

Stories from the brainreels transcript

February 21, 2014

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CHERYL: Welcome to Blog Talk Radio's "Stories from the brainreels." I'm your host, Cheryl Green, from StoryMinders coming to you live from Portland, Oregon, as I do every first Friday and some third Fridays at 1:00 pm Pacific Time to share stories, news, art, comedy, and discussion on brain injury and disability culture.

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Introduction

CHERYL: Hello, and welcome to one of my special 3rd Friday episodes. My guest today is Craig Sicilia who does a massive amount of work in the brain injury community around peer support, training and education. I'll be playing a pre-recorded conversation Craig and I recently had. Before we get started though, as always, a little bit of local disability arts news!

The [Disability Art and Culture Project's](#) Sex, Love and Disability III fundraiser is coming up on March 1st. The event is for adults only because of content. There's always quite a range of art and performance around celebrating the lives of people with disabilities, our loved ones, families, partners, crushes, desires, passions and pleasures. We look at the beauty and full humanity of Disability Culture. Our host will be comedian Margarita Smith. The evening will feature performances and videos from diverse members of the disability, queer, fat, sex positive, and body positive communities, as well as a silent auction. Proceeds go toward putting on our week-long Disability Pride Art and Culture Festival in May. Also, we'll be premiering my first ever music video called "Too Sexy For The Rain." Just a side note: this video has what my film teacher Courtney Hermann calls my "signature shooting style." That's her lovely way of saying the world moves too quickly for me, and I often can't get the camera in focus or don't remember to. Despite that, the lyrics, dancing and video are phenomenal!

Details about the fundraiser and the accessible venue (the Center for Intercultural Organizing) can be found on the Disability Art and Culture Project page on Facebook and <http://dacphome.org/> under the Events tab. Feel free to write to <http://dacphome.org/> or call DACP at 503-238-0723 (voice) if you have questions about the event or disability access.

Another very cool thing happening is the arts and crafts table at our annual Pacific Northwest Regional Brain Injury Conference. Saturday, March 15th is Survivor Saturday. All day long, there will be a table where artists with brain injury are selling their work. Joan Miller will have her hand-sewn, scent-free eye pillows; I will have my DVDs; and we hope to have others such as Kris Haas and many, many more. This is so exciting! These types of conferences have a lot of emphasis on research and rehab. It's great that they're making a space for us to sell our work. As I have said many times, artists with brain injury are artists.

I will be presenting at that conference on Friday afternoon talking about representations of brain injury in film. I'll screen everyone's old favorite comedy, "Cooking with Brain Injury." But the rest of the presentation won't be my personal story. It will be about what happens when inaccurate portrayals are in the media, and you don't know where to go to find accurate ones. What happens when people without disabilities pretend to be us instead of directors valuing our experiences and just hiring us. What happens when brain injury and disability are the butt of a joke instead of a complex experience the way it really is for us. It will be fun!

So now, onto my conversation with Craig. Please visit www.WhoAmIToStopIt.com and check out the post from February 18, 2014. There, you will find links to all the projects that Craig talks about in this interview.

The history of the Brain Injury Radio Network

CRAIG: Hi, Cheryl.

CHERYL: Hi!

CRAIG: I thought it was yesterday, but I don't know. We have two people with a brain injury that really didn't write it down. It could be any day!

CHERYL: [laughs] Oh, I didn't know if it was yesterday, or if it was today. And I thought maybe it was Monday! Since my radio show's not part of the Brain Injury Radio Network, I would love for you to tell my listeners everything about the network and everything that you do.

CRAIG: Well, everything that a lotta people do.

CHERYL: Yeah.

CRAIG: A lotta times people get known for something, but it's really the people that are doing it that are making it known. Brain Injury Radio itself was originally set up just to be kind of an after-hours support group once a week cuz there wasn't enough support here. So we started doing it on the phone. That's about 3 1/2 years ago, when we first started. It was 90-minute show once a week is what it ended up being. And then from there at about the 2 year point, it went every day from 7:00 to 8:30. Now it goes every day from 5:00 to 10:00.

CHERYL: Oh wow.

CRAIG: And there's 26 hosts from a wide variety of brain injury. Cuz you know TBI is just one way to get it. That's just the mechanism. I smashed my head. Other people've had strokes or aneurysms. So we're really trying to bring all of the folks together because even though traumatic brain injury's the number one cause of death, ABI is the number 3. A lot of people aren't aware of that. You put all of us together, there's 32 million of us supposedly, with all the different ways that are walking around with these cognitive deficits. And they're all very similar, which I found fascinating.

CHERYL: Yeah.

CRAIG: You know, as I listened, their challenges are almost exactly. The mechanism--how they got it--is different. The ABIs is really scary. Nothing happened, and all the sudden you're having this brain incident. There's no one that's worse than the other cuz there's different levels in all of them, just like ours. What's scary is we don't actually learn about it until we go out and figure it out. And that's kind of what motivated me because the lack of information really destroyed my life. It hurt my care cuz they're not knowing what was going on. You go to doctors. Sometimes they're more clueless than we are.

CHERYL: Mmhmm.

CRAIG: That really hurts your rehabilitation when you got one guy doing the right thing and the other guy doing the wrong thing.

CHERYL: So you said that the radio show originally started to be sort of like an after-hours support group. And now you've got it going on every night of the week. Is it still sort of like that?

CRAIG: It is. It's actually now part of our Peer Support Line. So the Peer Support Line goes right now from 8:00 am to 5:00 pm Pacific Time, seven days a week. And then at 5:00 o'clock, the Peer Support Line goes into the radio show. And see my ultimate goal is that people have support 24 hours a day, 7 days a week. You never know when you need that support. It's usually in the middle of the night, is when you really need it.

CHERYL: That's right.

CRAIG: So I'm working toward that. Lots of people are signing up. Laurie is the kind of lead in that division of it, the Peer Support Line. She's doing a wonderful job. And we're just building up teams. You gotta do it slow. People gotta be trained. We don't really advertise right now. So the calls are low, maybe 5, 10 calls a day, maybe 20 at the most. During the holidays it's a little heavy. If you're not advertising, that's pretty incredible, people reaching out like that.

