

Disability:
An Anecdotal Field
Guide for the Rest of Us

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VOL. I



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Published by Tracee Garner

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Chapter One

ADVOCACY

Key Takeaways

- *Look for those who care most for you, your safety and wellbeing. They will teach you your greatest advocacy lessons, and will demonstrate what you need to do as well as how to go about doing it.*
- *If those that are supposed to care don't rise to the challenge or are not present, trusted surrogates will become vital. People like this do exist: those that stand in but may have no biological relationship to you. Tell them how they can help you and tell them what you want.*
- *Advocacy is more than just participation in systems that affect your life. It's about the ability to have a personal choice, options and equity.*
- *Learn components of compelling storytelling, but remember to always tell the truth about how you are treated, how you feel and what you need to be successful. In that truth, powerful people can be compelled and supplied with motivation to take action on your behalf. If you don't care, why should they?*

I credit three resources as the most impactful of all in helping me find my voice. The first two are the state-run programs called Partners In Policymaking (PIP) and the Youth Leadership Forum (YLF-VA). The third, my parents, who were my first demonstration of what advocacy is all about, having to do so at every turn in those early years to ensure I had access to the things I needed.

PIP is a leadership and advocacy training program that teaches individuals with developmental disabilities - and the parents of children with disabilities - to become community leaders and catalysts for systemic change in their local community. While walking this path, participants learn how to obtain the best available services for themselves, their loved ones, and others.

Based on a national model, the overall goal of PIP is to develop productive partnerships between the people who need and use services and those in a position to create policies and laws that affect these services. PIP participants become influencers of change via opportunities to meet and speak with national leaders in the field of developmental disabilities. During class sessions, I would hear presentations about current issues and state-of-the-art practices, as well as policymaking and legislative processes at local, state and national levels.

Both PIP and YLF-VA operate throughout the United States: last I checked, only a few states didn't have the programs available. Their mission was rather simple, and some had anywhere from 5 to 10 important modules that included advocacy, working with your local legislators, and understanding the laws and rights of people with disabilities, as well as an overview of the histories that got us to where we are today. My personal favorite and most impactful component of the programs was understanding how to tell a story.

One of the benefits of the program wasn't just the content but that we - self advocates, which was the category I fit into, about to go into my second year of college at the time - were mixed with parent advocates. I think it was a good idea, all the more so in hindsight, for parents of children with physical and intellectual disabilities to witness the future through me: to see what could be when your parents supported and advocated for you.

My Mom often went with me, but by this time I was up and ready to go to meetings on my own. She had no real interest in the sessions - and, she may argue, I wanted the autonomy of attending events on my own as an independent adult. Trust me, she was plenty happy to stay in the hotel room, order room service, and watch television. It was a win-win. Mom had done this for me most of my later teenage years, but gradually she was realizing that, while I still needed assistance, it was important for me to be able to conduct myself as myself in meetings, with autonomy and independence, and without my mother hanging around all the time. Depending on your age, this transition may be a point of contention. More about that later, but it is important. There are often more parents taking part than self advocates, and it's probably because many self advocates may not have the support to attend.

Finding caregivers to travel for an overnight program is a recurring issue for those of us who require help and support. When I was participating in PIP - and as I know was the case for many similar programs—spending a night or so in a nearby hotel was a requirement. There are all kinds of logistical issues in finding caregivers to travel if you require one. Some state-sponsored programs do assist with some costs, but not all of them and not always.

The second category I've observed is made up of people who simply may not realize how important it is to tell your stories. When you frame your experience in a compelling way, they can help you drive home your points. These stories can be particularly potent when coupled with the benefits of such legislation as the Americans with Disabilities Act (ADA), the Rehabilitation Act, the Olmstead Decision and numerous other civil rights movements. These legal milestones have paved the way for our current level of collective participation in life - this very life you are living! -and continue to permit you access to everything. When you don't know the laws and policies that are specifically designed to help you, you can count on being largely ignored. Those in a position of power will pretend not to know about them unless you speak up.

