

IDD-HUMANISTS NEWSLETTER

Formerly Awl Weave Ghat

The Newsletter of the *American Association on Intellectual and Developmental Disorders'* (AAIDD)
Humanist Action Group – December, 2007 v.1 issue 4

This newsletter expresses the opinion of this subgroup and not necessarily of AAIDD

All data presented are opinions and alternative opinions may be printed in later issues.
Send feedback and submissions to jrmullin@verizon.net

Notes from the editor

Hello again! Some things have been going on with the group. We are up to 15 members which excites me to no end. We are showing slow but steady growth. I realize that some of you out there join every group to help support the AAIDD and probably wouldn't have joined this group otherwise. Nevertheless, I welcome the opportunity to hear different opinions and constructive feedback.

This group serves a useful purpose but has much room for improvement. In particular, the website needs more content. If you are sympathetic to Humanism, would you be willing to write a page or two and I could, if necessary, format it and publish it to the web. Also, speaking of the internet, we now own www.AAIDD-Humanists.org in addition to www.AAMR-Humanists.org. I expect to be able to drop the older AAMR title in a year or so

This issue is a month later than expected. I could say this was to make the issues fit into a more traditional March, June, October, and December schedule but the real reason brings up one of the topics I like to discuss when I can: medication side-effects. I'm a fairly hefty guy and take a few medications for blood pressure, diabetes, high cholesterol, etc. In the mid-summer my physician who I have much faith in, increased my blood pressure med. On the increased dose I became lethargic and much less focused. I looked up the drug online and these conditions were mentioned as infrequent side effects of the medication. After giving it a while to see if I adjusted, I mentioned this to my doctor. He looked surprised, said they weren't side effects, but changed my drug regimen anyway because some of my electrolytes were off and that was a side effect he recognized. After a few weeks, I was back to baseline and able to write newsletters, etc.

I can read well and research things on the internet and am willing to argue with my doctor a bit if I have to. All the people I work with who have intellectual disabilities can't (I recognize that some people with IDD can) and they often take a lot more drugs than I do. Many of the drugs others take are more potent or mind-altering and have harsher side effects. I worry that many people with IDD suffer from side effects from many of the medications they take but can't get to try alternative (but traditional) medications with fewer side effects.

I suspect that most of the readers of this issue have stories to share about people they know who got much better in some areas when they stopped taking a medication that

addressed a different area. One of my clients is on a phenobarbital taper while it is replaced with Tegretol for seizures and also to address a likely bipolar disorder. On this taper, which began after he was on a stable dose of Tegretol, to our surprise and delight, he began to communicate with us. Most of his many inappropriate behavior decreased significantly in frequency, he began to walk better, he started joking with us and he smiled for a change. He's blossoming as a person. His sister/guardian cried with joy when I told her about this improvement. Staff that were previously reluctant to work with him are now happy to work with this man and see what he can do. I've asked his doctors to accelerate the taper and am eager to see what will happen. He came to our institution several years ago already on the phenobarbital *so there was no way for us to know how it influenced him and there was no way for him to tell us*. That is my point. I could tell other stories like a friend whose weight goes from chubby to near anorexic based on her seizure med at the time. If you have stories you'd like to share in this area, feel free to submit it to me and I'll print it. It's no more an Humanist issue than most other medical issues but it's important to share these stories. I'd also be happy to share how various people have addressed this situation.

Jim Mullin

How do you talk to a person with IDD about Humanism in light of their friends' beliefs? (Part two)

In the last newsletter we talked about the nature of belief systems (even humanism) to try to convert others to their system. Generally, one would think a logical argument would serve to end these attempts. In real experiences, this isn't so and this is why there are conversions. The major reasons behind these successes are emotional factors of which two come to mind.

The first of these is probably exemplified in a talk I had with a friend last night. We were at the Holiday party at the Unitarian Church I attend. Don, my friend, originally came from the South and he was talking about how bland Unitarian services seem to him (no argument there!). Sometimes he missed the excitement he remembered at a few Baptist services he attended down there. He remembered singing and everyone hap-

pily participating. He didn't miss the Baptist religious teachings but he did miss the emotional experience. So I propose that the *group emotional experience* of a religious service may be a strong emotional factor. It's similar to why people pay big bucks to attend a sports event rather than watching it on the television for free. There's nothing like being caught up in the excitement. Once you've been caught up in the excitement, you want to go back again and again.

Personally, part of the reason I like Unitarianism is that is so bland (relatively, I do find it intellectually stimulating). I think it's easy to get caught up in a group emotional experience and adopt a silly or dangerous belief. Hitler's rallies in the 1930's and 40's are a very extreme example of this but politicians in general

are quite aware that a lively rally will gain them some new supporters. So I tend to avoid these situations when I can. I miss a little fun but I can lead a much more rational life.

The second of these emotional factors is a bit harder to avoid. I could be mean and call it emotional blackmail but it's not as drastic as that. Basically a friend wants to share their religion with you. To say "no" is to reject their friendship and good intentions and, after all, this is an opportunity to do something with a friend. So we say yes once and maybe a second time and so on. Every "yes" makes it harder to say "no" later. The friend thinks he helped you and you are reluctant to tell him/her otherwise. I can

remember being encouraged to do that as a child for both religious and non-religious organizations. I'm a lousy salesman so I never succeeded but I knew of others who had.

At this time, we have talked about the nature of conversion, and in particular, religious conversion. We have also talked about strong emotional factors that influence our ability to be influenced. In our next issue we will talk about how to address these situations in a very constructive way.

As always, I would like to hear feedback, either good or bad on these issues since I would like this newsletter to be a group effort if at all possible.

Website News

Slowly but steadily the website advances. I've put in more content but there are still areas which need further development. The site is now listed in a few search engines which is a help. Note that if you look up MR or IDD and Humanism on any search engine, you find that our website is the only resource available in this area. With a little more content, we can begin to promote the site and increase our value as a resource.

If you would like to help write a webpage or two, let me know. Visit the site at <http://www.aamr-humanists.org> or <http://www.aaidh-humanists.org> and check it out!

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