Ability Bias
Developmental Disabilities: Update for Health Professionals
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It is quite an honor to speak to you today. This room is full of great people. Lucy Crain and Gerri Collins-Bride have spent entire careers serving people with developmental disabilities; Alan Wilens and the amazing nurses we just heard from, have created 962 homes; we have developed a replicable model of care that can serve California's most medically fragile citizens; Karen Fessel and her team have fought to improve access to insurance benefits. We'll hear from many others over the next couple of days. Stacey Milbern, Shannon Des Roches Rosa, Hank Chambers. The people in this room… you… are a "Who is Who?" of dedicated advocates. We are committed to ensuring that people with developmental disabilities enjoy good lives.

We know we have a problem. We have all seen the numbers. The population of people who need services is rising faster than the general population. The resources we have dedicated to care for them are dwindling. The numbers of people diagnosed with autism have risen dramatically. We see the writing on the wall. We know that the systems of care that we worked so hard to develop over the past 40 years are not going to meet our needs for the next 40. Many of us are trying to make plans for our kids that we hope will last for the next 80 years. This generation has grown up in the community. We want to live independently, with people of our choosing, or with family. We have friends. We want to be a part of the solution, to work, to contribute, to vote, to direct our services, to have full access. We insist on, "Nothing About Us, Without Us." Like it or not, there will be change. We need to motivate the public and the legislature to act.

What I learned from Ari Ne’eman, one of the great civil rights leaders of our time, is that there are two ways to motivate people—hope and fear. Hope. And fear. There are historical precedents for both. And lessons to be learned from our past. Our approach to shaping the cultural narrative of disability, the words we use, will greatly impact the solutions we develop, and how disability is perceived in the 21st century. It will impact public policy. It will impact how people are treated. It will determine our children’s opportunities, and our families’ futures.

The language of fear is potent: Autism crisis, despair, devastating, dependent, suffering, unfortunate, bound, burden, threat to our safety. The language is alarming. It draws attention. It gets people to act. It raises money. It is also dehumanizing. It demonizes our patients. It hurts us, our friends and our kids. This language pervades the media, our culture, and as any person with a disability will tell you, it is commonly heard in medical centers and clinics. This language convinces people that disability is the scariest thing on the planet—something to be avoided, if at all possible. Disability is inherently bad and must be overcome; a flaw or a failing. Fear drives ability bias. 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 normal or keep their distance. Fear is a dangerous message.

The alternative way to motivate people is to use the language of hope. The language of hope is compelling. It taps into our core values. Our spiritual beliefs. Our best selves. Our commitment to justice, to diversity, to creating the kind of world in which we and our families want to live. The Developmental Disabilities Assistance and Bill of Rights Act, the Lanterman Act, the Americans with Disabilities Act. These are beautiful articulations of our values-- remarkable bipartisan pieces of legislation; supreme moments of consensus. Most of us will experience disability at some point in our lives. We are talking about how *we* want to be treated. This legislation frames disability as a natural part of the human experience. Disability does not diminish the right of individuals to live independently. It doesn’t diminish the right to exert control and choice over our lives, and to fully participate in and contribute to community. I think most people in this room believe this. We see examples of success in the speakers at this conference. The contributions of people with disabilities can only be fully realized through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of the United States. The Americans with Disabilities Act prohibits discrimination and ensures equal opportunity…not equal treatment, equal opportunity…equal opportunity for persons with disabilities in employment, State and local government services, public accommodations, commercial facilities, and transportation. The Lanterman Act states that the State of California accepts a responsibility for persons with developmental disabilities, and an obligation to them which it must discharge…an obligation…We, as a righteous and good community, have accepted an obligation to our citizens with developmental disabilities. This is what we want. This is what we demand. Self advocates, families, allies, service providers, clinicians, bureaucrats who serve us, politicians who were elected *by* us to represent us, to organize us, to help us meet our obligations, we are here to remind ourselves that together, we have accepted a responsibility. Each of us, individually and collectively, have accepted an obligation to our fellow citizens.

Is the task too great? Is the cost too high? Of course not. We are one of the wealthiest states in one of the wealthiest countries. We have done many things together that are a lot more complicated than taking care of a few of our most vulnerable citizens. We even have models for how to do it well. Do Californian's have to do it alone? No. The federal government is our partner. Do families need to do it alone? No. The state government is our partner. And we are in good hands with Santi Rogers, the new Director of Developmental Services. Santi is a partner. Our churches, our neighbors, our schools, our medical centers are our partners. Regional center clients represent less than one percent of the population. Many clients work and pay taxes. Others volunteer and help care for others. Yes, we need to shift some of our priorities. Yes, our state and federal budget need to reflect our values. But doing the right thing benefits us all. It strengthens the entire community. This is our message.