CHERYL: It really is. How can people get the number?

CRAIG: It's 855 (and that's toll-free) and then you just gotta remember the #4, then peer (P-e-e-r) 11. It's 855-4-PEER-11. There's also a website, which is www.4peer11.org. And if people wanna volunteer, you can also volunteer on that page. We'll put you through training. It's sometimes what not to do, is what we really teach. Because what survivors have to offer is their journey. When somebody understands, especially that first person that understands, it's powerful for that survivor and that family member.

CHERYL: Yeah!

Peer support versus support from experts

CHERYL: What do you think would be different if it were, say, speech therapists and counselors and social workers who have never had a brain injury but work with us a lot? What would be different if they were answering that line?

CRAIG: Well, you would have to listen tomorrow night. It is the best example I can get. We have a neuropsychologist who's less than a year into his TBI. He was working with pediatrics for about 30 years, and he thought he had it. You know, he thought he knew brain injury. Cuz that's what he did for 30 years. Now that he has a brain injury, he says, "I realize I knew nothing." He kinda wanted to go back to work. Now he's questioning himself. It's only a year. A couple years from now, once he gets past that, he'll be able to. But the thing is, is he gonna want to?

CHERYL: Yeah.

CRAIG: That's the question I ask. Cuz I no longer wanted to do what I did. I could've. I would've had to pace myself out, but I had no desire to do things the way that it was being done, how DSHS wanted me to do it. They don't treat people right. The laws ain't there to really help them anymore. They're there to protect the agencies. I think that they can empathize, but they can't really understand.

CHERYL: Yeah.

CRAIG: You know, they can't understand why this is happening. Cuz at a certain point, they get frustrated with us. And you know, "Why can't you do this?" Myself, as a behavioralist before my injury, I worked with developmental disabilities and younger people with behaviors. And I never could understand why they just couldn't get it together. I get it. [both laugh] And that really does help us be a little bit more sensitive, sometimes, I think.

CHERYL: I noticed that different hosts on the radio show sometimes have a different theme.

CRAIG: Yeah, and that's purposely. A lotta folks have come along and been hosts. They thought well, we need to just do it this way. I'll write the script. There is no injury that's the same. And so I'm trying to get as many perspectives as I can. And I do have a few caregivers on there as well. I wanna keep our caregivers healthy so they understand. Cuz if our caregivers get frustrated and abandon us, then we just lost our support. So those are huge. We've got all walks of life. We've got people of all different classes because a person with a lot of money obviously gets better, more consistent care than a person with no money and insurance. And so you need both aspects cuz you can still rehabilitate with no money. I don't see that the money's helped some people. I think the really good care that some people got wasn't so really good in the end. And they would agree with that, I think, that money doesn't buy your best care.

CHERYL: I experienced that myself, yeah. And then I would turn on the Brain Injury Radio on blogtalkradio.com and listen in and go, "Wait a minute! I wish someone had said that to me two years ago! Right. Oh that makes me feel so much better about what's going on." And it's what you said. It's that first-hand peer experience is so validating.

CRAIG: Right. And peers have so much knowledge. They have so much knowledge in what they done and what worked for them. People just gotta realize what may work for one person might not work for another person. But knowing all the tools, you're ahead of the game.

CHERYL: That's right, yeah.

Craig's journey

CRAIG: Even when you're diagnosed, cuz I was in a coma, and my neuro-surgeons and neurologists sent me to go get a test with the neuropsychologist. Yeah, I had no clue. Even though I was a behaviorist, I had no clue what a neuropsychologist was at this time. He's supposedly the best in our area. And so I went in there, and he wasn't there. So this other gal was there, "Oh, but I can help you." And so me and my then-wife, we didn't know that she wasn't a neuropsychologist or even what that meant. So we started addressing marriage counseling. Can you imagine, at your most whacked out point in time, you're going through marriage counseling? We didn't really have any problems up to that point. You know, no more than any couple. But boy, within a couple months, we had problems. [laughs]

CHERYL: Yeah.

CRAIG: That was the first part of my journey that was the tipping point, to really crumbling my life apart in front of my eyes right then and there. And then I did get some revenge, though, a little bit. Because a few years ago, it turned out that this neuropsychologist was retiring to do a band. I never meant to have a band. It was just a way to express. He asked if he could open for us. And I told him a certain place to go. His band showed up. Guess what? There's no concert there. [both laugh] He didn't show up for my appointment? I wasn't gonna let him play!

CHERYL: I love it.

CRAIG: He was just the biggest jerk cuz I saw him one time in the year and a half I was there, and he acted like he knew me by what this person wrote down based on their little test.

CHERYL: Mmhmm, mmhmm. I could talk till your ears bleed telling you the stories of my bad experiences with the neuropsychologists. But what I'd rather ask you about, though, is you said that you never meant to start a band, but you started one. Can you talk about that?

CRAIG: Like I said, my life crumbled very quickly after the bad care. I never played an instrument up to that time, but when I was sitting there alone, pondering, looking at the walls, I went out and bought a piano. Don't ask me why. I was writing. I was working with a lot of poems and some really dark stuff. So I started fiddling with it, and I was involved with this church. I used to go in there early cuz they had a really nice piano. People started listening. And next thing I knew, I was over in the Seattle area playing at a Christian concert that's called Big Splash and doing a couple songs. Very, very quickly we went from the Pastor Craig Band to [Insane From Pain](#). And there was nothing Christian about our music. [laughs]

CHERYL: I like that. Insane From Pain. I really like that name.

CRAIG: The headaches and the loud pitches, vision things that just used to drive me whacky. It was a good couple years before I really found any answers.

CHERYL: And did you get those answers from medical professionals or from interacting with other peers?

CRAIG: Well, my best help came from a speech-language pathologist. And it's because her husband had a brain injury, the mild one. So she kinda was able to understand it. And then of course combined with my Personal Injury attorney, who absolutely at that point, had the best medical advice in mind--which really bothered me in the long term that my lawyer had better knowledge than my doctors.

CHERYL: Yeah.

