

## Ability Bias in Professional Speech: Matching Our Rhetoric to Our Values

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**(slide)** I developed this talk with one of my mentors, Ian Ford. Ian is an Autistic advocate. He facilitates a support group for Aspies.<sup>1</sup> He is a blogger<sup>2</sup>, an author and a profound thinker about neurotypical social behavior. He is an expert in how cultures form ideology. I highly recommend his blog and his book, A Field Guide to Earthlings: An Autistic/Asperger's View of Neurotypical Behavior.<sup>3</sup> Ian couldn't come present today, but his ideas have influenced me and this talk. I want to thank the Special Hope Foundation for their support of my work with the self advocacy community, because it has advanced my thinking a great deal.

**(slide)** I am hoping that by the end of this talk you'll identify more subtle forms of ability bias and give examples of how it impacts care. I hope we'll all come away with more ideas about how to challenge ability bias, and how we can support each other. Putting this talk together has been challenging for me. My own thoughts and feelings have evolved. The subject is deeply personal. I want to warn you that I am going to talk about euthanasia, eugenics, abuse and neglect. I'm not going to mince words. I am going to start by talking about how the eugenic movement emerged. Then I'm then going to explain why I am concerned that a new eugenic movement is gaining momentum. And I am going to close by identifying opportunities to derail it and to ensure that we train health care providers in a way that will lead to respectful care.

**(slide)** First, how did we get from the Enlightenment thinkers to the eugenic movement? The Enlightenment thinkers... Louis Braille, Gallaudet and Helen Keller... They taught that education can be tailored to the individual, and that disabled people can learn. They built beautiful schools. But when the Great Depression hit, families were overwhelmed. Families didn't have

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<sup>1</sup> The Global and Regional Asperger Syndrome Partnership <http://grasp.org/page/grasp-support-group-albuquerque-nm>

<sup>2</sup> <https://ianology.wordpress.com>

<sup>3</sup> Ford, Ian. A Field Guide to Earthlings: An Autistic/Asperger's View of Neurotypical Behavior. Ian Ford Software Corporation, Albuquerque, NM. 2010. [afieldguidetoeearthlings.com](http://afieldguidetoeearthlings.com).

the resources to care for their loved ones, so they sent them off to school. The focus of the schools shifted away education. They became overcrowded and underfunded. Residents were viewed as sick or broken people. Doctors were needed to cure or fix them. So Doctors replaced educators. By the 1940's people were being pressured to send their loved ones away. The rationale was to protect of the social hygiene of the family. What was happening in the schools amounted to euthanasia by neglect. Residents of the institutions were subjected to forced sterilization and horrific medical experiments. People didn't live very long. They died of tuberculosis, hepatitis B, malnutrition and neglect.

**(slide)** How did we go from sending our kids to school to sending them away to die? How did intelligent people support euthanasia? It started with economic hard times. When people are overwhelmed, they are more likely to view people with disabilities as a burden and to adopt dehumanizing language... suffer; tragic; unfortunate; threat; dependent.<sup>4</sup>

When dehumanizing language becomes common, it leads to a subtle shift in thinking: I don't devalue disabled people. It is disabled people who don't want to live that way. After all, who wants to suffer or to be a burden? This thinking absolves people of guilt. It makes the disabled person appear complicit. It isn't me wanting to harm anybody; it's the disabled people wanting to escape from pain and misery. This shift in thinking is seductive, even if it is illogical.

The final leap in logic that enables public support for euthanasia is the idea that doctors will do the right thing for their patients. We are highly respected leaders. We go into medicine to relieve suffering. If doctors believe patients suffer, then euthanasia seems justified. If doctors think it is ok, then it must be good. Death becomes almost routine. I got this insight from Ron Manderscheid. I encourage you to read his article in the Spring Newsletter of the Autism National Committee.<sup>5</sup>

Could we go back down this road again? I fear we could. The economy stinks. Funding for services and supports is shrinking. Parents and caregivers are stressed. People's needs aren't getting met. Untenable situations are fuel for dehumanizing language...

This **unfortunate** patient...  
 I have **devastating** news about your child...  
**Dependent** on Medicaid...  
**Unable** to function in society...  
 Autism **epidemic**...  
 Wheelchair **bound**...  
 The mentally ill are a **threat** to our safety...

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<sup>4</sup> Douthat, Ross, "Eugenics Past and Future" New York Times Op Ed. June 9, 2012.

