimistic finger  
Has therefore pointed on the map the land that we should linger.  
On the fringes of the town, far out on the plain  
But the wheel has broken on the road and left us in the rain.  
In the heat of the rising dust that even to the flowers  
Shall weep for they have left us short of the land that is not ours.  
That long ago we met you here, or you met us the story  
Is one that maybe they forgot in place of other glory.  
Yes we the stolen children are some faint voice in a dream  
That echoed once and won't return in the bosom of that stream.  
But where the thunder rolled away shall come back even stronger  
In time to come and time won't wait another moment longer.

*George Hall*



# The 'King' and I

Originally published in *Flipside* issue 15 Spring 2006

I am sitting in my study looking out the window, the cool morning reminds me of some feelings I had when I was young and 22, that would last through to 27 when I left him - The King. I call him the king because I remember his big chair, he use to call it his throne. He would say, 'Hop out! That's the king's throne'. I would hop out and then he would sit down in it.

My mind drifts back to Monday mornings when I would get up early and go to work in hope there would be a taste of the magic potion waiting for me when I got home. In the beginning, taste is such a sexy word when used in the context of drug taking. I remember him saying in a dark warm calm voice that one simple word "taste..." There was no arguing, no fighting, just magic... Those times would soon pass.

When I first met him the cold mornings felt magical, I remember how resilient I was. I was resilient to the side effects of my first-time drug use and resilient to his abuse. I remember the feeling, walking to work. In the thick fog I would see my feet step one by one. Even now, I can feel the stockings on my tight slim legs; I remember what it felt like to wear black stockings with no socks. The cold air would make my legs tingle but I felt warm inside. The effects of the drug we consumed on the weekend were still in my system.

I walk fast. My hands are cold and I caress the spot on my arm where the king injected me. No marks, no lumps, no bruising, no pain, just pleasure, pure bliss. I am breathless with anticipation, wanting the weekend to come quickly so he can do it again.

I remember feeling my heart and chest ache with passion. I have a similar ache now... for what reason? ... I don't know. Maybe it's because I am revisiting the experience with the knowledge I have today, the damage done. I remember the feeling of my work skirt; it feels like I have it on now.

I remember feeling so safe like he was my very own protector, my bodyguard. He protected people for a living; I thought he would take extra care of me. I used to think I would just die if he ever decided to leave me. My heart would swell and my chest tighten with that thought.

"That won't happen, I would tell myself. "I won't let it. I will feed him the best food if I have to steal it myself. I will satisfy his sexual appetite even if I have to sacrifice my own values and morals. I will starve myself to look slim. If he gives me enough magic potion I will be able to tolerate anything. I just need that potion to keep things the way they are."

"Now that I have a plan to work on, he will be so busy keeping up with me and my plan that he won't have time to leave me, the problem is... I'm really in love with the magic potion... not him!" For seven long years my plan was to make myself irresistible to him so I would taste the magic potion forever. The last two years were a struggle. At this time I wanted to meet my maker but held on to a fine strand of hope. I could only remember that there was hope.

I felt the potion eating away at my body and my eyes became hollow, my mouth dry and my expectations unrealistic. The essence of life is breath and my breath was foul. I was further from reality than I ever was but it was at this moment that I needed all the

strength and wisdom available to human kind. I needed to be in touch with reality more than ever so I could realise what I was doing to myself. Killing myself.

I became addicted more than ever, my face was drawn and my bony hands always shook. I could smell the potion and would gag at the thought of him administering it to me.

The king became violent and I was stuck in a vacuum of addiction, sex and crime. I felt dirty and forgot who I really was. My arms were bruised, bleeding and lumpy. His gentle hands were now rough and he inflicted pain with every injection. My beloved magic potion turned into rock. Rock was more powerful and more magical than the potion itself. It became the new potion.

Life was not life anymore. It was an infinite frugal loop that stole my soul. Who was he to me? I now looked at him as having the hands of the Devil... he just kept chasing after the rock. I'd had enough, I wanted change.