The only other reason for lack of participation is lack of outreach, as is the case in almost everything for people with disabilities. Outreach to our group has always been an issue of missed opportunities: wasted marketing dollars using the wrong tactics and really failing to understand exactly how people with disabilities access information about community programs and services. In programs like PIP, I was one of so few self-advocates, and until I went through it, I had no idea how important and impactful such a program was going to be. I would argue that at 17 or 18 years of age, you tend to assume those that advocate for you will always be around to do so. We all know that's not the case, but even when we know such things, we still refuse to prepare: parents not only fail to prepare our children for worst-case scenarios, but often actively shield their children from the realities of how hard it is to get some of the things they need. The accessible van funds, the extended class time, the reasonable accommodations at school and a plethora of other resources end up being the same types of accommodations needed at work or college - the tutor in college

math, for example - and yet these things will need to be had over and over again in different forms, from young adult to older adult settings. Advocacy never ends.

And advocacy is the only thing that changes scenarios.

After participating in nine months of PIP, this advocacy program gave me the tools to speak up and articulate the issues of the day that bothered me. It made me look around and start to see the myriad small infractions happening every day against me, and my friends with disabilities.

I remember such an incident from high school. The Future Business Leaders of America were going on a school trip. A fellow person with a disability was part of the group, but the school did not want to pay for the accessible lift bus to take her. I hated this, but I said nothing. Throughout the years and decades that followed, it has almost felt like karma that transit and lack thereof have seemed like a constant nemesis, out to bother and plague me... until I too advocated for change. The big yellow school bus doesn't work in college, during summer internships and at other milestone moments of adulthood. Had I advocated for my friend back then, would the sheer lack of transportation options and my constant fight for more routes, times and accuracy have remained on my radar for so long? You'll never know for sure, but my point is that the things that constantly reappear in your life somehow tend to be the very issues to which you will find yourself lending your voice: to change systems, ideas, minds, hearts and the humans attached to them. From the ages of about 18 to 40, I seemed plagued by transit issues. I wouldn't drive until I was in my late twenties because I was denied state financial assistance for my vehicle modifications (extensive hand control system) from someone I now realize was prejudiced against me. He treated the state and federal money as if it were his own personal fund, although it was taxpayer dollars that were there to help me. The bottom line is that the

pain points and angst around the issues, as troublesome and depressing as they are, will be the very things that propel you to great action.

It's evident over and over again that whatever issues we initially feel like we can't do anything about or feel voiceless about, we can find our voice as we age or join with others who share similar roadblocks to help amplify all of our voices. The sooner you realize the truth of your parents' limitations and eventual weariness after advocating for you, sometimes for twenty or thirty years of your life and counting, the sooner you understand the critical importance of finding your own voice, learning your needs and uncovering how to be the best advocate you can be for yourself - and for a bunch of others who need you to champion their causes, too.

For as long as I can remember, I have encountered similar issues around not being able to participate: from the church ministry's inaccessible ball game to the ramp at graduation that went up to the stage but not back down on the other side. Yes, the school only wanted to pay for the ramp to go one way. When I got my diploma, it was so awkward and embarrassing to travel back through those waiting in line. You feel dumb: like you're on display as you navigate your way through folks who are focused on listening for their own names. (This particular story made the news, if you can believe that!)

The point is that all these little nicks and cuts and scrapes, seemingly incidental, will become a recurring theme in your life. It's through that constant annoyance and your growing awareness of others' oblivious ignorance that you will find the things you care about.

For some, many of these scenarios will seem so petty, but you might be more likely to relate if you have a high schooler. As insignificant as whatever they want and swear they

need is, somehow a parent will find themselves doing all they can to make it happen, because to that teen, it's important, and that also makes it important to you.

Looking back, that two-way ramp wasn't a huge deal, but other things like that - inaccessible events, the loss of social interactions because someone didn't have the forethought to find an accessible venue, poor planning by someone omitting inclusive practices altogether, or the school that says your accessibility needs aren't in the budget - yes, all of that builds up, and when it cuts you one too many times it hurts, plain and simple.

The only way through this is to keep talking, keep advocating, keep pushing back, keep trying, not just in shareable stories like these, but as a recurring theme that will confront you every single day of your life.

As I mentioned, way beyond the state-run programs, the number one best demonstrators of advocacy in motion I've ever encountered would be my Mom and dad. Down at the "school house", as my dad called it, he made sure to make the time to come down and tell all the white ladies gathered around about what I would and would not be doing. When he saw that I wasn't being challenged in my classes, he set about getting me moved out of special education and into general (then called mainstream) education. As I think back now, general education somehow sounded to me like general population: like a prison, where I may have to fend off some real bullies instead of being a top dog in the self-contained special needs class. In case you didn't know, there is a kind of hierarchy among people in the disability community. Sorry to burst your bubble, but it's everywhere. Race, class, gender and ethnic disparities have nothing on the "born with" and "acquired" disability groups. And yes, it's sad. If you haven't yet seen this, you will

eventually, and you'll have to chalk it up to being just another crazy thing among human beings.

