

# Trauma Informed Politics: An Inconvenient Truth About Disability and Abuse

by Thomas F. Coleman, J.D.

Guardianship procedures for adults with intellectual and developmental disabilities have been operating on “auto pilot” in most states for many years, perhaps decades.

Participants in these guardianship systems – judges, attorneys, investigators, and conservators – all have been playing their designated roles as though they are actors in a movie. They have been reading from assigned scripts without questioning whether the language is appropriate or the plot should be changed.

In most cases, the “guardianship movie” has no director. It plays over and over again without any critical reviews.

This scenario is beginning to change. Some members of the audience are asking questions and leveling criticisms. There is a growing chorus of voices calling for reform. In some states, task forces have been formed to analyze the guardianship system.

Organizations advocating for disability rights see guardianship as a form of governmental overreach and are starting to promote alternatives such as “[supported decision making](#).” Others are promoting non-judicial forms of substituted decision making – especially for medical decisions – such as simplified power-of-attorney forms intended for use by people with intellectual disabilities.

[Guardianship reform](#) and alternatives to guardianship are now entering the political arena. For example, a bill to authorize a simplified medical power of attorney was introduced in Nevada in February 2015..

A recently drafted “Supported Health Care Decision Making Act” is being made ready for its debut on the national political stage. The Arc of California is considering whether to sponsor such a bill in the California Legislature. It is just a matter of time before bills for guardianship reform and medical alternatives to guardianship are introduced in state legislatures everywhere.

A “model bill” for medical supported decision making agreements came to the attention of Spectrum Institute a few months ago. We were very concerned that it did not include protections against possible abuse, exploitation, and undue influence. Also, when someone sent us a

copy of the Nevada bill ([AB 128](#)) we noticed that it also lacked sufficient protections to reduce the risks that may cause harm to someone who is especially vulnerable.

Disability rights groups and disability services agencies were endorsing the Nevada power-of-attorney bill and seemed enthralled by the original version of a model bill for medical supported decision making. We weren’t.

We wondered how advocates for people with intellectual and developmental disabilities could support a bill that did not include sufficient protections for this susceptible population. The parents and advocates promoting such measures are good people. Many are working for organizations with laudable mission statements.

Why were we seeing legislative flaws that they did not? Why were they jumping on an advocacy bandwagon that, from our perspective, needed a navigational correction to put it on the right course?

After much soul searching and discussion, we believe we have found the answer to these questions. We see things that others don’t because we subscribe to a process we call “trauma informed politics.”

To be “trauma informed” a procedure or practice must adopt a perspective that people find to be “an inconvenient truth” and therefore are unwilling to adopt. The truth is that a large percentage of people with intellectual and developmental disabilities are victims of abuse.

Adopting this perspective is much like using a night vision device. Without such a device, you may overlook things that exist but are not readily visible due to the low level of light – things that can be hiding in plain sight. Using such a device, you may be able to see things that are otherwise invisible to the unaided eye.

By working for the last few years with Dr. Nora J. Baladerian, a clinical psychologist with expertise in the field of disability and abuse, I have learned that abuse of people with developmental disabilities is [extensive](#). Most cases of abuse are not reported. With the help of “night vision” data from surveys and studies of disability and abuse, we know that abuse exists at a level that most people do not want to acknowledge.

After hearing about newly emerging concepts of “trauma informed care” and “trauma informed therapy,” I wrote an essay about [“trauma informed justice.”](#) I argued that participants in the guardianship process – attorneys, investigators, and judges – should assume that a proposed ward or conservatee may be a victim of abuse. Don’t assume that a proposed guardian is a “good guy.”

To my amazement, when I looked at reports and [surveys](#) on the prevalence of abuse to people with disabilities, I learned the inconvenient truth about disability and abuse – by the time they become adults, most people with disabilities have been victims of abuse. This data has been widely available for decades. For too many people, the statistics have been seen but not acknowledged.

Another uncomfortable fact is that most perpetrators of abuse of people with disabilities are in the victim’s immediate circle of support – a parent, household member, relative, caregiver, or service provider. This fact should have major policy implications.

Once I knew these facts, I started to use “night vision” techniques to scrutinize policies and practices that affect people with disabilities. Using this knowledge about the prevalence of abuse, my political sensibility and legal perception were different than before. I started to notice flaws that I previously overlooked, defects that other legal or political colleagues did not see.

I used my newly acquired abuse awareness as I reviewed the model legislation for medical supported decision making. Because of enhanced perception, I was able to detect structural flaws that were not noticed by those who drafted the bill, despite their good intentions to promote independence and self determination for people with intellectual and developmental disabilities.

Dr. Baladerian and I both used such techniques to scrutinize the Nevada power-of-attorney bill. We used this approach as we reviewed the [testimony](#) of witnesses who supported the legislation. We suspected that legislators who received the testimony were not aware that most adults with intellectual disabilities have been victims of abuse and did not know who likely perpetrators are. As a result, legislators may have never considered using abuse awareness glasses to review the bill.

After our intervention, the Nevada bill was put on hold. It is being rewritten by the proponents. Whether they acknowledge the reality that abuse is common, and amend the bill to include necessary protections or even take a different approach entirely, remains to be seen.

We were fortunate that one of the primary proponents of

the model legislation for supported medical decision making agreements was open to suggestions. He reviewed a framework we developed that included the necessary ingredients for a trauma informed law and the model bill was amended. Now the process of trauma informed politics allows us to endorse the amended bill.

Once participants in the political arena are aware of the high rate of abuse of people with developmental disabilities, there should be less resistance to acknowledging other facts that also may be unpleasant but true.

Some people with disabilities lack the capacity to give informed medical consent and in such cases a form of substituted decision making is appropriate. That may be a guardianship, even if only for medical decisions.

Some people with disabilities lack the capacity to enter into a contract – which is what a medical power of attorney is and what a supported decision making agreement is. If such capacity is lacking, then these alternatives to guardianship are not appropriate.

A significant percentage of parents are not “good guys.” Such parents may not go to public policy conferences or contact legislators to oppose funding cuts to disability services agencies. Politically active parents are the visible tip of the larger parental iceberg. Unnoticed, but there anyway, are parents who should not be granted authority by a power of attorney and should not be appointed as a guardian or as a conservator.

New legal proposals should be scrutinized for their potential to increase the risk of abuse and for whether they have adequate safeguards against undue influence. Supported decision making may be fine for some people with disabilities, but it is not a “magic wand” that can be used to make the lack of capacity of others disappear.

The situation of each person will always need to be examined carefully to determine if capacity, abuse, and undue influence exist or not. The political process should acknowledge this fact, inconvenient or not. ◇◇◇

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