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**Draft Remarks of
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Presented to the Ninth Annual NACC Meeting on ICF
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*“How the Federal Government is Working to Tear Down Barriers for
Persons with Disabilities, and How Can we Use the ICF to Ensure Maximum Impact?”***

Good evening. I want to thank David Gray for inviting me to join you. It's a pleasure to be here. I believe I am the only person speaking at your conference on behalf of the Bush Administration, so David suggested that I speak about the President's "New Freedom Initiative" and potential federal agency prospects in using the ICF.

I'm going to wear two hats tonight. The first part of my remarks will focus on the President's "New Freedom Initiative" and how I see it weaving in with some of the aims of the ICF. The second part of my remarks will focus on my perspective of the ICF, and will serve to challenge you to continue your hard work on the ICF to ensure it has **maximum use and, therefore, impact** on the lives of persons with disabilities. I bring with me greetings from President Bush and from Secretary Tommy Thompson, and I commend you on completing this monumental effort of the ICF.

In preparing my remarks for tonight, I wanted to share with you a statement made by Vice President Hubert H. Humphrey. As you may know, the U.S. Department of Health and Human Services headquarters in Washington, D.C., is named the "Hubert Humphrey Building" in his honor. At the dedication of the building on November 4, 1977, Humphrey said:

"It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life -- the sick, the needy, and the handicapped."

Of course we no longer use the term "handicapped." Nor do we use the term "disabled." Those terms have been replaced with "persons with disabilities." And we also don't want to think of "persons with disabilities" in the shadows of life, but rather to nurture these persons in the sunlight of life. And we've actually gone a step further. Because a single common goal between the New Freedom Initiative and the ICF is to take the emphasis off of the prefix of the term "DIS" in disabilities, and replace it with an emphasis on **ABILITIES!** We are both focusing our time, our resources and our energies where they should be -- on the "abilities" of persons and how we can best meet their needs.

Since the day that Hubert Humphrey defined the "moral test of government," the federal government has taken many steps to improve the lives of persons with disabilities. But perhaps the most revolutionary steps were taken by both President George H. Bush and President George W. Bush. The last great reform was demonstrated when President George H. Bush signed the Americans with Disability Act. Because of that law, millions of Americans can now compete for jobs once denied them; enter buildings once closed to them; travel on buses and trains once unequipped for them. Thirteen years after the ADA was signed, we are, indeed, a better country for it.

And yet, we are becoming even better. On February 1, 2001 -- within TWO weeks of taking office -- President George W. Bush announced his “New Freedom Initiative” and laid out a bold plan to tear down the barriers to equality that confront many of the 54 million Americans with disabilities. And on June 18, 2001, he signed Executive Order 13217 ordering the Federal Government to assist states and localities to implement swiftly the Olmstead decision to ensure that “ALL Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.”

So the NFI and the ICF share common goals, with the emphasis on health and ability, rather than illness and disability. We’re really working to change an entire culture from focusing on what people can NOT do to what they CAN do and how WE -- not just the federal government, but the entire public and private sector need to actually change our environment to make it work for all persons. Never before has there been a President who’s made sweeping changes across the federal government to better ensure full community participation for all individuals with disabilities across the lifespan. So the time is NOW. We have a President and we have an Administration that is opening doors never opened before. The NACC and the World Health Organization have just completed nearly ten years of work in completing the “document” the ICF. Now -- you have to *carpe diem* -- seize the moment -- step back, really look at the ICF, and then tell us how to best use it.

Let me tell you about the President’s New Freedom Initiative and some of the ways that I see it paralleling to and interweaving with some of the objectives of the ICF. Within the Executive Order, the President articulated the following goals to best ensure full community participation for all individuals with disabilities. Some of the goals of the “New Freedom Initiative” include:

- C Integrating Americans with disabilities into the workforce;
- C Promoting a comprehensive array of community-based services and supports;
- C Promoting safe, decent house and home ownership;
- C Promoting integration in and sustained participation in the workforce;
- C Increasing access to assistive and universally designed technology;
- C Expanding educational opportunities for Americans with disabilities;
- C Expanding transportation options; and
- C Promoting full access to community life.