What can we learn from history? In the late 1800's, state schools were built with a message of hope. Louis Braille, Gallaudet, Helen Keller… They taught that education can be tailored to the individual, and that disabled people can learn. The schools were beautiful. Parents sent their children to learn. They demonstrated that people can communicate in different ways. Given a means to communicate…given respect, and the presumption of competence…people can make their lives a blessing. The hope was that people would graduate from the schools and use their skills to work and live in the community. But for the most part, that didn't happen. Despite the education, most people with disabilities still needed support and accommodation to thrive. At the time, support was only available in the institutions. So they stayed. Failure to create jobs and opportunities for people with disabilities in the community trapped people in institutions. That was a horrible mistake.

By the early 1900's the message of hope shifted to a message of fear. If we can't fully habilitate everyone, then maybe we can eliminate disability through science. Science can improve society through social control. The main tools for social control were reproductive technology and segregation. During this period, Martin Barr wrote an influential text that spread the concept that "feeble-mindedness," the term for intellectual disability at the time, is a defect, "mental, moral or both, usually associated with physical stigmata of degeneration." This led us to the view that people with disabilities, or even people deemed immoral because of their political, sexual or social behavior, are menaces to society…threats, crisis, despair, devastating, dependent, suffering, unfortunate, bound, burden, threat to our safety.

Classification systems at the time included at least three levels of "feeble-mindedness" ranging from most to least severe. An institutional service system developed in the schools. It served both those people who were less capable who were thought to require custodial care, *and* those who were more capable who were thought to require segregation and sterilization. Those more capable were thought to be the *greater* threat to society. And the institutions relied on the labor of more capable people to sustain themselves.[1] Then, as now, all people are a mix of strengths and challenges. The purpose of categorizing people by function had more to do with justifying different types of social control than any specific trait or characteristic. Under this ideological framework, many people's potential went unrecognized and undeveloped. Fear-based rhetoric popularized the idea that science was going to protect society from becoming overrun by people with disabilities; that segregation from the mainstream of society is necessary to control the threat; and reproductive technology and congregate care are the best tools for social control. I don't need to describe to this audience all the ways in which this social experiment failed, but if you are interested in learning more, I recommend Michael Wehmeyer's book, "The Story of Intellectual Disability."

What rescued us from that dark time, was a clear message of hope. In the 1970's we started to close 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 living conditions and lack of opportunity. In the 1970's we were still defining people solely by their disability. But, we believed that even disabled people can benefit from living in the community and from educational and social opportunities. At the time, this idea was an advancement—it was a message of

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[1] Michael Wehmeyer. The Story of Intellectual Disability. Brookes: Baltimore. 2013. P. 132-40.

hope. If people are treated more normally, they will function more normally. We developed a lot of good community resources for children—alternatives to institutional care.

By the 1990's this view had again shifted. With more exposure, people began to recognize that disabled people are more than their functional limitations. This led to the hopeful 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 disabled part which is their autism, cerebral palsy, epilepsy or psychiatric illness. And we insisted that people with disabilities shouldn't be defined solely by their disability. The disability is viewed like a chronic illness—something separate from the person—something that medical technology might someday cure or prevent.

During the same period, we made great strides in the field of genetics. By 2003, we had mapped the human genome. For the first time we were able to read nature's complete genetic blueprint for building a human being. This is exciting stuff. But what are we going to do with that information? What messages are we going to tell? We know from history that science—reproductive technology, mixed with fearful messages—messages that define intellectual disability as a genetic defect--are dangerous.

Anybody here see the film, Gattaca? In the film, reproductive technology is used to create designer people who rule society. Wealthy people choose the genetic makeup of their descendants. Genetics determines a person's opportunities. In the movie a natural-born man, who is genetically imperfect, wants to explore space. To get an opportunity he has to assume the identity of a genetically perfect man who was paralyzed in an accident.

