

**Jill's talk to Down Syndrome Association of Northern Virginia.
4/22/2021**

Hello, my friends, what an honor it is to be with you today, even if it is via Zoom. I was asked to talk about my self-advocacy work in removing the R word in government statutes that will make people in society more sensitive to what a hurtful word **retarded** is to people with Intellectual, Developmental Disabilities, or IDD.

So, where do I start? Hmmm..... Hey, I have an idea, lets start with me! I'll tell you about the struggles, trials and tribulations I went through being diagnosed as MMR, or mildly, mentally retarded, when I was young. I am certain that many here had similar experiences. In fact most with IDD did.

It wasn't long after that diagnosis that people started calling me a retard or retarded. I tried to tell them how hurtful that was, and my name was Jill, but no one listened. Did that happen to any of you? I can tell you that I sure didn't like it and it made

me feel so little or useless. And they called me that like it was my name or something.

What if your name was **RETARD**?

Really, think about it! Take any sentence you might use the word RETARD in and replace it with your name.

“That’s so Nancy.”

“You’re such a Bobby.”

“I feel like such a Rachel.”

Imagine your name meaning dumb, stupid or misguided.....simply because you didn’t meet an IQ score over 70!

Or imagine this scenario: A young woman walks into McDonald's. She is not able to read the menu to place her order. It is uncomfortable for a moment, as the cashier tries to take her order. The manager whispers to the cashier, "she must be **retarded**." The cashier looks at the young woman with pity and attempts to complete the order.

For many years, although mentally retarded wasn't our name, it was the first way people with intellectual disabilities were introduced to others.

Like I said, I am one of those people that was called a **RETARD** growing up, by children my age as well as adults, simply because I was different. Yes, I have a low IQ. Sometimes things have to be explained to me a few times before I totally understand what normal people understand the first time. I was the one that got picked **last** when choosing teams in school. I am the one whose phone **never** rang. I am the one who didn't get invited to parties or sleepovers – all because my

IQ was lower than most. All because I was a **RETARD!!** Ohh, that **dreadful** word!

So what do you do when something doesn't go your way? Sit home and cry about it? **NO! Stand up and fight!** With some help, that's what I did, and that's what you can do and that's what I want to talk to you about. Be a fighter. Stand up and be heard!

My life's story, which I will say a little about, will tell how my self-advocacy work was jump started in Virginia and moved to Louisiana in 2011. As a result of my and other self-advocates work, society is learning how hurtful it is to make reference to a person as a RETARD and it is our job as self-advocates to speak up at every chance and to educate people of that fact.

One might ask, how did I get started?

I was born in Cut Off, a little town south of New Orleans, in Lafourche Parish and my family and I moved to Virginia when I was young. Like many people with IDD, I struggled with life while growing up, not fitting in with any groups at school and being fired from lots of jobs after I finished high school, all the while being called a **RETARD**. I wanted to have **friends** like everyone else, but instead was made fun of and ignored. I was so lonely and so unhappy in those days.

But I had a burning desire in the pit of my stomach to never give up. I wanted to do better and learned that having an Intellectual Developmental Disability was nothing to be ashamed of and I was not a **RETARD** or any “**thing**” else, I was a caring, loving **PERSON** who was trying to find her place in this big world we live in. My parents told me that God didn’t make any junk and that all people could be great in their own way! And that is what I believed and still do.

After getting fired from many jobs I was not equipped to handle in the first place, I just started volunteering, looking for the right opportunity. As luck would have it, while volunteering at the Arc of Northern Virginia, the director there, Nancy Mercer, discovered my passion for self-advocacy and my fearless public speaking talent.

Nancy and the Arc of Northern VA had a problem to solve to help People with Disabilities and here was the issue:

Because of the high cost of living in Northern Virginia, People with Disabilities without family support, would have to be moved to Southern Virginia, away from people and things they were familiar with and it was devastating.

