Interview #3 Carol McDaid - Reflections on the historic 2001 Recovery Summit in St. Paul, Minnesota, and the start of the New Recovery Advocacy Movement



Forward – While I conducted this interview with Carol McDaid over the phone in mid May 2021, recently I also had the opportunity to visit with Carol and her husband John Shinholser founders of the McShin Foundation a few weeks earlier in their home. I visited as spring was breaking and the pandemic was lifting. They put me to work in their kitchen as we made dinner together. Later, we sat by a fire that John fed with old pallets (and what looked like old lawn furniture) and talked about the history of the recovery movement. We discussed what we could do to move it forward. It was an important visit for me and time with them helped put some bounce back into my step. Few people have poured more of their lives into the purpose of sharing recovery than this couple. It is clearly a labor of love. It was an honor to spend time with them. I hope that you enjoy reading this interview half as much as I enjoyed gathering it.

1. Who are you and what brought you to St Paul at that time?

My name is Carol McDaid, I am a person in long term recovery. My day (and sometimes night) job is being the Principal at Capitol Decisions, Inc. Capitol Decisions does policy work with special expertise in addiction and mental health policy. Helping to craft and pass laws to support better care for our people has been my life work. One of highlights of my time serving in this arena was an effort that led to a federal law to help people with addictions access care. This was when I was strategist and advisor to the Parity NOW Coalition, which was influential in passage of the 2008 "Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act (MHPAEA)." This landmark legislation requires insurers to treat addiction, mental, and physical health problems equally. The Parity NOW Coalition became a model for also successfully advocating for inclusion of addiction and mental health benefits in health-care reform legislation. Those legislative actions tie into the topic of this interview. That historic 2001 Recovery Summit helped to develop and organize the recovery constituency we needed in place to get this historic law passed.

As far as the 2001 St Paul Recovery Summit, it took some effort for me to get into that room. At the time, I was associated with treatment providers because of my work with Capital Decisions. The organizers wanted to keep a focus on recovery, so I had to use my lobbying skills to get in there. I cared about recovery and I wanted to be in the room. I think many of us felt that way because it was the first time the resources were there to accomplish the task. We all wanted to establish a national recovery advocacy organization and it had enough support at the time through a \$250,000 grant from the Robert Wood Johnson Foundation to be successful. There had been prior efforts to get it off the ground, but this felt different. I suspect that one of the reasons I was included was that I had made a decision a few years earlier in my work as a lobbyist working on parity to be open about my own recovery status. It is important for people who were not around back then to understand that this was not something people in recovery did back then.

2. Is there a particular moment or memory that stands out to you from that summit?

There are two moments that have stayed with me since that summit twenty years ago. The first was watching the interaction between Senator Paul Wellstone and Representative Jim Ramstad. It was really clear that they cared deeply about our issues and that there was common ground that both of them felt strongly enough about to rise above partisan dynamics. It took a lot of political courage, and we need to honor what they did for all of us. They are both gone now, but

their leadership and the way that they worked so hard for us made a lasting impression on me. It is important for people to understand that throughout our history, we have only been able to move things forward when our needs resonate on both sides of the aisle. Addiction does not know party lines and impacts all of our families. These two men found ways to work together on our issues that has left us an important and lasting legacy. That they did so is something that needs to be remembered and honored. It is also instructive for any future effort; we only succeed in our efforts when we have such bipartisan unity.

The second memory was at the very end of the event. We had these little torch-like things that they gave us all that emitted sparkles and lit up. As the event ended, we gathered as one in a circle and held these little torch sparkly things in the air. Together, we held a moment of silence for all we had lost and for the hope that we could come together and form something larger than all our individual efforts by working together. I stood there in silence and felt a sense of hope. I still have my sparkly torch. This work can have rough days, and on particularly hard ones I pull it out and feel that sense of unity in our movement and the hope I first experienced on that day and in that moment.

3. What did you see as the motivating factors that brought you all together for that historic summit twenty years ago?

It has to be acknowledged that a huge factor in us coming together was that \$250,000 dollar investment in us by the Robert Wood Johnson Foundation. It felt like a fortune at the time. There was almost no money around back then at all for things focused on recovery. Other than the SAMHSA Recovery Community Services Program there was virtually nothing for us. I think a lot of us knew this was probably are best opportunity to get a national recovery advocacy effort off the ground. As I mentioned there had been prior attempts, probably the most well-known of those efforts was when Senator Harold Hughes set up the <u>Society of Americans in Recovery (SOAR)</u> a decade earlier. What is also true is that there was a growing desire in the recovery community to start living recovery out loud. At that time, it was controversial and risky to even acknowledge your recovery status, the stigma against addiction and recovery was that strong.

Another factor is that people in recovery were not in the hearts and minds of the treatment providers in that era. A lot of the private sector care across the county at that time was private pay only. If you didn't have money, you did not get help, much of the services that were available across the county was in this acute care model and didn't really even connect with the recovery community. Much of the nationally treatment system was aligned around the acute care model because that is where the money was. It was not an inclusive model. We wanted to change that dynamic and focus resources on long term recovery supports. We are still working on that goal, but that is another story.

4. How have we done in accomplishing those early goals?

We have accomplished quite a lot!