<http://www.nytimes.com/2012/06/10/opinion/sunday/douthat-eugenics-past-and-future.html>

<sup>5</sup> Manderscheid, Ron "Code words for Murder" Autism National Committee Newsletter Spring 2012  
<http://www.autcom.org/pdf/AutcomNLSpring2012.pdf>

What can we do to ensure that health professionals provide respectful care?

I think it is a war of words... Words matter... Words shape belief... Belief shapes behavior... Belief shapes policy. As professionals, the words we use influence how people think. We are leaders in a new field of medicine. We need to craft our language carefully, to lead us down a better path. We've done this before. The eugenic movement was successfully challenged in the 1970's. I want to spend some time talking about how that happened. And how our ideas have evolved. Then I want to share some thoughts about where we can go from here. I want to suggest ways we can teach about ability bias and how we can use words to shape the ideas of our students. Shaping the ideas of our students will lead to respectful care...

**(slide)** The ideology of the eugenics and euthanasia was challenged in the 1970's. In the 1970's we started to close institutions. Many people in this room were heroes in that movement. You helped stop abusive practices. Many have helped close institutions by creating quality services and training in the community. But in the 1970's, nobody was challenging the idea that people with disabilities are "broken"—only that they don't belong in institutions. The Philosophy of Normalization holds that people with disabilities will function more normally if they live in a more accommodating social and physical environment. Some disability is caused by horrible living conditions and lack of opportunity. In the 1970's we were still defining people solely by their disability—a retard, a cripple, an epileptic, a lunatic. But, we believed that even broken people can benefit from living in the community and from educational and social opportunities. At the time, this idea was an advancement. If people are treated more normally, they will function more normally.

By the 1990's this view had shifted. In the 1990's people began to recognize that disabled people are more than their disability. This led to the view that only a part of a person is "broken." Instead of thinking that a person is defined by their disability, we insisted on "People First." People *with* disabilities have a healthy "normal" part which is their "personhood." They also have a "broken" part which is their autism, cerebral palsy, epilepsy or mental illness. And we insisted that people with disabilities shouldn't be defined solely by their "broken" part. The "broken" part is viewed like a chronic illness—something separate from the person—something that medical technology might someday cure or prevent.

This concept was an improvement over the idea that people are defined solely by their disability. But it is still problematic. It is similar to the rhetoric about gay people during the same era. For example, "Love the sinner; hate the sin." And "It is ok to be gay as long as you don't ask and don't tell and pretend to be straight." It is also similar to the rhetoric used in the same era about women. Women were thought of as a type of broken man who suffered from premenstrual syndrome and pregnancy. These things reduced their work productivity. Those perceived "flaws" could be mitigated with medical treatments such as ibuprofen and birth control. I remember being taught in medical school to compare everyone to a hypothetical 70 kg heterosexual, White male. I was told, this was the definition of normal.

**(slide)** But being gay, being a woman, or having a unique mind is integral to who I am. These aspects of myself can't be considered separately. I am not a series of deviations from the norm.

The Neurodiversity Movement is the challenge to the 1990's Person First ideology. We don't have to deemphasize part of who we are. Instead, we claim a right to be different, and whole, and Fabulous! Get used to it! The Neurodiversity Movement, in my opinion, represents a welcome evolution in our thinking. It gives me hope for my future. **(slide)** The Movement's main leaders, are disability advocates. This is how it should be. Men can't speak for women. Heterosexuals can't speak for gay people and abled people can't speak for disabled people. Most parents and professionals have been slow to embrace Neurodiversity.

It isn't yet clear if society will accept Neurodiversity. There is another eugenic ideology emerging—led by the medical profession. This time, the eugenic movement is being fueled by the hope that better understanding of the human genome will lead to ways to engineer more perfect humans. We can test for certain conditions or traits and abort babies who have them; or select for traits in a petri dish and implant only selected embryos. If, these methods fail, we can try to reengineer neural pathways through Applied Behavior Analysis or through stem cell treatments. One day we may even create genetically modified people.

To gain acceptance, that ideology requires dehumanizing language. In order to justify risky medical therapies, people have to first agree that having a neurodevelopmental difference means having a low quality-of-life. A person would only consent to treatment to re-engineer their brain to escape from what is perceived to be a horrible alternative— living with a neurological difference.

**(slide)** Why wouldn't we want to be bioengineered into more perfect people? Don't we all want our kids to be more perfect? The Neurodiversity Movement's answer is, "no." We all want to maximize our potential. We want the opportunity to learn, to love, to make a contribution. Regardless of our abilities and challenges, we want services, supports and environments that help us to be successful. But just like women don't want to be like men and gay people don't want to be like straight people, neurodiverse people don't strive to become more like the statistical norm—not biologically, not mentally, not behaviorally. The assumption that we should, is called ability bias.