Something happened and I had to leave. The plan went astray. I became pregnant and he refused me the potion. I wanted change but I wanted the potion more. I would yearn for it, beg and steal for it, but it didn't matter what I did, the king wanted an heir to his throne. So I was to have no more magic.

I had something growing inside me that I was forced to cherish. I could not cherish new life in this captive environment. I needed love and a safe place to be. If I were to keep this precious gift I would have to leave him, his magic potion and his fairytale Land of Oz. In a not-so-gracious manner, I left his kingdom of darkness and headed to the light. I left behind me a path of destruction that would make any future contact almost impossible. In addition to leaving him, I sent him to jail.

I was by myself, no potion, no love, no beatings. I didn't know how to be, and I can't even remember how I got through that time. After nine months I brought into the world an innocent life.

How could I, a wrecked 27-year-old woman who had only known danger, violence, drugs, sex, rock'n'roll and manipulation now provide for something so precious? I didn't know what unselfish love was. I had been living a fairytale of master villains, wicked sisters, and I was in hiding from the law. Simply, I would have to learn how to raise a child... so I did. I look back. The magic potion that nourished me in the beginning could have killed me. Years later I still have not found the 21-year-old girl I was before I met The King. In a way that's a good thing, because that girl was prepared to throw her life away for a man and his magic potion.

And while my child saved my life, it took a lot of love and nourishment for me to be able to care for and love her in a way that is pure. I made some mistakes along the way and it's not all fairytales with the ending 'And they all lived happily ever after...' But it comes pretty bloody close.

What about the magic potion? It can be found anywhere and the magic for me is evil.

What happened to the King? I tend to believe he is still trapped in his fairytale kingdom taking the magic potion. But you make up your own mind.

I am now someone different; I am capable of love and peace and aspire to be many things. Today I know what a good life is and I love my daughter with all my heart; I will protect her, and give her the tools she needs to love herself. Peace be the journey, my child.

Deb

## Regina Brindle: It was a lot of work

*Regina Brindle was the APSU Manager from 2006 - 2011. She is currently working as Consumer Participation Facilitator at UnitingCare ReGen.*

**APSU: When did you come to work at APSU?**

**Regina:** I started in March 2006. David Hartmann said there was a job going at SHARC that I might be interested in. I was interested in the position, so I applied for it.

**APSU: Was that your first position in the AOD field?**

**Regina:** Yes.

**APSU: Where did you work before that?**

**Regina:** I worked in community education. And before that in disability. I once considered working in drug and alcohol, but I didn't think that I could because I used drugs. People would suggest it to me, and I'd go I can't, I use drugs. How can I do that?

We weren't just about being indignant. We were ready to turn up and do the work.

**APSU: What was different about this position in APSU?**

**Regina:** Advocacy. I wouldn't have been interested in anything else. Maybe I would have been interested in residential services, but I wasn't going to do that because of my history. But I wouldn't have been interested in counselling or any other position. And I wouldn't have applied for a management position if it wasn't for advocacy.

**APSU: What was APSU like when you got there?**

**Regina:** When I got there... well, there was nothing. They had no staff there for the previous year, so there was no one running the program. They were just using the money getting part time project worker, but there wasn't anyone permanent running it. So when I got there I had all this angst. I had the Department with their 23 performance indicators and you got to fulfil all this stuff. I had the people who, when I contacted them, they didn't want to have any contact at all with APSU, what was this crap, and what was the point and what is APSU... that's sort of response I got. So it was a matter of building it all up. Most of the performance indicators that government gave us were about networking, going out to the regions, presenting at the regional providers' meetings, trying to do some consultancy with services, but that didn't happen for ages. And publications... it was all about communicating. So we just set it up fulfilling those indicators.