CRAIG: So she talked about you need to find some support. She talked about peer support. It really didn't sink in a whole bunch, but I started looking for a support group. There once was a support group here. The Brain Injury Association, which were now I guess the Alliance--our state, we have the Alliance. But they didn't really have anything here, cuz it wasn't important to them. So they never really held it together. And so I put an ad out in Craigslist. Took a little while before I got the first actual, rational person that had a brain injury. But once I met that first other survivor, that was enlightening. That's how we started our very first group is off of Craigslist ads. And it grew quickly to where we have groups all over the world now. We support several hundred groups around the world. See, what's unique about us is we don't wanna own any groups. We wanna support people having their own groups. Cuz the ownership hasn't worked. The Brain Injury Association hasn't ever been able to hold it together. So you need to create each group as a sustainable group that function on their own, they have their own leaders, their own decisions. Cuz every group is different, just like every injury is different. So yeah, we're actually on our 7th Edition manual how to start a support group.

CHERYL: Yes. You know what? I just passed the link along to somebody who wants to start up a brain injury support group in New Mexico through their Independent Living Resources Center. And he said, "What do I do? Where do I go?" And I sent him to your manual. I said, "Start with this, and if this doesn't work, you can call me back. But I'm not gonna be able to offer anything." That's great to hear you're on the 7th version of it.

CRAIG: We're on an international version. We just helped China start some groups. They have a lot of cultural and governmental issues to deal with as well as the TBIs.

CHERYL: Mmhmm.

CRAIG: And our groups in North Mexico. It's fascinating how culture plays a big role in recovery as well.

CHERYL: Oh, absolutely. And just in what the people around you think of what you're going through and how much information people can access.

How does a peer-run organization continue to be so effective?

CHERYL: So how is it that this organization keeps going so strong? I mean, you can tell I'm a very cynical person. How is it that your group is so effective year after year?

CRAIG: Well, we're poor, number one. So we do this with almost no money. So there's no target on our backs where these lawyers think that they can monetize us. And even then without the money, they've thought they could monetize us and make more money. So being that there's no money in it, we don't have anyone that really wants to get involved. Which is fine because we're not here to get rich. We're

here to support one another. So I think being an organization based on almost--well, it is--100% volunteers makes a difference. Nobody's here for the money. Nobody's here to make a living. A few people tried to become famous, and we're not here for that. I mean, if you become famous, great. But if that's your goal, you're in it for the wrong reason. You're in it #1 to provide support. And in the end what's powerful is you get as much out of it as you give, probably more. We have had sponsors. I do like to have sponsors cuz things cost money. Our blogtalk platforms, they're like \$249 a month for each platform now. You gotta have a little bit of money.

CHERYL: Mmhmm.

CRAIG: But we've made it. I work part-time in the schools. So I have a job. Everyone has a source of income. So nobody's trying to make this their source of income. And if somebody doesn't--and I don't begrudge them that--but I am gonna make sure that they stay on task. Cuz when it becomes about money, that's when it starts going downhill.

CHERYL: Yeah, I think so. Are there people who are playing significant roles in the group who don't have a brain injury?

CRAIG: No. We have advisers. But nobody is allowed to run a group, be on our Board of Directors, you have to have a brain injury. Well, I take that back. We have two seats on our Board of Directors for caregivers. And we're not talking paid caregivers, but direct family members, somebody supporting somebody with a brain injury. You can't just know somebody because we want their input when we make decisions.

CHERYL: Right, right.

CRAIG: But they don't get to hold an Executive office. They usually hold one of the committees or the departments. Actually, there's a Caregiver Information Department, both of our caregiver Board members.

Disability in general, not just brain injury, on Brain Injury Radio Network

CHERYL: On your radio shows, you talk about disability in general too, don't you? You don't talk about just about people with brain injury, and it's just us, and we're out on our own?

CRAIG: Yeah, no. You're absolutely right. I'm a firm believer that our rights are attached to other disabilities. If you look at other movements, especially like DD, developmental disabilities. And the only real criteria for that is you had your injury before you were 18. They get great services. They go for what they call waiver services. I'm seeing that happen all around the United States: survivors fighting for those waived services. What's interesting, they got waived services as they de-institutionalized. But within a decade of these waived services, now it's in community institutions. They hire people that typically are the bottom of the barrel. Not all of them, cuz there's some really great caregivers out there. But they get people that can't hold a job, that I wouldn't let watch my dog for a weekend, let alone a human being. These are the people, all the sudden, that are controlling people with disabilities. They are their keepers rather than their caregivers in a lotta cases. In our state--I don't know in every state--but in

our state they say that 4 out of 7 people with a developmental disability will be sexually assaulted in their own home in a 3-year period.

CHERYL: Oh my god.

CRAIG: Everyone I've worked with that I know has been sexually assaulted or raped. All of them have been stolen from. So they're exploited by the people that're supposed to be taking care of them. Because again, it's money based. They all started off with a good intention, but it became about money. And so these big companies are getting huge. Meanwhile, they're paying barely minimum wage to do a really important job.

CHERYL: Right, yes.

CRAIG: The money's there. I don't see any difference in most states, how they treat it. Connecticut's the best that I've seen. I got the chance to work with a guy named David Pitonyak. It's incredible what they've done there. They've actually put the services into the people's hands who are getting them. They get to make the choices. Imagine this: imagine you have these services. All the sudden the money got tight. And since you had these services, they've deemed you incompetent already in their little heads within the State. So here, you're this incompetent person. They assign you a guardian. They move you into a home, and they hook you up with three roommates you never met before in a home you didn't want and tell you your daily tasks of how your life's gonna be. And so people've gotten used to this. And for some of the older people who came out of the institutions, they're afraid to speak up because they're afraid to end up back in the institution. Cuz it is better being abused by minimum wage people than professionals.

CHERYL: Oh wow! [both laugh nervously]

CRAIG: Actually, my show tomorrow night is gonna be about one such case where an agency's currently trying to take this young man's rights away. They moved him into a diversion house, and they're just embellishing these things to have him put under community protection so they can get more money to serve him. And so his family's gonna come on tomorrow night and talk about it. The reason his family's coming, his sister and his mom both have brain injuries. And they're dealing with this system, trying to figure it out. I tell them, "You're not gonna figure it out. Even without a brain injury, you're not gonna figure it out."

