Students with Disabilities:
Nursing Education and Practice

Proceedings Manual

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Acknowledgements

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Preface

In Fall 2000, nurse members of the Rush University Medical Center Americans with Disabilities Act (ADA)Task Force began to address the needs of qualified people with disabilities who were interested in nursing careers. Persons with disabilities have generally been overlooked in serving the health care field. The issues revolved around reasonable accommodations and faculty support required for a student with disabilities to successfully complete a college of nursing program, and successfully pass a state licensure exam. Historically, nursing has been seen as a career requiring considerable physical function and strength. However, much of what the modern nurse accomplishes is done through cognitive function — assessment, problem solving, education, counseling and evaluation. The nurses from the Rush ADA committee presented the topic to the Dean's Office at Rush University College of Nursing. The Dean agreed to further explore the issues.

Initially, Rush College of Nursing explored feasibility issues on the topic of students with disabilities and nursing education on a local Chicago level by hosting a series of exploratory discussions with nurse administrators, nurse educators and experts in the area of disability advocacy and policy. From these preliminary discussions, those involved realized they had to continue the study and discussion of this important topic at a national level.

To that end, a select group of nursing educators, health care administrators, legal and health policy experts, and representatives of national disability rights organizations and advocacy groups, were invited to a symposium to address the issues related to the recruitment of people with disabilities into the nursing profession. There were 117 experts in attendance. The symposium was held on April 10 and 11, 2003, at Rush University College of Nursing in Chicago. Nineteen distinguished experts in nursing education, licensure, employment, health policy and legal aspects of disability rights and accommodations delivered the presentations which featured discussion and debate on recruiting qualified students with disabilities into the nursing profession.

The implications for accommodating nursing curricula and employment, regulations and licensure and the related impact on nursing colleges and employers could not be adequately discussed in a two-day

period. Thus, five priority issues were selected, starting with a student-faculty panel featuring students with disabilities. Three of the four students had successfully completed nursing programs and licensure exams, and were employed as registered nurses; one student was completing her final semester. The topics were: legal aspects of accommodations, nursing education curricula and accommodations, nursing employment and accommodations, regulations, licensure and policy, and a "perspective on how to effect change."

Each of the five experts was asked to present a position paper on one of the topics listed above, and five other experts were asked to respond to the paper corresponding to their expertise. Audience participants were invited because of their expertise on the topics either at the local, regional or national level. Following the formal presentations, all conference participants were invited to comment on the presentations. Subsequently, the author of each position paper was allowed time for questions, rebuttal or additional comments. The sessions were informative and spirited. On the second day of the conference, all participants divided into one of three groups: education, employment or regulations/licensure. In these break-out sessions, each group brainstormed a chosen topic and made recommendations for accommodating qualified persons with disabilities in the nursing profession.

We hope that the information and recommendations in these proceedings will be used as a guide by nursing colleges, health care delivery organizations, nursing regulatory representatives and persons with a need to know to take concrete steps in modifying nursing curricula, employment, regulations, licensure and policy for qualified persons with disabilities to allow their inclusion into the nursing profession.

Please note: Arial black font was used in publishing the proceedings. This was done as an accommodation, making it easier for a person with a visual disability to be able to read the report.

Katherine A. Pischke-Winn, MBA, RN
Kathleen Gainor Andreoli, DSN, RN, FAAN
Lois Kazmier Halstead, PhD, RN

CHAPTER 1

Welcome

Kathleen Gainor Andreoli, DSN, RN, FAAN, Dean [1]
Rush University College of Nursing

Welcome to Rush University Medical Center and Chicago. During the symposium the audience will listen to real stories from students with disabilities who attended nursing school, position paper presentations, responses to the papers, and audience discussions. We will then work together on strategic recommendations in the areas of education, employment, licensure and regulations for qualified students with disabilities entering the nursing profession.

Thank you to the organizations that contributed financial and in-kind support, the speakers and task force members for all the work you did bringing the symposium together.

Larry J. Goodman, MD[2]
President and Chief Executive Officer
Rush University Medical Center

Today, you will be discussing and thinking about an extremely fundamental question, which is, "What does it take to be a nurse?" This is a

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[1] Kathleen Gainor Andreoli, DSN, RN, FAAN, is the Dean of the College of Nursing and Vice President of Academic Affairs at Rush University Medical Center. Prior to arriving at Rush, Andreoli was the Vice President for Educational Services, Interprofessional Education and International Programs, University of Texas Health Science Center at Houston. Andreoli received her Bachelor of Science in Nursing from Georgetown University, her Master in Nursing from Vanderbilt University and her doctorate from the University of Alabama at Birmingham.

[2] Larry J. Goodman, MD, is the President and CEO of Rush University Medical Center, Chicago. In 1979, he was the chief resident in Internal Medicine at Rush and completed a fellowship in infectious diseases. His research has focused on infectious diseases, particularly gastrointestinal infections in HIV-positive patients. He is recognized for promoting innovations in medical education and has written extensively about medical education curricula and how students select a specialty for residency training.

critical question because it is time to consider what are the requirements to be a nurse; what are the requirements for training; and what are the requirements necessary to be a functioning, effective nurse on a patient care floor, in clinics, in education; and all the other areas in which nurses function?

This is an important, profound question, much like the question that led to a revolution in medical education. Over the past twenty years, medical colleges have examined what they call technical standards, the sorts of abilities that a person needs to be a functioning physician, whether it's communication abilities, functional abilities, or motor abilities. It is important to say what the standards are, and more important, why we have those standards, because physicians are educated and trained into niches and specialties of practice. You do not want an infectious disease specialist to perform your surgery. Physicians do not pretend to be able to do all aspects of medicine. There may be some things in the field of nursing that some people can and others cannot do, and this is already true. So the question is what are the requirements for training and where can people best fit in?

It would be a mistake to say that this is the right time to examine this question because of the shortage of nurses. The question resonates more broadly now because of the nursing shortage, but that is not the issue at all. The issue is not whether there is a glut or shortage of nurses.

Today is a day to begin to answer what the training requirements are for a registered nurse. Technical standards need to be identified and broadened. The harder questions are in the details; what are the restrictions, if any; what are the requirements for admissions; what are reasonable requirements; what are reasonable accommodations?

One last point: This is absolutely a question for the profession of nursing. First, decide for yourself and then bring the rest of us along with you.

David K. Hanson, Commissioner[3]
Mayor's Office for People with Disabilities

Hello, and welcome to the great city of Chicago. This symposium is about creating opportunities: creating opportunities for people to go to college and study in the field of their choice, creating opportunities for all people to dedicate themselves to careers in a healthcare profession, and creating opportunities for people with or without disabilities to realize their goals and accomplishments. And most of all, for creating opportunities for people to live the life they choose.

For many people, career opportunities are limitless, while for people with disabilities, career opportunities are few. This symposium is a major first step in correcting such an injustice. During the symposium, speakers and participants will invest their time, talent and expertise to explore new ways to remove existing barriers in the admission, education, training, recruitment and hiring practices—all of this will serve to increase the number of people with disabilities in the nursing profession.

However, in order to make this goal a reality, a number of other policies and procedures need to be implemented to remove existing barriers for people with disabilities in areas of transportation, education, healthcare, and housing. The City of Chicago and Mayor Richard M. Daley realize and understand these barriers and are committed to doing something about it. Recently, Mayor Daley signed an executive order creating a Mayoral Task Force on Employment of People with Disabilities to address the unacceptably high unemployment rate among people with disabilities of working age, which is approximately 70 percent. The goal of the Task Force is (at a local level) to bring the employment rate of people with disabilities as close as possible to the employment rate of people without disabilities.

The Task Force is commissioned for three years and it is unprecedented in that it is the first of its kind at a municipal level. It represents public and private sector partnerships and is composed of more than 100 members from the business, the economic development, disability and civic communities. It also has commitment from all levels of city

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[3] **Commissioner David K. Hanson was responsible for Chicago's unique accessibility review, which requires builders and developers to demonstrate that their plans meet all accessibility guidelines even before city of Chicago building permits are issued, a model that other cities emulate.**

government, as well as its sister agencies, the Chicago Transit Authority (CTA), the Chicago Public Schools, the Chicago Housing Authority and the Chicago Park District.

There are five work groups, each addressing a specific employment-related goal. Two of the symposium speakers, Marca Bristo and Robin Jones, are Work Group leaders who have worked with their respective Work Group members in developing a strategic plan to address barriers. Using these findings and recommendations, Chicago's municipal government will make sure, from a structural and employment program standpoint, that employment policies are acceptable to all people with disabilities. All professions and disciplines must internally examine their respective employment and education policies and resources to develop solutions for removal of these barriers in order to advance people with disabilities in their workforces.

That's why I applaud Rush University College of Nursing and the Medical Center for organizing and hosting this vitally important symposium. The work you have done and continue to do is desperately needed and will be appreciated by the future generation of youth with disabilities who want to have careers and not just jobs, but careers in the nursing profession.

CHAPTER 2

Keynote Address

Marca Bristo, MS, President and CEO[1]
Access Living, Chicago

I am very proud to be here as a nurse. This meeting is so long overdue. My role today is to help set the tone, to help add some context to the dialogue that we are about to have, to help answer why we're here in the first place and how we got here. To do this, I will step outside the practice of nursing and talk about what it is like to be disabled in America. Statistically, 70 percent of people with disabilities are not working. There are 54 million people with disabilities in the United States. That number is increased from the 37 million we started out with when we started to pass the American with Disabilities Act (ADA) in the late 80's and it is a population that is rapidly growing. We are here to stay.

The disabilities group is the largest minority group in the United States and the only minority group that every single person in this room can and probably will join sometime in their lives. So if you came here thinking this is someone else's issue, it is not —it is every single person's issue in the U.S. and in the world. The statistics —whether it's the unemployment rate, or whether it's the disproportionate number of young people with disabilities who graduate to no future, who are less well educated than their non-disabled counterparts because schools have failed them— only tell a little bit of the story. You can only get inside the disability experience if you start to learn more of the personal dimension. To help you understand what it means to be a disabled person, I will tell you about a few of my friends and colleagues: Ed, Judy, Tony and Pat.

ED. As a young boy, Ed contracted polio. He chose to live in spite of, at a very early age, wanting to give up. He spent every night on a ventilator and

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[1] Marca Bristo, MS, is a nationally and internationally acclaimed leader in the disability rights movement. She is the recipient of three presidential appointments from President Bill Clinton and one Congressional national appointment to a range of disability policy positions from 1994 until 2002. She has received numerous awards and honors, including the Distinguished Service Award for her role in the creation and passage of the American with Disabilities (ADA) landmark civil rights law.

nearly did give up in the 1950's, but made a decision to go on. He decided to go on to college and did not want to go to the only college in America that would accept kids like him, the University of Illinois, Champaign/Urbana; he wanted to go to the University of California at Berkeley. So Ed applied to Berkeley, was accepted and he made arrangements to show up on the first day of school only to discover that the campus was not accessible and was told he would have to live in the infirmary. Ed, if you ever knew him, said, "But I'm not infirm, I'm not sick. This campus has to change a little to let me in."

JUDY. Judy was born with a disability. Her mother took her to school on the first day when she was a little girl in New York City. And the school said, "Sorry, you cannot come here because you use a wheelchair. You're a fire hazard, our insurance will not cover you." The school sent her home. The school could send her home because there was no law then to say it was discriminatory. Up until 1975, nine million children with disabilities were kept out of schools. Later, Judy graduated from school and college, the same college, Berkeley, where Ed had broken down the barriers. Judy wanted to be a teacher in that same New York City elementary school system. When she showed up and applied for the job, guess what? They told her the same damn thing! "You cannot teach here because you are a fire hazard."

TONY. Tony wanted to be a priest. He was told, "We're sorry, you can't be a priest here because you have epilepsy." The reason is that particular religion believed that people with epilepsy were possessed by the devil. So Tony left. He and his family were not permitted to speak the word "epilepsy" because his family believed that, too. Tony did not speak to his family for twenty years because they believed he was possessed by the devil because he had epilepsy; their church had taught them that.

PAT. Pat is a nurse, a director of nursing at a major state-run medical education center in Alabama. Pat was diagnosed with breast cancer after an illustrious nursing career directing a nursing center. She was undergoing chemotherapy and felt pretty good. Then was told by the institution she needed to take a medical leave, so "she would feel better." The institution paternalized her into taking a leave she did not want to take. Then when she said, "I'm ready to come back," she was told, "Sorry, we gave your job to someone else; we'll give you another job, which, by the way, pays half as much as the job you were hired to do (and had done for several years)."

This is what it means to be a person with a disability in the United States. I wish I could tell you that all this happened before the ADA was passed, but it did not. Pat's experience is quite recent. Now I will give you the other side to these stories.

ED. Ed went on after graduating from Berkeley and wanted to go to work. The state of California's vocational rehabilitation system told Ed he was too severely disabled to work. They rejected him. They closed him out as "too severely disable to work," and told him he could not get state-supported services to become employed. Many years later, after Ed created the first center for independent living (like Access Living) and really created the worldwide movement of people with disabilities which is now all over the world, Ed was hired by the former governor of California to be the director of the same state agency that told him he was too severely disabled to work. That's justice.

JUDY. Judy, the person who could not go to school and then when she wanted to be a teacher, could not be a teacher. I am so proud that President Bill Clinton appointed Judy to be the assistant secretary at the Department of Education heading up all the education for children with disabilities in the United States. That's justice. Judy is now the advisor to the President of the World Bank working on disability policy for the whole world to make it more inclusive of people with disabilities.

TONY. Tony is former Congressman, Tony Coelho, who led the charge to pass the historic Americans with Disabilities Act. He did so by encouraging the rest of us to "bare the scar tissue," put it before the light of public scrutiny. When Tony told his story before a packed hearing, Senator Bob Dole and Senator Orrin Hatch wept. They wept because we live in America and this should be wrong.

PAT. I wish I had a good news story about Pat. Pat's case, and therefore indirectly the nursing profession, gave us the single worst Supreme Court decision that we've had under the ADA. Her case went all the way to the Supreme Court where she never received her day in court because the justices determined that Congress, and Tony Coelho, had overstepped national authority when the ADA was passed and brought state governments and employers under the purview of federal law. So, in an indirect way, the nursing field or at least the nurses at the University of Alabama brought us a terrible decision.

I hope you all feel this — feel an incredible opportunity to do justice here in a different way. Though you cannot reverse the Supreme Court decision, you can reverse the prejudice and the stereotype that underplayed that decision in the first place.

Now I want to briefly tell my own story. I'm a nurse. I broke my neck in a diving accident. I was on my way to becoming a nurse midwife. My story is a little different. I decided I wanted to get my graduate degree because I knew my career would flourish if I could either be an educator, a researcher or a nurse administrator. All my colleagues in the profession told me I would need a master's degree. I went to the Illinois vocational rehabilitation system, told them I wanted a master's degree and needed support for my master's education. My vocational rehabilitation counselor told me that I had unrealistic career goals. In spite of the fact that I was practicing as a nurse from my wheelchair, they rejected my request and said no.

Well, I had enough of a fighting spirit in me by then, even before I was in the disability movement, so I went to my boss and to the woman who taught me about midwifery and said I needed their help. And unannounced, I took the director of nursing and my instructor into my Illinois vocational rehabilitation appeal hearing and said, "I'm not going to say a thing. Listen to them." They told the appeal board that not only were they wrong, but they had hired me as a nurse. They told the board that I was practicing as a nurse and that my long-term career potential was in jeopardy unless they enabled me to go on to graduate school. We won.

We won because of the enlightened perspective of two nurses who chose to look at me differently. These nurses did not really know me, I had only worked for one of them for four weeks when I broke my neck. I originally lost my job. I did not have the ADA then. But shortly after my accident, out of the blue they called me on the phone and said, "Would you like to come back to work?" I was just stunned. I had begun to accept my new life as an unemployed person, trying to figure out how I was going to live with no money, with no healthcare at the time, and no transportation. And I was going through the process of trying to put the "happy face" on my fate and figure out something else to do.

When the phone call came I went to talk with my former boss and asked how could I be a nurse using a wheelchair? At the time, I did not believe I could do this. My nurse supervisors, Judy and Angela, took apart three jobs and put them back together and made all three nurses happier by

giving me a job. They did what we now call job sharing. They did this before the ADA was passed.

Why they did this I'll never really know. I think it's because they were just decent human beings and they just wanted to reach out and give me a chance. That's the opportunity that you can choose to do. So that the Ed Roberts', the Judy Heumann's the Tony Coehlo's and the Pat Garrett's lives are not played over and over again.

People with disabilities have begun to reclaim disability. For most of history society has defined us. Those days are over, we are defining ourselves now. We're doing it because we have created a movement that is helping each one of us to reject the outdated notions about disabled people and replace them with the notions we carry in our hearts and know to be true. This is an enormous revolution in thinking; a paradigm shift that this country has almost never seen before. Because we are asking you — no, we're demanding that you join us in this paradigm shift and throw out the medical model of disability which sees us as "patients" first —sick, to be cured or treated or fixed. At a certain point we cannot be fixed anymore. We're asking that you accept us where we are. This is very important because the medical model puts all the power in your hands — there is something wrong with us and you are there to help fix us. And it takes all the power out of our hands.

The disability rights model, also called the sociopolitical model or the independent living model, changes all that. It throws the medical model on its head and says, "There's nothing wrong with us." Yes, there are things we cannot do, but we have a responsibility to adjust and learn what we can do to be functional in our community. However, the world has met us halfway. The barriers that have kept most of us out are man-made barriers either in people's minds or in the world about us. As Mayor Daley, Mayor of Chicago, showed us last week when he ripped up Meigs airfield in the middle of the night, all it takes is a jackhammer to get rid of some of those barriers.

Something has to change at a deeper level inside people to do the real hard work. For example, today while we are meeting here, the City of Chicago zoning commissioners are evaluating a recommendation to allow a height exception to the zoning ordinance so we can build multi-family units three feet taller. This three feet will make the first floor accessible and get rid of the up and down of Chicago architecture. We are being told that it can't be done because it does not fit into the character of the Chicago

architectural landscape, "because we won't have the Chicago stoop, the porch." Take a look at the 10,000 people a day after the year 2012 who will be at the age where they are going to be likely candidates for nursing homes. Soon the world will wake up and realize the missed opportunity we had in 2003 as we're redesigning housing in Chicago, and understand that you too will need housing that was zoned to be accessible. Remember you were told that it didn't fit with the character of Chicago architecture.

So what is really going on here? Prejudice. People come up with all sorts of great excuses as to why they can't do things. Those of us in this room with disabilities hear this all the time. We hear all the lame excuses that are given about why we can't do something or go someplace or be part of something. This is an absolutely critical juncture. The ADA created a legal tool for us, and that tool is extraordinarily important. We could never have our day in court before the ADA. I don't want to undervalue how important the legal victory was. But those of us who wrote it —and the main author, Bobby Silverstein, is in the room and you will hear from him tomorrow — knew that we were doing something more important than writing a law, we were changing the world.

It was a symbolic victory to disabled people, almost of greater proportion than the legal victory. For the first time in the United States, we said that disability is a normal part of the human condition and that the world has to change a little to let us in. Bobby Silverstein put it in simple terms: The ADA means replacing exclusion with inclusion, dependence with independence and paternalism with empowerment. And that's what we are asking you to do.

Martin Luther King understood so much better than many of us that to get there requires much more than a law, when he said: Desegregation will break down the legal barriers and bring men together physically, but what is needed is to touch the hearts and souls of men so they will come together spiritually, because it is natural and right.

And that is what we are here to ask you to do today. We can argue all the legal terms, and we will, but we want you to understand that even if there isn't a legal reason for you to do this, and there might not be 100 percent of the time, do it because it is right. We have it within our power to do this.

Up to this point I have spoken to some extent about the legal and moral arguments. Now I want to talk a little bit about the more mundane and practical issues. First, look at the state of affairs in health care. We cannot get health care to people who need it. There is a shortage of nurses not only in our big institutions like Rush, but think of rural America where nobody's giving health care at all. How dare we not let people into a field that is crying out to heal our nation's ills. People with disabilities can and are doing those nursing jobs right now.

No nurse does everything. We're trained to be able to do everything, but once we've had that training, we do what everybody in the world does, we follow our hearts and we pick the path that we want to do and that we're best at. What makes you think that disabled people are any different? Most of us are not going to choose a part of the profession that we will not be successful in. It defies logic. We want to get raises, we want to get promotions. So if a disabled person cannot do a particular type of nursing, it is more than likely you are not going to see too many of us there trying to do it.

In some respects, nursing lends itself to accommodations in the simplest way possible because there are a hundred jobs in nursing and they are all different. Therefore, the essential qualifications of those jobs are what we should be looking at, not the field of nursing because it is too diverse.

Finally, and this is something you might miss, people with disabilities add value to health care. Who has been through the health care system more than us? Who knows how to navigate it better? Who knows how to get through the bureaucratic morasses better? Who knows where the public resources are? Who knows how to refer you to all those important but little-known networks? Who knows how to get peer support, which is most often the missing link in the whole healthcare system? We do, because we've had to do it for ourselves. Not only do we add value, but over time, we may save you some money. We will contribute and enrich the practice of nursing because we bring something to the table that many other people simply do not have — the experience of living with a disability.

This will require the nursing profession to do something that in some respects is going to be harder for nursing to do than other professions, and that is to throw out the medical model. Nurses have been taught in the medical model that disabled persons are your patients. We are the people

you have committed your lives, in some respects, to serve. Asking you to let go of that is a hard thing to do because it requires you to see us not as patients but as people.

This is a challenge I believe you are up to. This is not rocket science. What we're asking is common sense; it does not require vast researchers from the Massachusetts Institute of Technology. It takes commitment, common sense and an understanding of how our world has changed. My friend Justin Dart, who recently passed away and is considered the Martin Luther King of the disability rights movement, taught us that science and technology created a new human. Infants did not live when they were born severely premature, and now they do because of technology. There are many more senior-aged people because of new ways of looking at things, because of research, science and technology.

And yet that same technology and that same science can sometimes trap us out, but it does not have to. If you choose to join in this paradigm shift, there are many wonderful people here today who are going to teach us how to do that. These are nurses with disabilities who are enjoying tremendous careers, and you're going to hear about how they are able to do that.

You are also going to hear from another group of people who have not been allowed to continue their dreams in the field of nursing because of outdated attitudes. This week Karen McCulloh, a member of this symposium planning committee, has been in touch with a nurse from Alabama who has a visual impairment acquired after she became a nurse. This nurse requested a job reassignment to a position she could do because she was concerned that her new visual impairment might interfere with her ability to safely administer medicine. This nurse was not looking for a handout, she was caring for her patients. She went to her boss and said, "Work with me on this." The institution said no, so the nurse filed an EEOC complaint. The complaint is pending. Finally, they relented a little bit and they said okay, we will give you another job. They gave her another job doing the same kind of work including administering medications on the nightshift. This week she quit. Nobody should have to quit anymore.

To my colleagues in the field of —we have a lot of work to do. I'm so glad there are people like you who are there to give this person support, direction and hope; to help her fight the valleys of self-esteem as they dip because it is so easy to give up. It's so easy to blame yourself in the face of

these odds. Those in the disability community have an incredibly important challenge before us to continue to get the word out that times are changing. It does not have to be this way and people do not have to give up. Those of us in the field of nursing have an incredibly important opportunity here.

