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before the
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"Lessons from the Field: Learning From What Works for Employment
for Persons with Disabilities"

Chairman Harkin, Ranking Member Enzi and Committee members:

I am honored to participate in this Committee's examination of employment opportunities and barriers for Americans with disabilities. I bring to this discussion both my experiences as someone born with a visible disability and my experiences in the business community as a human resources professional and Chief Diversity Officer.

I am a baby boomer, born in 1959 in San Francisco, California at Letterman Army Hospital. The doctor who delivered me told my terrified parents that I had two broken femurs due to a brittle bones disease (Osteogenesis Imperfecta), and that I would not likely live beyond age two. He said that if I lived I would not walk or go to school. My parents carried me home on a pillow afraid that they would cause a fracture when feeding or caring for me. Although I would end up having more than 70 broken bones and 25 major surgeries to straighten and strengthen my legs, I have been able to live a full and active life.

Starting in the second grade I was able to attend regular public school. I went on to college and then entered graduate school for clinical psychology. I worked full

time, and went to school at night—still experiencing fractures now and again—but they were less frequent, and I was able to live independently.

Upon graduation I wanted to apply my skills in a corporate setting, but I faced many attitudinal challenges. Five different senior corporate executives told me that I should stop applying for more senior level positions. They felt I was "lucky to have a job," and should realize "someone like me" could not expect to be in a leadership position.

In 1987, when the COBRA act took affect, I decided to try a new strategy. COBRA created an opportunity for me. It allowed me to maintain my health benefits while I founded and managed "Bridge to Jobs," a non-profit job placement agency for people with disabilities. We were able to annually place approximately 400 people with disabilities into meaningful employment. I learned from this experience that many people with disabilities also belong to other disadvantaged and/or under-represented groups including people of color, older workers, veterans, and individuals living in poverty or are otherwise economically challenged.

In 1990 my Congressman, Norm Mineta, asked me to assist with the passage of a bill he was a key co-sponsor of in the House, the Americans with Disabilities Act. After much hard work by many, including the Chairman of this Committee, I was honored to be there on the White House lawn when President George Bush signed the ADA into law.

After that historic day, I thought about how best to make sure this legislation resulted in the intended outcome of ensuring that Americans with disabilities can fully participate in our society. I quickly realized the best place for me to affect change was back in the corporate sector--creating sustainable replicable models for full employment and inclusion of people with disabilities in the workforce.

In addition to my extensive business and corporate experience, I also have a great deal of family experience. My husband Dan, who also has a disability, and I have three children who are now teenagers. They each have various disabilities, and we have learned much about the contemporary challenges youth with disabilities face educationally, socially, and in preparing for college and a career.

In my professional life, I have been a "Chief Diversity Officer" (CDO) for 20 years in three different companies. Being the only CDO that I know with a visible disability, I have been honored to represent both the business perspective and the needs of people with disabilities in a variety of settings—including this important hearing. I have come to understand the enablers and barriers to fully including people with disabilities in the workforce. Today I would like to share my recommendations from these experiences.

Improving the Lives of People with Disabilities by Moving to a Social Model

I strongly believe that the foundation of any changes in our current system needs to be rooted in moving our view of disability from a **medical** model to a **social** model.

The medical model of disability is still prevalent in our country as evidenced by the manner in which Americans with disabilities are depicted through our language choices, media portrayals, fundraising activities, and program eligibility requirements. People with disabilities are routinely characterized as having some sort of deficiency, that their condition is inherently negative and needs to be ameliorated, and that the agent of remedy is some type of health professional's intervention. In the employment sector, we may do the most harm of all. Before individuals with disabilities are eligible for supplemental security income (SSI) or social security disability insurance (SSDI), they must declare they cannot work. This is the ultimate example of a deficit model approach, and is bad policy if we want individuals with disabilities to be part of the workforce.

A social model defines disability as different from the average, neutral in the absence of additional context, and located in the interaction between individuals and society. The remedy in the social model is ensuring that the environment is accessible and that attitudinal barriers are addressed. In this model there are multiple individuals who might assist in this process, and self-assistance is often the primary mechanism. There are signs that this model is gradually emerging in our nation's schools, programs, workplaces and policies, but we need to accelerate this paradigm shift to effect sustainable change and to ensure that individuals with disabilities are fully included in all parts of society.