CHERYL: Right, exactly. Yeah, no, it's not designed to ever be figured out. But if you have any type of cognitive impairment or anything that is distracting you from say quitting your full-time job and spending all day trying to figure this stuff out, yeah. You're not gonna be able to. That is scary.

CRAIG: And that's what we're fighting for are these waivers. Those waivers really turn bad for the people with developmental disabilities. And I don't see them in the long-run working any better for us. We have to be in charge of our care, not somebody else.

CHERYL: Mmhmm. Do you feel like people with brain injury or the brain injury community in general is part of the larger disability movement?

CRAIG: No. Brain injury community itself has struggles to get along with itself for the most part. [laughs]

CHERYL: Mm, good point.

CRAIG: There's some really good leaders out there, but they can't seem to play in the sandbox very long together without throwing sand over at each other's faces. Lots of egos. And I get it because a lot of them spent decades just trying to prove to themselves that they're worthy. And they've become isolated. And then with isolation, you become opinionated. But I think it's possible. I just think we got a lot of work ahead of us. Because being the Silent Epidemic--and we're silent because a lot of people have been making a lot of money over us for decades. They don't want it to work that way because then they wouldn't get the money. So we're fighting against people who have a lot to lose.

CHERYL: Mm. Yeah, I heard you on your show, one of the nights last week, talking about had to clean out the sandbox.

CRAIG: Right, we never get rid of anybody. When somebody gets to the point where they can't get along and they become destructive, they've gotta take a little break and maybe reflect. Everyone's welcome. I know that I've had times in my life that there'd be no sand in the sandbox. But things change! So let them reflect, let them think about it. Cuz usually people's attitudes are because they think they're not wanted. Everybody's always wanted, but you gotta understand other people's perspective. Cuz you don't have the right to tell somebody how they should be or they should feel.

CHERYL: Right.

CRAIG: Cuz everybody has a different journey.

CHERYL: So when something happens, and somebody is asked to take time away from the group or from the radio show and reflect, you let them know they're welcome to come back when they're ready to be more cooperative and to collaborate more, right?

CRAIG: Right. This particular person, he feels that he's not wanted.

CHERYL: Mm.

CRAIG: You can't make somebody feel wanted when you want them, and they don't feel wanted. And in all fairness to them, they've been isolated for decades. And so this was their first real experience playing with anybody. So you're gonna have mistakes.

CHERYL: Mm, right.

CRAIG: This is the only person that we had to go to this extent, and I'm hoping they come back cuz I value them.

CHERYL: You know, what a message that people really don't get very often. OK, so you made a mistake. So come on back. I hope you'll come back, rather than oh, that person is a jerk! The language that I hear when people describe people with brain injury: no empathy, self-centered, very egotistical, aggressive,

violent. I hear these words outside of our group, people looking in and using these words to describe us. I like the way you said it: "Well, yeah, he's been isolated, and he made a mistake." It's so compassionate, and here you are inside the brain injury community showing that we do have compassion.

CRAIG: You know what's cool, I'm seeing a change in some of the doctors. One in particular, a psychiatrist I've been working with, just their whole thought of it, they're now realizing the peer support, how powerful it can be. In the beginning, they were really standish back because you know, we could be dangerous. But she don't think that no more. She's like wow, this is huge. This is like a big part of it. Cuz she's seeing some really amazing things. Cuz we do need to be fixed at a certain point, when we first have our injury. But eventually, we're not broken anymore, and you're not gonna fix us. So stop trying to fix me. [laughs]

CHERYL: Right, right. [laughs] Now, would you say even a person who's still got impairments and still has trouble with things, that person's not broken, right? Is that what you're saying?

CRAIG: Well, at a certain point, they're not broken. They have to retrain themselves.

CHERYL: Mmhmm.

CRAIG: And some of these doctors, looking back, I'm sorry I ever even tried to let them retrain me. Cuz you try to do what they say, you take medicines. I'm not anti-medicine, but I think they over-prescribe medicine.

CHERYL: Yeah.

CRAIG: Probably 8 out of 10 people shouldn't be on them. Some people really do need them. But they just give them to everybody. And I see bad results on these medicines with people. Their whole life becomes numb, comfortably nothing, I guess.

CHERYL: Yeah, yeah. Our peers who are inside the psychiatric system--and I've often heard people refer to themselves as survivors of the psychiatric system--that's also a group of people who is over-medicated. And those medications are used to quiet people down. "Stop. I don't wanna deal with you. Take this medication. Be quiet."

CRAIG: Yeah! I had a doctor say that to me: "Go take your medicine and shut up."

CHERYL: Wow!

CRAIG: I had to be out of control because I wasn't on these medicines. And those medicines made me suicidal. And I never stopped being suicidal until I stopped taking those medicines.

CHERYL: Wow! Oh my goodness.

Disability, mental health, and identity after brain injury

CHERYL: Now I wanna ask you a question. I recently was accepted to give a poster presentation at the American Women in Psychology conference. OK. So I don't know how I got accepted, but one of the

things that I'm coming across reading these journal articles is you know people who have symptoms that go on and on and on, they're just over-identifying with brain injury. Do you have any thoughts on that?

CRAIG: I'll give you an example of somebody that I met shortly after my brain injury. I don't know how we became friends. I met this Russian gal, Olga. My family abandoned me. So she was there for me kinda just like a friend. About a few weeks into this, she went through the windshield of her car. Amazingly enough, she walked away, healed up pretty good. You know, her neck was sore, and shrugged it off. But about four months into this, she started really having these behavioral things, these cognitive things, these emotional things. So being Russian, her family brought her into this Orthodox church. Well, they locked her in a room and startled her with bright lights and loud noises and tried to exorcise her, do an exorcism on her for three days.

CHERYL: Oh wow.

CRAIG: And that just totally whacked her out for a long time. She was in so much denial that anything was wrong, cuz you know, you wanna be OK.

CHERYL: Yeah.

