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BREAKING NEWS:



Inspired by all the thinking that has been going on at conferences recently (especially over lunch and under trees), we're considering establishing a regular meeting of minds, a mini "think tank," here at Our Consumer Place. This would be made up of people who identify as consumers / survivors / people who hear voices / people with a lived experience of mental illness / mad folk, etc), so if anyone is interested in participating, please contact us!

5 WAYS OUR CONSUMER PLACE CAN SUPPORT YOU (AND YOU CAN SUPPORT US!)

- 1. **Is there an issue you're passionate about?** Maybe we can run a topical newsletter? Organise a talk fest? Help start up a group especially on that issue? Let us know your projects and dreams.
- 2. **Do you want something a bit different ...?** Sometimes we get feedback that consumers would like to hear more from consumers working on the ground?; or want the newsletter to be easier to read if you've not had a huge amount of education; or more details about when we're running Intentional Peer Support training... We can't please everyone, but we genuinely want to know how we can do things better, or just differently.
- 3. **Contact us!** Email us at service@ourconsumerplace.com.au. Call us on either 9320 6839 or 9320 6802. Or go onto our website www.ourconsumerplace.com.au. Just be in touch, ok!
- 4. **Write something.** We would love to include your thinking, experiences and ideas in our newsletter. Or draw something. Or do an improvised dance (although we might struggle to include this)...
- 5. **Know someone doing amazing things in the consumer world?** Let us know and we'll try to follow them up and include them in our newsletter in the future.



SOAP BOX

Consumers and smoking: Part 2

Just ask: the answer is 'no'

by Isabell Collins (Director of the Victorian Mental Illness Awareness Council)

(Previously printed in Of Substance vol.8, no.2, 2010 (p.16). Reprinted with permission. www.ofsubstance.org.au)

The issue of smoking bans on all psychiatric inpatient units and longer-stay psychiatric residential accommodation facilities has been a topic of concern for many consumers for some time.

People with a serious mental illness (schizophrenia, bipolar affective disorder or psychosis) also have a 25 yr less life expectancy than other folk (Lawrence et al. 2001).

Given the above statistics, no-one who cares about people with a mental illness would argue that something positive needs to be done about the high level of smoking and poor physical health of these people. However, is forcing someone to give up smoking at a time when they are at their most distressed state the time to do it? I would argue it is not.

The concerns of consumers are many in regard to the cessation of smoking in inpatient units and longer-term psychiatric residential units. For the most part, to ban a person from smoking at a time when they are at their most vulnerable and distressed is cruel and inhumane.

Most people who find themselves in psychiatric inpatient units are there as involuntary patients, thus their level of mental unwellness is so serious they require immediate treatment and care (often against their will) with many patients being suicidal and in a state of extreme distress.

Very few health service organisations have sought the opinion of people with a mental illness who use the service about whether a ban should occur or exemptions should apply. Exemptions are needed, particularly for people who are involuntarily detained in acute inpatient units, secure extended care units or other residential facilities where people are required to reside. This lack of consultation occurs despite various Mental Health Acts and the Commonwealth and State/Territory Health Ministers' Statement of Rights and Responsibilities which articulate clearly the responsibility to consult consumers.

Notwithstanding the above, the ease with which health services have imposed their will on consumers reflects a deeper issue of the negative organisational culture and attitudes that exist towards people with a mental illness.

While the physical health of people with a mental illness is well known to be of major concern, the approach to lessening the number of mental health consumers who smoke should be done in a respectful, dignified, holistic manner at a time when the person is not in an inpatient facility at their most vulnerable and distressed state of their life, or an involuntary patient in a secure extended care facility where they do not have the option to leave.

Reference

Lawrence, D, Holman, CDJ & Jablensky, AV 2001. *Duty to Care – Preventable Physical Illness in People with Mental Illness*, Perth: The University of Western Australia.

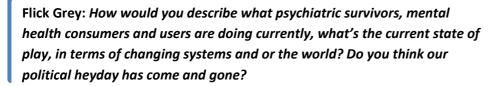
Check out VMIAC's online 'smoking ban' petition: www.petitiononline.com/advocacy/petition.html



INTERVIEW OF THE ISSUE -

Interview with David W. Oaks

David Oaks has been a psychiatric survivor and human rights activist since 1976. He is director of MindFreedom International. He lives in Eugene, Oregon, USA.