I'm going to close with something —I want to read a long quote. I don't do this often, but this one is so pertinent to today. This quote is from Deval Patrick, the former assistant attorney general at the Department of Justice under Janet Reno, who said these words as he was sworn into that post:

"This nation as I see it has a creed. That creed is deeply rooted in the concepts of equality, opportunity and fair play. Our faith in that creed has made us a prideful nation and enabled us to accomplish feats of extraordinary achievement and uplift. And yet, in that same instant we see unfairness all around us. We see acts of unspeakable cruelty and violence because of race or ethnicity or gender orientation. They present a legal problem to be sure. But they also pose a moral dilemma. How can a nation founded on such principles, dedicated to such a creed, sometimes fall so short? And let me assure you, that is a question asked not just by intellectuals and pundits but by simple, everyday people, every day. To understand civil rights you must understand how it feels to be hounded by uncertainty and fear about whether you will be fairly treated. How it feels to be trapped in someone else's stereotype; to have people look right through you. And what will be our answer? Will we sit back and claim that we have no answer? Or that it is not our business to devise one? Will we shrink from the moral dimension of our work? We will not shrink. I know because I can look around this room and see every kind of woman and man joined here in one brief but illustrative moment of harmony, common in our humanity and in our resolve. We have but so many moments, I think, where the confluence of opportunity and resolve is in this wondrous balance. And so it is right now."

And so it is right now. Thank you.

CHAPTER 3

Student and Faculty "Real Stories"
Panel Presentation

Four registered nurses and one nursing student came from across the country to tell their stories.

Bronwynne C. Evans, PhD, RN, CNS[1]
Assistant Professor
Washington State University, College of Nursing
Panel Moderator

Marca Bristo began by talking about the 54 million Americans with disabilities, and she told us some of their stories. We're going to continue using the vehicle of story to explain what it's like to be a nurse with a disability. One-fifth of the population has significant participation gaps in employment, education, access to healthcare, and income because they have disabilities. We have persons with disabilities who need discerning, effective care and we have students with disabilities who could provide that care in a much more enlightened way than many of us who do not have disabilities could. Although many practicing nurses <u>do</u> have disabilities, we just have not disclosed them nor sought accommodation. Education can create opportunities for disabled Americans while meeting the needs of clients and of health care systems that so desperately need nurses.

We are here to listen to "real stories" from each one of these panel members as he or she tells us about nursing practice and educational

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[1] Bronwynne C. Evans, PhD, RN, CNS, is an Assistant Professor at Washington State University, College of Nursing. She is a member of a task group examining the recruitment and retention of diverse students for the National League of Nursing, a 2002-03 member of the Peer Review Panel for the Bureau of Health Professions, Nursing Workforce Diversity Grants, and Chairperson for the Education Committee of the National Gerontological Nurses Association. She received a Bachelor's Degree in Nursing from Washington State University in Spokane, a Master in Nursing from the University of Washington, Seattle, and a doctorate in Education from the University of Washington, Seattle. Evans' career includes numerous published papers and videos focusing on topics of working with students who have disabilities and students from culturally and ethnically diverse populations.

experiences as a student with a disability. First, we will hear from the other panelists, then I will talk about faculty attitudes, and then we will have time for questions. We are here to listen to the stories of nurses who are not "super-heroes" but were excellent students and successful nurses.

Stories are powerful when told from the heart and adapted to individual situations. They contain a reflection on details that enables people to reach across time and space in concert with one another, and to personally share the experience in the story. You were drawn in by the stories that Marca told you this morning. Stories such as those can empower, inspire, inform and validate the practice of nursing. Stories can help us discover knowledge and uncover the knowledge embedded in our discipline, and they offer us an opportunity to experience health and illness from a different perspective. We hope that these "real stories" will help us move from our traditional medical-model thinking to a more contemporary way of looking at our nursing practice.

Victoria Christensen, BSN, RN[2]
Director of Nursing Services at the Carlyle Care Center, Spokane, Washington
Christensen is a nurse who uses a wheelchair.

I have approximately seven minutes to tell you what four semesters, five clinical rotations, nine site settings and sixteen clinical settings were like for me in nursing school. The problem was that everybody around me did not know what it meant to have a disability, and they did not know what it meant for me. In nursing, paraplegia is seen by eyes that have been steeped for centuries in the images of twisted legs on corn husk beds. These long-held beliefs were the highest hurdles for me to get over in nursing. Some of the people around me never were able to grow past that misconception. Then there were the nurses with the "can-do" attitudes. By their very nature,

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[2] Victoria Christensen, BSN, RN, is the Director of Nursing Services at the Carlyle Care Center in Spokane Washington, a community-based living facility for chronically mentally and medically ill people. She holds a Bachelor's degree in Bio Science from Washington State University (WSU) and a Bachelor's Degree in Nursing from WSU. At the completion of her Bio Science degree, a teacher directed her towards nursing, suggesting that her journey into the disability world would "bring a unique richness to your patient care." In July 1991, Christensen sustained a complete spinal cord injury in an accident. She successfully completed her BSN degree in 2001.

they were attuned to the "whole person" approach taught in nursing school. Those are the people I aligned myself with; they were ultimately the kinds of nurses that students want to be like.

Initially, I heard that the concern at school was whether or not I would be "safe" in the clinical setting. I could not imagine how anyone would be concerned that I would be hurt. When I realized the "safety" concern was in reference to my patient care, I was offended. One of the major issues was CPR. I considered where I was going and what I was doing at all times. I was not out in the middle of nowhere with my cell phone roaming around; I would be in a clinic or a hospital, around a lot of people.

I live in Spokane. The hospital where I did my medical-surgical rotation is in the top 100 hospitals in the country for excellent cardiac care. The reality of my needing to use CPR to sustain anyone was close to nil. But I took the concern to heart. When it was time for me to renew my CPR card, I hired an instructor who was a Registered Nurse. She came to my home and we concocted a number of scenarios where I jumped in and saved the dummy. The reality is that if I was required save a life with CPR in any of my clinical settings, the health care community was in serious trouble.

I requested an ambu-bag and carried it faithfully. I also carried a little sharps' container that I never had to use. When I made it to the cardiac floor, I asked what to do if someone coded and the nurse said, "Do what I do, yell!" Curiously enough, at the end of this rotation, we were given a little time to pick different clinical sites in the hospital. The cardiac nurses came back and asked if I would please do that time with them.

When I enter a patient room, I do a five-second scan. I can tell you how usable that room is going to be for me. I look for the oxygen located on the wall, I check the IV poles, I know where the patient's call light is in relationship to me. I'm aware of where everything is in the room. I never needed to make any major changes to increase my access to a patient. Everything in a room rolls around and so do I, so it worked out. And the truth is, most students practice things in their skills that they are never going to use in clinical. For all the practicing I did, it was a foot pedal on the sink that threw me the first time; I had never prepared for that. As it turned out, they were really very easy for me to use.

I did all the things that nursing students do. I picked patients who were medically interesting and who could give me skills practice. I went through

all the tubes, nasogastric feedings, medications, hanging antibiotics, simple dressing changes, flushing central lines, things like that.

I did all the things that nurses do. I made it to the hospital at 6:00 in the morning. I sat in shift report and took notes. I organized my work time to reflect my patients' needs for nursing, post-procedural protocol, medications, and doctors' rounds. I drank lots of coffee and totally extended my bladder.

One thing I did not do in nursing school were the tasks that the aides typically do. My classmates had to give bed baths, change sheets; those kinds of things take a lot of extra time for me. I felt I was there to learn how to be a registered nurse, not relive the time I already put in as a nurse's aide. I coordinated my day with the nurse's aides and got the patient care done. My classmates never felt that it was unfair that I did not have to do that little piece of the work that they did.

Med rooms in every clinical situation are different, hospital to hospital, floor to floor. If you are going to work in a place, I assume you make changes or adaptations for everything. There are so many people around a busy floor, you have to plan ahead. If I felt I could not do a task, I would tell you. I would have told you in school and I would tell you that today. A good example is how I can sterilely catheterize a patient successfully; it's not the traditional position, but it's not incorrect. I do it with the patient in a side-lying position. I have taught clean, intermittent catheterization to women with spinal cord injuries. It's not something they taught me in nursing school. I did use it to teach my clinical group as part of a teaching assignment.

The one thing I feel I gave my patients was a sincere connection to myself. In the nursing home the geriatric crowd knew I heard them when they talked about hating being so dependent on others for simple things. I also don't like being treated like a child. They openly appreciated that I was going after something that was a hard goal, but I was going no matter what.

My response from my pediatric patients at Shriner's Hospital was the best, because I, as an adult, was more like those kids than any one who treated them in any of the settings. This was probably one of my favorite clinical rotations.

There was a male patient with progressive heart disease who wanted to talk to me. He asked to talk with me again the next day to do some of his cardiac education. He was learning how to cope with a major life change and

it helped him to talk to someone who could honestly say, "I have a pretty good idea what you are going through," and show him how it could be done.

Like any nurse, there are some types of nursing that I would not do for all the money in the world and there are some types of nursing that I would not give up for anything. My first clinical day is miles away from my last clinical day. And that's miles away from where I am right now. I'm happy to say I am doing the nursing that I want to be doing.

Bronwynne C. Evans. I happen to know there is a lot more to Victoria's story than that, but she gave you an idea about some of her challenges when she came to the College of Nursing at Washington State University. It is important to note that Victoria is among the first students to enter a BSN program using a wheelchair.

Stacey M. Carroll, PhD(c), APRN, BC[3]
Carroll is a nurse with a hearing loss.

I decided during my freshman year in college that I wanted to be a nurse and was told the program would take the top 30 people based on Grade Point Average (GPA). I knew my GPA would put me in that top-30 group. So I applied to nursing school and I was called in for a meeting. The woman said, "We need to talk with you because we are not sure how you can become a nurse because you are "unique." My reply was, "Well, you're unique, too." I was told that they doubted they could take me into the program. I then went to talk to the Dean who, fortunately, was very well educated, very respectful of my position, and said it was no problem, I could be admitted. This began the long line of trying to prove myself through my undergraduate career.

When I was in my clinical rotation, a supervisor might say to me, "We have a lot of concerns, we're not sure that you can do this." By the end of the rotation, they would apologize and tell me they realized that I could do it and

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[3] **Stacey M. Carroll, PhD(c), APRN, BC, graduated summa cum laude with a Bachelor of Science in Nursing from the University of Massachusetts. She has a Master of Science in Nursing as a primary care health nurse practitioner from the University of Connecticut. She is a doctoral candidate in nursing at Boston College, where she was awarded a fellowship for full-time study. Carroll has worked as a staff nurse, a charge nurse, a research assistant, a clinical instructor, a geriatric nurse consultant and a nurse practitioner. She has a profound hearing loss.**

that I was very good at what I was doing. As I progressed through school, I think my reputation went with me and I did not encounter as much resistance toward the end of my undergraduate career. I had no problems in my master's or doctoral programs in terms of being accepted.

The main accommodation I had in my schooling was the use of a note-taker, because I cannot read lips and take notes at the same time. However, I had to meet all of the clinical requirements. For example, in the surgery rotation, I could not read lips when people had masks on. I had to have someone come in with me and take notes and tell me what was going on. Right now I am on a committee to develop a surgical mask that has a see-through piece on it and hopefully the technology will catch-up.

My most frustrating lack of accommodation in school was during group discussions. I need to know who is talking and need people to take a minute to let me turn to them before they speak. This is not an official "accommodation" and schools do not have to pay for it. They did not always take it as seriously as they should have, despite the fact that this "accommodation" was very important to me.

One of the great things about nursing is that there are so many different areas. However, I had a hard time finding staff nursing jobs. Despite getting excellent grades and letters of recommendation, employers were hesitant. I finally got a job, but there were numerous concerns that I had to address and find creative solutions for. One of the first questions that I would be asked was how I would handle a code. I would explain that I would be part of the code team that involved communicating with one other person because I communicate fine with one person. If a group of people are yelling, then I cannot follow that. I would make sure I was assigned to the appropriate team. It was never a problem while I was a staff nurse.

The other question I was asked all the time was about my use of a stethoscope – you would think it was the end-all and be-all of nursing. For my current job, I do not use a stethoscope. I am trying out a tactile stethoscope. Technology is catching up with people with hearing loss — we need to give technology a little more time. If for some reason I had a patient who needed an assessment with a stethoscope I would do what I call "task trading" with another nurse. We all have some sense of trading — things that someone else can do well, and things that I do well, and we switch off. It has worked very well for me.

Another concern that employers had was communication. I once had an interview that lasted an hour. We talked for the entire hour and the employer said, "Well, you seem to be very well qualified and we would like to consider offering you a position, except we have one really big concern." I asked what that concern was, and was told, "How are you going to communicate with the patient?" My response, "Well, since we've been communicating for an hour, I suppose just like I've talked with you." I'm not sure what this employer was thinking. I communicate very well with patients. Patients have said that they feel I am very attentive; probably because I read lips I focus on them, and I'm not doing ten other things at the same time.

Patients have said they can relate to me because I have been through something difficult and have been able to overcome it. This was especially apparent with I worked in the rehabilitation unit. Patients thought I was compassionate and understood what they were going through. I can also understand patients whom a lot of hearing people cannot understand. These are people who do not have their voices, who are on ventilators and can only mouth words. I can communicate with them with no problem. In fact, that is what my doctoral dissertation is: I'm interviewing those patients and am called in to translate for them.

Another concern that employers had was my use of a telephone. I use fax and e-mail instead. The occasional times I have to use a phone, I use the TTY relay or have someone else make the call for me.

I taught in a nursing program. The nursing program had a list of technical standards, one of which is hearing. I did not read the standards for hearing before I was hired. After being hired, I pointed out the standard to the nursing program. Because I did not meet it, I thought they might want to consider eliminating it, but they did not. Nevertheless, I feel strongly that there are different ways to get to the end result and you do not necessarily have to "hear" in a traditional way to get the job done; you can find a different way to do it.

Throughout all my experiences, I hope I convinced the people I worked with that there is more to nursing than the physical tasks. I have the knowledge, the critical thinking skills, and the compassion to be a good nurse and my deafness does not get in the way of my nursing skills.

Bronwynne C. Evans. Stacey is a wonderful example of what nurses with disabilities can bring to our profession. Although Stacey was initially discouraged, an enlightened dean subsequently welcomed her into nursing, understanding that a person with a profound hearing loss could be an excellent nurse.

Leora (Leo) Stopek, BSN, RN (LP)[4]
Stopek is a nurse with a vision disability.

I want to begin by describing to you what my disability entails. I was born with bilateral cataracts, which were extracted when I was seven and eleven weeks old respectively. Thankfully, this did not cause complete blindness. Without correction, my vision is about 20/200. With contacts, my vision fluctuates between 20/40 and 20/60. I am able to drive, which is a relief for me because it affords me independence that, while growing up, I was not sure I would have. My mother, who is also visually impaired due to the same condition, is unable to drive because of her disability.

At age eight, I developed glaucoma. The glaucoma is what complicates my visual acuity. When my intraoccular pressure rises, everything I see has a red hue. It becomes difficult for me to see and it's hard for me to read. When this happens, I have to ask other people to help me decipher written words.

While in nursing school, I used special accommodations. At first, I was nervous and afraid that I would not be able to accomplish my goals. Yet I was determined to be successful. My entire life I have always been determined to be successful with the things that other people thought I could never do. I have always tried to accomplish goals and show people they were wrong in their assessments of my abilities.

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[4] At the time of the symposium, Leora Stopek was a senior nursing student at the Niehoff School of Nursing at Loyola University, Chicago. She was on the Dean's list and is a Damen Scholarship recipient. She graduated in May, 2003, and successfully sat for the NCLEX state licensure exam during the summer. She is bilingual in fluent and literate Hebrew, and holds an advanced Judaic studies teaching certificate. Stopek-Heifetz married during the summer, 2003, and began her nursing career in Labor and Delivery at Northwestern Memorial Hospital's Prentice Woman's Hospital. Previously, she had experience as a nurse assistant in the Neonatal Intensive Care Unit at Shaare Zedek Medical Center in Jerusalem, Israel. Stopek spent her entire academic career with a visual impairment.

One accommodation that I have needed is to sit in the front in a classroom. I require this because the blackboard has a glare at certain angles and at certain distances which makes it difficult for me to read. For that matter, anything that has a glare is difficult to read for a person with a visual impairment. Additionally, I have needed to ask teachers when writing on the board, to write larger and very clearly. Very often teachers tend to crowd information in a small area on the blackboard and I cannot read anything that is not well spaced. I also need teachers to print, rather than use cursive, especially if they have poor handwriting.

Overhead projectors are also an issue for me because of the glare. I always ask teachers who use overheads to write legibly on them or to save the overheads so I can copy it after class. Sometimes teachers forget about my request and wipe the information away without thinking that I may need it. This would always frustrate me and give me the feeling of being an imposition to the teacher. When teachers grade papers, I ask them to please use a black or blue pen rather than green or light pink because I cannot read comments written in lighter colors. I also ask them to write their comments in large print. When my teachers did not write in large print on blackboards, overheads or on papers, I would have to remind them that I could not read it. They would either have to read it to me or rewrite everything in larger print so I could see it.

Most teachers I have had were very receptive and unbelievably helpful. I would begin each semester by meeting with my teachers and explaining my needs. All the teachers would say they understood, but often I would have to remind them several times throughout the semester about writing larger and more legibly.

I found that it is a teacher's attitude towards my accommodations that makes all the difference. If my instructors were open to helping me, by writing legibly and larger in black ink without making me feel as if I were a "problem," the class would run much more smoothly for me. I would then be able to concentrate on what I needed to learn, and not on overcoming barriers due to my visual disability.

Prior to my first clinical rotation, my assistant dean called me into her office to talk about my disability and said, "We want to help you. Let us know if anything is difficult for you." This kind gesture meant a lot to me. For that matter, in general, Loyola University was exceptional in meeting all of my needs. We discussed different barriers that I may encounter in the clinical

setting. In relation to using syringes, we discussed how they may be difficult for me to see because of the small markings. Syringes usually have black markings and are quite easy to see. I found measuring cups to be more difficult because usually the markings are clear, making line differentiation difficult for me. When I use a measuring cup to measure out medications, I often ask someone to me to show me where the amount, like 20 cc's, is. I then put my fingernail on the marking and pour out the correct amount. I always followup by asking someone to check the amount I have measured to verify its accuracy. It would have been easier if the clinical settings and hospitals would purchase a different type of measuring cup with black markings.

Another difficulty I encountered in the clinical setting occurred when using manual blood pressure cuffs. It is very difficult to read the markings on a sphygmomanometer due to the glare on the glass or plastic. What I try to do is locate a digital sphygmomanometer and use that. Most units have at least one digital device.

I found that reading my nursing textbooks for long periods of time made my eyes very tired. I had my textbooks recorded onto audiotape. In order to do this, I would have to e-mail a teacher at least a month before the beginning of a semester; I would explain my situation and request. I would need a copy of the course syllabus as soon as possible so that I could send it into the company that recorded the tapes for me. The syllabus would help them record in the order the teacher wanted the books to be read and allow them to skip any unnecessary sections. Many teachers complied with my request but I was often met with opposition. I was told the syllabus was not yet ready and I would have to wait. Teachers would sometimes only give me a copy on the first day of class. This meant that the book was not audio-recorded in the in the correct order and sometimes the readings were not completed by the time they needed to be read by me.

The most difficult visual barrier I have encountered in the workplace is reading physicians' notes, because for the most part they are not legible. I suspect nurses with perfect vision also have that same problem. When hospitals move to computerized charting, all staff will benefit.

I never had any difficulty administrating medications. I never had any trouble administering CPR. I am a certified CPR and first-aid instructor.

I do not tell people I have a disability until I require an accommodation because I am afraid they will view me differently. As I begin the interview process for my first job as a registered nurse, I struggle with the timing of informing my potential employers about my visual disability. I hope that whenever I do decide to disclose this information, I will still be viewed as an asset to the institution and will be chosen based on my many strengths which I feel will be an asset to the unit.

I was recently accepted into the nursing honorary society, Sigma Theta Tau International. I am proud of that and proud that I made the Dean's List every semester. I am looking forward to my nursing career.

Bronwynne C. Evans. One of the really important things we hear Leo saying is that she had difficulty with a few issues while in nursing school, but had more commonalties with fellow nursing students than dissimilarities. That is what most students with disabilities teach us — that they are more like our usual nursing students than not.

Gordon Ninde, RN[5]

Ninde is a nurse who uses a wheelchair.

I was injured in a fall just after I graduated with a bachelor's degree in environmental biology. My plan, prior to my injury, was to work for the Forest Service or Fish and Wildlife Service, doing field biology work. After my accident, this was no longer an option. I did my rehabilitation at Craig Hospital in Denver, which was a wonderful hospital and they did a great job.

I arrived home after rehab and had to move back in with my parents after being on my own for four years; this was an adjustment, but we made it work. One example of an adjustment: The house was a split level, so they made the downstairs accessible for me. My mother had to cook upstairs and

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[5] Gordon Ninde, RN, grew up in the mountains of Colorado and enjoyed climbing mountains, skiing, snowboarding and mountain bike racing. He was an avid mountaineer and rock climber. A climbing accident in 1992 in Durango, Colorado, left him a T9 paraplegic. Ninde received a Bachelor's of Science degree from Fort Lewis College and an Associate's Degree in Nursing from Pueblo Community College. He is a staff nurse working the night shift on a Medical-Surgical floor at Mercy Medical Center, a 200-bed facility in Durango, Colorado. Ninde remains active in mono-skiing, kayaking, rafting, camping and dog sledding.

bring the food downstairs so I could eat. I worked as hard as I could to try and find a place in the world as a paraplegic. I had no insurance when I got hurt, so I was on Medicaid, Medicare and Social Security Disability. It is very difficult to get off these government-sponsored benefits because you can only make so much money. If you make one dollar over the government regulated amount, then the benefit is taken away. It is very hard for anyone to live without health care, but even more so for people with disabilities.

I worked with vocational rehab and they got me a job in town with the forest service. I was doing computer work for the hydrologist. I was working, but I realized I could not make a career of this because I would —- I need to be active and doing things.

I went back to school at Fort Lewis to round out my degree, took more general biology and genetics courses, and started to re-plan what I would do with my life. I started to look at what else interested me. I looked at veterinary and medical school and looked at the financial and time commitment for both of those. I also thought having a disability would be a big deterrent to those careers. I learned about the closest nursing program and talked with friends who had been through the program. The more I looked into it, the more it appealed to me. Nursing is such a broad field and there is so much you can do. I thought that even with using a wheelchair, I would be able to find something to do in nursing.

I started the process of preparing to enter nursing school. I took all the prerequisites and tests and applied to the program. The school contacted me and they were not sure about admitting me. It is a small program with two instructors and they were not sure what to expect because they had no examples in Colorado of anyone going through a nursing program using a wheelchair. They did not know what to think about the legal aspects. Some of the other issues were my lifting/turning patients, CPR and additional aspects of care and safety.

I asked to talk with the instructors. At the end of the interview, they decided they would admit me and try to make it work. They later told me the reason they accepted me was because of my attitude — the positive attitude I conveyed about what I wanted to do and why.

Some of the accommodations made were the location of the nursing classroom, which had to be changed. The year prior to my entering the program, classes were being held in an upstairs room, up a flight of stairs.

The year I started school, the classroom was moved into an accessible building that had an accessible bathroom. I was provided a desk that I could wheel under with no problem. The hospital and clinical rotation sites also made accommodations. In the clinical surgery rotation, I was provided a wheelchair from the hospital that I could transfer into. This wheelchair was sterile so I could go into the Operating Room suites in it. During my home health rotation, the nurses helped me into the houses that were not accessible. If there were a few stairs, they would help me into the house and it was not a problem. I am able to get out of my chair. I cannot stand or walk, but I can crawl and climb upstairs if I have to.

Durango, Colorado, is a rural area, and my school used two hospitals for clinical rotations. The hospital where I currently work, and did the majority of my clinical rotations, has a very accessible environment. I could get to everything I needed to care for my patients. I also found that codes in a hospital setting are very controlled. When there is patient code, a team is always called and they respond immediately. One of the team members is a nurse from the intensive care unit and that nurse always arrives in a matter of one to two minutes.