**(slide)** Ability bias is the assumption that able-bodied people are the norm in society, and that people who have disabilities must either strive to become that norm, or should keep their distance from abled people. A disability is thus, inherently a "bad" thing that must be overcome. In this worldview, disability is a flaw, or a failing, rather than a simple consequence of human diversity. There is no evidence that reducing genetic variation leads to healthy communities. And ability bias is leading us down the path to a new eugenic movement.<sup>6</sup>

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<sup>6</sup> "Ability Bias in the Health Professions"

[http://developmentalmedicine.ucsf.edu/odpc/docs/pdf/practice\\_pearls/ability%20bias%20in%20the%20health%20professions.pdf](http://developmentalmedicine.ucsf.edu/odpc/docs/pdf/practice_pearls/ability%20bias%20in%20the%20health%20professions.pdf)

If there are competing ideologies, why not just embrace them all? People who want to celebrate their differences can do that. People who strive to be more “normal” can take advantage of treatments that help people look and function more like the norm. It is all about individual choice. Right? No. I don’t think so. Because individuals live in societies. They don’t truly have free choice. Ideology drives our research agendas, resource distribution, social environments, and access to health care and power. Ability bias is pervasive. Ability bias is present in the exam room. Even when we are trying to do the right thing, the voices of disabled people are largely drowned out by parents and professionals. When people make health care decisions, there is often subtle and overt coercion. For example, during prenatal testing, it is often presented as a given that a parent will think that it is undesirable to have a child with Down Syndrome.<sup>7</sup> Also, there are many examples of people being counseled against life-saving health care on the basis that such care is futile.<sup>8</sup> It isn’t futile because the patient is dying. It is futile because it won’t change the trajectory of the patient’s supposedly tragic life. There are cases where people who don’t have a terminal illness are being denied food and water and then given a morphine drip.

Most people with disabilities have stories about ability bias in their interactions with health professionals. Ability bias leads to treatments and research agendas that oppose community values.<sup>9</sup> For example, families have been sold chelation therapy to remove imaginary toxins; they have been sold aversive shock treatments to control behavior and surgery to arrest normal growth in order to make caregiving easier.<sup>10</sup> Pharmaceutical companies are developing new medications to control behaviors that may be adaptive or a form of communication. Ability bias leads to bad legislation such as gun control that scapegoats people with mental illness. And there are prominent people such as Dr. Phil<sup>11</sup> and Peter Singer at Princeton who openly promote euthanasia.<sup>12</sup> You can find more examples on the “Not Dead Yet”<sup>13</sup> or the Disability Rights and Education Defense Fund websites.<sup>14</sup>

Diversity is a good thing. People want to be compared to their own normal, their own sense of well-being, to have their competence about their own life and body recognized and respected;

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<sup>7</sup> “Understanding a Down Syndrome Diagnosis” <http://www.lettercase.org/>; online training on non-coercive counseling for physicians: <http://www.brighter-tomorrows.org/>

<sup>8</sup> Cohen-

Rottenberg, Rachel. “Amanda Baggs, the Pressure to Die, and the Case Against Assisted Suicide.”

<http://www.disabilityandrepresentation.com/2013/04/06/amanda-baggs-the-pressure-to-die/>

<sup>9</sup> Nicolaidis, Christine et. al. “Effective Partnering with the Autistic Self-Advocacy Community to Advance Intervention and Services Research” [http://aaspire.org/inc/presentations/nih\\_elsi\\_2011\\_slides.pdf](http://aaspire.org/inc/presentations/nih_elsi_2011_slides.pdf)

<sup>10</sup> Carlson, David et al. “National Disability Rights Network. Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights.” May 2012.

[http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing\\_People\\_with\\_Disabilities.pdf](http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf)

<sup>11</sup> <http://www.prweb.com/releases/2012/5/prweb9551185.htm>

<sup>12</sup> Johnson, Harriet. “Unspeakable Conversations” New York times. February 16, 2003.