In essence, this hierarchy says that those who acquire their disability are somehow at odds with those like me who were born with their disability. Or it may be the other way around. It's pure silliness, really, but it does exist. I personally never even recognized it was a thing until I was much older.

As far as my early years, I didn't feel like I wasn't trying. I just never really thought about it, period. It didn't matter enough to me, but looking back, I'm so glad that my parents recognized what was happening and as such took action and got me where I needed to be. This would make all the difference in my future.

I didn't really think of myself as pretending in those special needs classes: only that it didn't seem that hard. Maybe in kindergarten you simply lack ambition: you do color outside the lines, and for most of us, there's not much to strive for when that's acceptable. Yet, I remember being in special education classes, where I stayed until almost the fourth grade.

Being exposed to all these advocacy encounters would ultimately lead me to a point where I would be speaking up for others. Oddly enough, some advocacy was even for caregivers that assisted me. When they found out I wrote books, they would ask me to write things for them: those old government KSAs, letters to their landlord or tenant, or other persuasively worded letters for the purpose of getting something, getting out of something or getting something resolved. This opened my eyes to the fact that advocacy can be not only the spoken word, but the written word as well.

I was just wordy, verbose and direct in written form. Sometimes that also got me in trouble. Later, at about sixteen years of age, I can remember starting to write my own

letters for everything. Applying for the DMV placard (which I don't think you have to do anymore) to show proof of disability, recommendation letters, accommodation letters, requests, policy drafts... In every sector where I needed permission or support for a program or recommendation, I was the one who wrote the letter. For medical issues, I would often write the letter then ask my doctor to sign it, and the deed was done. I was pretty excited to start driving, but because I had to have extensive hand controls, I was required to do a six-page medical report every two or three years! I never want to lose my driving privileges, I thought, but what if at some point I missed this two-year re-up? After considering this, I wrote a letter explaining that I know when I'm sick and that I would never put others in danger, so could I please be excused from periodically proving my ability?

All of this taught me that you simply never know unless you try. I didn't run it by anyone. I didn't ask whether it was a good idea. I've always said, "let me try". What if my dad hadn't determined that I would do better in 'general population' school? I can never remember hearing my parents discuss any pushback or even an outright no, denying my access. Back then, he likely heard: "What does he know? He's not a teacher." But my dad knew me, he knew what I was capable of, and he also knew that without some pushing, I probably wouldn't rise to the occasion. All of this may have been so, but he didn't back down. We all should be confident enough to do the same.

Writing and speaking weren't overly important to me per se, but it was the only way I believed things were going to get done in a timely fashion, maybe even change. I also found them to be the best ways of honestly saying the things I wanted to say and framing my own story. Most of the time, I was only asking others to endorse it. I learned

that when I presented information and arguments to them in a compelling way, they did exactly that, and continued to do so to this day.

At some point, you'll have to take a stance and let others know what's right for you. It's about control - about having a say in what happens - but equally it's about dignity and respect. At all times, you should have a clear idea of what exactly it is you want and need to live your life. No one should deter you from making that happen; and only you will know what needs to be said in your specific situation. Look it up and see what has already been said throughout history, then build on that with the aim of getting further than those before you. State your case, then never accept "no" as a final answer. Keep trying, get their endorsement and bring others along with you.

Currently, 35 states have Partners In Policymaking programs. The core values largely state similar objectives across all programs, in that:

- People with disabilities are people, first. We are not "the handicapped" or "the disabled." Using People-First Language is a must.
- People with disabilities need real friendships, not just relationships with paid staff.
- People with disabilities are entitled to the full meaning of The First Amendment right to free speech. The ability to communicate, in whatever form, must be available to every person with a disability.
- People with disabilities must be able to enjoy full mobility and accessibility that allows active participation in community life.
- People with disabilities must be assured continuity in their lives through families and neighborhood connections.

- People with disabilities must be treated with respect and dignity.
- People with disabilities need to be in positions to negotiate to have their wants and needs met.
- People with disabilities must be able to exercise choice in all areas of their lives.
- People with disabilities must be able to live in the homes of their choices with the supports they need; and
- People with disabilities must be able to enjoy the benefits of true productivity through employment and/or contributions as members of their communities, and
- People with disabilities must be able to enjoy the benefits of true productivity through employment, volunteerism, and/or other ways to offer our contributions as full members of their communities.