A big part of being successful as a nurse who uses a wheelchair lies in developing good relationships with the people you work with. I try to do that right from the beginning with the aides and the other nurses. I try to develop a good relationship, develop respect for them and what they do, and communicate with them about what I need. When I ask them to do something for me, they do not have a problem with helping. I also have no problem with asking when there is something I cannot do or I cannot get. To get the job done and take care of patients, I sometimes have to ask a co-worker for help.

I will end with a quote that has helped me. It's about attitude. "Our lives are not determined by what happens to us, but by how we react to what happens. Not by what life brings to us, but by the attitude we bring to life. A positive attitude causes a chain reaction of positive thoughts, events and outcomes. I am a catalyst, a spark that creates extraordinary results."

Bronwynne C. Evans, PhD, RN, CNS

I am charged with talking about faculty attitudes and how those changed over time in our college of nursing, or did not change, as the case may be. Historically, nursing faculty members seem to display less positive attitudes in regards to students with disabilities than do nursing students and practicing nurses. However, a 1998 study found that faculty attitudes are generally more positive when they have had higher levels of contact with students with disabilities.

We have few students with significant disabilities in our nursing programs, so how can we get the contact that will help us improve our attitudes? In the school where I teach, Washington State University, our contact with students with disabilities, and most certainly with students using wheelchairs, was minimal. But we had robust administrative support and had Victoria (Christensen), a very strong student with whom to blaze trails.

We struggled with a number of issues. When Victoria was ready to be admitted, some faculty very strongly disagreed with her admission. We chose to view their resistance as important in the process because it made the rest of us learn about the ADA, explore the legal basis for accommodations, and creatively pursue adaptations of our teaching strategies for students with disabilities. We grappled with the differences between essential functions for nursing practice and essential education requirements. (This issue will be further addressed by Carolyn Yocom, PhD, RN, in chapter 7).

Our faculty had a huge concern about safety issues, including, "She cannot be safe because she cannot do CPR." This is an issue that appears and reappears in stories of nursing education for students with disabilities. Let me just say that this summer, I will have been a nurse for forty years, and I have given CPR only once, out on the road, to an accident victim. There are plenty of other people around healthcare settings to give CPR who are far better at it than I am, just as Victoria noted.

You also heard Victoria's story about using an ambu-bag, about moving out of her chair to the floor to do chest compressions, if she needs to do that. We did assign her to units other than the Cardiac Care Unit, but if she needed help with a few tasks such as hanging her IV's, she asked somebody to help her, the way a nurse of short stature would do.

Accepting a broader definition in regards to what students with disabilities must do was helpful to our nursing faculty. For example, in nursing, we are very fond of behavioral objectives. Think about Gagne's work with behavioral objectives and what he calls the executive subroutine, the intellectual subroutine that runs alongside the psychomotor skill. If we hold our students to the standard of knowing that executive subroutine so they can use their knowledge of the procedure, their knowledge of the patient, and their theoretical knowledge to do their nursing, we believe that they have, in essence, fulfilled their academic obligations.

I came to the process of educating Victoria as a novice in teaching students with visible disabilities. I had expertise in multicultural education, but no experience in helping students get through a program if they used wheelchairs. I learned as Victoria's teacher that the ADA addresses civil rights: Colleges of nursing cannot legally discourage applicants or question students as to what their disability is, nor insist that they self-identify and disclose their disability.

This new knowledge continues to be absorbed by our faculty, but we are not yet where we need to be. For instance, we started revising our ADA policy a year ago, but it is still not finalized. We realize we have to provide accommodations as long as they do not impair the integrity of our curriculum or cause undue hardship on our school, but we continue to grapple with these issues.

Faculty members are also learning to rely on students to tell us what they need, but as teachers, we are used to "calling the shots." Our paradigm of education is male-model, European, straight out of the German gymnasium. At times, this does not serve us well, because we must look to our students to be our teachers. For example, I learned to go into elevators ahead of Victoria and let her manage the door. I learned to say "students with disabilities" instead of disabled students, in order to define her first as a person and then as someone who has a disability. I also learned that Victoria was much more safety conscious than most students because she has to be more aware of her environment.

In terms of changing faculty perspectives and attitudes, three things were especially useful to us:

1. **Use the sociopolitical model of disability (mentioned by Marca Bristo) when defining disability.** Focusing on societal barriers for students with disabilities, rather than functional impairment, helped us look at our policies and procedures that bar those students. According to Beth Marks, who is a nurse and a disability activist and to whom I owe most of my understanding about disabilities, our schools of nursing have inflexible systems. They lack access to necessary resources, lack support systems and personnel, lack knowledge on the part of peers, faculty and administrators, have confidentiality issues, lack role models and mentors, and harbor overt and covert prejudices and discrimination. I would say all those things have been present in our college, and we continue to work on those issues.

2. **Seek out accurate information.** We relied very heavily on our university's Disability Resource Center (DRC) for this. Staff from the DRC came to the College of Nursing for a series of meetings and provided support over the phone. When the Dean appointed me as the College of Nursing ADA liaison, I learned that the ADA was intentionally written vaguely. The result of this intentional vagueness is that when you admit a student with a disability to your program, you have not set a precedent that you will have to live with forever. You may continue on a case-by-case basis, admitting academically sound students regardless of disability. That was a very helpful piece of information for our administrators, who strongly support admitting students with disabilities but also needed to think about the future ramifications.

3. **Provide personal contact with persons with disabilities.** We learn to understand and value others who are different from ourselves through day-to-day, reciprocal personal contact. However, there is such a clear imbalance of power in nursing education between the teachers and students that personal relationships may be difficult to achieve. Nevertheless, nursing education for students with disabilities is more likely to be successful if we change those power inequities and treat our students as co-learners with us in nursing practice and nursing education.

   Most of our faculty members were surprised and delighted and very proud of Victoria. But others were not. And that small fraction continue to believe her admission was not a wise decision, that it worked because Victoria is so exceptional. This resistance is a very real issue that all of us here today will confront when we go back to our colleges and universities and try to put what we have heard at this symposium into practice.

In closing, I am indebted to Jovita Ross-Gordon, who wrote in regard to sociocultural contexts of learning for adults with disabilities (2002, *New Directions for Adults in Continuing Education, 96,* San Francisco: Jossey-Bass). I hope that our stories today will provide insights as we create environments that maximize potential, foster self determination, and empower nursing students with disabilities. Capitalize on the self-awareness and experience of these students, and move beyond tolerance of differences to promote full inclusion and social justice for persons with disabilities who seek to enter our profession.

Audience Participation

Karen McCulloh, RN, President, of McCulloh Consulting and a disabilities rights activist. I am sight impaired and use a light cane. I have multiple sclerosis, am hearing impaired and wear hearing aids. I could not find a job as a nurse, so I started my own business.

Commenting on student Leora Stopek: Technology now provides talking thermometers, talking blood pressure cuffs, talking scales, talking calculators, talking everything. The adaptive technology that is available for nurses who are sight impaired is incredible. However, disclosure during hiring is an issue. If you are sight-impaired and don't use a cane or a dog, it sets you up for a dilemma. It is important in nursing, and to yourself, to be fair; there has to be some kind of disclosure with whomever you are interviewing. According to the ADA you do not have to disclose. My concern is that because your vision vacillates, you may get put into a situation where you have not disclosed, and then you may have a day where you're having poor vision. You are putting yourself into a stressful situation where you may have to say you cannot do some of the work your boss expects of you.

I think one of the issues for disclosure is accepting ourselves as people with disabilities and then trying to find acceptance from people who interview us for jobs. If you have acceptance, it makes you free in the work environment to disclose. From my personal experience, you really need to think about disclosing because it will create a baseline for an accepting and easier atmosphere at the workplace.

Bronwynne C. Evans. Thank you for that helpful advice. We found in our program, and I am not disputing in any way the validity of what you said, Karen, that students may not disclose because they <u>fear</u> discrimination or <u>fear</u> that they will be barred from admission or activities. Just as Leora said, "I am <u>afraid</u> they will view me 'differently'," and so it's more difficult to disclose.

Sheila Jesek-Hale, PhD, RN, Professor, Illinois Wesleyan University. I teach at an undergraduate nursing school and am on the student affairs committee, which deals with student policies. We had a student with a chronic disease who at times had to use a wheelchair. The university was very good about accommodating her. Our problem was with contractual agreements with hospitals, clinics, etc. They had restrictions about what students had to be able to lift ("X" amount of pounds), must be able to move, must be able to do. Although the university had no difficulty with the student, some of the agencies where we place students had difficulty with the necessary accommodations.

Bronwynne C. Evans. This is a very valid point. I was Victoria's first clinical instructor and I used many of my good relationships with clinical facilities to obtain a placement for her. I spent many hours smoothing the way with clinical staff. When faculty members have a student with a disability and they have to spend time negotiating with clinical facilities, that faculty member needs to have a lighter student load. Most of the clinical facilities were okay after clear explanations of the issues, but I did run into some resistance, both at the facility level and individual level. We know that every student does not have to have exactly the same experience to learn to be a nurse, so if the student is not wanted, one option is to move to a clinical facility that may be more accommodating. If the issue is forced, it may be very difficult for students and faculty to work in an unwelcoming situation.

Karen Moore, JD, Disabilities Rights Attorney. My advice on disclosure is to disclose. The issue is not whether to disclose, but when. You do not have a duty to disclose until you need something. Then you do have a duty to disclose because if you need an accommodation, you have to be able to demonstrate why. However, wait until you're further along in the process. Do not lead with your disability, lead with your skills. If you get a job offer or a second or third interview, there will be an appropriate time for you to indicate where you might need an accommodation. The problem you are bringing up is if you get the job and did not disclose, and then find you cannot perform a certain task. You've already got the job and now have to disclose

your disability. This is a really big issue because you do not want to disclose at a time when it will keep you from getting the job, but you also do not want to wait until you have the job and cannot perform something you were hired to do.

Also, regarding the clinical agencies the colleges have contracts with — those agencies have legal obligations the same as the school does. I would not back down from placing students who need accommodations just because there is something written in a contract. Everyone has to follow ADA guidelines and law.

Ray Campbell, President of the Illinois Council of the Blind, and employee of the DuPage Council Center for Independent Living. My question is for Leora Stopek. You have all mentioned there are hundreds of different jobs in the nursing profession. What jobs do you feel a person who is totally blind might be able to perform in your profession?

Leora Stopek. I think it would be something that does not necessarily rely on sight. My psychology rotation was on a non-medical psychiatric unit and a successful experience depended on the ability to communicate with a person rather than a visual assessment of the patient. Another option may be to work in a community setting where the nurse acts as a patient advocate and the job involves helping patients get services and/or equipment that will help them with accommodations, or meet certain requirements. I know there are many nurses in community settings who are involved in helping patients with disabilities as part of their jobs. Someone who already has a disability is familiar with various associations where help and resources can be found. I know there are many more areas like quality assurance departments, patient referral services, etc., that may be good places for a nurse who is completely blind to work.

Bronwynne C. Evans. Due to time constraints, this ends the "real stories" session. Participants may meet with our panel members at breaks, lunch, and in the evening.

CHAPTER 4

Legal Aspects of Accommodations for Students with Disabilities in Nursing Education

Andrew J. Imparato, JD[1]

Andrew J. Imparato, JD, President and CEO
American Association of People with Disabilities

Background

When Congress enacted the Americans with Disabilities Act (ADA) in 1990, it articulated four goals for public policy regarding people with disabilities: equality of opportunity, full participation, independent living, and economic self-sufficiency. Today, more than twelve years later, our nation has made progress toward reaching those goals, but there is still plenty of room for improvement. For example, among working-age adults with significant disabilities, only about one in three is working, notwithstanding the fact that a majority of these individuals want to work.

Among disability advocates, there is increasing recognition of the important role of higher education in facilitating the right of people with disabilities to make choices, pursue meaningful careers, and contribute to their communities. According to a 2002 survey from the National Organization on Disability, only about 12 percent of adults with disabilities have graduated from college, compared with about 23 percent of the general

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[1] **Andrew Imparato, JD, joined the AAPD in 1999. Imparato was general counsel and director of policy for the National Council on Disability, an independent federal agency advising the president and Congress on issues affecting people with disabilities. He has worked as a special assistant to commissioner Paul Steven Miller at the U.S. Equal Employment Opportunity Commission, as counsel to the subcommittee on disability policy chaired by Senator Tom Harkin of Iowa, and at the Disability Law Center in Boston. He recently wrote an essay on the U.S. Supreme Court's rulings affecting people with disabilities under Chief Justice William Renquist, part of a book addressing the court's impact on multiple constituencies. This book is entitled *The Renquist Court, Judicial Activism on the Right*. Imparato began his career after a degree with distinction from Stanford Law School and as a *summa cum laude* graduate of Yale College.**

public. Importantly, according to a 1999 study from the National Center for Education Statistics, for those individuals with disabilities who do graduate from college, outcomes in terms of early labor market participation and graduate school enrollment are the same as for those without disabilities. Accordingly, if we are able to close the education gap, we will have a much better chance to close the employment gap.

The percentage of students with disabilities participating in higher education has grown from 2.6 percent in 1978 to 9.0 percent in 1998, according to the National Clearinghouse on Post-secondary Education for Individuals with Disabilities. Notwithstanding this growth, many faculty members and administrators have indicated in surveys that they do not feel they have received adequate training in how to accommodate disabled students. In 1999, the American Association of Colleges of Nursing surveyed its member schools regarding their experience with the ADA. Eighty-seven percent of the respondents indicated that they have had experience with students having either physical or mental disabilities or both. Clearly, accommodating students with disabilities has become a real issue in colleges of nursing.

Legal Issues

Under the ADA and Section 504 of the Rehabilitation Act, colleges and universities are prohibited from discriminating against students with disabilities pursuing higher education. These laws define an individual with a disability as a person with a physical or mental impairment that substantially limits at least one major life activity, a person with a history of such an impairment, or a person who is regarded by others or perceived as having such an impairment. For a student who meets this broad definition, institutions of higher education are required to take whatever steps are necessary to ensure that a qualified disabled student is not denied the benefits of, excluded from participation in, or otherwise subjected to discrimination in the education programs or activities operated by the institution. This includes not just academic programs but also extracurricular programs, university-sponsored housing, and other activities conducted by the educational institution.

When a student with a disability discloses the existence of the disability and requests an accommodation or academic adjustment, the college may request reasonable documentation of the existence of the disability and the need for an adjustment. Once the documentation has been

provided, the college is required to make an accommodation that will be effective in ensuring that the student has equal access to the program. Academic adjustments include modifications to academic requirements and auxiliary aids and services. Examples of modifications to academic requirements include arranging for priority registration, reducing a course load, substituting one course for another, and moving a course from an inaccessible building or classroom to an accessible one. Examples of auxiliary aids and services include providing note-takers, recording devices, readers, qualified sign language interpreters, extended time for testing, TTY telephones, or adaptive software or hardware for school computers.

In providing an academic adjustment, colleges are not required to lower or effect substantial modifications to essential requirements. Although a school may be required to provide extended time on a test, for example, it is not required to change the substantive content of the test. Also, colleges are not required to make modifications that would fundamentally alter the nature of a service, program, or activity or would result in undue financial or administrative burdens. Finally, colleges are not required to provide personal care attendant services, individually prescribed devices, readers for personal use or study, or other devices or services of a personal nature, such as tutoring or typing.

In assessing the best way to accommodate an individual student, it is important for colleges to work with the student in an individualized manner to develop an accommodation that is effective. The school is not required to provide the exact accommodation that a student requests if another effective accommodation is available, but it is always a good idea to work with the student to gauge the effectiveness of various alternatives for that student. There is a great deal of variation within different disability categories, and for this reason colleges should avoid assuming that an accommodation that worked for a student with a particular disability will work for the next student with that disability. Also, the nature of an individual student's disability can change over time, leading to a need to reassess the ongoing effectiveness of a particular accommodation.

One key category of accommodations for disabled students is auxiliary aids and services. The regulations interpreting the ADA require that colleges and other public entities provide such aids and services "where necessary to afford an individual with a disability equal opportunity to participate in, and enjoy the benefits of, a service, program, or activity conducted by a public entity." Under Section 504 of the Rehabilitation Act, a college receiving

federal funds may not provide a disabled student "with an aid, benefit, or service that is not as effective as that provided to others." The Section 504 regulation states:

> [A]ids, benefits, and services, to be equally effective, are not required to produce the identical result or level of achievement for handicapped and non-handicapped persons, but must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement, in the most integrated setting appropriate to the person's needs.

In a 1998 primer on auxiliary aids and services for post-secondary students with disabilities, the U.S. Department of Education's Office for Civil Rights emphasizes the importance of looking at the appropriateness of a particular aid or service in a specific context. The guidance uses the example of a student who is hard of hearing, and notes that the type of assistance that student needs will vary depending on whether the class is being offered in a large lecture hall or a seminar. Noting that whereas the service of a note-taker may be adequate for a lecture hall, where the communication is usually one-way, the guidance points out that in the context of a seminar, an interpreter may be required to facilitate two-way communication.

Beyond Compliance

To truly open the doors of opportunity for people with disabilities to pursue nursing as a profession, it will be important for colleges of nursing to look for ways to incorporate affirmative strategies to integrate applicants and students with disabilities into broader efforts to ensure a diverse student body and a diverse nursing profession. Rather than simply responding to accommodation requests from disabled students who find their way to nursing, colleges should reach out to local, state and national disability groups and make it known that they are affirmatively interested in increasing their enrollment of disabled students. An important component of a successful outreach strategy might involve identifying nurses with disabilities who can serve as mentors and ambassadors to help with outreach, including by making presentations at high schools, colleges, state vocational rehabilitation agencies, and disability conferences.

Oftentimes, the biggest barrier to equal opportunity for disabled students is not a physical or communications barrier, but instead an attitudinal barrier. A college might have great written policies on accommodations, but if the faculty does not embrace these policies and approach accommodations with a genuine desire to find a solution, there is a real danger that students will encounter unnecessary friction when they seek to assert their rights. To help set the tone and emphasize the importance of equal opportunity as a college-wide priority, it will be important for the top leaders in any institution to use their bully pulpits to talk about the values that underlie the college's commitment to opening the doors to nursing to all qualified candidates. Similarly, to underscore the college's commitment to diversity in the nursing profession, it is very helpful for the college's marketing materials to feature students with visible disabilities in these materials. Ultimately, as the nursing profession diversifies, it will find that it is better prepared to meet the needs of the increasingly diverse communities it serves.

Resources

The U.S. Department of Education's Office for Civil Rights (OCR) has responsibilities for enforcing the federal laws requiring equal opportunity for qualified students with disabilities and others. Two recent documents OCR has issued that have useful information on this topic include:

"Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities," July 2002, available free at **www.ed.gov/offices/OCR/transition.html**; and

"Auxiliary Aids and Services for Postsecondary Students with Disabilities: Higher Education's Obligations Under Section 504 and Title II of the ADA," revised September 1998, available free at **www.ed.gov/OCR/docs/auxaids.html**.

The national information number for OCR is 800 421-3481 (voice) or 800 437-0833 (TTY). The U.S. Department of Justice also operates an ADA information line for publications, questions, and referrals. The number is 800 514-0301 (voice) and 800 514-0383 (TTY). The ADA homepage administered by the Department of Justice can be found at **www.usdoj.gov/crt/ada/adahom1.htm**.

The American Association of Colleges of Nursing's "Guidelines for Accommodating Students with Disabilities in Schools of Nursing" is available free at www.aacn.nche.edu/Education/ada.htm.

Addition to Position Paper Presentation

Andrew Imparato. I really want to commend everybody who was involved in conceptualizing this and organizing this conference. To me this is exactly what we need to be doing in every profession. We need leaders from the profession to come together with disability leaders and folks with disabilities who are working in the profession to work together to try to open up professions. Whether the profession is nursing, law, medicine, accounting or information technology, every field would benefit from this kind of symposium. I really want to commend all of you for putting this together and doing it at a very high level. It's crystal clear to me that you're taking this seriously and that you hope real change and systemic change is going to come out of what everybody is working on over the next day and a half. I'm privileged to be a part of it.

I thought what I would do is talk about why we have laws that require accommodations for students. You will be hearing from people who will talk more about the employment issues later today. Why do we have laws requiring accommodations for students with disabilities. Anybody?

Audience. To level the playing field, otherwise students with disabilities are set up to fail.

Andrew Imparato. OK, there's a ringer in the audience. One is to level the playing field, to give them an equal chance to succeed. The concern is if we don't level that playing field, we're setting some students up to fail. How can having nurses with disabilities improve the nursing profession?

Audience. By being able to better connect with their patients because their patients might have or develop a disability. They will be able to say, "Well, I have one too," be empathetic with them and sympathetic at the same time.

Andrew Imparato. Great. The answer was to be able to better connect with their patients and for the nursing profession as a whole to

better connect with a part of their patient population. I think that the basic questions of why do we have laws that require accommodations and why is this good for the nursing profession are important for everybody to be able to answer. As you go back to your institution, as you heard in the last panel, you will encounter professors, administrators, and board members who are not helpful. You will encounter people in the media who are going to write about one negative experience and blow it out of proportion. So I think it's always useful to go back to why are we here. Why do we do these things?

From my perspective, all the reasons that we think and talk about diversity are the best reasons to think and talk about disability. If you want a nursing profession that is diverse then you also want a nursing profession that is inclusive of nurses with disabilities.

I think what is important about the ADA are the broad goals. What did Congress say when they passed the ADA? They said that there were four big goals that we're trying to accomplish. The goals were equality of opportunity, full participation, independent living and economic self-sufficiency. Those goals are not easy. In many ways they are revolutionary. When you hold those goals up against centuries of people with disabilities experiencing exclusion, paternalism, and in some cases being targeted for extinction, those goals really are revolutionary.

I think some economists and some political thinkers get frustrated that the ADA was passed in 1990 and here we are in 2003 and we haven't seen huge changes in employment rates for people with disabilities. We haven't seen some of the decreases in disability benefit participation and other things that people had hoped would happen or talked about happening in the context of the ADA being passed.

I think Justin Dart did a nice job on a pretty regular basis pointing out that these things don't change in a period of ten years or thirteen years or fifteen years. It took centuries and generations to develop the barriers that people with disabilities face. It is going it take generations before we see the promise of those four goals really happening on a regular basis for people with disabilities.

I really appreciated the point Gordon Ninde made about the disability benefit system. I think one of our biggest challenges is a public policy challenge. How do we take the public programs where we spend most of our money, Social Security, disability insurance, Medicare and Medicaid and

make sure that those programs are consistently supporting the four goals that Congress established in the ADA? When an 18-year-old has to swear to the government that a disability prevents him or her from working in order to get health care, then we're basically expecting an 18-year-old to retire at age 18. That's clearly inconsistent with the vision of the ADA. That is our public policy. There have been small steps to change that. A law passed in 1999 called the Ticket to Work and Work Incentives Improvements Act, and it's a very small step. It didn't do anything about that basic definition of who's eligible for disability benefits.

The key legal concepts really come from two laws, section 504 of the Rehabilitation Act and the Americans with Disabilities Act. From my perspective you don't need to worry about which law you're dealing with. They pretty much require the same thing, and they're both federal laws. It's more a question of whom they apply to. Section 504 applies to any entity that receives federal financial assistance, which is true of most nursing programs. The ADA applies to everyone else. Both laws apply equally in most of the areas that matter. The obligation under both of those laws is that a nursing college not discriminate against an applicant with a disability or a student with a disability or an employee with a disability.

What does it mean to not discriminate? First you have to look at what does it mean to be a person with a disability. The definition of an individual with a disability under these two federal laws is an intentionally broad and inclusive definition. The first prong that sometimes gets referred to as actual disabilities is for somebody who has a physical or mental impairment that substantially limits at least one major life activity. The basic concept is you have an impairment, so it's something that's medically knowable. Then you look at how the impairment interacts with the person's life and if the person is substantially limited in a major life activity, that comes under that first prong.