<http://www.nytimes.com/2003/02/16/magazine/16DISABLED.html>

<sup>13</sup> Not Dead Yet <http://www.notdeadyet.org/>

<sup>14</sup> DREDF <http://www.dredf.org/healthcare-stories/>

to learn skills; to function better and to have their differences appreciated. **(slide)** We seek help for conditions that cause an imbalance in us as individuals—not merely because our traits or characteristics are different from the statistical norm. Balance isn't the same thing as normal. For example, some people find balance with a diet that would be dangerous to others. Some find balance with different lifestyle choices. Environments that are right for some, create imbalances in others. Even chemical balance can vary. This means that drug dosing needs to be individualized. The dosages we choose for average people may not be right for all.

To give you a concrete example, many people with epilepsy find balance even though they continue to have some seizures. The goal of eradicating all seizures can lead to intolerable medication side effects. Another example is cochlear implants. Cochlear implants are controversial in the Deaf community. Doctors shouldn't assume that everyone who doesn't hear wants one. If a person's brain developed without hearing, it forms its own balance. It is different from hearing people. The patient quality of life can go down when they are bombarded with too much sound to process. The value of being Deaf is no less than that of being hearing. It has advantages. For example Deaf people communicate easily in noisy situations where hearing people have difficulty... Many doctors tend to assume every Deaf person want a cochlear implant. I wanted to learn more about this. I searched for "cochlear implant failure" in PubMed. The only studies I found were ones that evaluate the ability to discriminate between sounds in a quiet, testing environment where the test is the only task and there are not other distractions. This is not a good measure of whether cochlear implants improve overall functioning or quality of life. To learn about the problems that cochlear implants cause, I had to talk to a parent and read the literature from the Deaf community...

We are leaders in the emerging field of Developmental Medicine. We are working to challenge ideology based on ability bias. I am proud of our alliances with the self-advocacy community, but we could do more. I look forward to hearing from Ari Ne'eman tomorrow. The Autistic Self-Advocacy Network has written an important paper calling for access to organ transplants for patients without regard to ability.<sup>15</sup>

I am excited to say that AADMD's ideological battles with adherents of Person First ideologies have largely quieted. I think advocacy organizations grudgingly acknowledge what we have been saying all along. There isn't some broken part of a person that can be treated with special therapeutic services that is separate from their healthy part which can be treated using clinical guidelines designed for the general population. As Matt Holder has articulated so well, that is a lousy paradigm for medical care. Also, the term "developmental disability" doesn't describe a person's neurobiology. Developmentally disabled means "eligible for certain resources." However it isn't a clinical diagnosis. The same person can meet the federal definition of developmental disability but not their state definition. The definition is arbitrary. For example, in California, a 17-year-old with a traumatic brain injury is developmentally disabled, but a 19-year-old with the same injury is not. These two individuals have identical medical needs. They

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<sup>15</sup> Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps  
[http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief\\_3.18.13.pdf](http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf)

should be in the same category when we think about medical treatments that might benefit them.

In putting together this talk, Ian and I discussed whether we can move away from ideology altogether? Can we stop replacing one dysfunctional ideology with a new one which will also have flaws? Can the goal of treatment be to find a person's individual balance? Can we celebrate variation in the way the brain works in different people? Can we stop trying to pretend that "normal" people are independent? In reality all people are closely interdependent. Lots of non-disabled people are dependent on others for financial support—for example, retired people, unemployed spouses, and the working poor. Even middle-class, working people aren't independent. Like people with disabilities, they hire other people to do most things for them. Those who earn money have more power to control their lives, but they aren't more independent. Can we just treat people as individuals and stop being ideological? Maybe we can.

AADMD members have done a great deal of work to confront ability bias. That work must continue. To be effective, we need to offer colleagues a framework in which to think about medical care that doesn't reinforce ability bias. What follows is my attempt to do that. Much of it will sound familiar to you, because I have borrowed heavily from your work.

**(slide)** I propose we teach the following fundamental assumptions...

We all have things we are good at and things we are not good at. Level of functioning is dependent on the extent to which an environment disables a person. High functioning or low functioning aren't meaningful descriptions of people's neurobiology or potential. Functioning isn't a characteristic. People have traits or conditions, but those traits are not in themselves disabling. Disability occurs when we fail to accommodate the need of individuals. Whether people experience disability or not, we can teach skills—we match our methods to our patients. If we have something effective, we can offer medicines or procedures to treat imbalances. For example, we can treat cataracts or glaucoma. We can teach skills such as braille. But we shouldn't treat blindness if a person considers it a trait. For example, someone who is blind from birth doesn't have a defect. They are whole. In the dark, relative to Seeing people, they are not disabled. However darkness is disabling to Seeing people. On the other hand signage is disabling to Blind people but not to Seeing people. The degree of disability is not a function of the person, but a function of their access to assistive devices and environmental adaptations that can eliminate the disability. A Blind person can be balanced, even if they never see. Another fundamental assumption is that the lives of people with disabilities are inherently meaningful and valuable. This means that health care should not be denied based on perceived quality of life. People with disabilities tend to be happier than they are perceived to be. And we should challenge people when they devalue the lives of people with disabilities by using dehumanizing language. We recognize people's right to self-determination. Nothing About Us, Without Us! Self-determination means that we must be at the table whenever issues that concern us are discussed. Our job is not to define or control. We are supporters and allies of people with disabilities. Physical, programmatic and communication access to health care is a