At Merck our philosophy about employees who have disabilities is that they likely have strengths that offset and are linked to their limitations. It is also likely that their limitations provide new perspectives that support innovative thinking. We believe that living life with some limits can hone skills and values that can enrich the contributions employees can make. The inclusion of people with disabilities in our workforce sets a tone, particularly in a health care company, which improves the work environment for all. It demonstrates a core principle, that better health care outcomes are achieved when consumers are empowered decision-makers that make informed choices due to heightened health literacy and confidence. Diversity is our nation's strength and competitive advantage in the global economy. We literally represent the world in one country, and if we could more consistently harness the available knowledge and insight of diversity of thought and experience through inclusive practices, we would be able to develop and deliver more innovative solutions faster than any other nation.

Educational Challenges

Schools are the source of our workforce, but as early as middle school we are starting to lose talent in our country. Unfortunately for students with disabilities there is all too often a crisis of low expectations. While access to public education is better today than in the past, often children with disabilities (mine included) are "tracked" away from college. While today's Individual Education Plans (IEPs) help, it is important that they be set up to enable students to attain the same academic standards as their peers, not just to pass standardized testing. An IEP needs to be viewed as an environmental enabler in our education system, much like a job accommodation in a company. The IEP should promote access to rigorous curricula that will enhance the opportunities for students with disabilities. It is important that we have the same standards for young people with disabilities. The tools available to access challenging curricula, including modified instructional techniques, assistive technology and accessibility as resources, will allow students with disabilities to achieve outstanding educational goals. This is consistent with the Elementary and Secondary Education Act expectations that are set forth, and we should be holding schools accountable for the rigorous academic achievement of students with disabilities.

One great program that is currently underway and is similar to the U.S. Department of Education TRIO programs is the Rutgers Future Scholars Program (RFSP). This intervention at grade seven identifies disadvantaged youth, including young people with disabilities, and offers them a variety of invaluable resources including:

- The program focuses on building the Scholar's social capital through collective efficacy. The RFSP is unique in that it creates a pipeline of support from 7th grade through college graduation (9 year continuum of support) providing academic year tutoring, mentoring, cultural and career-readiness activities, and summer learning cost free. Every year 200 Scholars are selected, and as of 2011 the program serves 800 students from across New Jersey. Lastly, which makes this program extraordinary, every Scholar is promised a tuition scholarship to study at Rutgers if they earn admission upon graduating from high school.
- Staff who work directly in the schools to obtain additional information about selected student, such as their Individual Education Plans. This informs the accommodations that are provided for the students while they are in the program and enables RFSP staff to maximize each scholar's multifaceted growth. All accommodations are defined and progress is tracked through the creation of an Academic Success Plan or Victory Plan. This is a key tool, enabling RFSP to provide optimal learning and accessible environments based on the students' strengths and challenges. As part of this planning school partners, parents, and the Scholar him or herself are included in the development of the plan.

- The program's goal is to provide a wide variety of promising students who are underrepresented in higher education with the support needed to graduate from both high school and college. Thus, the program focuses on the many dimensions of differences of the scholars and provides support so the scholars can maintain a focus on inclusion as well as fostering educational equity.

Public-private partnerships like the Rutgers Future Scholars and the U.S. Department of Education's TRIO programs demonstrate that this model of early support can have tremendous impact on students with disabilities when they are included in the target population.

Once a student graduates from high school and begins their college experience, a new set of challenges emerges. While there is frequently some form of disabled student services on campus, designed to gain access to accommodations and various types of academic support, student career planning and placement centers are less accessible. Those career planning and placement centers often direct students with disabilities who are seeking employment advice back to the disabled student services offices. Disabled Student Services office staff, while often very qualified to provide accommodation for students while they are on campus, often know very little about the career planning and placement process and the labor markets in which students with disabilities might be interested. This leaves students with disabilities without the type of job placement resources that non-disabled students receive.

But there is a solution: Career Opportunities for Students with Disabilities (COSD). In its 12th year, COSD is a network of over 1200 colleges, universities and national employers in the private and public sectors. They raise awareness regarding the unique challenges that students with disabilities face and help with career placement. They also encourage employers to specifically request access to students with disabilities during campus recruiting activities, and inquire whether or not the school coordinates their disability support services and career placement programs. The employers' advocacy, combined with information from COSD, leads more schools each year to adopt an integrated approach to supporting students with disabilities as they begin their job searches.