The second prong is a person who has a history of such an impairment. A person may have been treated for cancer at some point, but not currently experiencing symptoms. The person is protected against discrimination based on that history. A person may have been hospitalized for a mental illness and not currently experiencing symptoms. That person could still be protected under the history prong.

The third prong is being perceived or regarded by others as having an impairment or disability. That's really to cover people who are very qualified

for a position but, because of something that they say or something about them, the employer or the school is making an assumption that the person is substantially limited and not hiring or admitting the person on that basis. Let's say the person is on an Indian reservation and there's an assumption that people from that particular Indian reservation are going to be more likely to have a particular impairment. That would be discrimination on the basis of American Indian status. It also would be disability discrimination under the third prong, even if the person has no actual impairment. That last prong is really a catch-all that's intended to get at if somebody is treated unfairly based on something that's going on in the employer or the school's mind. That's still disability discrimination if what's going on in the mind relates to physical or mental impairment.

The obligation is not to discriminate. For schools, it means you don't discriminate in admissions, you don't discriminate in housing. If you're providing housing, you need to make sure that that housing is accessible for students with disabilities and that you're not going to charge them more for the accessible housing. They should pay whatever the other students pay. It means you don't discriminate in any programs run by the school.

The other basic requirement is that a school of nursing must provide academic adjustments as necessary to ensure that students with disabilities have equal opportunity to succeed at that institution. I think one thing that's important to recognize is you will have applicants and students with disabilities who need absolutely no academic adjustment.

There is the whole question about disclosure. I think it's important to recognize that for some people there really is no reason to disclose other than disability pride or trying to get qualified for affirmative action. Most of the programs that my organization runs are for people with disabilities. We don't ask for medical documentation of anything, but we do ask them to self identify so that we know that they're part of the group that we're intending to benefit from the program. I want to emphasize that every one of you has students with disabilities in your programs. You may not be aware of what the disabilities are or the breakdown. It's not a question of if you have students with disabilities but how many and in what combination.

I think that it is useful to think of disability as not being black and white. It is not a simple concept, nor a static concept. Your level of ability or disability, level of impairment can change on a daily basis, on an hourly basis. So it's important to recognize that diversity. Again, the basic

obligation on the part of schools is that you need to make some adjustments to give people equal opportunity.

There are two types of adjustments that I wanted to briefly mention. One is what sometimes gets called modification of academic requirements. An example could be arranging for priority registration or reducing a course load. Let's say a student is experiencing depression and needs to take a lighter course load while trying to deal with the depression or work out medication. That could be an accommodation. There are other disabilities that might require a reduced course load. Substituting one course for another can be an accommodation. Providing extended time for testing is a very common accommodation.

There's another category of academic adjustments called auxiliary aids and services. Examples of that could be providing note-takers for students not able to take notes themselves. Other examples are recording devices, allowing a student to record what goes on so that they can have the recording in an accessible format to listen to the material, and providing qualified sign language interpreters. I emphasize the word "qualified." Some schools think that one sign language interpreter is the same as the next. There are some people who are able to sign but clearly are not qualified sign language interpreters. It's a matter of understanding that it's a profession and that there are standards within the profession. If you're going to provide the accommodation, you want to make sure that the people you hire to do the interpreting are qualified and are at a high enough professional level that the student is truly going to get equal access to the information that the professor is conveying. Other examples could be providing text telephone or TTY in dorm rooms. If you provide a regular telephone for your students in their dorm rooms and somebody needs a TTY, you need to make that accommodation and give them a TTY in their dorm room. Equipping school computers with screen reading, voice recognition or other adaptive software or hardware is another example of this kind of auxiliary aids and services.

One thing that I think is important for you all to hear is that, under these two federal laws (Section 504 of the Rehabilitation Act and the Americans with Disabilities Act), a school of nursing is not required to lower or effect substantial modifications to essential requirements of its program. You don't have to lower your standards in order to admit and welcome students with disabilities into your programs. For example, although you may be required to provide extended test time for a student, you do not have to change the substantive content of the test in order to accommodate a

student. We can get more into some of this in the Questions and Answers, but the notion that you don't have to lower standards I think is an important one. Then it's really a question of how do people understand that and operationalize it. I think the panel you heard from earlier is a good example of people who have obviously been very successful as students and as professionals in the field of nursing and who didn't ask and wouldn't ask that the standards of the profession be lowered to permit them to succeed.

The other kind of qualifier that is important for schools to know about is that nursing schools do not have to make modifications that would fundamentally alter the nature of a service program or activity or would result in undue financial or administrative burdens. I think one of the other speakers said that the ADA was deliberately vague. I try hard not to use the word vague because that's a word that is used by a lot by people who are criticizing the ADA. I would say it's deliberately flexible.

The notion of what is reasonable is inherently a very fact-specific thing. It depends on the circumstances. You could have five different schools of nursing that are located in different areas with different budgets, different physical plants, different size of faculty, different size of the parent institution that they may be affiliated with. So the ADA requirement is going to flex depending on some of those factors. And the same is true for students. You could have five students who self-identify as blind who need five very different accommodations. Figure out what is reasonable and effective for each student. It's not going to work if you just give them what you haven given all the other blind students. It really is about listening to the student and understanding what will work for that student. The same thing is true for a student with a hearing impairment or a psychiatric disability or any number of other conditions. Be very wary of saying, "Oh yeah, I know how to do X disability because I did it for somebody last year." It really depends on the specific requirements and specific needs of that person.

The final thing I wanted to mention is that a nursing school does not have to provide personal attendants, individually prescribed devices, readers for personal use or study or other devices or services of a personal nature such as tutoring or typing. I'm getting all this from the Office of Civil Rights at the Department of Education. That's kind of the lead entity that is in charge of enforcing a lot of the disability nondiscrimination requirements under Section 504 and the ADA. I don't know that I agree completely with what I just said. That is the law.

I wanted to touch a little on admissions issues. A qualified individual with a disability for purposes of admissions is an individual who meets the skills, experience and education requirements of the position held or desired and can perform the essential requirements of the program with or without a reasonable accommodation. What people are going to fight about is what are the essential requirements of the program. I'm not going to try to answer that question. That would be a useful thing for everybody to discuss tomorrow.

I want to let people know that I read a document that I found from a Google search that helped me in preparing today. It's produced by the American Association of Colleges of Nursing. I don't agree with what they describe as the essential functions of nursing. It says you have to have the ability to see, touch, manual dexterity, gross and fine motor movement, ability to learn, think critically, analyze, assess, solve problems and reach judgments, and, finally, emotional stability, and ability to accept responsibility and be accountable. Some of those things we agree with. I think they are seizing on the wrong thing to define what is an essential requirement. You don't talk about ability to speak and hear, but talk about effective communication. I'm not going to try to resolve that question. I just wanted to get it out there and clearly it's been brought up by other panelists.

I wanted to read as a direct quote from this paper again, from the American Association of Colleges of Nursing. I assume it's a credible source. In terms of the nursing field, I have a real problem with this statement. I don't have a problem with the first sentence but the second sentence. "An individual may be able to master content and pass classroom examinations, but possess certain limitations or conditions that cannot be surmounted with present day technology." Let's assume that that's true. I'm not sure, but let's assume. This next sentence I have a problem with. "For example, it is unlikely that an individual who has no use of her arms and hands or is completely blind could be successful in a nursing curriculum." That to me is inherently suspect. I just encourage people to talk that statement through as we move forward in this group. The gentleman from the Illinois Council of the Blind certainly was pointing in the right direction. There most definitely are jobs within the field of nursing that somebody who has no use of their hands or arms or someone who is completely blind, no vision at all, could still do successfully, with or without a reasonable accommodation.

The last thing that I want to encourage people to think about is how to get beyond compliance. I mean you all are leaders. You're trying to take a profession that is a growth profession within our economy and make sure

that doors are open as widely as possible. Don't get so fixated on compliance with federal legal requirements that you miss an opportunity to go beyond compliance.

There are a lot of things that aren't required by law that can make a huge difference. What is the picture on the cover of your brochure that you use to market your institution? Does it have a person with a visible disability on it or not? That's not required by law, but it will send a very strong message. I just encourage people to think beyond compliance as you think about accommodations.

Also, whatever you do to accommodate students with disabilities, make those accommodations available to all students. If somebody needs extra time on a test, give it to him or her. I think most of the studies show that extra time on a test does not help the students who don't need the extra time for a disability-related reason. Again, I just encourage you to think about going beyond compliance.

I'm going to close with a quote from Martin Luther King that is very appropriate. This is my favorite quote from Dr. King. Dr. King said: "Everybody can be great because anybody can serve. You don't need a college degree to serve. You don't need to make your subject and verb agree to serve. All you need is a heart full of grace, and a soul generated by love."

Thank you.

Legal Aspects of Accommodations for Students with Disabilities in Nursing Education Response

Dale Atkinson, JD, Executive Director[2]
Federation of Associations of Regulatory Boards (FARB)

I also would like to thank everyone involved in putting this important symposium together. I think that these topics need to reach as broad an audience as possible. And I'm happy to be here and provide some of my remarks as a paper responder, although I try to refer to myself as more of a paper expander. If I wanted to respond, I could just say I agree with everything that Andy said.

The gap that I would like to try to bridge in response will supplement the comments that have been made. Somewhere between education and employment is licensure. And that's where my expertise falls and that's what I do on a day-to-day basis insofar as my representation of these associations. The groups that I represent are made up of regulatory boards involved in the licensure process. In doing that, they provide programs and services to the boards themselves. They're not professional associations and what have you. They have public protection in mind but they also have statutory mandates and legislative responsibilities to follow. All of this is mixed into the discussions and the issues that we're trying to address at this symposium. I think these may prove to be interesting discussions.

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The laws and roles that regulatory boards play are all set forth legislatively, and these boards then have to follow those laws to determine licensure eligibility. This is what I would like to focus on. Of particular interest and perhaps the easiest way to illustrate some of the points I would like to make is through the examination programs. That's the easiest way to illustrate issues of individuals with disabilities and how they may be impacted either adversely or positively in the process of becoming or going from being educated to being employed, getting to that licensure point somewhere in between.

These associations of regulatory boards that I represent develop and administer the licensure examinations in all jurisdictions. They're uniform programs. The states that choose to use them rely upon these associations because of their expertise in development and in the administration of examinations. They provide uniformity so that individuals who become licensed in state A and want to move to state B have taken a similar or same examination built on the same content. This is the easiest way to illustrate issues of individuals with disabilities who have gone through a process of being educated and now want to work. Licensure stands in between. Licensure stands in between for everyone, not just for individuals with disabilities.

I'm happy to say that these associations that I represent have been providing accommodations long before the ADA was enacted. They were savvy in understanding the issues of individuals who were seeking licensure through an examination process. So when the ADA came out, although it was watched and it was studied and discussed and debated, most of my clients did not have to make many substantive changes to their programs, insofar as the exams are concerned. These issues of awareness to disabilities I think were present within these associations and their policies and programs were understanding to the fact that individuals may need accommodations relative to the examinations themselves.

As an example, in social work last year we probably had over 800 requests for accommodations across the country relative to the exam program. Those accommodations are generally granted. There's a three-pronged approach to the process, dealing with the applicant for licensure, the association that develops and administers the exam and is responsible for ensuring the integrity of the program, and the regulatory board itself. It's important that these three entities work together to ensure that not only the

laws are met, but there is an equal opportunity for exam administration and completion relative to the licensure process.

Another point in relating back to the educational or academic process that we all go through prior to becoming licensed is the fact that those accommodations that are given within the educational setting help set the standard for the regulatory board to give and grant accommodations in the future. As we talk about educational programs and what accommodations should and should not be granted, that is setting the stage for the licensure process. The first thing that I advise regulatory boards when I'm asked the question about whether an accommodation is reasonable is, "What is the ADA standard?" What accommodations did the individual receive during his or her education? These professions are post-secondary and we're talking about a process through which an individual has become educated. So that question will be asked. And I think it's important that the educational institutions as well know that that's how the process will work, at least in part from the standpoint of providing these accommodations.

It's also very important for us to understand the role of each of these entities, academic and education, regulatory, and employment. Although the ADA applies across the board, different laws apply to different ones of these entities relative to how you will assess the legal issues that might come up. So there are some of these differences that we don't have time to talk about now, but at least we can lay a little bit of foundation. The accommodations that we see granted include readers, describers, physical access to the tests themselves, large print, extra time, and separate rooms. Most of the exams are given by computer, but there are paper and pencil administrations for those who need them as well. We can carry this list on as far as we would like. We do see a lot of requests for accommodation. That's positive because the awareness level is being raised by those who are going to need accommodation and those who are going to grant those accommodations as well.

The last part of my remarks I would like to refer to the general regulatory process. It is broad-based and the ADA applies to all the board activities, not just the exam. So we're talking about the application for licensure, the disciplinary process, post discipline, reinstatement of a license, continuing education, licensure renewal, a lot of topics. From a legal basis, a lot of issues do come up that are fully discussed by these associations that I represent as well as the regulatory board and individuals as well.

I'm happy to open up to questions right now. Perhaps we can address specific issues to make this as beneficial to the audience as possible.

Andy Imparato. I'm going to ask my old boss, Bobby Silverstein, to join us up here. I know if I get anything wrong, Bobby will know the right answer, because he wrote a lot of these laws that we're talking about.

Audience Participation

Martha R. Smith, Project Coordinator for the Health Sciences, Oregon Health Sciences University. My question is combined for two things that you each brought up. One is the changing nature of disability, what someone needs today might not be what they need tomorrow. And you brought up the issue of accommodation needs for licensure exams, which are determined by what students used when they were in educational settings. What we have is a Catch-22 developing for students with disabilities. As faculty and institutions are becoming more aware of universal access, they are providing better access for all their students, including extended test time as a matter of course. They are providing overheads as handouts, as a matter of course, not as a matter of accommodation. We have students who don't have a formal record of having used specific accommodations while they were in their programs. Now they go to a regulatory board that says we're going to base our decision on what you used in your institution when there might not be a formal history. So we have now set up students for situations where they've developed great strategies and they have faculty who have provided them with accommodations informally. Now the regulatory board says because you don't have a history to prove that, we will not provide you with that accommodation.

Dale Atkinson. Your point is well taken. I didn't mean to mislead anybody that that's the sole indicator of what accommodations might be given. Generally, that's the starting point for determining the reasonableness of the accommodation. We have seen in the past individuals who under the guise of certain laws try to take advantage of situations and as was discussed or mentioned earlier, perhaps everyone then should be given these accommodations. I have no problem with that. They're not time-based tests. Some of the other issues perhaps do impact the validity of the

exam to assess the content areas that it is intended to assess. Back to your question, it's not the sole determining factor. Frankly, if someone comes up and explains a situation like that, I think they would be granted the accommodation.

Andrew Imparato. The only other thing I would add is a lot of professions like the legal profession require passing an exam to practice law. I assume in the medical profession and in nursing and in other professions there are exams that are part of the licensure process. One thing that I have noticed is the higher up you get in the food chain, the harder it is to get an accommodation. Even if you have the exact same disability, exact same accommodation need, it's a lot harder to get an accommodation on a bar exam than it is to get an accommodation on the SAT, for example. Now, I'm hoping this will all change over time. I'm just saying one thing I have observed is some of the strongest attitudinal barriers are at that pre-professional stage where they are really trying hard to be a gatekeeper, in what I see is the worst sense of that term. Bobby, I don't know if you want to say anything on this question.

Bobby Silverstein, JD (Silverstein whispers/mouths his answer so that no one can hear his comment). There is one person in this room who understood what I was saying. I am now doing a reasonable accommodation for all the rest of you. And this point is very important. When we use words like accommodation and auxiliary aids and services, they sound like special treatment. If we're inviting everybody to participate who's qualified, all means all. And everybody should have an effective, genuine and meaningful opportunity to benefit from whatever it is we're talking about. So accommodation sounds like something special. It's not. When we start looking at policy tomorrow, I hope the standard and the criteria are genuine, effective and meaningful opportunity.

What we do tomorrow is also look at the purpose and function of an essential function or whatever it is that we want to talk about. We figure out what is the purpose and function. And ask that question 3,000 times. When somebody looks at a criterion, whether it's admissions or credentials or certification or licensure, you ask why. What is the purpose and function of this provision? We ask that question over and over and over again and make sure that we recognize again that this is not accommodation, this is not special treatment, this is genuine, effective, and meaningful opportunity.

Jean Bartels, PhD, RN, President-Elect, American Academy of Colleges of Nursing (AACN). Sitting right next to me is the past president of the Association of Colleges of Nursing. I wanted to make a comment and certainly agree with your remarks. We have a routine policy of looking at our position statements every so many years. Clearly, it's the reason I'm here, and as you pointed out, it's time for AACN to review its position policy on disabilities. I know that the organization (AACN) has continued to look at its membership taking active roles in interpreting the law. We have to look at our interpretation differently than we did at the time the current position statement was written. I'm reassuring you that this will happen. Again, there are a number of our schools that are doing some remarkable work, looking at how to make learning more accessible.

Andrew Imparato. Great.

Karen McCulloh, RN, Karen McCulloh and Associates. I just want to ask in regard to your regulation of the organizations that you work with, what policy or procedure do you have when you have a social worker or a veterinarian who simply is renewing a license? The renewal license forms come in, they write their checks for whatever amount, and they send them back. Do you have any questions on that renewal form that asks if that social worker or veterinarian has a disability, and if you do, then how is that handled and who makes the decisions? I will give you an example. The state of Alaska, and so many other states in the country are now asking on their nursing license renewal forms if you have a disability.

I have a friend who is sight impaired in Alaska who now has to attach a doctor's form to her renewal application, and is now limited to practicing community education. I was just wondering if there's any process in your organization that does this kind of thing.

Dale Atkinson. The licensure and renewal process is a state-driven issue. I will try to be as direct as possible. But the laws vary from state to state. The associations that I represent do not participate in and do not write applications for licensure or renewals. Based on my experiences with working with the boards on a state basis, the questions that are asked on either an application or renewal are going to be based upon the statutes as to what requirements there are for licensure. For instance, if the application has, say, three years between renewals and asks questions about education, examination, experience, moral character or whatever else is included in there, you file the application, pay a fee, and that's it. That's what the

licensure decisions are based upon, the questions that the application form has on it. Regulatory boards I advise should not ask questions that are not relevant to the ability of someone to practice. They should not ask questions beyond the statutory empowerment that was given to them; that they do not have authority to do. So the questions on the form should be limited to whatever their authority is. It's hard to answer your question with a yes or no. But that's the kind of advice that we deal with in regards to regulatory boards. The associations we represent are national, and they don't get involved with the state-by-state issues.

Margaret Younger-White, MUPP, Illinois Department of Human Services. I'm curious about the Office of Civil Rights interpretation of personal accommodation. One particular accommodation is tutoring. I can't imagine that there aren't individuals with disabilities who receive genuine access to a program and that tutoring would be viewed as a personal accommodation. I guess I wanted to hear your opinion.

Andrew Imparato. Let me try. This is one I definitely want Bobby to speak to. The reason I had concerns about it when I read it is I think it's not a simple concept. For example, to say that you do not provide a reader for personal use or personal study could be over interpreted. For example, let's say you assign a text for a class and you have a blind student who goes to the library to get that text. Just like all the other students, you do have to provide a reader or an alternate format of that text for the blind student to be able to read it the first time. You don't have to provide the reader for them to read it again when they're studying for the exam. It strikes me as a little odd, but that is as I understand it, the state of the law. I'm not sure it's easy to justify that distinction.

I think what the drafters of the law, and the folks who were in charge of administering it and implementing it, have tried to do is draw a line around personal care attendant services and other things that are personal in nature that can be very costly, and try not to get all that stuff lumped in under the category of accommodation. Again, in regards to the "beyond compliance idea," I encourage you to think about what are some of the barriers to full participation that may not be required by law but where we could help. For example, in orientation we can help to get a student access to personal assistant services if they don't otherwise know how to do that. I think there's a role that education facilities can play, even though it is not required by law, because it's personal in nature. Bobby, please, fill in with your comments.

Bobby Silverstein. In general, I definitely agree with what Andy said. Going back to some of the things I said a moment ago, ADA and 504 are civil rights statutes. Another way of describing civil rights statutes is: Is the same effective, genuine, meaningful opportunity provided to non-disabled folks? It's the same benefit, the same opportunity. Andy's description I think is fine and totally appropriate. If you assign a reading and say go into the library and it's not there in an alternative format, a reader is totally appropriate. But in terms of studying, you're not necessarily providing study aids to non-disabled folks. You may. If you do, make them genuine, effective, and meaningful. If you're not, equal opportunity says you don't have to.

This session is going late in terms of time. There will be a Website up in the next two weeks from my center: www.disabilitypolicycenter.org. One of the links that you can go to is the ADA and there's an article on personal assistant services or the obligation to provide personal assistant services under the ADA; what's required by law and what's not. This specific question is addressed in one of the documents on the Website.

Linda Laatsch, PhD, Rehabilitation Psychologist. I do assessment of individuals with disabilities for the licensing examinations. Generally if the individual is on medication that assists cognitive status, I ask the person for the evaluation purposes to not be on the medicine, so that I can measure the true extent of the disability. Now, I was asked by the examination licensing board to retest the individual on medication. Could you please state an opinion about that.

Andrew Imparato. Bobby encourages us all to really ask that question. From my perspective, what's the purpose? Is the purpose of your role to screen out people who are not qualified to be in the profession? That may not be the purpose.

Linda Losche. No, the purpose is to evaluate their need for accommodations for the exam.

Andrew Imparato. If the purpose is to evaluate the need for accommodations for the exam, that will enable them to show what they could do to get into the profession, then from my perspective, there is absolutely no reason for you to test them in the absence of medication. You should test them with whatever medication they will take and will be on when they are taking the exam. The only reason to test somebody in the absence of medication is if they're trying to really fixate on who is an

individual with a disability. This is in disagreement with the Supreme Court, who said you look at how people function while they are on their medications, and it disagrees with states like California that say you should look at them without medications for purposes of whether they're substantially limited in major life activity. That for me is the only reason to do that test. But it strikes me as bizarre. I'm not sure why they would do that.

Bobby Silverstein. This is facetious. I will preface it. It would be okay if and only if everybody who wore glasses were not allowed to use their glasses first.

Dale Atkinson. I agree. I have nothing else to add to that. Well said.

Thank you.

CHAPTER 5

Nursing Education Curricula
Position Paper

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The purpose of this meeting is to examine the feasibility of recruiting individuals with disabilities into nursing. My task is to assess the educational curricula and hopefully, generate discussion regarding whether or not an otherwise academically qualified individual with a disability can successfully complete a nursing program.

When Kay (Andreoli) called and invited me to give this presentation, I was reminded of a situation that I encountered during the first few weeks of my deanship at Ohio State.   The situation was this. An RN student who was legally blind as a result of severe diabetes had been admitted to the program but had been unable to complete the skills test. As a result, she was not able to advance very far.   This skills test was a laboratory, timed test that required students to go from one "station" to another and complete the skill such as taking blood pressures, temperatures, changing dressings and the like. When I think about it, it makes me laugh. Well, she couldn't see well enough to do that so she kept failing this test. Needless to say, she was getting quite frustrated and questioned the necessity of this particular test (as did I). At some point she did go to see a lawyer---she was very smart, you know. She figured, "Enough of this." I wasn't getting very far. That's how it came to my attention. Literally, this was my third week on the job. So I contacted the university attorney, we sat down with the faculty and said,

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"Now look, gang, this is the deal. This woman's been admitted to this program, so you are obliged to make reasonable accommodations to provide her with the opportunity to succeed, not fail."