right. As professionals it is our responsibility to ensure access to care. It is the law. Inclusion requires action. Our health care system is not yet fully accessible. We have to keep working on that.

Here is my proposal for how to teach a Neurodiversity perspective to health professionals.

**(slide)** I tie everything I teach back to these few basic principles:

- Health care for people with developmental disabilities is interdisciplinary team-based care with patients and caregivers at the center of the team
- The goal is to maximize wellness and function (i.e. individual balance)
- Everybody communicates and all behavior is communication
- Illness presents as a change in behavior or function
- Reducing disability means improving function AND treating the social or physical environment

I teach students to do a two-part assessment every time they encounter a new patient. Step 1: Map out their interdisciplinary team; Step 2: Map their neurodevelopmental profile. Doing this assessment forces us to learn about our patients as individuals in their social context. It helps prevent us from making assumptions based on a diagnostic label, appearance, communication style or other stereotype. It provides a structure for our patients to tell us what balance means to them.

**(slide)** Here is what I mean by interdisciplinary team based care with patients and caregivers at the center of the team. You can't work as a team if you don't know who you are working with. This seems obvious but this assessment is rarely done. The team has three categories: the service and support team; the direct care team; and the medical team including dental. Mapping out a person's team helps identify missing team members and helps the doctor understand the patient's social and physical environment. The social or physical environment may be what needs to be treated. Our patients don't suffer from having a unique neurobiology. But they do suffer from exclusion, intolerance, discrimination and lack of resources. This is tragic. This is devastating. Exclusion, intolerance, discrimination and lack of resources are a burden on families.

Patients and caregivers are at the center of the team. If the caregiver has unmet needs, the patient isn't going to do well. As part of mapping out the team, I do a caregiver assessment. Too often I see doctors treating the wrong person. For example, when a caregiver is stressed, instead of prescribing respite or additional staffing, they give a patient psychoactive medication in a twisted attempt to make them calmer in an untenable situation. Also, for our patients to thrive, sometimes we need to coach caregivers to support rather than to control. We need to provide structure to visits and team meetings to manage the power differentials. Various team members can have interests that compete with the patient's. I also assess a person's services and supports. If a patient doesn't have the services and supports they need to communicate a history, to make an informed consent decision or to follow through on a health care plan, putting supports in place needs to happen before trying to diagnose or treat. The care won't be

successful if the patient doesn't have the services they need. I see students get frustrated when they try to provide medical care to someone who doesn't have supports. Finally, I assess what accommodations I need to make to ensure that my patient can access my care. For example, do I need to make home visits; use an exam table that lowers; offer longer appointment times or educate my patient in a different way?

**(slide)** Here is what I mean by a neurodevelopmental profile. Illness presents as a change in behavior or function. Therefore it is critical to describe a patient's baseline. I use Phil May's framework for this, but there is no need to pathologize it. Instead of talking about neurodevelopmental disorders, I talk about a neurodevelopmental profile. If we want people at the table we can't talk about them like they are broken. Everybody has a neurodevelopmental profile. We can ask students to map their own. A profile helps me think about strengths and special powers and discourages me from fixating solely on weaknesses and deficits. It helps me understand what it means for my patient to be balanced. The neurodevelopmental profile is a critical part of a new patient assessment. Understanding a person's neurodevelopmental profile is key to avoiding diagnostic overshadowing. Diagnostic overshadowing is overlooking signs of illness because the signs are assumed to be a part of a person's baseline traits and characteristics. Diagnostic overshadowing is a form of ability bias. Constructing a neurodevelopmental profile is also critical to thinking about risks for associated complications such as gum disease and pressure sores.