CRAIG: I remember my first year. You just wanna be OK. You don't want nothing wrong with you. So she's in denial, making things worse to the point of suicidal. I think a lot of us have been there. And so they put her on all these medicines. And these medicines, of course, whacked her out even more. So finally after some time, her parents kicked her out, she's now in a mental health place. She never has really got it together. The medicines have her so melancholy that she's neither hot nor cold. And she's just now--this is what 5, 7 years into it, and she's just now finally dealing with that to going through the windshield.

CHERYL: Wow!

CRAIG: And that was the same thing. You know, it has to be mental health. We don't know what's going on in people's lives. When they can't see it to figure it out, they always wanna bring it back to mental health.

CHERYL: Yeah.

CRAIG: And that's not always right.

CHERYL: And they can interact, and they can both be happening at the same time.

CRAIG: Oh yeah. And you deal with these doctors like that, you're gonna have mental health issues from these doctors. [laugh]

CHERYL: Oh! What an excellent point! [laughs] I hadn't thought about it that way, but when you say that, that's definitely my experience. I mean, I was really suffering from panic attacks for a while. And guess when I was having panic attacks? In the car, on the way to the doctor's office. And I would just go

overboard with it. Part of the going overboard was the symptoms of the brain injury. You're more prone to go overboard. But yeah, you make a good point about that.

CRAIG: When I changed insurance--and this is probably the last time I went to see a doctor for my brain injury. I went in to this gal. I can't remember what was going on. She wanted to prescribe something, but I had in my records put that I have a SEVERE reaction to psychotropics. And so she was looking. "What's your allergic reaction to psychotropics?" I go, "Death." [laughs] So I wanted to make sure somehow they didn't start pumping me up with these things again cuz I really had these thoughts of death. So actually, it's on my records that my allergic reaction is death. [both laugh]

CHERYL: That is the ultimate allergic reaction, yes!

CRAIG: Yeah!

CHERYL: Good for you.

CRAIG: That was the best way I could describe it. But I walked in there, and she tells me, "Oh yeah, I know all about brain injury." I go, "Really? What do you know?" She didn't tell me anything, of course. But she knew all about it. Just because she maybe had an extra day of training, she thinks she knew about it. And I'm not saying that she doesn't know the medical part of it.

CHERYL: Mmhmm.

Back to the knowledge peers have

CRAIG: But the psychological part of what goes through our heads is what really impacts us the most.

CHERYL: There's so much going on that can't be learned from a book. And as soon as you say, "Oh, I know a ton about that!" you're actually putting up a wall. Whatever knowledge you already had, you feel like you're full and you don't need any more. And so then when you meet a new patient, you're not actually gonna learn anything from them. We have something to give. We're not just receivers of therapy. We can teach our therapists and our doctors about our experiences. But I have certainly seen people who say, "No, I'm an expert. I'm an expert." But then, they don't accept anything that you're going through. "Nah, that's not real!"

CRAIG: Right.

CHERYL: I thought you were an expert!

CRAIG: And the cool thing is that you're now seeing survivors become these professionals now, Occupational Therapists, Speech-language Pathologists. And I hope this doctor goes back into neuropsychology because what a powerful advocate in the neuropsychology world that would be for us to maybe rethink how they treat us. So, you're seeing it happen. You're seeing them become lawyers. One of our Board members, Lisa Rivero, just passed her Bar exam. So it's exciting to see that we're becoming these professionals. This is also proving we're not stupid like they think we are.

CHERYL: That's right!

CRAIG: For some reason they think brain injury, they think that we become stupid. I think we become smarter because in a lot of ways to compensate, to wanna live and succeed with what we have going on is amazing in itself.

CHERYL: Mm, absolutely. And a lot of people in the larger disability community also say you know, we really are worthwhile and we're valuable because we're human to begin with. But when you have a disability, some kind of impairment, you really have to be adaptable and creative in this world and to make things happen and to advocate for yourself. So in fact, there is quite a lot of valuable experiences and information that we just gather just by being ourselves and being out there.

CRAIG: Oh, absolutely. And all of our great inventions came from people with disabilities. People forget that. I did a film, a short little animation a number of years back called "Are You In?" From George Washington, Abraham Lincoln, all of our great leaders, Roosevelt, they became great leaders after their disability. And they're normally cognitive, with the exception of Roosevelt. Well, he became blind, and he had polio. So he had a physical thing. But can you imagine what he had to go through? Cuz they used to prop him up like a puppet because they didn't want the world to see him weak. And what a great leader he was, cuz our economy was far worse then, and he got us out of it with nothing.

CHERYL: And at a time where it was so humiliating for someone to see that you had a disability. And thank goodness we're past that. Well. Some of us are past that.

CRAIG: No, we're not.

CHERYL: We're not, I know. As I said it, I thought--

CRAIG: People wouldn't vote for the President if they thought he had a disability. And that's what's scary because even with a person with disability, we're taught to judge instantly. We judge. And I try not to, but I do it. We all do it because we got these pre-notions of what it is.

CHERYL: Yeah.

CRAIG: And usually when we really get to know it, it's not what we thought.

CHERYL: Yes! Yes, we're segregated from an early age. We absolutely are taught to be ableist and to look down on someone with disabilities the same way we're taught to be racist in this country. One of the cool things about all these shows, the programs is that you're having real conversations. And anybody can listen in and come and have a conversation in the chat. So that's how you get to know that we're real people and that we have something to offer, and we're not just oh, that person's slow and is never gonna make any progress! Well, 12 months passed. You're not gonna get any better!

CRAIG: Were you told that? I was told at about 18 months, this is where I'm gonna be. And I was a nut! So it's like oh man, talk about giving up hope! This is how I'm gonna be? And my life's just falling apart. It was getting worse. I don't wanna do what I taught myself to do for 10 years as a living. This is where I'm gonna be. And I believed it for a while.

CHERYL: Yeah. You know, I wasn't told anything quite so concrete.

Cheryl's training as a speech-language pathologist pre-injury and experiences being in speech therapy

CHERYL: But I am trained to be a speech-language pathologist. I never went into the field because I became a patient in speech therapy after my brain injury. I decided that I would never go into the field. But in my training, I was certainly told first 6 months, first 12 months, first whatever, and then it's over.