Well, they were not sure this could be done and they offered all kinds of reasons for this including that if she were to earn a degree from OSU that it would devalue the degree because she couldn't meet the same requirements as everyone else. I tried to impress upon them that she never could do what they were asking - that she would continue to fail if they didn't make any accommodations. At last they relented - and there's a happy ending to this story - they did make the necessary accommodations. They consisted primarily of verbally testing the student's knowledge of the procedures focusing on the theory and principles rather than requiring her to perform the skill within a specified period of time. The faculty were then obligated to consider how they would make accommodations for her when she was enrolled in the required clinical courses. They did and the student completed the program and went to work as a counselor for a diabetes association.

That is just one example of how making reasonable accommodations allowed a student with a significant disability to be successful. To begin the dialogue as to whether or not students with a disability can be accommodated without compromising academic or professional standards—that's what everybody's talking about, what they're worried about--I will discuss the standards that guide the development of nursing curricula. I will start with the accreditation process and standards that are used in that process since the purpose of accreditation is to assure that education programs are of sufficient quality. Basically, accreditation is an assessment process to determine whether programs achieve what they identify they want to achieve. That is, how successful are they in producing products of their program that meet their explicit mission and goals and how well do those graduates measure up to the standards for professional practice.

The Commission on Collegiate Nursing Education (CCNE) is one of two accrediting bodies for nursing education and focuses exclusively on baccalaureate and graduate programs in nursing. The accreditation process is guided by a set of standards (Commission on Collegiate Nursing Education, Standards for Accreditation of Baccalaureate and Graduate Nursing Education Programs, 1998) designed to foster continuous improvement, a valuing of innovation accompanied by an expectation of a high level of accountability to the publics served, including consumers, students, employers, programs and institutions of higher education.

The self-study and on-site evaluation require programs to address four standards. Three of those relate to Program Quality as it pertains to

- Mission and Governance
- Institutional Commitment
- Resources and Curriculum and
- Teaching-Learning Practices.

The fourth standard addresses Program effectiveness as measured by: Student Performance and Faculty Accomplishments. The Standard that is most relevant to our discussion is Standard III, Program Quality: Curriculum and Teaching-Learning Practices.

This standard requires that the curriculum:
- Build on a liberal arts and science foundation,
- Possess a clearly stated mission and set of goals,
- Identify student expectations,
- Be guided by professional standards and expectations of the communities of interest, and
- Be sequentially and logically organized.

Furthermore, this standard requires that learning experiences be designed to provide students with the opportunity to meet the expectations of the curriculum. In other words, students must be given the opportunity— the learning experiences—to meet what the program expects. The standard applies to both undergraduate and graduate programs with the expectation that the master's curriculum will prepare graduates to function in an advanced practice role. So, basically, accreditation requires that the program identify the set of standards that have guided the curriculum. At this point those standards are not articulated—in other words, there isn't a specific set required—but this issue is currently under review by CCNE as it undergoes its first revision of these standards.

The process does not prescribe any particular content or courses that must be present in the curriculum or program. Rather, it depends on the program directors knowing what the professional standards are, designing curricula to meet those standards and then engaging in ongoing processes that evaluate outcomes and guide changes for continuous quality improvement. The process hinges on the existing professional standards—in other words, the various curricular elements that are deemed essential to produce either an entry-level or advanced practice professional nurse.

The first professional standard to be considered is the requirements for licensure. For the entry level, the first consideration is that an individual must pass the NCLEX examination, which is a cognitive test. So, for example, if a student with a disability has successfully completed a program, he or she may need accommodations to take the exam. A student with a visual impairment may need adaptive technology and so on. For example, one of our students with a learning disability needed to be alone in a quiet room when she took examinations. In this case she was accommodated by our state board, but not without some hassle. The board required a whole new set of documentation on her disability, even though she had been accommodated throughout her four years of college. I wrote a letter certifying to that extent, that that was the case. Licensure is granted upon successful completion of the NCLEX examination. Beyond that, once licensed, Registered Nurses are expected to perform in accordance with each state's practice act. So the only ability needed to pass the NCLEX is a cognitive one.

The other standards that guide the development of curricula are those promulgated by professional organizations. I am going to focus primarily on three sets of standards for purposes of today's discussion. They are *The Essentials of Baccalaureate Education for Professional Nursing Practice* (American Association of Colleges of Nursing, 1998) *and the Essentials of Master's Education for Advanced Practice Nursing* (American Association of Colleges of Nursing, 1996). *Nurse Practitioner Primary Care Competencies in Specialty Areas: Adult, Family, Gerontological, Pediatric, and Women's Health* (U.S. Department of Health and Human Services, Bureau of Health Professionals, Division of Nursing, 2002) developed the National Organization of Nurse Practitioner Faculties and the American Association of Colleges of Nursing.

The Essentials of Baccalaureate Education identifies five components of a professional education. These are liberal education, professional values, core competencies, core knowledge, and role development. The liberal education component consists of those courses taken outside of the nursing major directed at providing students with the ability to, for example, develop problem-solving skills, integrate concepts from the basic sciences, interpret quantitative data. These courses differ from school to school and are frequently influenced by local requirements. The nursing major consists of a series of courses, some with required clinical practica that provide the student with learning information to function as a professional nurse.

The nursing major consists of a series of courses, some with required clinical practice, that provide the student with the clinical opportunity to learn information needed to function as a professional nurse.

The curriculum is expected to provide students with the opportunity to learn the core values of the profession—altruism, autonomy, human dignity, integrity and social justice. These are typically interwoven throughout the nursing major, but some of the stories I heard this morning make me think that perhaps the faculty need to revisit the learning of these core values themselves.

Nursing's core competencies are critical thinking, communication, assessment and technical skills. As with core values, these competencies are woven throughout the curriculum and typically increase in sophistication as the student advances through the required course work.

Let me say a little bit about technical skills, because I think this is something very relevant. Some examples of what's on the technical list are vital signs, personal hygiene and so on and so forth.

Professional nurses are expected to possess core knowledge of health promotion, risk reduction and disease prevention; illness and disease management; information and health care technologies; ethics; human diversity; global health care; and health systems and policy. And finally, graduates are expected to possess knowledge of their roles as providers of care, designers/managers/coordinators of care and members of their profession.

When these were being developed by the organization there was much debate surrounding the inclusion of technical skills as a core competency and it is just this that today and tomorrow we need to discuss and debate. The issue boils down to whether a student who possesses a physical disability that limits the capacity to, for example, provide ostomy care or respond to a Code Blue or start an IV can successfully complete the required course work? Or, would it be sufficient for a student to learn *how* to do these skills and understand the scientific principles behind the skill but not be able to perform it?

The question can also be asked as to whether or not, in today's health care environment, is it the professional nurse who does or should do all of these tasks or can and should many of them be delegated? Put another way,

are the other domains of professional practice such as problem solving, assessment, and critical thinking more important than the performance of a particular skill for professional practice?

Turning now to the *Essentials of Masters Education.* This document identifies the core content that is deemed essential for all masters' students irrespective of the advanced practice role for which the student is preparing. The document assumes that this core knowledge provides the base upon which the clinical knowledge is built and allows that the content of the clinical portion of the program will be driven by standards developed by various specialties.

And the graduate core consists of content such as research, policy, ethics, professional role development and so on. The essentials of masters education also identifies that students should have advanced health assessment, advanced physiology and advanced pharmacology.

Basically, the core content is didactic content obtained in a classroom or through reading and comprehension. *The Essentials* does not dictate specific courses but rather limits the discussion to content. It is then the responsibility of the program director to configure this content however he or she chooses. But, the accreditation self-study will ask the program director to identify where the content is located in the curriculum.

Turning now to an example of professional standards that should guide master's programs. The National Organization of Nurse Practitioner Faculties (NONPF), in partnership with the American Colleges of Nursing (AACN) developed a set of standards for the preparation of nurse practitioners—*Nurse Practitioner Primary Care Competencies in Specialty Areas: Adult, Family, Gerontological, Pediatric, and Women's Health.* The standards delineate core as well as specialty competencies. I will limit this discussion to the core competencies; they are:

- Management of Patient Health/Illness Status
- Nurse Practitioner-Patient Relationship
- The Teaching-Coaching Function
- Professional Role
- Monitoring and Ensuring the Quality of Health Care Practice and
- Cultural Competence

Of relevance to today's discussion is that competence in assessment is the requirement to "perform a complete system, or symptom-specific physical examination." The question must be asked if certain physical disabilities would preclude meeting this requirement. Or, put another way: Are there reasonable accommodations that would allow students to meet this objective?

In reviewing existing professional standards, it is safe to say that cognitive skills and critical thinking dominate. Yet, technical skill development is not non-existent. The question before us is whether or not a student with a disability who is otherwise academically qualified can successfully complete a nursing curriculum.

A variety of disabilities can affect students and they may be otherwise stellar candidates for admission to our programs if we are willing to make accommodations. For example, you may have students with mobility impairments due to conditions such as cerebral palsy, MS or spinal cord injury. Some students have medical impairments—often invisible—caused by arthritis, asthma, or seizure disorders. And, learning disabilities are fairly common. All of these would require the program to make *reasonable accommodations* once a student was admitted. For example, making accommodations in the taking of examinations by allowing for more time, or utilizing the services of a scribe. Some students may need a note-taker; others need faculty to be patient if they are late for class due to their mobility limitations. Still others need special seating **in an accessible classroom,** so they can hear the instructor or see the blackboard. Others need assistance in their laboratory courses or flexibility in meeting requirements they might have missed because of illness.

A student with a learning disability may need more clinical time to meet the objectives of the course. A student with a hearing impairment may need special equipment to hear heart or breath sounds. A visually impaired student may need lab assistance, or print material in an alternative format and preferential seating in the classroom.

Accommodations in taking examinations including the NCLEX are commonly needed. Depending on the nature of the disability, a student may need additional clinical experiences to meet the objectives of the course. There is simply a wide range of disabilities requiring various accommodations. So, for me, the answer to the question as to whether or not a student with a disability is a reasonable candidate for admission to a

nursing program is a qualified "Yes." Qualified in the sense that some disabilities may, by their very nature, exclude students from pursuing a nursing curriculum. But not all disabilities do that. The challenge for faculty is to give this topic careful thought and to open up their minds, shake off old conceptions and prejudgments of what it takes to be a nurse and determine how and if a student with a disability can be successful in the program. Certainly, there is not much in the national standards driving nursing curricula that would preclude admitting students with disabilities.

Addition to Position Paper Presentation

Carole Anderson. Over the years, I have learned how to deal with physical facility issues in making some accommodations, which is no small matter at OSU because the campus is huge. When you make these accommodations you really improve the learning environment for all students. You make accommodations for some but most of those accommodations are very sensible and good teaching-learning practices. I think it is important to keep this in mind and it certainly does not lower standards.

A student with a learning disability may need more clinical time to meet objectives. Faculty struggle with this, trying to discern if this means the student is getting some advantage that other students do not have. They may need special equipment, or more time and so on. In my own experience, I found that mental disabilities seem to be the most difficult for faculty to understand and accommodate. Typically, if it became apparent that a student was, for example, struggling with depression, the first response is to try to insist that the student withdraw from the program until he or she had the depression treated. Well, that may not be the best thing for the student.

As we heard this morning, reducing the student load may be a better option than making some sort of accommodation. In my experience, faculty have a great deal of difficulty doing this because they think they are giving the student some sort of special treatment.

Another disability is one caused by drug and alcohol use or abuse. Faculty have a great deal of difficulty with this. Nursing faculty tend to be very puritanical and some still want to see it as a sin if you drink too much, which means the world is full of sinners.

As I mentioned before, accommodations may be needed to take the National Council Licensure Examination (NCLEX). Depending on the nature of the disability, a student may need additional clinical experiences to complete the course objectives. There is a wide range of disabilities requiring many different accommodations.

An interesting project is under way at the Oregon Health Sciences University, called the Health Science Faculty Education project. Sponsored by the Oregon Health Sciences Center on Self-Determination, it is one of twenty-two federally sponsored projects to assist health science faculty in meeting the educational requirements of students with disabilities. The web site is: www.healthsciencefaculty.org; and www.exceptionalnurse.com is a resource for student nurses and practicing nurses. It contains a lot of information about legal aspects of your career and accommodations.

As I said, the answer for me, as to whether or not a student with a disability is a reasonable candidate for admission to a nursing program, is a qualified "Yes." It is qualified in the sense that some disabilities may by their very nature exclude students from pursuing a nursing curriculum. Marca Bristo said this morning that most people, 99.9 percent of individuals, do not want to deliberately set themselves up for failure. I think we can assume that if someone has a significant disability that would preclude that person from being a nurse or working as a nurse in a certain area, he or she is probably not very likely to attempt to do that. You have to trust the ultimate wisdom of the individual.

Again, the challenge for the faculty is to give this topic careful thought and to open up their minds, shake off old conceptions and prejudgments of what it takes to be a nurse, and determine how and if a student with a disability can be successful in our programs. Certainly there is not much in the national standards driving nursing curriculum that would preclude many students with disabilities. Thank you.

Nursing Education Curricula
Response

Beth Marks, PhD, RN, Research Associate Director[2] Rehabilitation Research & Training Center on Aging with Developmental Disabilities (RRTC-ADD), Research Assistant Professor, Department of Disability and Human Development, University of Illinois at Chicago

Thank you to Dr. Anderson, who presented several nice examples of how students with disabilities have been able to achieve success in nursing school. Additionally you also addressed the importance of maintaining academic and professional standards, which I think most of us want to see happen.

As Dr. Anderson mentioned, nursing's core competencies continue to evoke controversy in the ongoing debate. Dr. Anderson gave us a qualified "Yes" in response to the question as to whether or not a student with disabilities is a reasonable candidate for admission to nursing programs. This is "qualified" in the sense that some disabilities by their very nature exclude students from pursuing a nursing curriculum. I think that no student should be excluded on the basis of disability.

In nursing education, the hidden curriculum drives academicians to ask the question, "Is there a place in nursing education for individuals who do not meet the traditional requirements of an academic program, such as the disabled student"? From a disability perspective, a more appropriate question might be the following one, "How can we recruit and retain persons with disabilities into the nursing profession?" Second, we might ask, "What do individuals with disabilities bring to the relationship with healthcare

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recipients"? Third, "What do individuals with disabilities bring to the nursing profession"? Last, "How can we provide an educational program that creates an accepting environment for all students, not just those with disabilities?"

With the disability perspective in mind I would like to advance the debate from the question, "Do persons with disabilities have a place in the nursing profession?" to the more salient question, "When will persons with disabilities have a place in the nursing profession?" I invite you to challenge the nursing profession to move beyond what is legally mandated to persons with disabilities and to consider the moral and ethical imperative for enhancing cross-cultural concordance between healthcare providers and healthcare recipients. Specifically, I would like to offer the social model of disability as a framework that will sponsor the recruitment and retention of persons with disabilities into nursing. The use of this model will enhance cultural competence among nursing students and nursing professionals. Within a social model of disability, as nurse educators, we must first address our prejudices toward persons with disabilities and recognize the value and the viability of the hard-won rights of people with disabilities.

Second, we must expand our understanding of disabilities beyond abnormalities and deficiencies. Dr. Carol Gill at the University of Illinois at Chicago states, that "the social model distinguishes an individual's impairments or differences from the social consequences or social oppression." Within a social model, attitudinal and architectural barriers are seen as central to disablement, not merely the intrinsic limitation of the disability. Dr. Gill further states that while nature can impair, only society can disable. It is society that must be fixed; to ameliorate disability, not people.

Third, we must accept and accommodate people with disabilities. We will discover that a student's success is highly dependent on the availability of accommodation and not on the type or a severity of disability.

Fourth, the social model of disability encourages us to recognize the intrinsic value that persons with disabilities bring to the nursing profession to enhance culturally competent nursing care.

I want to revisit culturally competent care. This is a concept that was brought up years ago by one of our nurse theorists, Leininger, and I think we need to revisit the concept and think about including people with disabilities. A couple of months ago I did a literature review just to see where people

with disabilities fit into the concept. I found that there were several disability task forces and not one article mentioned disability as a culture, not one article included a person with a disability as even a minority person who might want to talk about cultural competence.

So, the concept of cultural competence helps to address the factors that contribute to disparities in healthcare services. The primary goal is to deliver high quality, equal healthcare to people regardless of cultural background, including persons with disabilities.

Dayton and Corrello define cultural competence as the ability of health care systems to provide care to systems with diverse values, beliefs and behaviors. In addition, it tailors services to meet consumer, social, cultural and linguistic needs.

Every year Rush Medical Center holds an award ceremony named the Eugene J-MA Thonar, PhD Award. The award is given to someone who has contributed to advancing the rights of persons with disabilities, specifically in healthcare. Beverly Huckman, Associate Vice President for Equal Opportunity and Chairperson of the Rush ADA Task Force, was presenting at the award's ceremony and talked about a patient who was deaf and was receiving dialysis. During the first week of treatment, all the hospital funds allocated to pay for interpretive sign language for this patient were used. Ms. Huckman's question to the audience was, "How can we think about being able to accommodate patients with disabilities?" My thought was that if we start to include in nursing schools students who are deaf and who are proficient in sign language, we would be able to accommodate not only this patient, but other patients who use sign language. Rather than relying on interpreters to interpret nursing care, patients and the nursing profession would benefit from having nurses who used ASL as their first language. Moreover, we would not need to spend money for interpreters.

When we think about cultural relevance and we think about educating a lot of people, if we include someone who uses sign language as their primary or native language, I think we will broaden the services we can provide to patients. We know the intrinsic value students and professionals from different backgrounds add to and enrich the nursing profession. Unfortunately the values and practices that exclude students with disabilities continue in nursing education. What attitudes and values are conveyed to the public when we maintain and perpetuate the message, "You can be our patient, but you cannot be our peer?" Attitudes change the most

when people with disabilities work side by side and in equal status and partnership with their non-disabled peers.

How can we attain cultural competence for healthcare recipients with disabilities who are receiving nursing care? First and foremost, educators must challenge out-moded professional perceptions that nursing students with disabilities impose an inherent threat to the public distinctly different than other students. Within the social model, disability status is more a liability than one's ethnic, gender or racial background. We need to be open to nontraditional ways in which the criteria for achieving the core competencies can be met. Nursing students with disabilities will foster a new set of knowledge, skills and abilities in the nursing profession. Essential functions need to be redefined accordingly.

Moreover, people should be permitted to use a range of technologies and strategies to carry out the essential functions of their jobs. Persons with disabilities have the potential to improve nursing care and to advance culturally relevant care with their unique understanding of disability issues.

In summary, while the content and methods of nursing curricula influence the nature and quality of patient care, professional education concerning disability has been harshly criticized for promoting and failing to challenge negative stereotypes associated with disabled people. The hostility and abuse that is routinely experienced by students with disabilities from their peers, faculty and potential employers is illustrated in Dr. Carol Maheady's 1999 article. In her study, a nursing student with a back injury reported that other students teased her a lot while she was in a body cast. She was in a geographic area where it snowed a lot and fellow students would push her over snow banks; they would razz her and say, "She's a turtle, she can't get out of her shell." To label students with disabilities in nursing school as needing to jump through hoops negates and re-imposes society's ablest devaluation and sanctions discrimination.

If we expand the nursing curriculum beyond the medical definition of disability, students and faculty will share an understanding of the social determinants that impact the disability experience. This will transform professional relationships with healthcare recipients who have disabilities by providing culturally sensitive care. By using the social model, nurses with disabilities will be perceived as valuable professionals whose skills and talents are not only needed but highly desired by the nursing profession.

In a 1976 article about nursing education, Ashley La Bell wrote, "We cannot continue to spend so much time teaching bed-making while the need to understand problems of the aged go unmet. To do so is surely an instance of misplaced priority. Strategies for helping the aged cannot be developed with our heads lowered while tucking in corners of sheets." Are nurses afraid of the internal chaos that might be released if their heads were raised and they looked about to really see?

To make Ashley La Bell's comment relevant for today's presentation, we cannot develop nursing care strategies for healthcare recipients with disabilities with our heads lowered tucking in corners of sheets and focusing on other technical skills. Are we also afraid of the internal chaos that might be released if our heads are raised and we look about to really see?

Audience Participation

Julia Cowell, PhD, RN, Rush University College of Nursing. I really appreciate the presentation both speakers gave. I wonder if we need to look at the opportunity to expand employment opportunities and educational opportunities for people with disabilities beyond the care of individuals. For example, in public health nursing programs — which are not guided by the standards for advanced practice from the American Academy of Colleges of Nursing (AACN) —we have skill guidelines from our professional groups that allow really any person who can critically think, problem solve and draw on theoretical frameworks to have a very rich career. I think in our effort to standardize nursing education, which we have to do to make sure that we share a high level of preparation to guarantee successful care for the public, in some sense we have narrowed the practice of nursing for other people who are interested in other kinds of advanced education.

Carole Anderson. I do not disagree with you. My intention was to use those standards as one example. I think you are right; there are other examples and yours is a good one.

Sheila Dugan, MD, PT, Rush University Medical Center. I am a physical therapist and a physician, not a nurse. My question in terms of getting advanced degrees in public health nursing as your entry point is still, what about basic nursing preparation? I think that is where we need to make

a statement or at least critically analyze it. I think that is the crux of the issue for our work.

      Carole Anderson. That is true. The bachelor's degree is prerequisite. But there are lots of people out there with undergraduate degrees already who then may suffer a disability, who could then go on for an advanced degree. Which, by the way, is a very reasonable approach to career advancement. Maybe a career in public health might be more gratifying after a certain kind of disability.

      I think the issue at the entry level is one where we really have to think about more broadly than to say how can we accommodate students. There are some sacred cows in nursing as there are in every profession. One of them is that you have to meet the objectives in a certain clinical course in a specific period of time; either 10 weeks, 12 weeks, 16 weeks. And if you don't meet the objectives in that specific timeframe, you will fail. I think there are people with certain disabilities who might need 20 weeks or 22 weeks to be successful. Can we give them that time and let them succeed? I think it's those kinds of things we need to think about and open up the possibility.

      There's a fair amount of rigidity in any profession about how to get to the end point. We have a difficult time saying there are lots of different roads to reach that end point; we want to say there is only one road to that point. I think that's also true of medicine and they have struggled with the same thing.

      Catherine Ellyin, master's prepared nurse, Abbott Contract Labor Services and *Nursing Spectrum* advisor. After the panel discussion today, I spoke with Dr. Bronwynne Evans. My concern was the lack of insight and rigidity from faculty about how to reach the outcome of a successful nursing student. Some faculty at WSU were still having concerns about Victoria Christensen, even after she had a successful nursing school experience. I question whether or not faculty have insight into their attitudes and if they have insight into how they might teach students regarding maximizing their full potential if they (the faculty) have some barrier mentalities. I am concerned that faculty may not have this insight. I think we have a wonderful, challenging opportunity here before us to help faculty think more broadly based in terms of how they perceive students and how the students are as individuals and honor their uniqueness. If students experience this in

school, they can honor the uniqueness in the patients and families they will serve.

Carol Anderson. I think nursing faculty have a more challenging job today than they have ever had for a variety of reasons. One of the challenges they face is that the student body is really very heterogeneous. For example, at the Ohio State University we developed a program for second-degree students that's a master's program. This caused a great dilemma. Faculty asked how can these people with different academic backgrounds, who have never worked as nurses, not need the entire undergraduate nursing program. Faculty have really struggled with these students. And yet these are very bright, very capable students. They come with lots of different kinds of experiences and add a lot of richness. We've told faculty, "Don't worry about what they come in with, worry about what they're going to go out with." Worry about how you are going to get them from here to there. You do not want to convey to the students that they don't know anything. In the meantime, of course they don't know much because they are students and they're here to learn.

Jim Williams, PhD, Department of Cell Biology, Research Scientist, Rush University Medical Center. Of those faculty who struggle with students with disabilities or change, do you have any sense of how many of those faculty have significant exposure to someone with a disability in or out of the workplace, or have a disability themselves?