Every year, contemporary information, resources and training are disseminated by COSD via conferences, summits and webinars to professionals in both higher education and employers. The goal is to enhance awareness of career development strategies and to foster best recruiting practices of college students and recent graduates with disabilities, including veterans. COSD Career Gateway provides direct service to college students through a nationwide, online, no-charge job posting and student resume database specifically designed for college students and recent graduates with disabilities. Finally, COSD coordinates "Student Summits," regional networking events that bring together up to 60 college students, veterans and recent graduates with disabilities with

employers in an intimate and relaxed setting to network and get to know one another. The purpose is to help students become more confident and be able to more positively present themselves to employers. These summits also allow hiring managers to become more comfortable interviewing students with disabilities in a no pressure setting.

Other supports are needed to further the COSD model. For example, grant funding is needed to establish **Communities of Practice** with higher education institutions to identify the best method for each campus to outreach to students with disabilities for career development activities and to benchmark methods of collaboration between student disability services and career planning and placement. In 2010, a demonstration project, funded through the Medicaid Infrastructure Grant, was conducted with nine higher education institutions in New York State. The result was each campus identified their own unique model programs integrating disability support service and career placement services. These models were shared among the nine IHEs. A more extensive communities of practice model using this approach could be very helpful if it were replicated across the country.

In addition, research is needed to specifically identify the barriers that prevent college graduates with disabilities from making a direct transition to work. This research should be conducted by disability categories to allow a more targeted plan to help students with specific types of disabilities that have a significantly more difficult time in finding career employment. This includes students with psychiatric disabilities, intellectual disabilities, autism and sensory disabilities (blindness and deafness). As you can see, COSD is a great model for accessing college students with disabilities, but for companies of all sizes to access candidates at all career levels, additional partnerships are needed.

Employment Challenges

At Merck we collaborate with and support the US Business Leadership Network® (USBLN®) where I am proud to serve as a board member. It is a national disability organization that serves as the collective voice of over 60 Business Leadership Network affiliates across North America, representing over 5,000 employers. The USBLN® helps build workplaces, marketplaces, and supply chains where people with disabilities are respected for their talents, while supporting the development and expansion of its local BLN affiliates.

The membership of the USBLN believes that the following public policy changes would expand the pool of job candidates and entrepreneurs with disabilities:

- establish appropriate affirmative action expectations for people with disabilities as with other under-represented groups. We also suggest there be an expansion of the census survey to include questions that help

bridge the gap between occupational information and demographics inclusive of people with disabilities and veterans. For those that are unemployed, we could leverage the educational attainment tables to set more aggressive hiring goals. In the interim, it may be worth establishing a percentage hiring goal for a location as the available pool of talent with disabilities varies across the country due to practical matters like access to public transportation and other forms of infrastructure that are required.

- evaluate the impact of developing a standardized definition of disability across all federal programs. The USBLN believes that federal agencies need to have better alignment about when it is appropriate to ask about a disability and necessary accommodations and supports; in addition, companies need to make the self-disclosure process for employees with disabilities something that is both easy to do (separate from requests for workplace accommodations) and as risk-free as possible.
- evaluate the impact of modernizing the Social Security definition of disability by defining disability in a manner that acknowledges the interaction between the person's disability and the environment, and does not require the individual to prove their inability to engage in substantial gainful activity
- create employer incentives to increase the availability of effective workforce retention policies and programs to keep working adults with newly-diagnosed or recently-exacerbated medical conditions
- develop financial incentives for businesses to provide transportation subsidies for employees with disabilities.
- promote international accessible design standards for building environments, transportation vehicles, and information and electronic technology.
- create incentives for the parent and academic communities to promote STEM careers for students with disabilities
- authorize research to collect hard data about the discretionary spending power of people with disabilities, the actual and potential employment pool of persons with disabilities, the disability market share, and the long-term ability of people with disabilities to retain employment
- authorize a comprehensive review of statutory and regulatory authorities addressing procurement and acquisition of Federal contracts and develop proposals for revisions, as necessary, to insure increased utilization by, and awarding of contracts to, disability-owned business enterprises