David Oaks: I call myself a psychiatric survivor – certainly a lot of people refer to themselves as consumers or users – but I do think that at MindFreedom, people tend to identify as *survivors of abuse in the mental health system*. That voice tends to get lost a bit, but it's important to remember that voice. It'd be like if we were reforming the Roman Catholic Church from abuse, it would be important to very clearly have an organisation of those who have experienced abuse.

I agree with an academic paper I read somewhere that said there have been two big changes over the last few decades. If you go to a meeting about mental health issues – say at a county, or local, or city, or district level, or province or state, you will now find an individual who identifies as a user of the mental health system, on that council. And also, there is some acknowledgement in the language to include user/survivors in there.

I think the main thing is, really, that we exist! I think the key achievement is that our social change movement exists. Because for centuries there has been this kind of oppression, and only briefly in the 1800s was there a known group of survivors organising — maybe at a few others times. There has always been this abuse, but now there is actual organizing going on, internationally, and has been for decades — nowhere near what we had hoped, over the years, in terms of how much, but the fact is that we're here.

And the struggle is that much more important now, because the biggest increase in the history of mental health is about to take place over the next 10 to 20 years. What has been happening in the richer countries hasn't been happening in the vast majority of the world. And now the battleground for the mental health system is in poor and developing countries, in Asia and Africa. This is the globalisation of the mental health system. So as never before, we are poised to engage with challenging the system on this global stage.

So, no, the heyday is definitely in front of us. How well will do, though, is up to each one of us. The key question is unity, whether or not we can unify. And by unity, I don't mean lock-step conformity. No, nobody's suggesting that! And I don't mean hierarchy. I mean people working together in a spirit of mutual co-operation, even when – especially when – there are significant differences of opinion. I think that is the key for oppressed people – are we going to work together or not? And if we do, I think we will have one of the most exciting and beneficial non-violent clashes ever. And as MLK [Martin Luther King] said, he didn't make conflict, he just made it visible.



FG: What place does activism have in mental health? What three top areas would you target?

DO: Near and dear to my heart! Thank you for mentioning activism! I think that the big challenge – the elephant in the room as they say – since the mid-80s, is mental health system funding of this field. The mental health system is eager to bottle the spirit of empowerment – which we used to call power. And while there are some well-meaning people in the mental health system who do want that, I think minor reform is actually a problem. What's driven the mental health system to increase for decades is this kind of reform effort. So, if you ask the average mental health leader, they'll say they think the mental health system needs "activism," it needs "reform" and everything. But we call for a non-violent revolution purposefully, because reform is actually a problem – reform has *grown* the system for 200 years!

The system will not fund real activism. So, for example, I think we need to be questioning the power of the drug companies, what we call "the bully model." Having only one choice is no choice, and we are pro-choice! We don't want to be cornered as being anti-this and anti-that, like anti-drug or anti-psychiatry. We're pro-choice or anti-bullying. And so, I think a top issue is to point out the bully in the room, which is the very narrow, very medical model that is used as the organising system.

It's not the model itself which is the problem – we have members who very much utilise the medical model – you know, vitamins and nutrition are very much medical model – but it's the bullying. So I think, this is one of the top things that has to be discussed. I think that the system-funded change has tended to leave that out. I'll go to several-day-long conferences, about recovery, and peer-support, and mental health alternatives, and hear nothing about the power of the drug companies. You know, they are putting one-year-olds on neuroleptics, they're forcibly drugging people in their own homes. And the drug companies are paying for pushing this – the USA parents' group gets more than half their money from the drug companies.

And so in terms of the role of activism – how could we have a peace movement, or an environmental movement or a women's movement, funded by corporations and the government? And I'm not denouncing the system-funded folks, I don't think we should denounce them, when they are doing good work. System funding is crucial – we should be asking for more of it – but we need to be smarter about also supporting independent activism. And that's often the missing part in a lot of organising. People start getting money for conferences, drop-in centres, consulting, peer-support and all that, they need to keep aware, just like the disability movement, that everyone needs to support activism as an ingredient.