Carol Anderson. I think we heard this morning that probably all of us have exposure to a lot of people with disabilities whether we know it or not. And if you are a nurse, it would be hard to have avoided exposure to people with disabilities. What we know from the literature is that people with disabilities are isolated, segregated in society. Maybe this happens less frequently now because increasingly more people have a social kind of exposure than ever before; public places are more accessible now. But it is my understanding that persons with disabilities still tend to live segregated lives, so in all likelihood, faculty don't have much exposure to people whose disabilities are visible.

Judge Jean DiMotto, JD. You must be wondering what a felony judge is doing here. I spend most of my time in felony court, but a couple times a month I speak to nurses and nursing faculty around the country about legal issues. So I'm listening to the kind of issues that have come up. It seems to

me that most people who are attending this symposium today are either advocates, very open-minded about the issue of disabilities and accommodations, or want to be more open-minded and informed about the issue. As a judge, I am use to hearing both sides of issues. Let me pick out just one thing you said, Carol, because this is something I hear about as I teach nursing faculty about the legal aspects of failing unsafe clinical students and they are not talking about students with disabilities. We know there are not many of these students in nursing programs.

Say there is a student with a disability in an eight-week or ten-week clinical rotation who cannot meet the objectives in that time frame, but could meet the objectives with double the time. I would hazard a guess that many faculty would say those students whom we don't identify because their disability is not visible, or who have not self-identified, could also meet the course objectives if we double the time. So taking this another step, it suggests that we need more clinical time for all our students on the premise that it seems most of us agree that accommodations for people with disabilities would often benefit everyone. I would think the counterpoint to this is that it would expand the time to graduate a nurse to double, and there are cost/time issues and lots of other issues around this.

Can I hear a response to: If another student who would otherwise fail with no known or self-identified disability fails at ten weeks, but twenty weeks would help, how would faculty deal with this?

Carol Anderson. I think most faculty would fail them at ten weeks. I think that the majority of students can meet the objectives in the time that is given to them; we're not talking about a lot of people. In my experience in working with students, it becomes pretty apparent that there are some students who with just a little more time are able to succeed. And I would say, give the time to them. That time does not have to be cost-free. It doesn't have to be free to the students; they may have to pay additional tuition. What is so wrong with giving them a little more time? But, I think faculty would struggle with this.

Judge Jean DiMotto. I do hear them struggle with that. They would say if a student without any known or disclosed disability has missed three clinical dates out of an eight-week rotation, that's a substantial period of time to miss. If they allow make-up time, even if the student paid for the make-up time, it is the faculty's additional burden, if you will, to accommodate that make-up time for the student who has not been there.

If you say it is no cost – not that the student wouldn't bare some extra cost for the extra accommodation – it seems the framework of the structure of the curriculum would make that difficult. As I've listened to nursing faculty around the country, that's the response.

Carole Anderson. You mean that there are some structural kinds of pragmatic problems to be able to make this accommodation. And that may be true. Resources are getting to be a bigger issue. There is a huge shortage of nursing faculty. So I do think there are some pragmatic problems; you're right. If we really want to do this I think we have to try to do it; have to try to extend the time and figure out how to get it done. There are ways to get it done.

Judge Jean DiMotto. Would you suggest we try to do this for students with known or identified disabilities, or students without known or identified disabilities?

Carole Anderson. I think the accommodation is one thing. I think allowing all students the opportunity to succeed is another thing. If a little bit more time will help a student succeed, I'm suggesting you should probably give it to them, rather than cutting them off at some arbitrary term time.

I say the same thing about tenure now in my position. What's the magic in six or seven years? We have had that time-frame for 100 years. Why do we have to make some sort of career-breaking decision in six years? Seven years? What's so sacred about the time? Except for some of the pragmatics, which I admit are very real.

New Speaker. I spent some time in nursing service, but I've been in education for a long time. I just want to say that when our students graduate there is some notion that they can probably be employed somewhere. I'm from downstate Illinois and I do not see the gates of most hospitals opening their doors to people with physical or mental disabilities. I think it would help if service and education once again would try to work together and create work environments where the students' during summer, weekends, breaks, holidays, etc., could transition into the workplace and help education and help service.

Carol Anderson. I think there are a lot of projects going on like that across the country.

Nancy Hogan, PhD, RN, Professor, University of Miami School of Nursing, Florida. I think there is another thing that I've thought about for a long time and none of us want to talk about. We're in a place here where we're talking about nearly everything. It is not uncommon to have clinical rotation of six hours where the first hour is spent in pre-conference, the last hour in post-conference, one to two 15-minute breaks during that six hours, and a half-hour to hour lunch.

Carole Anderson. That's one of those dirty little secrets.

Karen Ward, JD, Civil Rights Attorney. I would like to respond to the judge's question. If what she's saying is that the faculty are using the difficulty of extending these special things to all people as a reason not to do it — they're just not following the law. If they're saying we will try to give it to people without disabilities because we ought to have a goal for everybody's seat filled—that is a good thing.

But the duty is to accommodate the person with the disability. And how you deal with the rest of the people has got to do with your philosophy, your resources and lots of things. If you use the latter to get around doing the former, you're not doing what you are supposed to do.

Paul Jones, MD, Assistant Dean of Students' Services, Rush Medical College, Chicago. One of the things we have been doing on the medical college side is accommodating students with extra time to help them through our curriculum and to level the playing field. What we didn't bank on was when we successfully degreed those students, they ended up with the mark of extra time on their transcript. This is then viewed by residency program directors as a student perceived as having some kind of trouble during his or her education. So I would very much warn you that one of the things that you need to begin to look at and think about is the aftereffects of bringing students in, graduating them, and making sure that it isn't an nursing degree with an asterisk on it. It needs to be a full degree.

Carole Anderson. Yes, absolutely.

Paul Jones. I think there is a court case exactly on this topic, but it pertained to the legal profession in terms of the bar exam having asterisks on them for extra time. And it was found to be illegal. So if this is happening in your profession, I'd really question the legality of it.

Carole Anderson. You're saying that metaphorically, aren't you?

Paul Jones. I'm saying it metaphorically. Even so, it sounds like a standard practice; it may not be an official policy.

Carole Anderson. I think what Dr. Jones is saying is that when you look at a transcript where the student did not finish in four years, it looks like they had academic difficulty.

Andrew Imparato, JD, President and CEO, American Association of People with Disabilities (AAPD). I had a comment responding to Dr. Mark's point about cultural competence. I think that's a really good way to think about why the folks who train nurses should incorporate some disability issues into their training; to increase their awareness and sensitivity. I also wanted to add the notion of empowerment and independent living as something that could be taught/trained as part of cultural competence. Again, from my perspective, it would help with all patients, not just patients with disabilities.

I think it's possible to make it part of cultural competence that people would have a basic understanding of an independent living philosophy of disability. It is an independent living philosophy of life in general, self-advocacy, those types of skills and why those skills are particularly important for disenfranchised groups, whether they are people with disabilities or others. I just wanted to throw that out to you.

CHAPTER 6

Employment and Accommodations for People with Disabilities in Nursing Professions

Karen E. Wolffe, PhD[1]
Career Counseling & Consultation

The purpose of this paper is to address employment and accommodation issues for individuals with disabilities who wish to enter the fields of nursing or related health care professions. Although my paper has a cross-disability focus, I also share with you a number of examples from a series of interviews that I recently completed with current and former nurses who are blind or have low vision. I also compare blind and visually impaired people to people with other disabilities throughout this paper as my experience with this population is extensive and I can give you definitive and specific references. Finally, I have included as an appendix to this paper a detailed listing of resources for information and adapted medical equipment that may help you in your efforts to accommodate individuals with disabilities in your programs or employ.

Passed in 1990, the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in employment, state and local

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governments, public accommodations, commercial facilities, transportation, and telecommunications. Public and private postsecondary educational entities are covered by the ADA and as a consequence cannot exclude otherwise qualified individuals with disabilities from their programs. In addition to the ADA, the Rehabilitation Act Amendments of 1973, particularly Section 504, protect individuals with disabilities from discrimination. This law states the case for protected individuals clearly: *No otherwise qualified handicapped individual...shall solely by reason of this handicap be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance* (p. 22678).

These two pieces of federal legislation, the Rehabilitation Act and the Americans with Disabilities Act, protect people with disabilities from discrimination when pursuing postsecondary education or seeking employment. The Department of Education (DOE) Office for Civil Rights is charged with enforcing §504 and the ADA with regard to whether colleges and universities are properly balancing the statutory rights of people with disabilities and the schools' legitimate concern for protecting the integrity of their programs (Milani, 1996). The Office of the Americans with Disabilities Act, Civil Rights Division, in the U.S. Department of Justice enforces the ADA with regard to employment. Although §504 and the ADA mandates apply to schools of nursing and facilities where these students may ultimately find employment, the medical field presents some special considerations due to its "Do no harm" ethos that holds patient care sacrosanct (Steinberg, Iezzoni, Conill, & Stineman, 2002).

In fact, it was just this concern that led to the Southeastern Community College v. Davis ruling (1979), which allowed a nursing program to refuse admittance to a nearly deaf student because she could not show how she would be able to physically hear a patient's call for assistance (Helms & Weiler, 1993). However, it is equally important to note that there is concern among nursing practitioners with disabilities that this propensity to develop lists of technical standards and perceived "necessary" skills may be restricting access to nursing schools with no empirical evidence that such skills are, in truth, necessary for all nursing jobs (Carol, 2002; Coates, 2002; Marks, 2000). These practitioners argue for listing the essential functions by specific nursing jobs rather than generating generic lists of skills needed by nurses per se.

You may ask, "Who exactly is covered by these laws?" A person with a disability is anyone who has a physical or mental impairment that substantially limits one or more major life activity (for example, caring for oneself, maintaining a household, or working); has a record of such impairment; or is regarded as having such impairment. When determining whether an impairment "substantially limits a major life activity," three factors must be considered: the nature and severity of the impairment; the expected duration of the impairment; and the permanency or long-term impact of the impairment (AACN, 2002).

There are approximately 53 million adults in the United States with disabilities, according to the 2000 census. I ask you to consider what we know about the employment of these people. People with disabilities have been and continue to be underrepresented in the labor market. According to the most recently completed National Organization on Disability (NOD) survey, conducted by Louis Harris and Associates in 2001, of working-age people with disabilities (that is, those aged 18-64), only 32% are employed, as compared to 81% of their same-aged peers without disabilities. However, if you disregard those individuals who say that they are unable to work due to their disabilities, the figure improves to 56% of people with disabilities and able to work who are employed - - still less than the 81% employment rate of non-disabled people, but an improvement nonetheless.

Among the employed people with disabilities, 36% state that they have encountered some form of discrimination in the workplace. Just over half (51%) of those who have experienced discrimination say that they have been refused jobs for which they are qualified. Other common forms of discrimination have included being denied a workplace accommodation, being given less responsibility than co-workers, being paid less than others with similar skills in similar jobs, and being refused a job promotion (Harris, 2001).

The more severe the disability, the less likely the individual will be employed (NOD/Harris, 2000). For example, people who are legally blind (that is, those with visual acuities of 20/200 or less bilaterally, with best correction; or bilateral field losses of 20 degrees or less) aged 18-69 are employed at a rate of only 30%. If you remove from the computation those aged 55 and above, the employment rate improves to 42%, 32% full-time and 10% part-time (Kirchner, Schmeidler, & Todorov, 1999). We know from a study that was conducted in Illinois in the mid-1980s that the bulk of employed blind people work in public agencies (Harkin, Kirchner, Esposito,

Chandu, & Istanbouli, 1991). We also know that employed blind and visually impaired individuals are not, typically, working in health care or medical professions except as rehabilitation counselors, social workers, psychologists, or medical transcriptionists. There are few nurses, fewer doctors, and only a smattering of other health care professionals with visual impairments (AFB, 2002; Kendrick, 2001). I suspect, but cannot say definitively, that this is true for other groups of people with disabilities as well...that has certainly been the case in my observations over a career spanning almost 30 years as a rehabilitation counselor, special educator, and career consultant. However, we do know that among the individuals who are employed as health care professionals there are a number of highly successful workers.

There are numerous case histories and articles that indicate that people with severe impairments can perform the essential functions of most nursing jobs (Carol, 2002; Coates, 2002; Kendrick, 2001; Watkins, 2002). One of the best Internet sites for reading first-hand accounts of people with disabilities in the nursing field and other health care professions is maintained by the Oregon Health & Science University in Portland Center for Self Determination – the Health Sciences Faculty Education Project (www.healthsciencesfaculty.org). On this Web site, you can read about nurses with hearing impairments, learning disabilities, and physical disabilities; you can read about doctors with developmental disabilities such as cerebral palsy, sensory impairments (blindness and deafness), and chronic health impairment. Although these individuals acknowledge that they encountered difficulties on the road to becoming nurses or doctors with disabilities, such case studies allow us to see the possibilities. A common theme runs through their stories: They chose fields that enabled them to be successful and they were responsible for determining what accommodations they needed in order to be successful with their disabilities. I think their insights can serve us well as we investigate the viability of people with disabilities entering the field of nursing and what accommodations may prove important in order for them to be successful in the preparatory programs represented here.

For example, one of the most common disabling conditions is learning disability – it is a disability that you likely have encountered or soon will encounter in the student population you serve (Magilvy & Mitchell, 1995; Maheady, 1999). One estimate I saw when doing research for this paper indicated that 400,000 students with learning disabilities are currently enrolled in colleges in the United States (Pawlowski, 2000). Although

learning disabled students are entering colleges in greater numbers than ever before in the history of higher education, many of these students are reluctant to present themselves as disabled. A nursing college faculty member, who is visually impaired, confirmed in an interview that students with learning disabilities are more common in her college program than students with any other disability (J. Herman, personal communication, January, 22, 2003). Dr. Herman, the interviewee, indicated that the primary difficulties these students encountered both in the classroom and during their field work related to processing information from the written texts and writing tasks —the didactic tasks as opposed to the applied or clinical tasks. Although a number of learning disabled students had successfully graduated from this program, they performed best when they made use of available accommodations. The types of accommodations that they used included extended time on written examinations, secluded areas for test taking, readers, taped texts, and scribes. Dr. Herman indicated that because nursing is an applied science she felt these students with learning disabilities could be successfully employed, as long as their supervisors realized that they would need longer to learn new information presented didactically.

This observation is borne out anecdotally by Steve Patten (Articles, 2003), who works as an OR scrub nurse and has a severe learning disability. Patten's disability, dyslexia, affects his ability to read and write. When he was in nursing school, Patten dictated lengthy case management reports to his wife who typed the reports for him. However, working in OR he discovered that most of the documentation required was done on a one-page form that he memorized and simply completed with checkmarks, circles, and plus or minus markings. He uses a computer that has word prediction software built in for writing more detailed notes (Articles, 2003).

Although the Association of American Medical Colleges tracks the demographic characteristics such as gender, race, and ethnic origin of medical faculty, it does not track faculty with disabilities (Steinberg, Iezzoni, Conill, & Stineman, 2002) nor, presumably, students with disabilities. A recent *Journal of the American Medical Association (JAMA)* article which looks at reasonable accommodations for disabled medical faculty, certainly gives us insight into one of the viable employment opportunities for graduates from your programs: teaching. In their faculty roles, these individuals with disabilities share two important attributes that they bring to the field of health care — their ability to be role models to patients with similar disorders and the enhanced rapport with patients that comes as a

consequence of having experienced, in many instances, prolonged treatment and care in hospital settings (Steinberg, Iezzoni, Conill, & Stineman, 2002).

This notion of enhanced rapport with patients is a reoccurring theme in many of the anecdotal accounts of nurses with disabilities (Articles, 2003; Carol, 2002; Coates, 2002). Molly Jenkins, a nurse with a hearing impairment, reports that her patients often feel a loss of control during their illnesses and think of medical personnel as being on a higher level. She feels that they see her as a little bit less than perfect and that her imperfection makes her more real to them (Articles, 2003). Another nurse with a hearing disability, who is a lip reader, says that her patients report that because she looks at them and pays attention to what they are saying they feel they are getting exemplary care from her (Carol, 2002).

Candy Moore, RN, who is a faculty member at Elgin Community College in Illinois, is also a woman with a physical disability. Her concern is that the diversity of nursing jobs cannot be captured in a single set of standards. For example, she points out that a poison control center nursing position may require hearing but not a significant lifting requirement. She also notes that in most nursing programs greater emphasis is placed on psychomotor skills than on cognitive skills and affective skills. She worries that her colleagues in nursing education are sometimes too far removed from day-to-day nursing jobs to realize how much work is shared between nurses on the job. Finally, she points out that the board exams that nurses must pass for licensure may pose barriers to nursing candidates with disabilities because they do not allow the same accommodations that one can find in training programs and on the job (Articles, 2003).

In an effort to capture first-hand accounts of people with visual disabilities performing as nurses, I conducted a series of interviews during January 2003. I was able to complete six interviews with current and former nurses. The interviewees were all legally blind, but had some remaining functional vision; three of the nurses had additional disabilities (diabetes, rheumatoid arthritis, and hearing impairment and multiple sclerosis).

Two of the six interviewees are no longer working in the nursing profession. One left because she felt she could no longer see well enough to function safely in her job as a school nurse and the second was forced from her position as a supervising nurse because the hospital administration where she worked no longer felt that she could function well enough visually to provide back-up support to her staff. The former is currently working for a

national nonprofit organization in a professional position and the latter has returned to school to pursue a career as an attorney.

The remaining four nurses are actively engaged in nursing; however, none provide bedside nursing or hands-on patient care. One is the faculty member I mentioned earlier whose primary work is as a researcher and nurse educator. One is providing counseling and education to diabetic patients at a military hospital on an outpatient basis. Another is working with elderly patients as a case manager and provides information and referral services via the telephone. And the fourth is working as a nurse in a low-vision field where she has designed her own job in patient education and does some in-service training to professionals working with people who have low vision.

I spoke with all six of these nurses at length. They are all working-aged women, living independently throughout the United States – in West Virginia, South Carolina, Illinois, California, Ohio, and Oklahoma. Some of the questions that I posed to this group of nurses are highlighted below and their responses are synthesized and bulleted below each query:

What information do nursing college personnel need to have to make good decisions about whether or not a visually impaired person can succeed in a nursing program?

- They need to recognize that they do not know everything about blindness and visual impairment — they will need to ask students what they can functionally do and how they see best (lighting conditions and glare are important factors to consider).
- They need to know that being visually impaired does not automatically eliminate a person from successfully functioning in this field. However, during the interview process they should ask some of the same questions a prospective employer might ask: How will you perform specific tasks? What accommodations will you need in order to perform safely and efficiently?
- They need to choose candidates with visual impairments or other disabilities by the same criteria and high standards by which students without disabilities are chosen: Good grade point average, maturity, ability to communicate effectively, ability to think creatively, ability to problem solve, and so forth.

What types of nursing positions are viable for individuals with visual impairments and which are not?

- Nursing positions that are viable include case management (particularly where there is computer-based charting), data collection and management for insurance companies and hospitals, research, intake, outpatient education and counseling, health management presentations, risk management, legal consulting, areas of public health, pre-op and post-op patient education, psychiatric nursing, in-service training, and nursing education.
- Nursing positions that are not viable include operating room nursing, bedside nursing, emergency room, trauma units, and community health nursing may be difficult without a driver.

Are there tools (accommodations) that schools should have at-hand for nursing students with visual impairments?

- Computer access with speech and magnification systems, video magnifiers, tape recorders, scanners, reader services, and various adapted medical tools, such as talking blood pressure cuffs, thermometers, and glucose monitors; syringe and injection aids, including those with magnification guides; and textbooks and related materials in alternative formats such as Braille, large print, or electronic media.

Can nursing tasks be safely performed by totally blind people or only those with low vision?

- Although totally blind people can safely perform many nursing tasks, not all tasks required in clinical settings can be performed (changing surgical dressings while maintaining a sterile area, starting/changing IVs, placing GI tubes, noting skin coloration or the presence of a rash, for example). Because a great deal can be accomplished with the remaining senses, especially hearing and smell, it's possible that someone with no functional vision could learn enough to pass the clinical portion of their exams with theoretical content, knowing that they would work in a setting where those skills requiring sight would be performed on a day-to-day basis by others with fully functional vision.

Are there successful nurses with low vision who have come through your program?

(Author's note: This question was addressed only to the individual who is teaching at the university level.)
- Only one individual with low vision has come through our program to date. She has graduated and is working as a certified diabetic educator.

What advice would you give fellow nurses about working with or for an individual with a visual impairment?

- Don't move things around without informing the nurse with a visual impairment.
- Name and describe things you are referencing rather than saying things like, "It's over there. Bring that (pointing) to me or take that (pointing) to the patient."
- Treat your colleague with professional respect. Don't treat colleagues like patients.

What do you think about the viability of using intermediaries such as CNAs to help visually impaired nurses with visually demanding tasks?

(Author's note: This query elicited two distinctly different responses...on one side positive and favoring the use of CNAs with supervision by the nurse and on the opposite side negative and adamantly opposed to using CNAs to help with visually demanding tasks.)
- As long as the nurse provides direct supervision, the use of CNAs to help with routine, visually demanding tasks seems appropriate. The use of intermediaries is common practice in medicine.
- This is an appalling idea and one that makes me feel very uncomfortable! There are studies that show morbidity rates increase with the use of fewer RNs and the increased use of CNAs.

What special equipment do you use or have you used in order to perform your nursing responsibilities?

- All of the interviewees indicated that they used assistive devices on their computers either to enlarge the text or to provide speech output. They also indicated that they used scanning equipment,

tape recorders, and human readers at times. Most of the interviewees used electronic note-taking devices with speech or Braille output, low vision devices such as video magnifiers or handheld magnifiers, and drivers or public transportation. Most of these nurse practitioners also used adapted medical devices with speech output, e.g., talking blood pressure cuffs, thermometers, and scales.

Overall, the interviews I conducted with these visually impaired nurses and the anecdotal evidence I found in my literature review reinforced my belief that people with disabilities can perform successfully as nurse practitioners, nurse educators, and in related jobs that enable them to use their nursing skills, such as consulting with insurance companies and providing information and referral services. In order to function effectively, nurses with disabilities often benefit from technological and environmental accommodations. Possible accommodation recommendations compiled from a number of relevant articles (AACN, 2002; Helpful gadgets, 2003; Steinberg, Iezzoni, Conill, & Stineman, 2002) that can improve access to academic and work environments include the following:

<u>Physical environment access</u> – ramps, accessible parking, automatic doors, shuttle services with wheelchair access, internal doors and bathroom doors with push rather than pull handles, signage in large print and Braille, lowered shelving and filing access, preferred seating in classes or training, vibrating pagers, and so forth.

<u>Access to medical equipment</u> – amplified digital stethoscopes, talking blood pressure cuffs and thermometers, one-touch automatic inflation blood-pressure monitors, glucose monitors with digital and audio output, injection/syringe aids (for example, *Count-a-Dose™*, *Inject-Aid*, *Holdease*, *Vial Center Aid®*, *Inject-ease*, *Load-matic*, *Insul-eze*, *Syringe Magnifier*), digital large print display thermometers and blood pressure monitors, large display and talking scales, and so forth.

<u>Information access</u> – reader and scribe services; reading machines and scanners; video magnifiers or closed circuit television sets (CCTVs); tape players; laptop computers; electronic and human note takers; FM systems; taped, Braille or electronic versions of texts and handouts.

<u>Social and emotional access</u> – encourage nurses who have experienced disabling conditions or chronic illness to provide in-

service training for faculty and prospective employers. Use successfully employed nurses with disabilities as role models and mentors (services such as the American Foundation for the Blind's AFB CareerConnect™ can facilitate in this process). Work closely with area rehabilitation specialists to stay abreast of the latest developments in assistive technology and adapted tools for people with disabilities.

