

THE NEED FOR MORE ADVOCACY

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Advocacy: public support for or recommendation of a particular cause or policy.

How do you find time to advocate when you are overwhelmed with clinic responsibilities?

For both the seating clinician and a supplier Assistive Technology Professional (ATP), the demands of clinic life can seemingly take up every hour of every day. Meeting consumer and employer needs, documentation, funding, and the constantly evolving issue of funding policy demand our attention. Just this paragraph alone should be motivation to advocate.

What if we had advocated all along for our profession? Could we have influenced the policymakers to see what we do has enormous value and changes consumers' lives? Would we have then been able to ask for, and get, better reimbursement? Would we be paid

for all the shadow work, documentation, phone calls, and all the other ancillary things we do that are not reimbursed? Could we have made the case for, "It's not just a wheelchair!" I don't know, but maybe.

What else happens when you don't advocate? A policy

and coding system that does not meet current practice and is biased against many disabilities. Remember, policy and coding are developed by the Centers for Medicare and Medicaid (CMS), but most state Medicaid programs, and most private insurances follow Medicare policy. Competitive Bidding, consolidation, clinics closing and skilled professionals leaving the field while very few, younger, less skilled professionals fill the ranks. How about the "in home rule?" It still exists, still wreaks havoc. What about the consumers? Long delays in clinic appointments for new equipment. Many times, endless, sometimes senseless denials that can take months to resolve. My favorite is issues with repairs and component replacement.

What happens on a Friday afternoon, around 4:30 p.m., when a young mother of two kids, needs new power wheelchair batteries? Unfortunately, there are many barriers to making this happen. One barrier is her funding requires a prescription before the supplier does any work. The chances of that happening on a Friday night is zero.

What happens when a young manual chair user rolls into clinic unannounced because he doesn't know what to do when his Roho cushion has a catastrophic failure. A failure we cannot repair in clinic. His insurance also requires a prescription before we can replace it. So, now this consumer needs an appointment with his primary care physician. Try getting an appointment quickly on a regular day, let alone during a pandemic, and we then still need to order his replacement cushion. Not days, but weeks go by, resulting in hospitalization for a pressure injury.

What if we had advocated and showed our profession globally benefits society — society as a whole, the consumer and the funding source? Benefiting the consumer should be obvious. Benefiting society is a little more abstract but follows the belief system we should do the right thing for our fellow human beings. Causing someone to suffer because of policy and regulation goes against that belief system. And benefitting the funding source has several advantages. One is societal. Since many consumers receive funding through public assistance, saving money is beneficial to all. For the want of the cost of a Roho cushion, with proven efficacy for the consumer above, the ultimate cost was a hospital stay — costlier, by far. We need to show, maybe prove, our worth to change the course we are on.

If you are a RESNA certified ATP and/or a NRRTS Registrant, you are bound by a Code of Ethics and a Standards of Practice. The primary tenet is to "keep paramount the welfare of those served professionally." If you are not participating in changing the system, are you keeping the welfare of consumers "paramount?"

“ONE BARRIER IS HER FUNDING REQUIRES A PRESCRIPTION BEFORE THE SUPPLIER DOES ANY WORK. THE CHANCES OF THAT HAPPENING ON A FRIDAY NIGHT IS ZERO.”

FIGURE 1



Rep. Joe Crowley meets consumers for the first time.

Other aspects of both organization's Standards of Practice and Codes of Ethics require you remain current on relevant funding and policy issues that affect your consumers and your profession. By being involved in advocacy for your profession, you are helping to keep the welfare of the consumer paramount.

So, how do you advocate while the demands of life swirl all around you? There are many ways to advocate and promote the good that we all do. One is at the point of service, and it's probably the easiest. When you are in clinic, anytime you are interacting with a consumer and especially when working on a new intervention, take the time to explain the issues of policy and funding that are going on and that are impacting what you are able to provide for them.

We have seemingly endless examples of poor or inadequate coding, policy and payment issues. How about diagnosis driven coding? If you are working with a 20-year-old college student with a spinal cord injury, you have many more choices for intervention than for another 20-year-old college student with juvenile rheumatoid arthritis. If you are doing what Medicare calls a "free upgrade," explain it to your consumer. Let them know maybe someday, if things keep going the way they are, you may not be able to do an upgrade again.