The Administration’s goal, and indeed our SHARED goal -- is to increase opportunity and to embrace the abilities and talents of these persons in every way we can. The President’s Initiative is aimed at **eliminating the barriers that unnecessarily hinder Americans with disabilities** as they seek to participate fully in the life of their communities. I think the KEY WORDS here are **unnecessarily hinder**, because with the technologies we have today and those being developed for the future, and the federal government, the states, the private sector -- all of our stakeholders working together -- it is simply unnecessary for persons with disabilities not to be able to lead fully independent lives.

In the New Freedom Initiative, the President directed the Departments of Education, Health and Human Services, Housing and Urban Development, Justice, Labor, and the Social Security Administration to evaluate their programs to improve the availability of community-based services. The Initiative was not simply “accepted,” but -- in truth -- it was **overwhelmingly embraced** by the federal agencies that were directed to evaluate their programs. Several federal agencies even volunteered to join the President’s “New Freedom Initiative,” including the Department of Transportation, Veterans Affairs, Small Business Administration and Office of Personnel Management. The Equal Employment Opportunity

Commission and the National Council on Disability also offered to help. **HHS was asked to take the lead.**

For those of you who may not know, in direct response to the New Freedom Initiative, the President and Secretary Thompson created the New HHS Office of Disability -- establishing for the first time ever -- an office within HHS dedicated specifically to oversee the coordinated development and implementation of policies, programs and special initiatives within HHS that impact persons with disabilities. The new Office was officially created in October 2002. As a person who's dedicated my own life to improving the lives of persons with disabilities, I am truly pleased to be appointed as the first Director of this office. The rapidity in which this office was created demonstrates the President's and Secretary Thompson's commitment to level the playing field for persons with disabilities and to keep the commitment at the forefront and in the spotlight of the Administration.

For those of you who don't know, the HHS Office on Disability provides a central location in the Department of Health and Human Services for individuals with disabilities to gather and to be heard. It provides a place where all interested parties can come together and develop cross-cutting initiatives that can be replicated. It provides a place where there is timely consideration as well as ACTION taken by the Department on issues raised within and outside of the Department about services and supports that individuals with disabilities need to live in and contribute to their communities. And it provides a focal point to interact with other federal agencies charged with implementing the "New Freedom Initiative."

I'd be happy to provide you with more details on my office following my remarks, but now I'd like to elaborate on some of the specific goals articulated in the "New Freedom Initiative" and weave those in with some of what I see in the ICF to hopefully gather and exchange ideas on how we might work together to better meet our goals.

One of the goals I mentioned was "Integrating Americans with Disabilities into the Workforce." Let me tie that in with Chapter 8 of the ICF -- "Major Life Areas -- Work and Employment." We are working throughout the federal government and in partnership with the office of Disability and Employment at the Department of Labor to see how we can partner and also be the catalyst to engage all the other agencies that are concerned with employment and transportation to partner so we're all on one team -- ONE TEAM, working toward the same goal. We are looking at how to change the environment so that -- especially with the use of assistive technology -- we can remove environmental barriers, physical barriers, and so forth so those with disabilities can work. We're very aggressive in telecommunications and implementing Section 508 of the Rehabilitation Act, where -- by law -- every employee with a disability must have the assistive technology they require to function. The law, as you probably know, is that persons with disabilities must have any assistive technology or electronic devices they need in order to work. The law applies only to the federal government, so perhaps there is a way you could work with us to extend that to ALL places of employment, public or private and to all employees nationwide -- to create a different kind of statute where these provisions are made at no cost to the employee.

Employment issues tie in with transportation issues. And another goal of the President's "New Freedom Initiative" that I mentioned is "Expanding Transportation Options." In order for employees to get to work, they obviously need transportation. Likewise, I see you address transportation needs under "Environmental Factors." (e540) We, too, are looking at how to change and adapt transportation in rural, suburban, and urban areas because they are all different and require different solutions. Still there are people with disabilities in all of these various

geographic areas, and we are working to ensure they have access to transportation to get to work. Similarly, there are many different types of transportation, so whether it's the type of vehicle, the type of transportation, such as public buses or trains, we're trying to dovetail transportation systems with the employees' needs. We are working to adapt the various types of transportation environmentally so persons with all types of disabilities have access to transportation and that when they need it, it is available.