Another issue I would say is other human rights issues. We've been talking about involuntary electroshock, because that's very unifying. People are sometimes not so sure about forced drugging, but most people are sure that involuntary shock over the expressed wishes of the subject has got to go. So, it's a very unifying point about an abuse that isn't numerically maybe as big as other abuses. Actually, we're critical of all shock. But forced shock really focuses us. How can there be any empowerment, any recovery or any self-determination in a system that allows that electricity be forced through our brain? It's worse that water-boarding. It's torture. We need to bring this up, for example at the UN, now that we're in the tent of the United Nations and the Human Rights scene. We need to push really hard that this is torture – and use the "t" word. And things like forced shock are growing internationally as the western medical model is exported. Drugs are expensive, so shock is going up.



The third key issue is to promote a range of humane, empowering alternatives, especially peer-run, peer-support alternatives. There are good jobs in "them thar hills," as old time gold miners used to say in the USA about gold where you can hire people who were formerly considered un-hireable, disabled, and now they are providing peer support, and being a role model. So, the whole upsurge of interest in alternatives, the Finnish and the Scandinavian models, the Open Dialogue Project, Mosher's Soteria House model, and all of these ... a huge rainbow of alternatives need to be provided! It's like organic food – we should be very clear that there is natural care. MindFreedom has a directory of screened alternatives, but it's actually pretty small, which is telling.

FG: What would you expect to be different if we lived in a community that embraced people with mental health difficulties or who experienced madness?

DO: One of the big issues for us is the universality of our issues. I talk about 'sanism' although some people prefer 'mentalism.' Sanism is an enormous -ism, I'm still plumbing the depths of this -ism each day, I'm just amazed. In the Western model, we are apparently thinking, rational beings and so forth. For me connections with the environmental movements have been really important. The tragedy of the climate crisis and environmental devastation is so nightmarish, but there is benefit to our connecting with their movement. We know that to be human is *not* to have a grip on reality. And what is called "normal" is one of the most dangerous things to the planet. Certainly the worst kind of what is called "normal" are the people who claim that they're normal, that they have a firm grip on reality, that they are certain, that they can tell us what to do. And I'm not kidding about this, this is not word play, this is deadly serious, this is Planet Earth in trouble and we are connected to all the movements, we sprang from all these movements — civil rights, women's, anti-war — all these movements work together and we emerged from that in about 1969/70, this particular phase of organising.

We're all interconnected, and this is the tricky part for us, is the fact that if any human is considered crazy, all of us are crazy. I tend to think everybody is crazy. So, for example, I just came from a meeting where one of the participants, was cutting herself and weeping in the toilet over a relationship, and yes, she was having an overwhelming crisis. But her similarity to the world is more than her difference. The world is cutting itself and the world doesn't have a grip on reality. When people really get in touch with that universality, that is an overwhelming thing. And we need to be going to the people who have had extreme and overwhelming emotional issues, who have gone through it and have reached some level of recovery, and take notes. Because this is about everybody.

So with this vision what would the world look like? Well it wouldn't be different just for the 5 or 10 or 20% of us considered "troubled." Would the emergency rooms look better? Yes, that's important, but it would be more like it takes a village to heal a mind. There would be enormously more support for a huge diversity of mental and emotional feelings and thoughts, and enormously more listening to one another and connecting with each other.

As Martin Luther King used to say, "The salvation of the world lies in the hands of the creatively maladjusted" and the world's in dire need of a new organisation, the International Association for the Advancement of Creative Maladjustment. That was no joke! Not all maladjustment is good, it was *creative* maladjustment, but you're not going to have change without a crazy person. If to be totally different from everyone else is to be crazy, then one person has to start, and will look crazy. Something



that really motivates me is that this is a planetary issue that we're dealing with here. I think why the oppression against us is so fierce is that we are a reminder – that person weeping in the corner is a reminder that your heart is weeping right now. Don't look down, because the floor is glass and you're looking at the whole universe below you and you may fall. So let's turn to each other and hold each other, and support one another, because nobody has a grip – we're in universal crisis, every moment.

FG: What are some things that could happen in one day that would give you a really good night's sleep where you woke up feeling hopeful and ready to take on the world?

DO: I like that question. As Judi Chamberlin reminded me when I visited her in hospice – I thought we'd have this real heavy talk – but she reminded me that when we were younger, 30-something years ago, on the wall of the drop-in centre for the Mental Patient's Liberation Front, we had a sign that said "Overthrow Psychiatry by Tuesday." Since then, one of my sayings is "Non-violently overthrow the mental health system and have a nice day."