CRAIG: Right.

CHERYL: That's your main window of opportunity to recover, and after that good luck to ya! I was taught these things, and I was trained that I might have to say these things to people. Then, I had my brain injury, and I started going to support groups. There was this man at one group who'd had a really significant traumatic brain injury 20 years ago. One day, he came in and he said, "Hey! I went to a restaurant for the first time in 20 years, and it wasn't too loud." He finally recovered the ability to filter out all the noise and not be over-stimulated 20 years later. Everyone in the group was like, "Yeah! What do they know? Why do they tell you you only get 12 months and then you're done?"

CRAIG: My speech-language pathologist, she didn't work on speech with me. She worked on my impulsivity, which had nothing to do with my speech. Even though they wrote that off, the treatment was definitely alternative. But I was able to control what came out of my mouth. People think I have a big mouth now and say what I want. Well, you shoulda seen me with no filters. Boy! [laughs]

CHERYL: Right, right! Well, that's the thing is that I kept trying to get my speech therapist to help me on that kind of thing, and she wouldn't. She wanted to just do worksheets and learn how to fill out my day planner, which is really important. But primarily we did worksheets to try to improve my attention skills. And I would come in sobbing and crying and screaming about all these terrible things I'd said to people and was screaming at people, pushing a guy on the bus. But she wouldn't work on any of those things with me. It was so frustrating. And now, I give presentations in the speech therapy departments at two universities to the graduate students. I explain to them let me tell you why it's important to listen to what your patient wants to work on. And it's not just words. It's not just speech. There's all this social stuff and communication and yeah. That's--woo! Impulsivity and blurting has definitely been a challenge for me.

Craig's healing and the overmedication of our children

CRAIG: Yeah. And it still is for me. I have a pretty passive personality, but when I get angry, I have a tendency to be impulsive. I've learned to walk away for a couple of days and really ponder it before I say it. You know, I try to. I'm not 100% at that, but I'm working toward that!

CHERYL: Yeah, yeah!

CRAIG: But it was Interactive Metronome, of all things--I don't know if you ever heard of that. It started timing my body with my brain. And then I actually became a clinician on that, and I'm using that with

kids that are quote-unquote ADHD. And really, they just have a lotta energy in a lotta cases and don't know what to do with it.

CHERYL: Yeah.

CRAIG: And so you teach them a mechanism to time everything together. It's not the answer all, but once you start getting a handle on it, then you come up with your own answers as life goes on.

CHERYL: Uh-huh. And isn't that great to learn how to tune in and realize that you do have some of your own answers that you can find for yourself and you can follow these things? I mean, we all have agency. We all have some level of control over ourselves. And it's so great when we're told that, and we have the opportunity to express it and use it. Way to go!

CRAIG: Right. And that Ritalin, man. That's just destroying these kids.

CHERYL: Oh yeah.

CRAIG: That's our main goal is to get these kids off of the Ritalin. Cuz that energy's a good thing, believe it or not!

CHERYL: Yeah.

CRAIG: May not seem like it at the time. But yeah, if you take away their energy, you take away their ambitions. I can't imagine not having the ambition to wanna do anything, especially as a kid. That's when the world's so big and wonderful. And man, you destroy it for them as a kid? I can't imagine what it's gonna be like for them when they get older. Well, I can, I guess. [laughs]

CHERYL: Right, right. You know, you're also pumping these young, still very much developing brains full of chemicals. What is that doing to the development of the brain? What are you setting that person up for later in life when you've gotten them addicted as a child?

CRAIG: Right. And what's scary, they've put more effort into new studies than they do to working with people. Everybody's got a study. There's so many studies coming out right now. Everybody's got a cure. There is no cure, folks!

CHERYL: Right.

Washington State TBI Fund, Ed Roberts, and People First

CRAIG: In our state, we fought for what's called the TBI Fund. There's roughly \$1.9 million a year. And about \$80,000 goes toward peer support groups. So we're actually with that \$80,000 able to offer grants to support groups for refreshments and maybe some events and stuff. Works out to \$3 a person is what it works out to.

CHERYL: Oh.

CRAIG: The rest of the money that goes to the council, a conference. We used to have a really good conference, but we've lost our coordinator. We're on our 7th coordinator in 6 years, the DSHS representative. So evidently that job's the kiss of death for these guys.

CHERYL: Yeah!

CRAIG: I'm not quite sure why. It's been just fascinating. And people ask, "Hey, would you help us advocate for more money?" I go, "Why? So you can waste more?"

CHERYL: Yeah.

CRAIG: I don't know. The money goes toward professionals telling us what to do, it seems, more than anything else. We're kind of a threat. And Social Work in itself is how do you take care of somebody rather than how you teach them to take care of themselves. I go back to the Independent Living Movement. There's actually a man named Ed Roberts that pulled me outta my suicidal state. I don't know if you know who he is. His journey was incredible. He was a young man with polio, and he was discounted. He came, and he was like Darth Vader in his chair, talking to me. He spent a week with me when I was in the hospital, telling me to get off my pity pot. And I never really understood what he was talking about until here more recently. The Independent Living Movement's where we belong, not in the Socialist Social Model, is what I call it. I think Social Work could be good, but we're teaching people how they need to fit within the system rather than how they need to figure out how to fit within their own life.

CHERYL: So did you say you spent time with Ed, or Ed visited you when you were in the hospital?

CRAIG: Yeah, he visited me in the hospital.

CHERYL: Wow!

CRAIG: He followed me. Before my injury--and I still work with this organization called People First. We passed, in 2004, the nation's first Respectful Language Law. So he was really following us. That was wonderful. Of course, back then I was--not that I didn't have the best of intentions--I really didn't understand what that meant until I started seeing the prejudism in my own life. Yeah, we can change the words any way we want, but until we change people's minds, the next word we come up with is gonna become that new word.

CHERYL: That's right!

CRAIG: We just took mental retardation out of the people's records. OK, cuz before it was mental retardation, it was feeble-minded, it was idiot. So there's been a word for that all the way up through history. And that word has become a stigma.