The summit itself was organized through the <u>Johnson Institutes Alliance Project</u>, which led to the establishment of <u>Faces</u> <u>& Voices of Recovery</u>, our own national organization focused on advocacy led by and for people in recovery. As a policy person, of course I would want people to know how this effort laid the foundation for the passage of MHPAEA and the inclusion of addiction services as essential benefits in the Affordable Care Act. We made history. These laws have laid the foundation we can build on moving forward, and it was made possible in no small way because we set in motion a recovery advocacy movement during that historic 2001 Recovery Summit in St Paul. Obviously, much more work on parity, full implementation remains to be accomplished.

One of those critical moments came in 2007, right after a national recovery month event. Our bill was stuck and we needed to show leadership we were a constituency of consequence. Because we all worked together, we flooded the Speaker Pelosi's offices with over 10,000 calls asking for movement on our Bill. We shut all the lines down, which created the momentum we needed. The speaker was behind us, but we needed to show we had the support. As President Truman once said, "I want to help you, but you have to make me do it" and we did! By the end of the day, Wendell Primus called and asked us to stand down and that the message was heard. It worked. It happened because we were able to come together through the framework created out of the vision, we had at that summit in 2001. We now have mandated benefits as a result. There is a long way to go to ensure everyone who needs help gets it. That work continues but it is only possible because we built the foundation to carry the effort forward.

We also helped give voice to people in recovery and helped people communicate about recovery in ways that reduce stigma and normalize recovery. For people who were not around then – understand that at that time, the very act of

saying openly that you were a person in recovery from an addiction was a revolutionary act. We normalized it. We have a long way to go, but the work that was done was significant.

5. What do you see our greatest successes to date are?

I would go back to that last point – people are willing to be open about recovery. Up until then, it simply was not done. Nobody talked about that thing in the middle of so many living rooms across the country. Addiction is common in many of our families across America. When it was talked about it was whispered. When members of Congress or Congressional Staff became aware I was in recovery, they would ask me to stay after a meeting and whisper that they had that thing in their family too, and then they would ask for help. We made recovery audible. We didn't need to whisper anymore. We became a constituency of consequence in DC, something that is so hard to do but is so easy to lose. That one act of being open has normalized recovery and helped people talk about addiction and recovery in ways that have helped hundreds of thousands of people get help. Thousands of lives have been saved. We never need to whisper, ever again. Can there be a bigger success than that?

6. What did we miss if anything looking back at those goals?

Looking back, I think we took unity for granted. History is clear. We have never gotten anywhere without unity of purpose. It is my sense that some of that unity has been lost along the way. We should have focused more on being unified and working out any issues we have as a movement behind closed doors. It is certainly not too late to focus efforts on unity and I think it is vital that we do so. When we are not unified, we get divided up and we all lose. Our pathway forward must be to figure out how to walk together in ways that meet our collective needs. When we fail to do that, we are not taken seriously and all the resources that could save lives and build recovery community flow elsewhere.

7. What are you most concerned about in respect to the future?

That lack of unity I just spoke about is a huge concern. We need to get our focus back. We are that house that cannot stand divided. Elements of this have always been present. We organized the summit in ways that were inclusive of MAT on purpose. We focused on multiple pathways of recovery as our foundation. It was important at that time to recognize and value recovery pathways that were not well understood or widely accepted – like MAT which at the time meant methadone. History needs to show that the 2001 recovery summit was organized to be inclusive of MAT. We have done this; MAT is certainly now seen as a viable and worthy pathway of recovery. In some ways, the pendulum has shifted. I see a lot of open bashing of 12 step recovery and persons who choose abstinence-based pathways. It is destructive to our common purpose and must stop. We focused on multiple pathways to honor all of them. It was then and remains now the right thing to do. Unless we unify around that, we all lose.

People must stop attacking each other publicly, it does immeasurable damage to all of us. We need to build bridges, not burn them! We fight each other while someone else eats our lunch and the resources flow away from us. It may even be true that the seeds of such discontent are sewn by groups who would directly benefit from our disunity. It is a bit ironic that we worked so hard to get money for recovery and very little of it has gotten to the ground. This is in part because of our infighting. The money has largely flowed to other groups because of the open division in the recovery ranks. We must recognize this if we are to carry this movement on to the next generation. I hope this is broadly recognized sooner rather than later.

8. What would you say to future generations of recovery advocates about what we did and what to be cautious of / your wishes for them moving forward?

We need to plan our work and work our plan, together. This means more than chasing the next minuscule grant or stepping on each other for a sliver of pie or personal notoriety. I would ask the next generation to look at what we have done and capitalize on our successes and learn from our mistakes. It is true that because of some of our errors we have lost unity and direction, but it is all fixable! It is not too late. We don't have to fall into the ash bin of history that so many before us have ended up in when ego and greed become our focus. This will not be our legacy if we all work together!

We have to keep our eye on our common purpose, getting more people access to services that support and sustain recovery. Accomplishing that is not just good for us and our family and friends, but it is also good for America. People in recovery are a huge force for good across the nation. When we come together, we help carry the vision forward of access to what individuals and families need to obtain and sustain recovery. There is no other condition where we see such a

turnaround. Addiction is a massive drain on our country's resources and communities, yet recovery leads to health, productivity and civic engagement. I think many of us want to see this effort picked up and carried forward. A lot of lives are in the balance, and I am hopeful it will happen! It must happen. If you are reading this, we need you. I hope you join us. We can achieve great things together.

We can continue to make history! We must, lives hang in the balance!

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