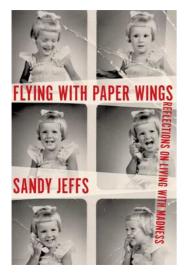


For me personally, it involves being in nature, being outdoors with wilderness and friends and directly challenging oppression in a creative way, such as creativity, art, peaceful activism, mutuality and healthy movements and supporting one another in a thoughtful way... I'd go to sleep with a grin on my face!

You know, I have glimpses of that. My partner, Debra and I, we have our little garden and our cat and our friends, and I'm in a men's group and I seek to take care of myself and to enjoy things, not get totally absorbed by the movement. But it's a struggle, I think we all struggle with it.

... So, bring me to Australia!





INTRODUCING ... (A CONSUMER DIRECTED INITIATIVE)

Sandy Jeffs, renowned Australian poet and public speaker introduces her latest book "Flying with Paper Wings: Reflections on Living with Madness"

Flying with Paper Wings is a story of survival. Sandy Jeffs grew up in a family torn apart by domestic violence and alcoholism. A recurring image for Sandy is of her mother slumped in the corridor, bruised and bleeding, after her raging father has beaten her. Though she shared with her older brother and sister the fear that one day their father would kill their mother, or that she would commit suicide as she so often threatened, the three

siblings rarely spoke of their constant horror, none daring to share it in or outside their small Ballarat home. At thirteen, Sandy was the victim of a sexual assault about which she had remained silent until this memoir. This story breaks the silence. Getting a studentship and going to La Trobe University in 1972 was her ticket out of home. She managed to graduate with an Arts Degree after a struggle. During this time she also came to terms with her sexuality and became part of an alternative family.

The main motif of the story is Sandy's descent into madness. Diagnosed with schizophrenia in 1976, Sandy's world unravels and disintegrates into suicidal withdrawal and psychosis; she goes on to experience its full range – from billowing psychoses requiring hospitalisation to periods of chronic depression and gradual recovery. With many admissions to Larundel, a Dickensian madhouse on the edge of town, she found herself in the company of bizarre strangers who populated its wards. With the loving care of her friends, Sandy finds some respite and remains well from 1992 until 2005 when she suddenly plunged into psychosis. It was a bitter blow.

Flying with Paper Wings offers insights into hearing voices, the tantalising world of delusions, the vivid hallucinations manufactured by a mind in the grip of madness. It invites the reader in to the psychotic mind and shows how its repertoire is unlimited, indeed limited only by one's limitless imagination!

Despite this, she has been able to develop her gift for words, beginning with the poetry that helped her express something of her experience of madness and the madhouse. Poetry became an important tool for Sandy. With it, she processed a lot of her demons and it helped her to wade through the muddy waters of her madness. Poetry gave her back an identity which had been relentlessly stripped away by her schizophrenia.

A decade ago, Sandy decided to retrieve records of her admissions to mental institutions. She set the medical observations about this stranger who was herself alongside her own subjective impressions. It prompted her to begin writing her story - of being drawn into the underworld of madness and returning to tell the tale. In its telling, she seeks self-understanding, but also to discover to what extent nature or nurture are implicated in her illness, how an ill-formed and fracturing identity can be rebuilt, and how, as a society, we might nurture nature so that mental illness brings least suffering to all.

Flying with Paper Wings is available at bookshops and online at www.sane.org





What is Intentional Peer Support (IPS)?

In this edition, Flick Grey writes about **Intentional Peer Support**, as developed by Shery Mead (based in the US). If you've read Our Consumer Place's newsletter before, you may have noticed that we often mention Intentional Peer Support (including an article in the last edition about the Brook RED

centre in Brisbane). Flick and Merinda (both staff here at Our Consumer Place) attended a week long course run by Shery Mead and Chris Hansen here in Melbourne, in early 2009, and then another week of "Train the Trainer" (also run by Shery in Chris) in Brisbane in early 2010. We are both very excited by the possibilities this model offers. Here, Flick shares some of the basic principles of this model.

Intentional Peer Support (IPS) is radically different to anything else I've experienced in mental health. It's practical and transformative at the same time. And it's so simple – in theory at least! Basically, it challenges us to rethink the idea of "help." It involves unlearning how we have learnt to give and receive "help." Instead, it encourages us to build mutually respectful, challenging, *intentional* relationships.