The USBLN's flagship program is the *Disability Supplier Diversity Program* (DSDP). DSDP is the nation's first and only third party certification program for disability owned businesses and includes service-disabled veterans. The certification is a rigorous process that includes a site visit. It offers the Disability Owned Business Enterprise the opportunity to market its certification and to connect with USBLN member companies. The program advances economic opportunities for all entrepreneurs with disabilities, by working with America's top corporations to broaden corporate supplier diversity programs to include disability-owned businesses. The ultimate goal of the Disability Supplier Diversity Program is to develop and grow an infrastructure that will foster a mutually beneficial relationship between corporate purchasers and disability-owned businesses.

The business community needs research to effectively build the business case to broaden corporate supplier diversity to include disability-owned businesses. The research should:

- identify the pool of entrepreneurs/potential suppliers with disabilities;
- identify barriers and facilitators experienced by disability suppliers;
- examine issues of capacity development, job creation, effective relationships with corporations, and inform more targeted capacity/business development for disability owned businesses; and
- identify facilitators and barriers to becoming a successful supplier and coming to scale as a business, and working effectively with corporations.

Once a company has successfully recruited people with disabilities, the next step is to ensure full inclusion in their workforce and workplace. At Merck we have a **"Workplace Enablement"** program that provides supportive, productive and flexible work environment solutions for employees with both non-apparent and visible disabilities. This not only ensures we are fully compliant with regulations, but positively impacts return to work after a health event, and enhances productivity for employees, their managers and peers who can quickly access appropriate accommodations solutions.

There are four key pillars in the program:

- Inclusion messages that ensure the program is well understood and easily accessed by employees, managers, and the human resources community.
- Linkages to our broader health and wellness initiatives to ensure all employees are proactively engaged in our fit and healthy efforts.
- Ensuring full compliance with ADAAA and OFCCP guidance and associated documentation requirements.
- Training for managers to support confidence and capability by addressing any concerns around language choices, accommodations, and performance management; linking these efforts to the broader talent objectives (e.g. retaining top talent after the advent of a health challenge),

the business case for disability inclusiveness, an overview of the ADA Amendment, and some case scenarios to "make it real."

At Merck we also have evaluated other aspects of company life to ensure full inclusion of people with disabilities:

- We have created guidelines and checklists for ensuring meetings are accessible and that accommodations are readily available for travel, hotel requests, accommodations for presenters with a disability, and dietary needs.
- We have evaluated and addressed various access issues to Merck facilities for both guests and employees to make sure our environment is safe and welcoming.
- We ensure that development opportunities, both virtual and classroom, are accessible.
- We routinely included closed-captioning during major business meetings and make this service or sign language interpreters available to colleagues upon request for smaller meetings.
- We offer a variety of work/life tools and resources, including ready access to flexible work arrangements, and a variety of home health support through an external partner.
- We include entrepreneurs with disabilities in our supplier partner programs.
- Merck has partnered with eSSENTIAL Accessibility, a provider of a software-based service, to make online environments fully accessible to individuals with physical disabilities.

Our desired outcome at Merck is that candidates and colleagues who have a disability believe that "Merck is always there for me. They know that I am not defined by a disability, but by the contributions I am able to make to my team's goals."

Finally we have a very active Employee Resource Group for colleagues with disabilities, caregivers and allies. The members of this team have helped us to develop our approach, as outlined above, in keeping with the social model of disability. The Employee Resource Group has played a key role in executing our disability support and diversity programs. We truly believe that our efforts to fully include people with disabilities in our workforce will help Merck to achieve our mission: ***to become the most trusted and valued healthcare company to all people.***

Final Recommendations

Prior to joining Merck in 2001 I interviewed with many Fortune 250 companies, most of them on the East Coast. I was surprised and dismayed that despite my strong resume and ten years of experience as a successful and well regarded diversity leader, I was repeatedly rejected as a candidate and explicitly told it was

because of my disability. In one particularly memorable situation, after several phone interviews, I was flown to New York City for an interview. Upon meeting me the recruiter cancelled all my other interviews. He explained that the firm was not comfortable considering someone like me for the role. However, given my subject matter expertise they wondered if I would be open to working "behind the scenes" if they hired someone with strong media and government contacts who did not have diversity experience. Obviously, I declined the offer.