In closing, I remind us of Dr. David Hartman's thoughts, which he expressed at the close of the first chapter in his book, *White Coat, White Cane*, "At some point you just tire of doubters and doubting, and you want to just walk away from them and get on with it. And yet they come." (Hartman & Asbell, 1978). We know that many impaired individuals who leave the field of nursing do so at the insistence of hospital administrators who can't believe that someone with a disability can function safely and effectively as a health care provider. We also know that some number of interested parties are discouraged from entering into nursing and related health care professions because people don't believe that they can be successful (Carol, 2002; Steinberg, Iezzoni, Conill, & Stineman, 2002).

Let us not add to the doubts and doubters. Let us ensure that students with disabilities, who are qualified and able, can enter and successfully complete college nursing programs. We do so by ensuring an accessible and welcoming learning environment. We do so by recognizing the difference between patients and students. Let us also ensure that once they have satisfactorily completed their training that they can go to work - - as nursing professionals. We do so by actively working with employers to help them understand how disabled nurses can be viable and productive employees. We do so by hiring disabled nursing professionals.

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Appendix A
Information and Sources for Accommodations

Information

American Association of Colleges of Nursing: www.aacn.nche.edu

American Foundation for the Blind: www.afb.org

Association on Higher Education & Disability (AHEAD): www.ahead.ie

American Nurses Association: www.nursingworld.org

Disability Central: www.disabilitycentral.org

Exceptional Nurse: www.exceptionalnurse.com

Federal Disability Information Source: www.disabilityinfo.gov

The George Washington University HEATH Resource Center:
www.heath.gwu.edu

Health Sciences Faculty Education Project: www.healthsciencefaculty.org

National Council of State Boards of Nursing: www.ncsbn.org

National League of Nursing: www.nln.org

NurseWeek News: www.nurseweek.com

Nurses with Disabilities – Stories: www.minoritynurse.com

Office of the ADA, U.S. Department of Justice: www.usdoj.gov/crt/ada

Office for Civil Rights, U.S. Department of Education: www.ed.gov/offices/ocr

Health Care Tool Suppliers

The following companies carry a variety of assistive devices to facilitate medically related tasks, including: talking thermometers, scales, glucose monitors, and blood pressure cuffs; syringe and injection aids, including those with magnification guides; amplified stethoscopes; tweezers with magnifiers; eyedropper guides; and many other tools.

Acu-Life Products: (800) 633-4243, www.healthenterprises.com

Diabetes Home Care: (800) 544-5433, www.diabetespartners.com

Diabetes-Supply: (800) 779-3374, www.diabetes-supply.com

Disability Specialtys: (888) 892-7878, www.disabilityspecialtys.com

Dynamic Living: (888) 940-0605, www.dynamic-living.com

EnableLink: (Canadian) www.enablelink.com

Independent Living Aids: (800) 537-2118, www.independent.iving.com

LS&S Group: (800) 468-4789, www.lssgroup.com

Life Solutions: (877) 785-8326, www.lifesolutionsplus.com

Maxi-Aids: (800) 522-6294, www.maxiaids.com

The Medical Supply Company: (888) 633-8282, www.medsupplyco.com

National Assistive Device Center: www.hitec.com/nadcenter.html

Science Products for the Blind: (800) 888-7400

Speak-to-me: (800) 248-9965, www.speaktomecatalog.com

SPI Supplies: (800) 242-4774, www.2spi.com

Nursing Employment and Accommodations Response

Martha Younger-White, MUPP[2]
Bureau Chief
Bureau of Accessibility and Safety Systems

I'm extremely grateful to be here and feel as if I am in the presence of not just my peers, but of my mentors and teachers. I want to acknowledge Rush University Medical Center for its long-term partnership with the State of Illinois in regard to employment for people with disabilities. At every job fair we have ever sponsored, Rush's Human Resources Department and Rush's Equal Opportunity Affairs Office have always sent in their registrations early. In addition, on our last National Disability Mentoring day there were four students who are deaf/hard-of-hearing who came to Rush to learn about nursing and about attending a nursing college.

I will respond to Dr. Wolffe's presentation by telling you that it was very easy to agree with the comments she made. As a coordinator for the Americans with Disabilities Act for the Illinois Department of Human Services, my bias is that I come to employment issues from a civil rights perspective. I never assume that people know what the Americans with Disabilities Act is about. I think of it as a tool, and when our agency talks to employers about it, we try to impress upon them that it is a tool that helps them invest in their workforce.

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[2] **Martha Younger-White, MUPP, currently serves as the Bureau Chief of the Bureau of Accessibility and Safety Systems at the Illinois Department of Human Services. She is responsible for assuring statewide compliance with the Americans with Disabilities Act in all of the department's programs, services and activities. She has worked on issues affecting people with disabilities for over 15 years within both city and state government. She worked for the City of Chicago Department on Aging and Disability for eight years in a variety of capacities, including Director of Disability Advocacy Services assuring city services were accessible and available to people with disabilities. Younger-White is a graduate of Northwestern University and the University of Illinois, Chicago, with a Master's degree in Urban Planning and Policy. Her most notable project for the state of Illinois, recognized by Governor Jim Edgar, was overseeing the installation of the nation's first pay TTY in over 10 Illinois rest areas, for persons who are deaf or hard of hearing.**

I will address the issues from this civil rights perspective and the ADA. In a nutshell, the Americans with Disabilities Act of 1990 (ADA) is the single most powerful and far-reaching disability rights law ever enacted. The ADA enables more people with disabilities to enter the mainstream of American life. It extends to people with disabilities the same civil rights given to others on the basis of race, sex, national origin and religion. It guarantees equal opportunity in employment, public accommodations, transportation, state and local government services and telecommunications. The ADA is patterned after other existing civil rights legislation such as Section 504 of the Rehabilitation Act of 1973. Section 504 states that, "No qualified individuals with a disability in the U.S. shall be excluded from, denied benefits of, or be subjected to discrimination under any program or activity that receives federal financial assistance." Protections under the ADA non-discrimination provisions are not predicated on the receipt of federal financial assistance. Title I of the ADA covers employers with 15 or more employees and says employers may not discriminate against qualified individuals with disabilities. Title II covers Public Services. State and local government may not discriminate against qualified individuals with disabilities. This includes the hiring of nurses and technicians and other health care workers by state and local governments.

Title III covers public accommodations. Businesses and nonprofit services that are public accommodations must comply with non-discrimination requirements. Public accommodations are private entities that own, rent, lease to, or operate facilities such as restaurants, hotels, theaters, shopping centers and malls, retail stores, museums, libraries, parks, private schools, doctor's offices, day care centers and other similar places used by the public. Many of the services that hospitals provide are covered under the public accommodation provision of Title III. One of the beauties of the Americans with Disabilities Act is that it is broad enough to include different aspects of community life.

I won't reiterate the statistics about people with disabilities; instead I want to talk about the community around people with disabilities. If we count those supports of family and friends the number of people in the disability community would jump from 54 million to 100 million. Because the ADA does cover the family of the person with the disability, it recognizes the support system that needs to exist within the disability community.

As a state agency that has worked on employment issues for the disabled for the ten years since the ADA was passed, we are very

disappointed in the high unemployment rate among the disabled. This disappointment is balanced against the positive news from the Louis Harris poll, which shows the greatest gain of employment among those disabled individuals who were 18 to 29 years old. Nearly 57% of persons with disabilities who are able to work are working in this age group compared to 72% of those without disabilities (a gap of 15 percentage points).

I want to give some of the credit for this increase to the institutions of higher education. Students coming through higher education have more skills and this makes them more employable. In spite of these education gains, jobs for the disabled still tend to be lower skilled and lower paid. Now over two-thirds of people with disabilities are earning incomes of $15,000 or less, which is considered poverty.

In addition to employment, important issues from the Louis Harris poll include access to transportation and access to health care. People with disabilities are twice as likely to report that transportation is a problem and on one or more occasions they did not get the medical services they needed in the last 12 months.

This access issue is complex, since obtaining employment might result in loss of Medicare or Medicaid benefits. How can you re-enter the workforce and not lose your access to those needed benefits? I'm proud to say that Illinois, under the Social Security Administration's "Ticket to Work Act," has started a Medicaid buy-in program that no longer penalizes workers with disabilities who want to return to work. Rather it allows them to extend their Medicare coverage through the seven-year period that the law allows and through the "Health Care Benefits for Workers with Disabilities Program" extends Medicaid coverage to those who work under the Illinois Department of Public Aid. I want to commend Illinois for that. Such buy-in programs vary by state, and people with disabilities who are returning to work should to see if it is available where they live.

One of the issues in the employment area for people with disabilities is the narrowing of the definition of what constitutes a disability — per recent U.S. Supreme Court rulings under the ADA. Once again, people with disabilities need to check with the state they reside in. In some cases, the Illinois Human Rights Law has a broader definition of disability. The burden of proof is not as high as it is at the federal level. In addition, the state law covers employers with one or more employees, so it expands on the definition of who is covered for purposes of employment.

Illinois has also made some smart decisions in terms of environmental barriers. The Illinois Environmental Barriers Act is an act concerning environmental barriers in public facilities and multi-story housing units. The EBA was amended in 1996 to ensure that the most stringent requirements of state and federal access laws are in force in the state of Illinois. We have combined the federal and state standards; now architects only have one reference to look at when they are planning accessibility for a building.

In terms of ADA coverage, I would add the ADA does not cover a person who is using illegal drugs. However, if someone had a history of illegal drug use and has been rehabilitated, that might come under the definitions of history of disability. This includes not just street drugs but legal drugs that are being used in an illegal way.

The National Council on Disability has a very beneficial Web site. It includes an analysis of the Supreme Court cases that is very useful for a practitioner in this field. The site also includes a chart that lists all of the court cases, the results of those cases and the employment implications of those cases. I am not going to spend more time covering Supreme Court cases, but be aware of this Web site and be aware that the Supreme Court is redefining disability in these court cases. Potential employers need to know those court decisions.

As I read the case stories as presented by Dr. Wolffe, one of the questions that keeps coming through is, "Where is the knowledge of the spectrum of employment activities under these employers?" It is not just hiring practices that must be nondiscriminatory and accessible, but promotional opportunities, training and compensation all need to be nondiscriminatory for people with disabilities.

The ADA is not an affirmative action law. It does not tell you that you have to hire people with disabilities. What it says is that you must hire a qualified individual without regard to his or her disability status. In other words the applicant with a disability must have the skills, knowledge, and experience for the job, and be able to perform essential functions of the job with or without reasonable accommodation.

Many employers are concerned about asking medically related questions. Be aware that you can't ask medically related questions before a job offer has been made. This means that information related to one's

disability status cannot be obtained on job applications and I think this is true for educational applications also.

After the job offer has been made an employer can make those health inquiries, but only if the employer makes them to everyone who has been offered a job. Again, an employer cannot differentiate for a person with a disability.

In reviewing material for this presentation the issue of "safety" came up. Are people with disabilities safe in the work environment? Or, are they safe for their patients? I found absolutely no data that suggested that they would be a safety risk to patients. I noticed as I looked at job descriptions for our facilities where there are nurses, that we often define essential functions as must hear, must see, must walk. Instead we should be defining these job descriptions in terms of specific work behaviors and functions that individuals are expected to perform. For example, "Can you detect a heart murmur?" Perhaps people can detect this in different ways, but it is the function not the method that we should be trying to identify in job descriptions.

We get a lot of questions about accommodations. It is one of the most important concepts within the ADA because it levels the playing field. I have not heard much today about what accommodations really cost. A good resource for this information is the Job Accommodation Network. Staff there tracked the cost of accommodations for various employer groups and discovered that about 15% of accommodations cost nothing. The $1 to $500 category represented another 51% of the requests. In terms of new construction, accessible features only add on one-half of 1 percent to costs. So actual information about costs can help counter cost concerns.

Our agency is a $1.4 billion agency. An example of an accommodation is a computer with adaptive software that costs approximately $5,000, and it is hard for an employer to claim that the $5,000 accommodation is too expensive. The total size of your organization's budget has an effect on how difficult an accommodation might be perceived to the hiring institution. Smaller sized hiring institutions should be aware that there are some tax credits that can help them with some accommodation expenses. These credits include the disabled access tax credit, which provides small businesses (30 or fewer employees) with a tax credit for accommodations for employees and customers with disabilities, available every year up to a maximum benefit of $5,000. The architectural and transportation tax

deduction allows businesses to take an annual deduction of up to $15,000 for expenses incurred to remove architectural and transportation barriers for persons with disabilities in the workplace. And last, there are other tax credits if you hire someone with a disability, for example a tax credit such as the Work Opportunity Tax Credit that will pay the first year's wages of the new hire if you hire someone with a disability. This is oftentimes a great appeal for employers.

There are enforcement provisions for the ADA, and it is important that people with disabilities understand their rights. However, we have found that issues can often be more easily resolved when an agency or an employer has an effective internal system for resolving complaints. A study by the American Association of Colleges of Nursing (AACN) found that 91 percent of schools of nursing do have policies to address the ADA law. There have been 17 ADA lawsuits against schools of nursing.

Finally, I want to say that employers do need resources when they want to hire people with disabilities. I know there are criticisms of the vocational rehabilitation programs, but they are a support to employers and applicants. That's their job. Most states have agencies, like the Illinois Department of Human Services, with a Vocational Rehabilitation (VR) Program funded under the Rehabilitation Act, that are ready, willing and able to help employers comply with the ADA. First, the VR program can offer technical assistance. Vocational counselors can match job sites with qualified customers with disabilities so that there is little disruption in accommodating employees. Many VR programs provide disability awareness training to help non-disabled workers overcome irrational fears and concerns of helping a co-worker with a disability. The goal of the VR programs is to help employers integrate people with disabilities into their workforce through statewide job referral and placement services.

I think it is important to acknowledge the important positive model that the Centers for Independent Living model provides. This model directs us away from the medical model and the idea of "fixing" people and towards the ideals of empowerment and self-determination.

I want to add that with collaboration we can serve people with disabilities and look at the ADA as a benefit and a tool, and not simply as rights for people with disabilities. Thank you.

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Appendix A

Information and Sources for Accommodations

Information

Center for Teaching Effectiveness: www.udel.edu/cte/disabilities.htm

Cornell University - Employment Accommodation Series: www.ilr.cornell.edu/ped/products.html

Equal Employment Opportunity Commission: www.eeoc.gov

Job Accommodation Network: www.jan.wvu.edu

Health Sciences Faculty Education Project: www.healthsciencefaculty.org

National Council of Independent Living Centers: www.ncii.org

National Council on Disability: www.ncd.gov

National Organization on Disability: www.nod.org

Regional Disability and Business Technical Assistance Centers: www.adata.org

Social Security Administration: www.ssa.gov

U.S. Department of Labor, Office of Disability Employment Policy: www.dol.gov/odep

Audience Participation

Ray Campbell. I am Ray Campbell, President of the Illinois Council for the Blind. We are an affiliate of the American Council for the Blind and I would like to talk about resources. The American Council for the Blind in Illinois is a resource to persons with visual impairments as well as to employers and to anyone who has questions, in particular about how to accommodate someone who has a visual impairment.

There's also the National Federation of the Blind, which has chapters in most states. There are plenty of resources and plenty of people who are willing to assist you in hiring people with visual impairments. We just need to be asked. I want to make sure you are all aware of these resources and

the many different things that are out there to help employees and employers.

Karen Wolffe. Ray makes a good point and I think I would also want to add that consumer groups with people who have other kinds of disabilities are also a wonderful resource and certainly one of the best sources to find good mentors for folks in your programs.

Also, we have been helped by a number of the organizations to which we are very grateful in the preparation for materials for this conference.

Jamie Siegel, adaptive technology specialist. The problem isn't resources and it's not the people who are blind trying to get work. Many times, the issue is with the employers. I go to job sites to see how we can adapt their equipment to see if it will work to hire a person who is visually impaired.

I have a client who became blind, and the state of Illinois would not spend the money to adapt the software so this client could continue to work. He had been working for the state 15 or 20 years and they would not give him his job back by using adaptive technology. Currently, this person is in a vocational rehabilitation program trying to get a different job. In my experience, the issues are with the employers and assisting with adapting technology to help persons with disabilities to be able to work.

New speaker. I'd like to address that because it sounds like in this particular example, the rehabilitation program was the party involved. One of the things I know that our counselors struggle with in a post-ADA era is that employers have an obligation to accommodate. And though vocational rehabilitation services has often been a resource for employers, it doesn't ameliorate their responsibility to purchase accommodations on behalf of their employees. Not everyone is going to qualify for the vocational rehabilitation program. So part of our job is to educate employers about what their responsibilities are. Therefore, we use education as our first resource and second, if there's personal equipment that might follow that person beyond a particular job, then that's when vocational rehabilitation can kick in and actually support the personal equipment. This is based on federal regulations that we must follow.

Martha Smith, Faculty education project, Oregon Health Science University. All these people who were employed or are now employed as

physicians and nurses and dentists, none of them got their jobs because of vocational rehabilitation. They did it on their own.

Martha Younger-White. One of the things that concerned me was the number of times people have to leave employment. I want to remind people that reassignment is a form of accommodation. You must look within your agencies and see if there is a vacant job this person might qualify for before you consider what other arrangements are available to this individual.

Karen Wolffe. I would also mention that vocational rehab gets "dissed" a lot. I am a former rehab person myself and the greatest problem with rehab is that it is an unknown resource to many people, which is a huge issue.

Those of you who are in this room today can become part of the information sharing that's needed in the community to let employers know that they need to try to retain employees who become disabled, and to use rehab as a source for recruitment of people with disabilities. If you ask employers, many of them will say they never heard of vocational rehabilitation.

M.J. Smith, Second Vice President of the American Council for the Blind. I know blind people are talking a lot because we always do. (Laughter). I've had five jobs in my working career and all of them were in private industry. I'm here to tell you that it doesn't take a rocket scientist to get one.

I'm now going to "diss" rehab. If rehab would have more employment specialists and people who actually went out and talked to employers, showed them people with disabilities who could do the job, I think 70 percent of employers would go a heck of a long way in assisting their employees who need assistive technology to continue working and doing their job.

One of the things that use to please me most is the counselors who would send blind older children to me when I worked at Sears and let them work with me for a day. I would tell them the good, bad, and ugly about the Sears programming. And five or six or seven years later, I would see some of these kids placed in jobs. Mentoring is a wonderful tool to use.

Howard Rosenbloom, JD, Equip for Equality. I am deaf and deaf folks talk a lot as well. (Laughter)

I have a question regarding the rehab field. I have had a lot of experiences with rehab counselors, and I don't know if they're aware that there are careers in professions such as nursing and any medical fields. I don't see or hear about that a lot.

I'm hoping that will change in the future, starting right here. We're talking about the field of nursing and we need to make more rehab counselors aware of these opportunities.

Martha Younger-White. I was at a job event a week ago, and one of our employment resource staff came up to me and said, "Have you heard Rush University is having a symposium on nursing as a career for persons with disabilities? Is there any way I could get invited to that because I would like to know more about it?" I assured this person that I would be bringing back information. Certainly, I think we typically find in vocational rehabilitation programs people who have come up through the ranks. They haven't always been in the business world themselves, so therefore the connection that needs to be made with employers from their employer perspective oftentimes is missed.

I point you to people like Aileen Anderson with The Fox-River Valley Projects with Industry because she comes at it from a different perspective in terms of starting from the employer and working back to those in rehabilitation to make that connection happen.

Aileen Anderson, Director of The Fox Valley Project of Industry. The Project with Industry (PWI) is a national program. They've been around for 30 years and there are about 125 in the country. PWI's work with Human Resources and with the Office of Rehabilitation, which is part of the Department of Human Services (DHS/ORS). We are the missing link, we are the liaison between businesses and people with disabilities — it's a two-way street.

Businesses need to be educated as to the advantages of hiring people with disabilities. And the job seekers need to be educated as to how to package themselves to employers.

Session ended due to time.

CHAPTER 7

Regulations, Licensure and Policy:
The functional abilities essential
for competent nursing practice

Carolyn J. Yocom, PhD, RN, FAAN[1],[2]

In nursing, as in any profession or occupation, the practitioner (job holder) must possess a unique set of knowledge, skills and abilities[3] (KSAs) that permit the individual to competently carry out his or her job responsibilities. Two groups of KSAs are essential to the practice of nursing: those that are domain specific (i.e., specific to nursing) and those that are non-domain specific. The non-domain specific abilities underlie the performance of domain specific tasks and activities. For example, without the ability to grasp a catheter (with or without an accommodation), it is impossible to insert it into a body cavity. (Whether the ability to insert a catheter into a body cavity is essential for licensure and employment as a nurse, while germane to the focus of this conference, is beyond the scope of this paper.) Another example of the relationship between a non-domain

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[1] Associate Professor and Director, Office of Research and Grants, College of Nursing, Rutgers, The State University of New Jersey, Newark, NJ. When the studies described in this paper were performed, Dr. Yocom served as the Director of Research Services at the National Council of State Boards of Nursing. The opinions expressed in this paper are those of the author and should not be construed to reflect the policies and positions of the National Council of State Boards of Nursing.

[2] Carolyn Yocom, PhD, RN, FAAN, is an Associate Professor and the Director of the Office of Research and Grants in the College of Nursing at Rutgers, The State University of New Jersey. She also serves as the Coordinator of Out Reach Programs and as the Project Director for the Rapid Progression RN to MS program. Prior to joining Rutgers in September 2000, Yocom served as the Director of Research Services at the National Council of State Boards of Nursing. She also taught at the University of Illinois at Chicago. She has a diploma in nursing from Abington Memorial Hospital, a BSN from the University of Pennsylvania, an MSN from Case Western Reserve University and a PhD in Nursing Sciences from the University of Illinois at Chicago. She has numerous publications and externally funded research and demonstration projects. She currently serves as a consultant to the Commission on Graduates of Foreign Nursing Schools.

[3] "Ability" is defined as the relatively enduring attributes of the individual performing the tasks of an occupation. (Fleishman & Mumford, 1988; McCormick, 1979).

specific and a domain specific ability is as follows: The ability to store information in short- and long-term memory is essential for information processing and decision-making. An application of this ability is exemplified by the collection, storage, analysis and interpretation of a patient's signs and symptoms for the purpose of problem identification and its nursing management. These behavioral components of practice are an integral component of competence (National Council, 1996) and therefore have relevance to the regulation of nursing practice, the education of future and current nurses, and their subsequent licensure and employment.

Passage of the Americans with Disabilities Act (ADA) provided individuals with physical or mental disabilities protection from discrimination in areas such as employment, public accommodations, communication and access to services. To be covered under the act, individuals must demonstrate that they possess either: (1) a physical or mental impairment that substantially limits one or more major life activities (e.g., walking, seeing, hearing, learning, etc.); (2) a record of such impairment; or (3) that they are regarded as having such an impairment.[4] Title I of the ADA prevents discrimination against employees with disabilities and requires that an employer provide a disabled employee with a "reasonable accommodation."

Within nursing education, service and regulation, passage of the ADA raised a number of issues, including the need to specify the non-domain specific functional abilities that a nurse must possess in order to provide safe and effective nursing care. Explication of these abilities would be useful in evaluating existing regulatory, workplace, and educational policies and inform any needed revisions as a consequence of passage of the ADA. To address this need, the National Council of State Boards of Nursing undertook a series of studies (Chornick, 1993a, 1993b; Yocom, 1993) that culminated in a study designed to validate the non-domain specific functional abilities essential for nursing practice (Yocom, 1996). The methodology and selected results of the study that pertain to the practice of registered nurses will be summarized in this paper[5].

A job analysis methodology was used to identify and compare the abilities required by nurses employed in a variety of positions and work settings. The target population was all licensed practical/vocational nurses (LPN/VNs) and registered nurses (RNs), including advanced practice nurses

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[4] 28 C.F.R. §36.104
[5] Republished with the permission of the National Council of State Boards of Nursing.