As we emerge from the Great Recession and try to regroup, what is the message we want to send? What path are we on? Where do we go from here? The Person-First concept is another message of hope—hope that we can connect with the basic humanity of each individual. It is a step up from mere tolerance and awareness. But it falls short of complete acceptance. Person-First rhetoric is similar to the rhetoric about gay people during the 1990's. 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 could overcome premenstrual syndrome and pregnancy to be as productive as a man. I remember being taught in medical school to compare everyone to a hypothetical 70 kg, heterosexual, White male. I was taught this is the definition of "normal."

But being gay, being a woman, or having a disability is integral to who we are. These aspects of identity can't be considered separately. I am not a series of deviations from the norm. Our views of disability continue to evolve. Neurodiversity is a hopeful evolution from 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! The next step to full inclusion and full access is a language of acceptance…eventually a language of appreciation and celebration of the unique perspectives and gifts that people with disabilities contribute. The Neurodiversity Movement's main leaders, are disability advocates. **[Slide: Nothing About Us Without Us]** 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.

The "problem" with having people with disabilities at the table, is that sometimes they say the darndest things! Like our research agendas don't reflect community values. Or the therapy, diagnostic test, or service we just spent our careers developing, isn't actually one the disability community wants or appreciates. Or maybe they don't want a cure. Or maybe they want a service that doesn't yet exist, or that isn't ideologically compatible with the services that do exist. Now what? Do we hear the message through a filter of fear? Is it a threat? Or do we hear it through a filter of hope? No doubt, there are some people who will get defensive and dismiss people's lived-experience by saying, "You don't know what's best for you," or "Your opinion doesn't count. It's those other disabled people we are talking about," or "You don't appreciate all I have done for you!" But I think the people in this room will listen, learn, partner, and work together to improve.

So what are disabled people telling us about housing and health care—the two big challenges we need to tackle if we are going to succeed in achieving full integration? What we have learned from many experiments with setting up schools and segregated communities of various sorts? Congregating disabled people in protected places--places that are outside of the mainstream of life-- is corrupting. Linking services to housing is corrupting. No matter how idealistic the founders; no matter how beautifully appointed the grounds; no matter how high-quality the staff, over time, clustering disabled people together favors a shift in focus from the needs of clients to the convenience of staff. When the general community doesn't regularly interact with disabled people as neighbors, coworkers and friends, then public support dwindles. Fear of the unfamiliar takes hold. People don’t have personal experiences to counteract their stereotypes. Gradually, congregate settings have a tendency to rob residents of choice, relationships and opportunity. They rob the public of the opportunity to benefit from living, working and studying with disabled people. This may not be true for every individual, in every situation, in every institution, at every stage in life, or at every moment in time. But we have ample experience and solid global research to conclude that congregate care is bad public policy. We are fortunate to live in an era where our laws reflect this, and where we have strong legal protections through the Olmstead decision to ensure that, regardless of ability, people have a right to be served in the community. This is a wonderful legacy that I hope we are wise enough to protect. We need housing options that allow people to live in their own homes or with family.

Since the policy evidence for this is overwhelming, consistent and robust, why aren’t all of California’s institutions closed? One reason is that change is hard. But I don’t think that is the only reason. As a parent, a professional and an advocate, I am well aware of what it takes to support someone with a complex disability in the community. And I’ve seen first-hand the horror of what happens to people who can’t access the support they need. When we close institutions and fail to invest in community supports… When we fail to maintain and monitor them… When we starve them of resources… When we lose track of people…When we sit back and wait for them to ask for help….it isn’t pretty. In fact it is ugly.

What happens when I’m gone? What happens when I am disabled, and can no longer advocate for my son? I’ve had my share of nightmares about my son being left to the care of my corpse. I get the fear. The fear is potent. Expressing fear is cathartic. But fear is destructive. A UCSF Nobel Laureate discovered that stressing out caregivers destroys their telomeres causing them to age. **[Slide: Telomeres]** It accelerates the process of going from looking like this **[Slide: Barbie]** to looking like this **[Slide: Senior Barbie]**. While my family clearly needs help, more fear definitely is not what I need to be happy and healthy. Caregivers who are well-supported, have good outcomes for health and quality of life.