Take Action

- A child's primary caregiver and those he/she spends the most time with will be the largest influence on them, and that means you have power for how they will relate (or not) to everything.
- I would argue that teaching advocacy can be had at just the months old mark for any child, with teaching kids to ask outright (or using some form of language to inform their parents, or others, of their needs, even non-verbal). It does not matter the method; it matters that someone can learn to understand and the child can learn to not only be heard but understand they must do a single act to propel others to action, even if that simple action is needing water or other sustenance.
- Never be afraid to offer correction. Not everything your child will do is appropriate and will result in positive reinforcement or reward. It can't be solely a reward system. This is not the real world. See what they want before offering everything through conversation and negotiation with time. This will help with getting them to the things they need through push and pull mechanics of diplomacy and compromise.
- Always be questioning. The best way to gauge where your child/youth/young adult is at one subject is to just ask. These may be issues they've seen in the course of a day, the day's headlines, news and find the time to look up pending legislation and policy, particularly ones that pertain to disability, civil, race, reproductive, gender and human rights. Talk about current rules and regulations and how it may or may not affect them and others like them.

- Don't deny your children the opportunity to participate in things away from you/away from home. These experiences build confidence. One example is that there is a certain vocational rehabilitation venue that contains both young adults with behavioral issues related to their disabilities and those with disabilities brought on by substance abuse issues. There is no judgment in either the why or how these groups came to be. My point is that in helping make parents a determination in whether or not to send their child to this facility, it is important for them to consider NOT the facility and its issues but the child and what is their level of self-autonomy. While this might seem horrifying to consider, kids are around all types of people on a daily basis in the community; in a closed, contained venue, some kids can attend the week, or month long cohort, returning to home life fine, while others are not ready to be in this environment, easily duped, manipulated, coerced and sometimes irrevocably pressured into bad behavior. As scary as this might sound, there are things you can do to ensure you know whether or not this can be option for your child prior to signing off on their participation. One way is to often, offer your children different scenarios to gauge their response to matters as well as their resourcefulness. If you need to set up scenarios in a controlled environment, do that. You will know exactly what your child is capable of and identify weak spots for bad behavior and worst-case situations before they can occur. No test is perfect. That is absolutely true, but having some sense of where your child is at mentally and emotionally can help you know what programs they should and should not participate in. A week long camp, a day-support program, or a day camp are all good short-term programs that can strengthen your child's ability, and so many parents in an effort to protect

their child may find themselves denying opportunities to participate, which is not at all helpful either. You want your child, eventually, to be able to get along without you and expose them to different people and scenarios without you there to rescue them.

- Do not attend meetings without your child present unless absolutely necessary. Children, even if coloring, or you've given them something to occupy them and keep them quiet, can still be in the room because they ARE STILL LISTENING and WATCHING THE BODY LANGUAGE OF YOU and OTHERS IN THE ROOM. Both your body language and how you handle things and that of others in a position of authority, e.g., their teachers, therapist, counselor and others. I would suggest that having your child present could have a positive effect in that you might be willing to fight a little harder and, in the cases of some IEP meetings, you may work even that much more not to succumb to your emotions such as crying or yelling simply because you don't want to exhibit that kind of behavior for your child to witness. While these meetings are extremely volatile and schools often come across as bullies, seemingly pitting parents simply trying to advocate for their child's needs against decision makers who come off as doing whatever they can to withhold everything from you and your child. It should not be such a marred and emotionally charged space but unfortunately though all parties have what's best for the child, it comes down to what they are and are not willing to pay for to make that happen, (and yes, who has more resources and lawyers to ultimately win). That's unfortunate. Arm yourself with knowledge. There are classes you can take. Use what you've learned from your day job and the business world about negotiation tactics and influencing others. Where

funding is an issue, find your own funding sources in the form of grants and scholarships for therapies and treatment programs. Apply, apply, apply. There are a number of programs that are available until your child is eighteen. Those programs often dry up as your child ages, making them no longer eligible regardless of financial need. Lastly, fundraise. Many campaigns through popular crowd funding platforms can work for you and other families for a good cause. Should you have to do this, no, but to get your child the things he/she needs, you may have to and it can mean everything between success, access and inclusion or failure.

- Practice making statements of need and help your child to craft these statements, periodically practicing so they are ready to go at any opportunity they are asked to speak up.