I am interested in contributing to society, and fortunately when I interviewed at Merck, I found the perfect match. At Merck I feel I am truly part of our mission to enhance and save lives by addressing unmet medical needs. I believe I can have particular impact in under-served communities. When I interviewed at Merck, their chief concern was whether or not I was willing to relocate from California to New Jersey, a move I have learned is not all that common in our country. Now having served as a Chief Diversity Officer for twenty years, I would offer the following parting thoughts regarding full inclusion strategies for people with disabilities:

Recommendation #1: Like many who identify as a person with disability from a young age, I was told that I was "special." Everything I was involved with was "special." This included the special school I attended for the first few years, the reason why the local newspaper featured me regularly in the Sunday living section, the wheelchair I used after a broken bone or surgery, the place where I received healthcare, and the various adapted activities I engaged in—all were "special." Fifty years later, we still commonly use special to describe the ways our society thinks about people with disabilities and the associated products, services, and activities we use. The intent was and is to depict these things in a positive light. The reality is that if you are special enough to be periodically featured in the Living or Community section of your newspaper, whatever health condition you are managing is the least of your worries. You have now entered a world where people are either characterized by society as "poor souls" who are dependent on others, or "inspirational heroes" who make those who don't have a disability shake off their worries and say, "If they can do X, (fill in the blank activity), why then I should stop feeling sorry for myself and do more with my life!"

Recommendation: Avoid the word special when referring to programs, services, building, and other supports related to disability. We have done a good job of eradicating "handicapped," "crippled," "confined," "afflicted," and various other damaging words to describe people with disabilities. Let's go the distance and work on this last word that damages self esteem and sets people apart. For firms that have a global footprint, they may want to consider adopting "differently able" or other country-specific language which translates better than "disability." Unfortunately "disability" in some languages translates as not valued or less valued. It is also important to take the time to ask and seek to understand how each sub-community of people with disabilities prefers to be referred. For instance those with hearing impairments prefer to be referred to as "deaf,"

individuals who are of small stature, like my husband and I prefer “short-statured” over “midget,” and people with intellectual disabilities prefer “developmental disabilities” vs. “mental retardation.” Words matter.

Recommendation #2: Managers of people with disabilities sometimes assume that everything is fine because the person with a disability who works for them is not complaining, even if they have remained in an entry level role for an extended period and are not interacting with people outside of their immediate work area. These employees are highly vulnerable to reductions in the workforce as their skills often become dated and they are typically not visible to more senior leadership when business decisions are made about layoffs and workforce reductions.

Recommendation: Make sure programs for individuals with disabilities continue to enhance their job skill development after the person is hired. Ensure managers continue to follow the progress of people with disabilities once they join the firm to ensure they are reaching their full potential to contribute to the business. If people with disabilities are languishing in entry level roles, find out why, even if they are not complaining, and support them to grow and develop. If a firm has low expectations, of anyone, those employees will likely live up to those low expectations.

Recommendation #3: Caregivers should be considered. My husband Dan and I both have disabilities ourselves, and are also caring for three children with disabilities. We also care for my mother who is challenged by various conditions. We are just as grateful for the resources and supports that we have access to as caregivers as for the workplace accommodations I have had available to me over the years. A company's reward for addressing the needs of caregivers as part of their corporation's disability strategy is more engaged employees who are getting the support they need to care for a loved one so they can focus at work. Examples of resources we provide along those lines at Merck include elder care resource and referral, college planning resources for parents of children with autism spectrum disorders, a robust Employee Assistance Program, back-up child care, flexible work arrangements and various internal networks for caregivers to exchange ideas and resources.

There are some risks to focusing on the care-giving population as part of an overall approach to addressing disability at work. The "out" caregiver population is usually much larger than people who are willing to self-identify as having a disability. As a result the needs of this group can over-shadow the needs of the individuals who are differently able, and they do tend to be different. Caregivers are often focused on how to help their loved one get the quality health care and education-related support they need. People with disabilities are focused on career development, accommodations in the work environment, inclusion in

company social activities, and social justice/equality issues like other under-represented populations in your workforce.