CHERYL: Mmhmm.

CRAIG: Then, if you really step back, we label ourselves!

CHERYL: Mmhmm.

CRAIG: So those labels in itself are harmful. It's the labels that hurt us, not so much the word. It's what we associate with the labels. And to get services, guess what you need?

CHERYL: You need that label! Mmhmm.

CRAIG: You need a label! Yeah. And so we're fighting to get a label from day one almost.

CHERYL: That's right. And things like applying for Disability. You mentioned this before where you're spending years trying to prove to yourself that you are valuable and worthwhile and competent, however long it is that you're fighting with yourself to prove to yourself that you are worthy. And then you go to try to fill out something like a Disability application where you have to prove how useless you are! [laughs] It's so confusing!

CRAIG: All that money that goes to those lawyers. There's too much money being made on that. If you figure out how to make it so that people get Disability, and then take it away. I think they should get it, and then penalize if they're frauding the system. They're so worried about someone frauding the system. That money can mean the difference between keeping your home and becoming homeless sometimes. Actually, so many people lose everything, and they just needed a little bit. That's all they needed. I just can't imagine. And it's just so much stress on these people's lives. We make up the prison population, the homeless. We make up the majority of that.

CHERYL: That's right.

CRAIG: And actually, it comes down to them not being able to hold it together for that extra month or that extra couple months. It's our system that's there to help us that hurts us sometimes.

CHERYL: Mmhmm. The more services you take away and the less you fund services, the fewer of us can access services. And when you have a cognitive impairment, and you don't have a lot of energy, and you can't figure out where to get services or how to fill out the applications, you're really dropped.

The power of a community-based, community-run support network

CRAIG: A powerful thing about our network, since it is all community based, and it's all ran by each community, and anybody can leave anytime they want, say all the money in the world goes away. They're still gonna be there. They're not going anywhere. They're dedicated to their community. They're supporting each other. These professionals, what happens when the Brain Injury Association or Alliance loses its money? Services disappear every time. It's not consistent. Some of them are good, but most of them cause more damage than good, I think. They divide our community cuz they're so trying to fight for this money. It's just interesting to watch. They get so much money.

CHERYL: Is there anything else that you wanna big up about the stuff that y'all do?

Brain Injury Camp, Penny Condoll, and the Moving On curriculum

CRAIG: I think that the camps that you're seeing around the nation. We do the Northwest Brain Injury Camp. It's July 21st to 28th this year. It's absolutely free. You just gotta get here. It's powerful. It gets people in a community that's all their own. If you're on the East Coast, and you're an enthusiast, Warren Jackson, he does a camp with guns and bows and arrows. I would just refuse to give a whole bunch of survivors guns at my camp. [both laugh] I don't think I could handle it. It's a wonderful thing, but his camp is just beautiful too. They're popping up all over the place. You know, you need to practice. What a great way to practice your social skills than with a group of survivors in your own community for a week.

CHERYL: Yeah, yeah! And away from all the hubbub and the fast pace of being in the city.

CRAIG: We have no cell service. So people, it takes them usually a day of technological withdrawals to really get there. Cuz we're all so connected nowadays to technology. Yeah, that's a big part of our camp is getting rid of that technology too. It's amazing when you have nothing on your plate, how rehabilitative that is. You leave refreshed. Most people have a great, really positive experience. The last thing I wanna share for your listeners. The original thing was with Dr. Wayne Gordon. He's just really a wonderful man out of Mt. Sinai. About 5 years ago, myself and Penny Condoll, we got permission to get his curriculum. It's called "Moving On." You can get that on any of our websites, the workbook and all that. But since then, we've developed it into "Moving In." I'll kinda explain that. We're doing this in the community colleges at different programs. We do it at a SEER program, which stands for Supportive Education Employment Rehabilitation (ed. note: Supported Education and Employment Enhancing Rehabilitation), meaning we're helping people either move on to get degrees or to jobs. Cuz typically McDonald's isn't our dream job.

CHERYL: Yeah, yeah.

CRAIG: The whole focus is to retrain people's skills. Moving In is about accepting and actually appreciating who you are with your injury. Cuz now it's part of who we are, not part of why we're not who we are.

CHERYL: Oh, that is neat!

CRAIG: We're teaching people to succeed. We telecast that now. I don't know about your community college, but it's absolutely free for survivors. And we've actually turned it into almost a rehabilitation center to where we have behavioral classes. We do computer training. We do Brain Train, which is a self-paced cognitive rehabilitation. Cuz we have no services here.

CHERYL: Right.

CRAIG: So we've created services within the community colleges, and people are getting degrees.

CHERYL: The Moving In, is that on the 4Peer11 site?

CRAIG: It is not. The Moving On is, the 1st one. That is a Personal Futures Plan. Cuz you gotta start with a goal. You gotta have a plan. I have the workbook on there. We have one for the students and one for

the teacher. If you go to Tools on TBIWA.org, it'll be up. You'll see Moving On. It'll be a pdf. It is usually under Tools. It'll be under Support. And come up with a plan. You need a plan to get out of anything. If you're going somewhere, like if I'm going to New York, I'm gonna get a map. And that's what the first one is, is actually having a visual map of what you're gonna do, what you want, your supports. You spell it all out. You have a plan. And then of course, your plan changes. So this plan is constantly developing. So we spend two years with people, the first year doing that. We start off with a curriculum called Reaching My Own Greatness.

CHERYL: Wow.

CRAIG: It's identifying what you're good at, what you wanna do, what you like to do, learning what your gifts are. And then we do Moving On. And that's the second quarter. That's developing this plan. And then we do Mixed Voices, becoming part of your community. So that's the first year. So it takes time. It takes a lotta time to relearn all this stuff. After two years, I'd say 80% of the people, they don't even come to support groups anymore. I kinda gotta stop doing that, or I'm gonna lose my members. No! [both laugh] They start developing a life again that they like. They can go to sleep at night and feel happy that wow, I'm glad I'm alive. The alternative is "God, I hate my life. It sucks." That's not a good alternative.