**APSU: Did those indicators change?**

**Regina:** They changed, yes. They got less. We were able to consolidate them a little bit. But it was hard going. And at the time I came aboard they were doing a research project with some organisation in America, so there was that project going on as well. But there really wasn't much. It was really about building it all up and getting it going. And yes, it was a lot of work. Services didn't really want to know us. Moreland Hall was interested and that was it. When I was going to regional providers' meetings people sort

of tolerated me, but that was about it. We had to prove our stripes I guess. And the Department helped with that as well.

**APSU: So Department was supportive?**

**Regina:** They were supportive. And then we had the client charter of rights to do. APSU talked to the whole lot of people for another project before I came on board, so we used that data, all the transcripts, and I went around and I think I ran 10 focus groups around Victoria to put together the charter. That project was a big undertaking. I put that together and because of that work I had to connect with services and that helped a lot, because we were paying people, so they were happy to have clients come and it was a good way of making the connection. The Peer Helper Training was another one, setting up the Peer Helper placements was a way of connecting up with people and then the meetings and...

The first thing I had to do when I got there was the dual diagnosis forum and getting a bunch of people for that. The Department liked that I could get people together. Miriam and myself could get people together and be serious about it in terms of having people's involvement, so we weren't just going to do it ourselves. Department kept telling me "We need people. We don't just want people who work at SHARC, we want other people." They kept repeating that. Once they realised that was going to happen, they were very supportive, because they realised that we weren't mucking about. We weren't just about being indignant. We were ready to turn up and do the work. And we got going the Flipside as well.

**APSU: Were those core activities, like the Peer Helper Training and the Flipside, being done before you?**

**Regina:** They were. Peer Helper Training was run by the Recovery Support Services (RSS) at SHARC and not by APSU. And when David was managing RSS he thought it was more appropriate that we did it. And we were happy to do it. And Flipside was put together with organisational control, so I had to wrestle that back to APSU. I had to wrestle stuff back at APSU, because it was being managed by the organisation, not as a separate concern. And that's why Department was unhappy. Because they realised that it was becoming a bit more part of SHARC. They really wanted something separate - part of SHARC, but separate. So there were some projects there, and we could present at conferences and things like that. But there wasn't a lot of money that we had either.

**APSU: Did money change at all?**



*Regina (left) and Miriam (right) during their time at APSU*

**Regina:** No, it didn't really change. We got some philanthropic funding. The first lot of the money we got was for the Peer Helper Training. Miriam had put that submission in, and we got \$30,000. So we ran 3 training rounds with that. And then we got some more money through another philanthropic. I remember they made me rewrite the submission 3 or 4 times. We kept on getting philanthropic money for projects. I got the peer campaign money and at the same time I got the dual diagnosis money (n.b. federal funding under the Improved Services Initiative). That opened it all up. Suddenly we had all this resource, we could get staff, it looked like we were a powerhouse. That really shifted things. When I had that money I had 2 peer advocates and the coordinator

for the peer campaign, and it was all to promote peer work. Once we went to the Southern Region Managers meeting, there was the coordinator and the peer advocates, because they all wanted to be part of it. And it ended up to be this big fight at this meeting. No one stuck up for us, except for the woman from Salvos. The point is they didn't like the fact that there were so many of us, because there were 4 people from APSU. It was pretty funny actually. But the whole thing was that there was such a big divide between consumers and the staff there. They were all coming up with all the bad experiences they had. There was totally this hard

core divide. Us coming in and talking the way we did, it just rubbed everyone the wrong way. Plus it was 4 people. And then I had this one team member who was very strong and determined, and didn't take into account that she was in a professional forum. When I look back at it now it was pretty funny, but it was pretty heavy at the time. But it showed that the attitude was really negative.

**APSU: So they were against...?**

**Regina:** Oh against the whole idea of peer work or consumer participation. It was clear. It wasn't something that they could do, they weren't resourced for it, and they didn't want to.