Recommendation: Combine the two groups to create a critical mass for disability initiatives. Because there are some common interests, this can help programs be sustainable and help companies identify and train workplace "allies" who will create momentum. Separate and clearly articulate the needs and priorities of the two groups making sure that both are experiencing visible and substantive progress towards their most pressing concerns.

Recommendation #4: Companies should foster an environment where people are comfortable with their disabilities. Then they are able to more freely ask for what they need to be fully productive, engaged, and included. It is useful to look to the lessons learned from the work those of us in the field of diversity and inclusion have done in the Lesbian Gay Bisexual and Transgender (LGBT) community, which faces many similar challenges around being out at work:

- Ensure benefits plans and flexibility policies are equitable and accessible (e.g. eliminate pre-existing condition clauses in medical plans, provide coverage for mental health support, manage employees by objectives vs. face time).
- Engage allies in the workplace, and provide them with the language and tools of empowerment like "differently able" and "wheelchair user." It was a big deal for the LGBT community when company leaders could say those four words in the acronym. We need to do the same for those who have been traditionally known as "handicapped." Refer to this group in a manner that is empowering and deserving of respect as colleagues and consumers vs. in the context of philanthropy. Create "safe space" efforts where allies are available as visible confidantes to interrupt misinformation and champion full inclusion.
- Make sure your business case is strong and well articulated for this population, which is well represented both in the labor pool and marketplace. LGBT and disability populations are very similar in size and buying power.
- Ensure that senior level leaders who have a disability are visible as role models and have them address head-on the perceived risks around being out and the importance of bringing all of who you are to work.
- Invite other Employee Resource Groups to support disability efforts. Since all other groups include people with disabilities there is a strong case to be made for everyone getting involved in the efforts for this constituency. Remind your ERG members that cultural differences can lead to additional challenges for people who have a disability, and if we are to address the needs of this population, as we have done with LGBT, we need to be courageous enough to say out loud how these cultural norms compound the challenges people with disabilities face.

Recommendation: Apply best practices and lessons learned from LGBT advocacy work in addressing needs of employees who are differently able.

Recommendation #5: With the current conflicts in the Middle East and the many service men and women who are returning with both hidden and visible disabilities, there is a new call to action we must meet. The military is looking for corporate partners to help them in supporting veterans who are transitioning back to civilian life. Now more than ever it is important that we invest time and effort in understanding the transferrable skills that these men and women learned during their service and how they might be applied in our industries. We also need to educate ourselves in the various hidden disabilities that are all-too-prevalent in this population including post traumatic stress disorder, traumatic brain injuries, and various other chronic health conditions that are the result of the extreme and dangerous duty they lived through.

Recommendation: Develop partnerships with military leadership to understand and transition returning veterans. At Merck we have formed a Veteran's leadership network that is made up of about 500 men and women from all branches of the military who have informed our outreach, recruitment, accommodation, and inclusion efforts in a manner that is respectful, sensitive, and credible. We are encouraged by the enthusiasm of our Merck veterans who are applying their can-do spirit to the challenges associated with matching returning veterans with our job opportunities.

I feel very fortunate to have had several people in my work life who gave me the opportunity to demonstrate that I am differently able. Their names and faces are always with me. I know how important it is to evaluate a person with a disability to determine what they are capable of and what they have not yet demonstrated. We should all strive to be that person who sees what is possible.

Since the Americans with Disabilities Act was signed into law 20 years ago many things have changed, but I think we can all agree that we have not yet achieved the vision of economic empowerment and meaningful employment for people with disabilities that we all dreamed of that day on the South Lawn of the White House. As we near this milestone anniversary let's celebrate the laudable successes, and redouble our efforts to address unemployment and under-employment of people with disabilities.

In closing, as parents, my husband and I know we can continue to be strong advocates for our children in partnership with the schools they attend to make sure they are fully prepared to compete for jobs in our country. But if they are to fully contribute to this nation as Americans with disabilities, we will need your help.

I will not be the Chief Diversity Officer for the company they go to work for some day, and I am counting on the leadership of our country to make sure that public policy and legislative efforts are in place that not only help the U.S. to be more competitive in the global marketplace, but also ensure my children are not stigmatized, marginalized or excluded from contributing to their full potential.

I am at your service if I can help in any way.