I need hope. We need hope. Hope that the citizens of California will make good on their promise. That we will pass on our values to our kids. That the resources we build today, will be sustained tomorrow. That my child will continue to have the support he needs to make his life a blessing. For people with complex disabilities to thrive in the community, *we need a solid infrastructure beneath their supports.* I’ll say that again, because it is my new mantra. People with developmental disabilities **need a solid infrastructure beneath their supports.** We need housing delinked from service provision and plans that are resilient; robust; and dependent on no single service provider. The type of infrastructure we need is intensive case management; small case loads; crisis services; housing options; integrated vocational programs; day programs; protected ways for families to leave money and homes for their kids; independent consult and assessment services; a full range of services and supports available for purchase that will evolve as our children's needs change. A service and support structure that includes input from a variety of experts, and can rebuild itself when elements fail. While we want people to use mainstream services and accommodations as much as possible, the reality is that many people with complex disabilities need services that are so specialized that they can't be adequately met with modifications to mainstream resources. The two main things that lead to people back into institutions are inadequate access to housing and health care. What the parents of the people currently living in the institutions are telling us is that we still have work to do on building the solid infrastructure beneath the supports. We need to build infrastructure in order to ensure that *their* children, *our* children, the people with the most complex needs, have good lives in the community. We have accepted a responsibility.

What is our role as health care professionals? We have a lot of influence over the lives of disabled people. We control access to medical care. Often, we also control access to education, employment, transportation, housing, services, supports, assistive equipment, and public benefits. In many situations we even control the opportunity to make decisions and to form and maintain relationships. We influence research questions, funding and methods. Our research drives public policy. Public policy is starting to fund more long-term care and habilitation services through health care insurance. This gives doctors even more control. With that power comes the responsibility to become self-aware about ways in which we are shaping the cultural narrative of disability. We need to listen to people with disabilities; partner with them; learn from our history. We need to challenge ability bias when we see it…when we can't get our patients safely on a scale or exam table …when we tell a woman that birthing a baby with a disability is a "bad outcome"… or when we see reports that describe a patient solely by deficits rather than by strengths. Our words, our actions and our leadership matter. Our power to combat ability bias is potent. When we hire people with disabilities to work with us; when we scoop up a baby with a disability and rock them on our knee; when we talk about strengths and potential; when we train ourselves and our staff; when we buy accessible equipment; when we go to Washington and Sacramento and bring our patient's stories; when we boost their messages, we have a tremendous opportunity to improve quality of life for disabled people.

Yes, we can expect a doctor's office to have an accessible exam table and a wheelchair scale. We can expect clinicians and their staff to learn some basic cultural competence; to address their patient's directly and listen and respond respectfully to their concerns. We can expect double appointment times. But for many, these accommodations aren't enough. People with disabilities have told us what they need—clinicians who have deep expertise; clinics that are staffed differently; medical case management; alternative formats for education materials; assistance with health care navigation and decision making; flexible scheduling; specialized transportation or home care; coordination with long-term care; collaboration with families and direct care professionals; services which are not readily accessible such as hospital dentistry, custom wheelchair design, crisis and behavioral services; transition support; specialized mental health; and augmentative communication specialists. We have been told that we need equipment that is accessible, and staff who know how to use it. This is not a modified mainstream service. It is a special service designed around the population it serves.

That is the infrastructure we need to build—a community-based health care delivery system that wraps around people who live in the community, and which can provide a key piece of the solid infrastructure that supports successful community living.

Fear-based rhetoric isn't going to get that infrastructure built. Fear leads to exclusion, pity, bullying and restrictions on opportunity. Fear isn't going to get our family welcomed in our synagogues or mosques, or supported to complete higher education, or trained in a marketable skill. Fear is not going to motivate the public to hire our kids, or pay them a fair wage. I'm not naïve enough to think that moral imperative arguments are strong enough to sustain a robust system of care. We need leverage. For the past 40 years our leverage has been the closure of institutions. We argued that without sufficient community support, disabled people will return to institutions which are more expensive and more restrictive. But California has already made a commitment to stop admitting people to institutions. Where will our leverage come from now? Fiscal conservatives are no longer our allies because we are no longer saving taxpayers money by moving people into the community. We actually need more resources. Many service providers in California haven't had a cost-of-living raise in 15 years. That is not ok.

In addition to building the stable infrastructure under the supports, ultimately, to sustain it, we need to build a strong and sophisticated political and advocacy infrastructure. We need to register to vote. Every one of us. We need to break down barriers to political access. We need to hold politicians accountable. If necessary, we need to spread our message of hope in ways that cannot be ignored. **[Slide: Civil Disobedience]**.

So I leave you with this message:

- Motivate with hope
- Protect our civil rights legislation
- Learn from history-let's not repeat the same mistakes
- Follow the lead of the self-advocate community
- Build housing and health care infrastructure
- Engage and organize politically