Many of us have experienced being "helped" in ways that were unhelpful, even damaging. Receiving "help" can lead to having our wishes or experiences ignored, being labelled and given "help" based on this label (rather than our own experiences), or being pushed in directions we don't want to go. These experiences of "help" can range from receiving relatively harmless advice to human rights abuses (e.g. involuntary "treatment"). People who want to "help" us can be well-meaning, but the experience of constantly being on the "receiving" end of help can shake our confidence in ourselves, and teach us that other people know better than we do. When we're in a position to help others (e.g. as peers, or as friends), many of us slip into these same patterns of "helping" — it's often hard to know what else to do.

Instead of being based on "helping," Intentional Peer Support provides tools for building relationships in

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which both people learn and grow. This starts with establishing a connection: we all have experienced how different a relationship feels when there is that "spark" of connectedness, when both people are listening to each other and truly present. Without this connection, the relationship is more superficial. In Intentional Peer Support, you are pushed to be honest – with yourself and the other person – about when connections are lost. For example, someone might say something that upsets you,

or surprises you, or there may be a misunderstanding. The aim is to re-establish connection, e.g. by saying "I had a really strong reaction to what you just said, and I'm sorry, I disconnected. Can we go back ..." and to move through this discomfort.

The second "task" of IPS is to explore "world view," thinking about how we make sense of our experiences, ourselves and the world. IPS recognises that we all understand things differently. One example is that we can move away from seeing people through the lens of their diagnosis. If diagnosis is important to someone, we can ask things like "what does it mean to you when you say you are depressed?" or "how have you come to understand your feelings and behaviours as "borderline"?" This process is about reconsidering the "stories" that we might be stuck in. I know that for me, this was one



of the most powerful aspects of the first training course – consciously rethinking my own "mental illness story," as *meaningful experiences*, rather than as a set of "symptoms."

The third task is called "mutuality," but really it's about staying honest and responsible to each other. This is the part that really challenges our ideas about "helping," because most helping relationships are

It feels good and useful to be able to help someone else, to "make a difference." An Intentional Peer Support relationship involves actively resisting the temptation to slip into this style of helping. Instead, it's about honestly owning our part.

very lop-sided: one person is seen as having problems, while the other person helps them with their problems (in the nicest, most caring way, of course!) It feels good and useful to be able to help someone else, to "make a difference." An Intentional Peer Support relationship involves actively resisting the temptation to slip into this style of helping. Instead, it's about honestly owning our part. So, for example, we might say "I've noticed that we seem to have become stuck in this conversation. Have you noticed that too? How have you been feeling about it?" or "Sam, I'm not hearing the voices that you are, but you sound really upset. I know I've hated it when I think people are saying nasty things about me. It sounds like you're feeling hurt and wanting to defend yourself?" This part is hard to do hypothetically like this, but

it's not so much about "getting it right" as staying honest about our experiences, and resisting the urge to "be helpful".

The final task is "moving towards," which involves actively thinking about where we each want to head. Usually, the focus has been our problems – our "symptoms" or behaviours that cause us pain, or things we're unhappy with in our lives. IPS encourages us to think about what we want, because if we focus on the problems, we're more likely to stay stuck in them. For example, if we think about "being less stressed," the focus remains on our levels of stress. It's about being creative and focusing on what gives us energy, rather than trying to "cope." Again, I found this part of the training challenging but incredibly rewarding.

Although Intentional Peer Support is framed in the context of peer-support in mental health, it's really a model for social change that is relevant well beyond mental health. In fact, I've found the skills I've learnt in IPS useful in the rest of my life. Shery Mead writes "Ultimately, this course is about building a healthier world – one in which people aren't labeled but rather understood through the lens of their experience." (Intentional Peer Support: An Alternative Approach 2008, p.5)

Our Consumer Place will be running training in Intentional Peer Support later this year, so please contact us if you are interested.



NEWS IN THE CONSUMER WORLD:

Some very distressing news from Townsville, where a 27-year old Indigenous man died on April 15th, after being forcibly injected with anti-psychotics and restrained by police, after seeking help for his mental distress. The man had been hearing voices and was very distressed, and had a history of being treated for bipolar disorder and schizophrenia. He was finally admitted *voluntarily* to a mental health ward after being sent away several times (due to the lack of availability of a bed). 24 hours after admission, he was dead. Our deepest sympathies go this man's family and community, and we send our support to Gracelyn Smallwood, his aunty, an Aboriginal activist and nurse who has been speaking out about this tragedy and fighting for justice.