**APSU: Do you think that it was because they misunderstood the concept of consumer participation?**

**Regina:** They didn't know about it, but also there was clear dichotomy between people who use the services and people who work in them, and they didn't want that divide crossed. And then we came with the notion of peer work, and for them it was sort of like people just wanted to come into treatment and leave. Those were the messages we were getting. People don't want to do it, they just want to get help and that's it. They didn't have enough capacity to do that stuff.

**APSU: What were they basing these assumptions on?**

**Regina:** There was no evidence to support what they were saying.

**APSU: Because I find it surprising how many people are interested in working in the sector after they used the services. It's so prevalent, I see it all the time. So**

There was clear dichotomy between people who use the services and people who work in them, and they didn't want that divide crossed.

**that assumption just seems so out of touch. It means that there was no dialogue whatsoever.**

**Regina:** Yes, that's right, there wasn't any dialogue. But in fact, a lot of people with drug use experience come into the workforce. So it didn't actually represent what was happening in reality. But this Southern Region meeting was the cracker of meetings. And they muscled me. Here is me, they saw me as the consumer rep, and I wouldn't shut up. There were times when they told me "can you please be quiet", they would shut down what I was saying.

**APSU: So none of them were supportive?**

**Regina:** None of them were supportive and I had to push my way into that meeting. I would report on what APSU was doing. The thing that worked was when I started giving lifts to one of the managers. I got her on my side cause of the lifts. This was over a period of time. But no matter what I did, I would never get consultancy from them. Taskforce and Salvos counselling service were all right. But all the others... And thank god there was someone from VAADA, so there were people there that I could mix with or say a word to at least. Straight after the meeting I would leave because nobody wanted to talk to me.

**APSU: So in some way your strategy was to attack on many small fronts?**

**Regina:** Yeah, and if they'd open the door we would be in. Taskforce and Depaul House were pretty good. They started opening their doors a little bit. There was a VAADA network meeting and consumer participation was on the agenda. Networking with people on that meeting helped a lot. You just had to really get out there and make relationships. Sometimes I'd go all the way to Warrnambool and there would be two people at the meeting. You had to do stuff like that and be prepared to do it. I mean it was good work, but it was hard as well. Because what you were doing wasn't seen as important, and it wasn't seen as viable. Even when people would say that consumers are really important, they wouldn't want to do the practice. There were always mixed messages. For example at conferences there would be a separate little forum about consumer participation stuff, and the same people would come to those forums. Always in the afternoon, and everyone would be half asleep and there would be 10 people in the room at most. The only time I saw big room was when Moreland Hall came to present on their charter.

**APSU: Do you see change in attitudes today?**

**Regina:** I think there has been some shift, but there is still long way to go. I think that part of the problem is that the government doesn't fund these activities. It has never funded APSU properly. So many times I've asked for money, proposal after proposal. The hardest thing was that we were so poorly funded to do such a big job. That's just cruelty. Sorry to say, but I do think that. And the irony is that people who were doing the work had all used services. So we were people who they were saying needed looking after. I mean, I don't see it that way, I don't see myself as someone who is in need of help, but that's their mentality, not mine. I always felt angry about that. And in fact, the last proposal that I put in and was rejected, when they knocked me back I started crying. I

The hardest thing was that we were so poorly funded to do such a big job. That's just cruelty.

cried because it was like fuck! You never changed anything. And when I came for funding and service agreement it was a lecture. You know, it wasn't like what can we do to help you... sometimes it was a bit like that, but mostly it was a lecture.... I mean, I really liked people in Department on one level, but all that stuff really pissed me off. I understand that it all comes from Treasury and "there's nothing in the coffers", that's what I'd hear all the time, and I get that. But that was hard, to expect that from a little service. We had to present to people and we had to be in places where there were a lot of people who saw themselves as very qualified and very knowing, and we had to walk up with our little views. They were not little views, they were important views, but it felt that way.