CHERYL: No, it's not. What you said, people are sort of building the life that they like. That's so valuable and fabulous! Oh my goodness. I really only knew the tip of the iceberg of what's going on. This is so wonderful.

CRAIG: Then the students. You guys, survivors out there? Reach out to your high schools because they are the ones that're getting the short end of the stick.

CHERYL: Yes.

CRAIG: We're ruining these young minds and dis-enabling them. Start a Student First group and start empowering these kids to reach out to their dreams. Cuz they're incredible, some of these kids. But you'd never know it because they're tucked away in the system.

CHERYL: Right, and like you said, dis-enabled. Mmhmm.

Survivor ID card, entrepreneurship, and support

CRAIG: One other thing we do that's been valuable for some people. And it's a Survivor Card. It is a PVC card. It has the PDF 147 on one side, which is what the government can scan. Then it has on the front side, a QR barcode, which can lead to a website. It's offered free on that with the card purchase. And it can have your medical information, your emergency contact. Because of Otto Zehm and Tommy Manning, what happened to them with the police, that's what motivated me so people have this card. I don't know if it would've made a difference in either of them. So that way you have this emergency card, and it's not just this piece of paper. It's a credit card type card with real information taking you to a real place.

CHERYL: I've seen the pictures of it that you have. What you can get in other places is just that little card: "I'm a brain injury survivor!" And you write a couple things on there. And then it's got 700 symptoms listed on the other side.

CRAIG: Right. And Tommy had one of them, and he got beat up with that card because he just went for it, and it was all crumbled up. So we make this. It looks like an ID. And our goal is to attach it to the Health Department so that Health Department can be an advocate for us. Cuz they really have done the most. Public Health through NHO has actually changed policy to make us part of the system rather than be the system for us. You gotta start somewhere, and they're the ones that are willing.

CHERYL: Yeah.

CRAIG: SurvivorID.org.

CHERYL: Oh, great. Any other words of wisdom I can record you saying?

CRAIG: Oh, I don't know if they're wise. All I know is you gotta get people together cuz I believe you get a group of survivors together, really brainstorming, you're gonna have a lot of answers coming out of that group.

CHERYL: Absolutely, yep.

CRAIG: You do some unique things. The artistic side of our brain is something that I'm seeing a lot of people benefit from. Whatever it is that gets their passion, whether it's drawing, clay, writing. I mean that's a part of our brain, an expressive part, that I think is very healing. Because until you express and let out what's inside, you can't really let go.

CHERYL: Oh yes, very well said. Mmhmm.

CRAIG: So that's something I want people to learn more about. You don't need to have as professional quality of films as you do. Even if you just shoot these short little things. I mean, you'll get better, but you gotta let it out. That's just a huge way to do it. I wish somebody up here would do that with films. I just think that's powerful. How do people find your films? I think people always ask me. I keep forgetting.

CHERYL: So, my first two films, "Cooking with Brain Injury" and "Friending with Brain Injury!" I've got trailers up on YouTube and Vimeo. Those are not films that people can just watch for free. You kinda have to buy the DVD from me. But you can watch the trailers. My website is www.StoryMinders.com. You can find all the information about my different film projects there. I keep a blog at www.WhoAmIToStopIt.com. That's the place where I always write about the radio shows that are coming up. I write about other disability-related documentaries. And I have lots of different artists with different kinds of disabilities who share their artwork there, mostly people with brain injuries. So there's a lot more activity going on on WhoAmIToStopIt.com. Those are the two main places to find me online.

CRAIG: You know, you can stream it and have them pay for streams.

CHERYL: Every time I've looked into how to do the streaming or digital downloads, I get so overwhelmed by the information I haven't moved forward with it. But I really should do that because nobody buys DVDs anymore.

CRAIG: Cuz of all the web stuff, we started what's called Green Geeks and then Able Green Geeks. We offer hosting for companies, and so we actually do that for people.

CHERYL: Oh! You do? Oh! Where do I look that up?

CRAIG: I'll send you a link on it. These are people with disabilities. We're a hosting company. We got this year's Best Hosting from the category. Cuz we do self-service hosting. We set people up, and they run their own hosting. And we got an award for best hosting.

CHERYL: Oh! Oh my goodness.

CRAIG: And we're all green. We use windmills along the Columbia River. That's how we get our power. It's all windmill power.

CHERYL: Well, yeah. So very soon people will be able to download my movies! Thank you! That's super exciting. I'm looking forward to that.

CRAIG: That's what we're gonna do with "The Hidden Epidemic," the movie Bill Brown made. It's gonna be streamed. It's just a way. Nobody buys DVDs.

CHERYL: Yes, streaming. That is what I really should be doing. Good point.

CRAIG: Oh, no problem.

CHERYL: Look at that: peers helping peers.

CRAIG: Yeah! Yeah, that's our thing now is creating employment. And entrepreneurialship is where I see survivors making it.

CHERYL: Yes.

CRAIG: Cuz I know I can't do the typical. I'm self-employed. Even though I do contract with the schools, it's self-employed. I couldn't do it any other way. I think I'd have a real hard time.

CHERYL: Absolutely.

CRAIG: And I definitely can't live off Social Security because then me and the kids, we'd be living in my car.

CHERYL: Oh yes. I can't thank you enough, Craig. It's so nice to talk to you. I have really enjoyed listening to the episodes on the [Brain Injury Radio Network](#). And I've called in and talked to the hosts. I've been on shows. I was on your show one time. I really appreciate how inclusive the radio network is and how anybody can really just call in and participate. It's so wonderful. And all the hosts are so dynamic. I am

gonna really encourage people to get involved with the peer line and with the radio network and all these other things.

CRAIG: Thank you for the interview!

CHERYL: Thank you very much, Craig.

And lastly, I forgot to mention one more thing at the beginning. Right after recording this interview, Craig offered me a spot on the Brain Injury Radio Network.

Please listen in to my brand new show called "The Art of Brain Injury." It's a call-in show, instead of interviews like this one.

The 1st Tuesday of every month

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www.blogtalkradio.com/braininjuryradio and search for "The Art of Brain Injury"

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