What about the de-population of the K0009 Code? You can't provide a titanium frame even when using an ABN for a consumer self-pay of the titanium frame. What about hand rims, any type, on initial issue? What about the K0955 code? A headrest is a headrest. The examples are endless. Many are masked by the desire to help the consumer. We all understand the need to help the person who is right in front of us, but if we

don't change the current system, we will be very limited in our ability to help anyone in the future.

One of the most powerful forms of advocacy is getting right to a state or federal representative. Many seating and mobility professionals are reluctant to use this approach. I understand the "fear," but it really isn't scary or hard. A few points to keep in mind. One is all politics are local. Interacting with a state or federal representative on a local level is very impactful. Done right, you can speak directly with the representative as opposed to meeting with staff. I'm not discounting dealing with staff, but after doing this for a long time, getting to the "boss" has a lot of benefit. Another point to keep in mind is campaign issues are different than legislative work. Each representative typically has two websites. On the federal level, I'll use Rep. Dan Meuser as an example. His official House of Representatives website is <https://meuser.house.gov/>. Here is where the business of being a representative happens. The other website, more important relative to what we are discussing, is the campaign website. This is Meuser's: <https://www.meuserforcongress.com/>. Here you can see what a legislator is doing relative to activities in their district. I use Meuser as an example because he is a personal friend and he is a friend, and advocate for our profession and industry.

On campaign websites you can see what your representative is doing in their district. You can also sign up for newsletters and can contribute to their campaign. The two things a representative needs are votes and money. Even a small contribution is helpful and will typically put you on a campaign event email list. You will receive notices of upcoming local campaign events. I can't encourage you enough to attend one of these events. Your representative will be present, and you will have the opportunity to speak to him or her directly. You don't need a script. Speak from the passion in your heart and soul. I guarantee you will get their attention.

Another very powerful advocacy tool is an on-site visit by your representative. Seeing what we do firsthand is abundantly powerful. I pursued Rep. Joe Crowley for years at his campaign events pleading our case for a Separate Benefit Category (SBC). I needed to push through the issue of waste, fraud and abuse, and the fact it is not "just a wheelchair" — finally getting him to my office to meet consumers and clinicians.

Here is a picture of Crowley and his first visit (see Figure 1).

I don't know for a fact, but judging by his posture, he never saw a consumer up close like this in his life. During this meeting he got to meet many consumers, clinicians and hospital administrators who articulated their individual experiences with the provision of seating and wheeled mobility. I continued to develop my relationship with Crowley, and he finally agreed to introduce the Separate Benefit Category in May 2009. We are still fighting, but it is almost eligible for a driving permit!



FIGURE 2 Rep. Joe Crowley visits with Jean Minkel in the clinic about the value of seat elevation.



FIGURE 3 Rep. Joe Crowley sees firsthand the benefit of seat elevation.

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As time passed, we continued what had become a very solid relationship with Crowley and invited him to another on-site visit. This time in a clinic setting.

The value of having a relationships with policymakers is best shown in pictures.

Crowley is 6 feet 5 inches tall. In the first picture, Jean Minkel is explaining to him the benefit of seat elevation (see Figure 2). In Figure 3, Crowley is seeing firsthand the benefit. Look at his posture. Time and experience have made him comfortable in our world!

Game changing events like this are not hard to organize. I, the NRRTS staff, and Don Clayback at NCART are always available to help you with the process.

The last advocacy tool we'll discuss is the annual CRT Conference in Washington, D.C., that has occurred every year; with the exception of the nightmare that is the year 2020. This conference is sponsored by NRRTS and NCART. It is an educational, advocacy and, at times, enlightening conference. One of the most significant benefits of the CRT Conference is never written down anywhere. It doesn't appear in any brochure, it's not listed on the agenda. It's the ability to be with colleagues, friends and fellow advocates who share your same love and passion. We don't know how the future will unfold for 2021, but updates will begin to flow as we move into the new year.

Some people ask me why, at this point in my career, I still advocate so fiercely. While I can see the finish line in the distance, I'm not willing to go fishing just yet.

“A SOCIETY GROWS GREAT WHEN OLD MEN PLANT TREES IN WHOSE SHADE THEY KNOW THEY SHALL NEVER SIT.”

I'm a big fan of old cultural sayings that can take very broad issues, sometimes difficult to articulate, and distill them down to a few lines. My favorite, from the Greek culture is what drives me. "A society grows great when old men plant trees in whose shade they know they shall never sit."

I hope you found this article useful. I also hope you join in advocacy efforts. And for those of you nearing the end of your careers, let's plant a few trees!

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