In other news, some amazing, recent conference presentations have inspired us. Tina Minkowitz, psychiatric survivor and human rights lawyer from the US gave a conceptually rigorous and deeply inspiring vision for the directions we need to move in the mental health field if we are at all serious about human rights. Rufus May (the "doctor who hears voices") had the room utterly spell bound with his discussion of support networks of people who hear voices. His connection with the human spirit was truly awe-inspiring. Jeff Cheverton, from the Queensland Alliance, presented a compelling case for a national anti-discrimination campaign, drawing on the best examples from around the world, and Catherine Smith showcased the amazing work the Queensland Alliance is doing in terms of true consumer leadership.

OUR CONSUMER PLACE UPDATE: WHAT HAVE WE BEEN UP TO?

We've had contact with several consumers who are interested in some kind of peer support that is specific to the diagnosis of borderline personality disorder (not necessarily "officially diagnosed" – it could include anyone who self-identifies as potentially benefitting from this kind of support). We have started networking to begin working out what might work, in terms of being useful and sustainable. Let us know if you are interested, or have thoughts on the matter.

We finally (!) finished editing our booklet titled "So, you've got a mental illness? ... What now?" that introduces the basics of consumer perspective. We will be launching it in the near future, so stay tuned!

We have also met with many people, too numerous to mention individually, who are working on various consumer-led projects, or are interested in supporting consumer-led projects.

THUMBS UP/THUMBS DOWN

- 1. **Thumbs up** to people who are not consumers but who understand "consumer perspective" and don't try to speak for us.
- 2. **Thumbs up** to Tina Minkowitz, for her clarity of vision and strength in speaking truth to power. Truly inspiring! Tina talks about ending coercion in psychiatry, using international human rights law.
- 3. **Thumbs up** to the work of "Hearing Voices" groups, changing the culture, from medicating the voices away, to exploring what meaning they have for the person who hears them, and what relationship people want to have with their voices and their experience of hearing voices.
- 4. **Thumbs up** to a national "anti-discrimination" campaign, drawing on experiences in other countries. Let's move beyond the kinds of "anti-stigma" campaigns that make us into objects of pity and charity!



- 5. **Thumbs up** to the artists whose work was displayed in the "I am" exhibition at Federation Square, run by Mind and Doutta Galla. It's always great to see 'mental illness' break out of the margins, where it's so often associated with secrecy and shame. This exhibition was proud and rightly so!
- 6. **Thumbs down** to people in the mental health field who refuse to recognise our common humanity, who describe us as "lacking insight" and rationalise the use of coercion, when we are distressed, crazy, or acting in ways that other people disapprove of.
- 7. **Thumbs down** to the closures of drop-in centres for people with 'mental illness.' Deinstitutionalisation might have sounded like a good idea, except there was meant to be increased support in the community. We here at Our Consumer Place have heard far too many first-hand accounts of centres closing down, leaving people especially older people with a long history of living with mental illness isolated and without the connections that have been crucial to their wellbeing.
- 8. **Thumbs down** to the proposed changes to the NSW *Mental Health Act*, so people admitted to hospital involuntarily will have much longer to wait for their detention to be reviewed currently a magistrate is supposed to review their case within a week, but this period may be extended to a month!
- 9. **Thumbs down** to the idea of "serious" mental illness (or "severe" or "significant"). Although used in many mental health contexts, what does this mean for other "mental illness" that is apparently not serious? *Frivolous* mental illness? *Insignificant*? *Pretend*? *Funny*? People suicide who have diagnoses of clinical depression, post-partum depression, borderline personality disorder, bulimia, and many other diagnoses (or no diagnosis!), none of which are technically classified as "serious." Why are we/they not taken "seriously"? And, it can give the impression of "us and them," where "those people" with serious mental illness are given pessimistic outlooks, or think of ourselves/themselves as "the real consumers."
- 10. **Thumbs down** to the common failure on the part of services to differentiate between what is 'just life well lived' and what is 'therapy'! We **DON'T** want everything turned into therapy. For many of us it takes away the joy of participation and achieves nothing.