Here was Nancy's solution that she proposed to me:

"Jill, The Arc of Northern VA, with me as the spokesperson, has been trying, unsuccessfully, for over 10 years to convince the

VA legislature to provide differential funding for People with Disabilities who lost their support structure. I want **YOU TO BE THE NEW SPOKESPERSON!**"

Oh my God, I thought, **ME**, to speak to the Virginia legislature? (pause) What the heck, I thought, if Nancy believes I can do it, I **CAN DO IT!**

Nancy had me testify before the Virginia House of Delegates and Senate finance committees and advocate for the funding to individual members. At the end of the session, an appropriation was made for (pause) **\$15 Million** (pause) for differential funding for People With Disabilities! That was my first self-advocate success and it made the many people with IDD following this initiative and me **very, very happy.**

My life got so much better after that. I was working hard, making fundraising calls and doing lots of neat things for the Arc of Northern Virginia.

But Nancy wasn't finished with me just yet!

The next year, she said that our agenda was to **eradicate** the R word in Virginia statutes. Well, I didn't know what eradicate meant, but I was game. So we planned our strategy for the upcoming legislative session for removing the word "Retarded" and other hurtful references to people with Intellectual, Developmental Disabilities in Virginia state statutes.

After planning our strategy, we put it to work. The Northern Virginia delegation was very supportive of the idea but warned us that it would likely take 2 to 3 sessions to pull it off. **No problem!** I, along with other self-advocates, worked hard, testified before several committees, met with members and their staff and got it done in **ONE** legislative session! The "R" word is **NO MORE in Virginia!**

Virginia did it so Maryland wanted it!

Someone in Maryland learned of what we did in Virginia and wanted the same, so we helped prepare them. But instead of the Maryland state delegation, people there went to their US Senator and a bill that we helped direct through the process, called "Rosa's Law", was passed to remove the R word from all Federal Statutes. I, along with other self-advocates attended a bill signing in the Oval Office of the White House with the **President of the United States when it was signed into law..... not bad for an IDD Cajun girl from South Louisiana!!** (pause and smile)

And to top it all off, a woman in Texas, whose daughter interned at the Arc of Northern Virginia, heard about my good work, and being an author, decided to write a book about my life and she titled it "Jill's Journey, A Victory Over the R Word"! Wow, what an honor. I was so humbled that she would think enough of my work to write a book about it.

And it didn't stop there. I thought to myself: We did it in Virginia, we did it with the federal government, how bout Louisiana?

As I said earlier, my family and I moved to New Orleans in 2011. In 2014, we heard that a New Orleans State Representative who was also Speaker Pro Tempe, Walter Leger, was proposing a bill for the Louisiana House of Representatives that would remove the R Word and other hurtful references to People with Intellectual, Developmental Disabilities, from the Louisiana State Statutes.

I thought to myself, how do I get to him?

I networked and with the help of my dad and friends, was introduced to Representative Leger and told him about my self-advocacy work in VA and Maryland and he invited me to testify before the Health and Welfare Committee in March of 2014, which I did..... and the bill passed unanimously out of

committee, then passed the senate committee, the full Senate and signed into law by the Louisiana Governor.

Its **GONE, VANASHED!**

I am happy to report that the R word is **no more** in **Louisiana!** And I am just thrilled to have played a role in removing the R word from Virginia, Louisiana and the Federal Government. It sure makes me feel good and I want to encourage you to do the same in your state. Be **strong**, be **brave**, be **unafraid** to talk to your state representatives or senators about removing the R word from your state's statutes or other initiatives that support people with IDD. (SLOW & DELEBERATE) It's the first step in helping people in our society understand how insensitive the use of the word **Retard** is, it's the **right** thing to do and will make you feel **very, very GOOD** and be Happy and that's what life is really all about, finding happiness, right? (pause) So like Nike says, **Just Do it!!**

Thank you very much for your time. I'll open it for questions.