"Home ownership" is an important goal in the President's "New Freedom Initiative," which I see parallels "ICF's Chapter 6 on Domestic Life -- Acquiring Ownership of a House." In the President's "Foreword" to the "New Freedom Initiative," he summarizes this part of his vision in a single sentence. He writes: "Home ownership has always been at the heart of the "American Dream," citing that in 2001, Congress passed the "American Home Ownership and Economic Opportunity Act of 2000," which reforms Federal rental assistance to give individuals who qualify, the opportunity to purchase a home. In the same document, he announced that the Administration would implement Public Law 106-569, which allows local public Housing Authorities to provide recipients of Section 8 vouchers who have disabilities with up to a year's worth of vouchers in a lump-sum payment to finance the down payment of a home.

As we all know, the bottom line comes down to money. The President's "New Freedom Initiative" budget proposal represents an unprecedented \$2.1 billion in planned new spending over five years, with \$417 million in new spending for FY 2004. The budget proposal supports and builds upon the momentum of activities to support states in community integration for persons with disabilities. The budget reflects some specific demonstrations on "housing" in **"Money Follows the Individual Re-Balancing Demonstrations.** This represents \$1.75 billion over five years, with \$350 million proposed for FY 2004. This innovative and exciting demonstration will assist states in developing and implementing strategies to "re-balance" their long-term care systems so there are more cost-effective choices between institutional and community options. Federal grants would pay the full cost of home and community-based waiver services for one year, after which the participating states would agree to continue care at the regular Medicaid matching rate.

But we still need to do more in the way of universal design. Along those lines and to further parallel with your goals in "Chapter 6, Domestic Life," perhaps we could explore new ways of coding with the Department of Housing and Urban Development in how homes are built and also how they might be retrofitted. We might explore ways with other agencies that are interested in housing that have the ability to and the authority to use discretionary funds to do that. We are working closely with HUD, and you might be familiar with Secretary Martinez's joint "Notice of Funding Availability," which is a grant funding totaling \$35 million in fiscal year 2003, with \$20 million from HUD, \$10 million from HHS, and \$5 million from the V.A. Some of these funds will be invested in assisting persons with disabilities to promote home ownership.

To further enhance full community participation, we are working actively on the development and implementation of HAVA -- Help America Vote Act of 2002 -- to help support states in ensuring that individuals with disabilities have the systems and technologies to participate in the electoral process. Last month, Secretary Thompson, released \$13 million in grants to states and territories to support this effort.

And just quickly wrapping up some of our other efforts within the "New Freedom Initiative" that I think will interest you. HHS's new Independence Plus waiver templates give states the tools to create programs that allow people with disabilities and their families to best

decide how to plan, obtain and sustain community-based services, placing control into the hands of the people using the services. And the HHS Office of Civil Rights has been working with CMS and the states to ensure that the Olmstead obligations outlined in Title II of the ADA are meeting the highest of standards. One effective means by which states can meet their Olmstead obligations is to transfer funds currently used to support individuals in institutions to support these individuals in the community. Since 1996, HHS and the Robert Wood Johnson Foundation have provided grants to states to support demonstrations of a “Cash and Counseling” alternative for providing long-term care support to medicaid recipients with disabilities. Under voluntary projects in Arkansas, New Jersey and Florida, some people with disabilities receive cash allowances to purchase the care and services they feel will best meet their needs and supportive services to help them manage their cash allowances. In mid-April promising findings from this demonstration on self-directed care was released by HHS and the Robert Wood Johnson Foundation. The findings indicated that Medicaid recipients with disabilities who direct their own supportive services were significantly more satisfied and appeared to get better care than those receiving services through home care.