**APSU: Where do you see the shift in thinking specifically about consumer participation?**

**Regina:** I think there has been some shift, but it's not a big shift. Because I think part of the problem is that it needs to be pushed by the government. They need to not just put it in some little tiny print in a document somewhere, but say yes, you need to put this practice in place. You need to make sure the services are relevant to the people that use them. But they don't. And they don't have any guidelines around the practice. Not that I'm saying they should control it, but at least get in and join the party and try to support the practice.

And look, it's policy change and policy change is slow. It's like advocacy, you push and push at something and you just keep pushing and it might be that you die and it never changes. I don't think that it's something that can happen in a hurry. But I do believe that we need to look overseas a bit more. There are some very interesting practices overseas,

much more systemic, across a lot of services. That would be interesting to start thinking about that and about consumer participation beyond just the immediate people that use services, but about community taking care of its services. It's much more than what we're doing, and it can be. Another problem is also that services are so insular. Organisations see themselves as impenetrable and just on their own. That doesn't help because the practice of consumer participation is about the person who uses the services and anyone that's connected to them, and they often move from service to service, so how organisations

are structured is incongruent with that experience. That needs to shift, in terms of organisations being connected to each other in a non-competitive way.

**APSU: What changes would you like to see?**

**Regina:** I would like to see a consumer participation unit in every AOD course, so that staff are trained in it. I would like that clients are immediately given options for participating when they access a service, just like they are given the treatment options. Not that they have to do it, but as an offer from the very get go. That organisations consider in their structure how they can involve consumers in their governance. And that should be the whole governance structure. For example, they have board training and board

There were a lot of people who saw themselves as very qualified and very knowing, and we had to walk up with our little views.

guidelines, and that should include how you get consumers involved, how to train them and mentor them and constantly have that ongoing process.

I would like that consultation is part of the government's policy making process, that any policy change includes the people that policy is going to impact on. You don't exclude them, or don't consult them and then go and just make the decision between two people in a room, which is what they do. That practice in the government also needs to shift.

In terms of peer work, what I would really like to see is areas of specialisation in peer work. For example, a peer worker that is an expert in a single session work and that sort of stuff.

And in research I'd like to see more relationship between research bodies and people who use services, in terms of them having input in either research design or ideas for research or whatever it might be. Peter Darroch (n. former APSU Steering Committee Chair), for example, was very interested in alcohol and nutrition and he was going to all AOD research symposiums to push this point and he could never get anywhere. He would talk to researchers and they'd go yeah, we need to look at that, but they'd never take it up. And it's a no brainer. Of course you need to look at nutrition when someone is recovering, especially from chronic alcoholism. But things like that, how do you connect that up? I don't have answers to that, but that needs a discussion. Otherwise it's this whole dichotomy between disease model and some other thing, there doesn't seem to be anything in between. Even here with the consumers, it's like we see what we do here as a totality and this is the story, but there are so many other stories out there. We need to somehow let that information come in to direct research.

## Recipe for a peer helper

Originally published in *Flipside 11 Winter 2005*

Ingredients:

- \* 1 tablespoon of compassion
- \* 3kgs boundaries
- \* Couple of cups of good advice
- \* Pinch of bad advice (just to mix things up)
- \* 4 cups of support
- \* 1 litre of love
- \* A sprinkling of good humour
- \* A measured amount of honesty
- \* Empathy
- \* Experience
- \* Hope

Method:

- \* Chill the advice overnight then fold in 4 cups of support skills – equal parts listening,

sharing your experience and leading by example. Simmer your honesty on a low heat.

- \* Whip compassion until peaks form and consistency becomes solid.
- \* Combine 3kgs boundaries with 1 cup of gelatine – chill until firm.
- \* Allow ingredients to rest.

Combine:

- \* Compassion
- \* Honesty
- \* Boundaries
- \* Hope

The combination of these ingredients should form a solid yet pliable consistency, which is absolutely the stuff a peer helper is made of. Serve with a litre of love and a sprinkling of good humour!



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