Under cognition, I have students describe how people communicate and learn. I spend time teaching the difference between speech, language and communication and about the range of ways that people communicate. I describe a patient's ability to solve problems and to remember, to concentrate and to organize; I describe their intellect; their ability to manipulate abstract ideas; to use numbers and shapes. I note processing speed. I explain why people with intellectual disabilities make better rehab candidates than elders with dementia. Because their short-term memory is preserved, people with intellectual disabilities can learn. Under mental health and behavior I talk about interpreting behavior developmentally. I talk about adapting the Diagnostic and Statistical Manual for intellectual disability. I talk about behavioral phenotypes and how changes in behavior can be a sign of illness such as a dental abscess. Under neuromotor function, I teach the gross motor function scale. I teach about swallow and bowel issues; spasticity and tone; about movement disorders and fracture risk. Under sensory, I talk about how to screen for vision and hearing problems. I talk about sensory integration differences and atypical pain behaviors. Under seizures I talk about unusual seizure presentations and about medication side effects, dosing and interactions. I explain that most people with complex disabilities did not acquire functional limitations through progressive medical illness. They are not sick. They are not in decline. They are NOT dying. They benefit from aggressive medical treatment when they have acute medical problems such as aspiration, infections or bowel obstruction.

Diagnostic labels are important to note. But they are just descriptive terms. They are not a part of someone's neurodevelopmental profile. They don't define the person. They can serve as search terms to look up research or guidelines that might apply. They can be used as

descriptors such as Autistic, anxious, quadriplegic or obese. They can be a positive cultural identity that can connect my patient to others with similar experience. Diagnostic labels are also sometimes used as part of eligibility requirements for certain services. They help me understand what my resources are.

I teach students that it is never ok to skip this two-part assessment when seeing a person with a complex disability for the first time. It is fundamental to their care. Without knowing who I am working with and my patient's baseline, there is no way to know if my patient is out of balance. Sometimes, all I can do is a five minute version of this assessment. Sometimes a team does a detailed assessment that takes days to complete. But it is never ok to skip it. I tell students, "If you don't do this assessment, you will inevitably make incorrect assumptions. You will treat traits and characteristics that aren't broken. You will make bad clinical errors due to diagnostic overshadowing." Most of the worst medical errors and complications that I have encountered (and that I have made) could have been avoided by doing this initial assessment. I tell them about my mistakes. There was a time when I thought that poor dental hygiene was a part of being developmentally disabled, because I had never met a patient in a group home with a full set of teeth and sweet smelling breath. The neurodevelopmental profile is critical. If I meet a patient who uses a wheel chair and is non-verbal, but I see on their profile that at baseline they use a walker and speak in short sentences, then I know something is wrong. Something happened that got them out of balance and I need to investigate it. That may be the only hint I have that they have a medical problem. I ask students to present a one or two sentence neurodevelopmental profile at the beginning of every patient presentation. For example, "Mr. Smith is a 56 year old man with an intellectual disability, focal seizure disorder, moderate hearing loss and spastic quadriplegia-gross motor function scale 4--who communicates primarily through facial expressions and gestures and whose baseline demeanor is calm and cooperative."

**(slide)** Illness presents as a change in behavior or function. Steve Zelenski took me out to dinner before he passed. May his memory be a blessing. Steve taught me how to think systematically about the differential diagnosis of a change in behavior or function. I use his HURTS mnemonic as a starting place to think about secondary medical complications. **(slide)** A change in behavior or function can also signal problems in the patient's social or physical environment such as abuse, need for attention, or pursuit of control.

That wraps up my outline of Developmental Medicine --the synthesis of the lessons I have learned from you, and from leaders of the Neurodiversity Movement. This is my attempt to suggest language and a framework for the next generation of health professionals as they learn to talk and think about health care for neurodiverse people. There is a lot to be done. The people in this room are already doing a lot.

**(slide)** My main plea is that we challenge dehumanizing language whenever we hear it. Respectful language will lead to the assumption that our patients want to live a balanced life, that our role is to ally with and support our patients, and that healthcare will lead to good outcomes. When I hear things that make me cringe...She has suffered enough from her

disability...She is a burden to her family...the exam was deferred because the patient couldn't get on the exam table...We don't have a self-advocate speaking because parents can speak for them... When I hear these things, I used to just let it go. But now I hear it as a threat. I hear it as fuel for the eugenic movement. And I have gathered some courage to speak out. I try to address ability bias every time I hear it, like I try to do when I hear sexism, or homophobia. This sometimes means challenging colleagues who are in powerful positions and whose research agendas are highly profitable to the university. This takes courage. I want to open up discussion now. How do we partner with the self-advocate community? We have access to power. How do we share it? How do we support each other to do this work? **(Slide)**