These findings are, of course, not surprising -- but they are convincing. They show that if “A” is the situation, “B” is the result. Which leads me to the second part of my talk today which is to focus on the ICF and how it might achieve maximum impact. The ICF represents years and years of work. The document is now completed. I applaud all of you. Now that you have met the challenge of providing a coding classification, I think in order to maximize its impact, another challenge lies ahead. You’ve developed the codes, now, in order for them to work, tell us what to do with them. From a public policy perspective, the codes as they stand are really of use in an academic and clinical setting, yet I know that limited use is not what you intend. I think the ICF is a remarkable, astounding accomplishment, yet we still need more research to find out if its going to work or not. We need to “actualize” its potential. Since it is recognized by the World Health Organization, health providers and government agencies might be able to attend to factors other than the person’s structural and function impairments. But you have to show us how.

In studying the ICF, I’m trying to figure out from my own perspective as the Director of the HHS Office on Disability, how the classification system can be helpful and useful in what the federal government is trying to do. Yes, it serves as a “common language” within the academic/clinical community. But how can we use this -- in reality -- that would be most effective. How can we best use it within the federal, public and private sector especially now with a President so receptive to changing the current environment that he has dedicated a budget and has the entire federal government working to tear down barriers for all those with disabilities. The timing is perfect.

You have the document. Now you need to be persuasive as to why this is needed and what do we do with it. In other words, as a policy maker myself, I ask myself “if I do A, I will accomplish B.” That is what is needed. As it stands now, the classification system is excellent, yet we need to take it a step further to ensure its practical applications. It looks good on paper, but how do we in public service apply it? How are we going to make it work? So there’s a “disconnect.” There is now a classification system, yet the question remains HOW DO WE BEST USE IT?

The ICF provides me -- Margaret Giannini -- with a framework for saying “there’s more to being a quadriplegic than having lack of neural control.” My frustration as the Director of the Office on Disability is that if I’m going to do a management plan on my employee, who happens

to be a quadriplegic, how can I best use the ICF to develop a management plan in ways that I don't already have available to me?

Currently, home ownership is not determined or even based on codes. It is based on access and availability. It's not even based on affordability. Because the money lender will give you money so you can get the mortgage and you can also get co-ownership so that anybody is allowed to give you the down payment so you can own your own home. I don't know how I can use the ICF in that kind of arrangement.

In order for the ICF to work there needs to be measurements and standards. For example in Chapter 7, I noted "Interpersonal Interactions and Relationships," which address "respect and warmth in relationships," "appreciation and toleration in relationships." My question is "how do we use this?" "How do we measure this?"

The key to the success of the ICF lies in developing measures. That in order to measure progress towards ICF goals, standard measures are needed. That the development of measures and providing meaningful data for payment and reimbursement are needed. That currently existing codes need to be expanded and new ones added for insurance companies. And that for ICF to work, CMS and other funding entities should set boundaries of what will and what will not be reimbursed.

Our goal is to better service the consumer. We must work together at all levels to find the ways and the means. There are many individuals, groups, agencies and entities working to improve services for and access to services, but we need to ensure that we have an integrated and coordinated network. We need not just to interact, but to work within a connected and effective and efficient system. I know this is something we can do.

So the key activity for the NACC and for this conference is to develop a strategy for step II, in order for step I - the ICF -- to be completely successful. The challenge is to expand the health and well being "conceptually and scientifically," and engage in a pragmatic discussion of how the different components of the ICF classification system can be better understood and used. In short, the ICF, from my perspective, needs a system of reliable measures and coding systems that are pragmatic -- not just of use within the academic or clinical setting -- but for local, regional, and national public policy.

I congratulate all of you in creating for the first time ever a classification system that is internationally accepted and that provides a framework for talking about disabilities that is so extensive. Now, I ask you to develop a strategy that answers the question "How are we Going to Make it Work.?"

I have seen an inspirational quote that reads: "I never said it would be easy . . . I only said it would be worth it." You have the support of the President, the Secretary, myself, and an entire Administration. You have the support of the international community. You have completed the ICF. Now, I challenge you to take it one step further to ensure maximum impact.

In closing let me quote the renowned anthropologist Margaret Mead, who said "never doubt that a small group of thoughtful, committed people can change the world. Alone we cannot change the world, but working together we can accomplish much." Let's DO It! Thank you very much.

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