(APNs), practicing in the United States. Based on response-rate knowledge gained in previous job analysis and role delineation studies, a random sample of 10,000 nurses was taken from all nurses currently licensed in 28 states.[6] Collectively, the sample represented all nurses licensed to practice in urban and rural areas of large and small states in all geographic regions of the United States.

A self-administered questionnaire, developed based on focus group input (Chornick, 1993a), pilot work (Chornick 1993b), a literature review, and consultation with experts, contained 97 representative attributes (see Table 1) grouped within 16 functional ability categories: Gross motor skills, fine motor skills, physical endurance, physical strength, mobility, hearing, visual, tactile, smell, reading, arithmetic (counting, measuring, computing), emotional stability, analytical thinking, critical thinking, interpersonal skills, and communication skills (written, oral). Content validity and internal consistency of the total scale and all subscales were supported. Final assignment of attributes to subscales was based on the results of a factor analysis.

Each participant was requested to indicate if it was essential for him/her to be able to possess a specific attribute in order to provide minimally safe and effective care to his/her clients. Additional items requested demographic and work environment (setting, position title, shift/hours worked, involvement in direct client care) information.

A multiphase mailing process was used to collect data. The initial mailing included an explanation of the study, a questionnaire and a stamped, return envelope. With postcard follow-up to non-respondents and adjustment for non-deliverables, a 36.6% response rate (n=3,660) was attained. Of these, 2,677 (73%) were RNs and APNs who were currently employed in nursing at least 20 hours per week. A follow-up telephone survey to randomly selected non-respondents revealed no significant differences between this group's characteristics and responses and those of the respondents. The demographic and work environment characteristics of respondents was also compared with those of participants in a role delineation study performed during the preceding year and for which there was a higher response rate (Yocom & Chornick, 1995). No statistically significant differences were identified.

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[6]States providing data tapes to the National Council for use in another project, granted permission for their use in this study.

The RN participants practiced in one or more of 19 different types of acute care, long- term care, community and home care settings. The most frequently reported position titles were those of: staff nurse (51%), charge nurse (27%), home health or community health nurse (14%) and supervisor (12%). Although the full variety of work shifts and shift lengths (8, 10, 12 hours) were reported, the majority worked eight hours per day on the day shift. Eighty percent reported they provided or assisted with the provision of direct care; 14% provided indirect care and the remainder were either not engaged in clinical practice or did not respond to the item.

The percent of participants indicating that possession of an attribute was essential to their delivery of care on the previous workday was calculated for each item. Participants were also grouped based on three factors: the specific work setting (e.g., acute care, anesthesia, occupational health, psychiatry), type of position (e.g., administrator, staff nurse), and level of involvement in the delivery of patient care (e.g., direct, indirect). To be included in an analysis, each sub-group had to contain data from a minimum of 30 respondents. The percentages of subgroup members indicating that an attribute was essential was calculated for each attribute and then examined for each subgroup within a factor and for various combinations of factors (e.g., staff nurses involved in direct patient care by type of work setting). For the purposes of this study, an attribute was determined to be essential for the delivery of safe, effective patient care if 95% of those in the analysis group responded affirmatively to the stimulus question.

As a result of these analyses, a core set of non-domain specific, functional abilities essential for RN practice was identified. For RNs working in any employment setting, in any position and involved in the provision of either direct or indirect patient care (i.e., the entire group taken as a whole, n=2,537), 17 attributes were identified[7]. These were as follows:

Attribute	Functional Ability Category
Write with pen or pencil	Fine motor skills
Hear normal speaking level sounds	Hearing
Read and understand columns of numbers	Arithmetic competence
Tell Time	
Monitor own emotions	Emotional stability
Transfer knowledge from one situation to another	Analytical thinking

[7] Source: Yocom, (1996); Table 23.

Attribute	Functional Ability Category
Process information	
Evaluate outcomes	
Problem solve	
Prioritize tasks	
Use long-term memory	
Use short-term memory	
Sequence information	Critical thinking
Establish rapport with clients	Interpersonal skills
Establish rapport with co-workers	
Interact with others	Communication skills
Convey information through writing	

Placing all the RNs in one group prior to identifying the core attributes eliminated the inclusion of attributes that are essential in settings where very few individuals worked (e.g., industrial settings and out-patient clinics). Therefore, another step was introduced: All items where 95% of the individuals employed in any position and involved in the provision of either direct or indirect patient care within a specific clinical setting were identified and then the data were compiled. This resulted in the inclusion of four additional attributes to the "core" group of attributes identified above[8]. These were: *Perform multiple responsibilities, synthesize knowledge and skills, respect differences in clients, explain procedures.* Therefore, these 21 core attributes are essential for safe and effective practice as an RN. With the exception of "writing with a pen or pencil," "hear normal speaking level sounds" and "convey information through writing," these attributes represent higher level cognitive functioning and psychosocial abilities.

Additional attributes associated with psychomotor functioning and the senses are essential when work setting and level of involvement in the delivery of patient care are considered. Based on a high degree of uniformity in responses, the multiple settings in which RNs were employed were collapsed into twelve settings, each with a minimum group size of 30. These 12 settings represented critical care (ICU, ED, PAR), acute care (medical-surgical, pediatrics, labor and delivery, nursery), anesthesia, surgery (in- and out-patient), psychiatry, long-term care (intermediate and skilled care), residential care, home health, occupational health, outpatient clinics, physician offices, and school settings. A total of 78 essential attributes, representing all 16 functional ability categories, were identified. Of these, 29 were identified as essential for practice in all 12 work settings. These are

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[8] Source: Yocom (1996); Table 22.

identified by an (*) in Table 2. As with the previously identified 21 "core" attributes, the majority represent higher level cognitive functioning and psychosocial abilities. The essential attributes for RNs providing direct care in five types of clinical settings (acute care, anesthesia, critical care, surgery and long-term care) are reported in Table 2. As can be seen, there is a great degree of similarity among these four settings.

In the remaining settings, the diversity was much greater. For example, RNs providing direct patient care in psychiatric settings, indicated that, in addition to the 21 core attributes, the following were also essential[9]:

Attribute	Functional Ability
Maintain physical tolerance	Physical endurance
Defend self against combative client	Physical strength
Walk	Mobility
Move quickly	
Hear auditory alarms	Hearing
See objects up to 20 feet away	Visual
Detect smoke	Smell
Speak on telephone	Communication skills
Teach	
Identify cause-and-effect relationships	Critical thinking
Negotiate interpersonal conflicts	Interpersonal skills
Establish therapeutic relationships	Emotional stability
Handle strong emotions	

This study demonstrated that the level of involvement in delivery of patient care, work setting, and position impacted the types of functional abilities that an RN must possess in order to provide safe, effective patient care.   Despite this diversity, a core set of 21 attributes, representing eight functional ability categories was identified. Of these, the majority represented higher cognitive functioning and psychosocial skills. In addition, there are a large number of attributes that are common to a majority of the various work settings and, although not reviewed in this paper, job positions.

The knowledge gained from this study can be used to inform policy evaluation and decision-making by boards of nursing and by employers and educators. The position-specific and employment setting-specific information can be a valuable resource during career counseling opportunities— both with practicing nurses who acquired a disability

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[9] Source: Yocom (1996); Table 19

following initial licensure and with individuals considering nursing as a career.

Within each state, the board of nursing has a legislative mandate to protect the public from incompetent providers of nursing care. When evaluating the competence of licensure applicants and licensees, the board cannot ignore or dismiss this mandate. *However, the presence of a disability that impacts an individual's ability to demonstrate competence in these areas should not be considered in isolation from the use of accommodations to compensate for a noted "deficiency."*

In the event a nurse (or prospective nurse) has a disability that negatively impacts performance of the essential "core" abilities/attributes or those that are specific to a position/role or work setting, answers to the following series of questions are critical:

1. Can the individual, with or without reasonable accommodation, engage in the activities that are essential for the delivery of safe, effective nursing care?
2. In what clinical setting(s) or positions is the individual best suited for employment?
3. Does the individual have insight into the implications of his/her disability?
4. In the event of "accommodation failure," does the individual have insight into the potential consequences as they relate to patient safety?

Table 1. Functional ability categories and Representative attributes.[10]

Gross Motor Skills	**Smell**
Move within confined spaces	Detect odors from client (e.g., foul smelling drainage, alcohol breath, etc.)
Sit and maintain balance	Detect smoke
Stand and maintain balance	Detect gases or noxious smells
Reach above shoulders (e.g., IV poles)	**Reading**
Reach below waist (e.g., plug electrical appliance into wall outlets)	Read and understand written documents (e.g., policies, protocols)
Fine Motor Skills	**Arithmetic Competence**
Pick up objects with hands	Read and understand columns of writing (flow sheet, charts)
Grasp small objects with hands (e.g., IV tubing, pencil)	Read digital displays
Write with pen or pencil	Read graphic printouts (e.g., EKG)
Key/type (e.g., use a computer)	Calibrate equipment
Pinch/pick or otherwise work with fingers (e.g., manipulate a syringe)	Convert numbers to and/or from the Metric System
Twist (e.g., turn objects/knobs using hands)	Read graphs (e.g., vital sign sheets)
Squeeze with finger (e.g., eye dropper)	Tell time
Physical Endurance	Measure time (e.g., count duration of contractions, etc.)
Stand (e.g., at client side during surgical or therapeutic procedure)	Count rates (e.g., drips/minute, pulse)
Sustain repetitive movements (e.g., CPR)	Use measuring tools (e.g., thermometer)
Maintain physical tolerance (e.g., work entire shift)	Read measurement marks (e.g., measurement tapes, scales, etc.)
Physical Strength	Add, subtract, multiply, and/or divide whole numbers
Push and pull 25 pounds (e.g., position clients)	Compute fractions (e.g., medication dosages)
Support 25 pounds of weight (e.g., ambulate client)	Use a calculator
Lift 25 pounds (e.g., pick up a child, transfer client)	Write numbers in records
Move light objects weighing up to 10 pounds (e.g., IV poles)	**Emotional Stability**
Move heavy objects weighing from 11 to 50 pounds	Establish therapeutic boundaries
Defend self against combative client	Provide client with emotional support
Carry equipment/supplies	Adapt to changing environment/stress
Use upper body strength (e.g., perform CPR, physically restrain a client)	Deal with the unexpected (e.g., client going bad, crisis)
Squeeze with hands (e.g., operate fire extinguisher)	Focus attention on task
Mobility	Monitor own emotions
Twist	Perform multiple responsibilities concurrently
Bend	Handle strong emotions (e.g., grief)
Stoop/squat	**Analytical Thinking**
Move quickly (e.g., response to an emergency)	Transfer knowledge from one situation to another
Climb (e.g., ladders/stools/stairs)	Process information
Walk	Evaluate outcomes
Hearing	Problem solve
Hear normal speaking level sounds (e.g., person-to-person report)	Prioritize tasks
Hear faint voices	Use long-term memory
Hear faint body sounds (e.g., blood pressure sounds, assess placement of tubes)	Use short-term memory
Hear in situations when not able to see lips (e.g., when masks are used)	**Critical Thinking**
Hear auditory alarms (e.g., monitors, fire alarms, call bells)	Identify cause-effect relationships
Visual	Plan/control activities for others
See objects up to 20 inches away (e.g., information on a computer screen, skin conditions)	Synthesize knowledge and skills
See objects up to 20 feet away (e.g., client in a room)	Sequence information
See objects more than 20 feet away (e.g., client at end of hall)	**Interpersonal Skills**
Use depth perception	Negotiate interpersonal conflict
Use peripheral vision	Respect differences in clients
Distinguish color (e.g., color codes on supplies, charts, bed)	Establish rapport with clients
Distinguish color intensity (e.g., flushed skin, skin paleness)	Establish rapport with co-workers
Tactile	**Communication Skills**
Feel vibrations (e.g., palpate pulses)	Teach (e.g., client/family about health care)
Detect temperature (e.g., skin, solutions	Explain procedures
Feel differences in surface characteristics (e.g., skin turgor, rashes)	Give oral reports (e.g., report on client's condition to others)
Feel differences in sizes, shapes (e.g., palpate vein, identify body landmarks)	Interact with others (e.g., health care workers)
Detect environmental temperature (e.g., check for drafts)	Speak on the telephone
	Influence people
	Direct activities of others
	Convey information through writing (e.g., progress notes)

Table 2.   Functional Abilities/Attributes essential for the delivery of safe, effective nursing care by RNs providing direct care and employed in the following areas: acute care (AC) , anesthesia (AN), critical care (CC), surgical suite (SU), and long term care (LT).[11]

Gross Motor Skills	**Reading**
Stand and maintain balance (*AN, LT*)[12]	*Read and understand written documents (e.g., policies, protocols)
Reach above shoulders (e.g., IV poles) (*LT*)	**Arithmetic Competence**
Reach below waist (e.g., plug electrical appliance into wall outlets) (*LT*)	*Read and understand columns of writing (flow sheet, charts)
Move within a confined space (*AC, AN, CC, LT*)	Read digital displays (*LT*)
Fine Motor Skills	Read graphic printouts (e.g., *EKG*)
*Pick up objects with hands	Read graphs (e.g., vital sign sheets) (*LT*)
**Grasp small objects with hands (e.g., IV tubing, pencil)	*Tell time
Write with pen or pencil	Measure time (e.g., count duration of contractions, etc.) (*AC,SU, LT*)
Pinch/pick or otherwise work with fingers (e.g., manipulate a syringe)	
Twist (e.g., turn objects/knobs using hands)	Count rates (e.g., drips/minute, pulse)
Squeeze with finger (e.g., eye dropper) (*AC*)	Use measuring tools (e.g., thermometer)
Physical Endurance	Read measurement marks (e.g., measurement tapes, scales, etc.)
Stand (e.g., at client side during surgical or therapeutic procedure) (*AN, LT*)	Add, subtract, multiply, and/or divide whole numbers
Sustain repetitive movements (e.g., CPR) (*AC, AN, SU, LT*)	Compute fractions (e.g., medication dosages) (*SU*)
Maintain physical tolerance (e.g., work entire shift)	*Write numbers in records
Physical Strength	Calibrate equipment (*AC, CC, SU, LT*)
Push or pull 25 pounds (e.g., position clients) (*AC, AN, LT*)	Convert numbers to and from metric system (*AC, CC, SU, LT*)
Lift 25 pounds (e.g., pick up a child, transfer client) (*AC,AN, LT*)	**Emotional Stability**
Move light objects weighing up to 10 pounds (e.g., IV poles)	Establish therapeutic boundaries
Carry equipment/supplies (*AN*)	*Provide client with emotional support
Use upper body strength (e.g., perform CPR, physically restrain a client) (*AC,AN*)	*Adapt to changing environment/stress
	*Deal with the unexpected (e.g., client going bad, crisis)
Squeeze with hands (e.g., operate fire extinguisher)	*Focus attention on task
Mobility	*Monitor own emotions
Twist	*Perform multiple responsibilities concurrently
Bend (*AN*)	Handle strong emotions (e.g., grief) (*AN*)
Stoop/squat (*AN*)	**Analytical Thinking**
Move quickly (e.g., response to an emergency)	*Transfer knowledge from one situation to another
Walk	*Process information
Hearing	*Evaluate outcomes
*Hear normal speaking level sounds (e.g., person-to-person report)	*Problem solve
Hear faint body sounds (e.g., blood pressure sounds, assess placement of tubes) (*AC,CC,SU,LT*)	*Prioritize tasks
	*Use long term memory
Hear in situations when not able to see lips (e.g., when masks are used) (*AC, CC, LT*)	*Use short term memory
	Critical Thinking
Hear auditory alarms (e.g., monitors, fire alarms, call bells)	Identify cause-effect relationships
Visual	*Synthesize knowledge and skills
*See objects up to 20 inches away (e.g., information on a computer screen, skin conditions)	*Sequence information
	Interpersonal Skills
See objects up to 20 feet away (e.g., client in a room) (*AN, SU*)	Negotiate interpersonal conflict (*AN, LT*)
See objects more than 20 feet away (e.g., client at end of hall)	Respect differences in clients
Use depth perception (*AC, LT*)	*Establish rapport with clients
Use peripheral vision (*AC, CC*)	*Establish rapport with co-workers
Distinguish color intensity (e.g., flushed skin, skin paleness)	**Communication Skills**
Tactile	Teach (e.g., client/family about health care) (*AN*)
Feel vibrations (e.g., palpate pulses)	*Explain procedures
Detect temperature (e.g., skin, solutions	*Give oral reports (e.g., report on client's condition to others)
Feel differences in surface characteristics (e.g., skin turgor, rashes) (*SU*)	*Interact with others (e.g., health care workers)
Feel differences in sizes, shapes (e.g., palpate vein, identify body landmarks)	Direct activities of others (AC,AN,SU)
Smell	*Convey information through writing (e.g., progress notes)
Detect smoke (*CC, SU*)	Speak on the telephone (An)
Detect gases or noxious smells (*CC, LT*)	

NOTE: * Identified as essential by 95% of RNs in each of the 12 work settings who were providing direct patient care.

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Addition to Position Paper Presentation

The purpose of the presentation is to discuss a study published by the National Council of State Boards of Nursing (NCSBN) in 1996. The study identifies essential functions and abilities as they relate to the practice of nursing. Dr. Yocom presented the intent of the study and how the data from the study should be used in contrast to how the study has been misused.

The focus of the paper is related to passage of the ADA and the issues this raised with regard to nursing practice, education and regulation. The NCSBN study focused on identifying the non-domain specific functional abilities that a nurse must possess in order to practice and provide safe, effective nursing care in specific types of positions, roles or job settings.

Explication of these abilities would be useful in evaluating existing regulatory, workplace and educational policies and could be used as the basis for any needed revisions as a consequence of the ADA implementation. The study has been thoroughly described in Dr. Yocom's preceding manuscript. A key point here is to understand that this study represents the final step in a three-step process used to identify the non-domain specific skills needed to be able to practice nursing. Specifically the steps were:

- A focus group consisting of individuals with disabilities and without disabilities was convened.
- An employer survey was conducted.
- Job analysis completed by employed nurses.
- Purpose was to validate the essential non-domain-specific functional abilities or attributes that a nurse must possess in order to perform nursing activities safely and effectively in a variety of work settings and positions.
- The target population was all registered nurses (RNs) and licensed practical vocational nurses (LPN).
- A random sample of 10,000 nurses was selected to participate.
- A self-administered questionnaire was used to collect data. Each respondent was asked to indicate if possession of the ability or attribute was essential for him or her to possess in order to provide safe and effective care to patients within the respondent's current role, position and job setting.

The study identified 97 attributes assigned to 16 categories of functional abilities. The lists are appended to the manuscript. Dr. Yocom

emphasized that "This is not 'THE' list that you have to possess; rather it is a representative list of the skills and abilities that you may have to possess. Think of this list as the items on the questionnaire. This is where people have been misusing the study by stating that if you want to be a nurse, you've got to be able to do all of these things included on the list. That is not true! This was only part of the questionnaire."

Dr. Yocom addressed the methodology and results. She discussed content validity and internal consistency of the total scale and subscales. She described the respondents and noted that the final sample represented a 36 percent response rate, which "was a little bit lower than we had expected." She also noted that "We believe one of the reasons for this [low response rate] was the purpose of the study, and that individuals who did have a disability, even though we promised confidentiality of responses, may have been hesitant to respond for fear of some type of retribution or the initiation of an investigation by the board. This may be a valid concern based on some of the information that we heard in the focus groups."

Dr. Yocom addressed the methods used to evaluate respondents' data and assure its validity through the use of a telephone survey to a randomly selected group of non-respondents. Since there were no differences between the two groups, it was concluded that the respondent data was representative.

Dr. Yocom continued with a thorough discussion of the data analysis phase of the study. She addressed the identification of what are the essential nondomain-specific abilities that a nurse needs to possess.

She stated: "Well, first we had to define essential. When you look at the dictionary definition of essential, it means something has to be present. However, in research we consider something called measurement error. Therefore, we set our definition as follows: for an attribute to be identified as essential, 95 percent of the respondents in an analysis group had to indicate that, to provide safe and effective care, it was essential for them to possess the attribute or the characteristic that they were responding to."

Dr. Yocom continued: "Now, when we looked at the data analysis results for all RNs and APNs, regardless of position, work setting, and involvement in direct or indirect care (n = 2,677) a group of 21 attributes were identified as essential for practice. In other words, they said these are

the attributes that nurses need to possess, this is the core list that you need to be able to do to function as a nurse."

Dr. Yocom presented the tables of core essential abilities: "Write with pen or pencil; hear normal speaking level sounds; read and understand columns of writing, in other words, columns of numbers, think of flow sheets; tell time; perform multiple responsibilities concurrently; monitor your own emotions — in other words, keep them under control; transfer knowledge across situations; process information; evaluate outcomes; problem solve; prioritize tasks; use long-term memory; use short-term memory; sequence information; synthesize knowledge and skills; establish rapport with clients and with co-workers; respect differences in clients; be able to interact with others; convey information through writing — think broadly — and explain procedures. These are the 21 core attributes or abilities; they represent 8 of the 16 different categories of functional abilities.

"I think you're hearing now a lot of the things some of the speakers were saying this morning and this afternoon. If you think about it, the majority of these represent higher-level cognitive skills and communication and interpersonal skills. You didn't see things on this list like 'pick up a tube."

Dr. Yocom continued with a discussion of practice setting. "Based on the high degree of uniformity in responses across the multiple settings in which RNs were employed, the numerous settings were collapsed into 12 groups. Within these 12 settings, a total of 78 essential attributes, distributed across all 16 categories, were identified when we looked at each of these 12 settings. Of these 78 attributes, 29 were essential for practice in all 12 areas." (These are identified in Table 2).

"The essential attributes for RNs providing direct care in five of the areas—acute care, anesthesia, critical care, surgery, and long-term care—are reported in Table 2. As can be seen, there is a great deal of similarity among the four settings." As an example, let's take the very first one that's on the list under gross motor skills. It says stand and maintain balance. First of all, it does not have an asterisk in front of it, so its not one of the 29 attributes that applies to all 12 settings.

"In the remaining settings, the diversity was much greater, such as in psychiatry, occupational health, the outpatient clinics, physicians offices

and school health. For example, in psychiatry, nurses involved in direct care as a staff nurse, there is a different set of additional attributes, not the 78 included in Table 2. In addition to the 21 core essential attributes, the additional attributes are: Defend yourself against a combative client; walk; move quickly; pinch, pick or otherwise work with your fingers; maintain physical tolerance; speak on the phone; teach; identify cause-and-effect relationships; negotiate interpersonal conflicts; establish therapeutic relationships; handle strong emotions; hear auditory alarms; see objects up to 20 feet away; detect smoke. This should gives you a feel for the differences in the attributes essential for practice in psychiatry as opposed to the more traditional acute care and medical-surgical units."

Dr Yocom referred back to her paper to describe the following issues. This study identified the attributes essential for involvement in delivery of care. Delivery of patient care, work setting and position impacted the types of functional abilities that an RN must possess in order to provide safe, effective patient care.

"Despite this diversity, a core set of 21 attributes representing 8 functional ability categories were identified. That's across all nurses, all settings, et cetera. Of these 21, the majority represented higher cognitive functioning and psychosocial skills. In addition there are a large number of attributes that are common to a majority of the various work settings and, although not reviewed in this paper, today, to various job positions. There are also a large number of psychomotor attributes that are essential for care delivery in the acute care, critical care, anesthesia, long-term care and surgical settings."

The knowledge gained from this study can be used to inform policy evaluation and decision-making by boards of nursing and by employers and educators. The position-specific and employment setting-specific information can be a valuable resource during career counseling opportunities both with practicing nurses who acquired a disability following their initial licensure and with individuals considering nursing as a career.

Within each state, the board of nursing — as we heard about earlier — has a legislative mandate to protect the public from incompetent providers of nursing care. When I say incompetent, this is an equal opportunity group. So when evaluating the competency of licensees, the board cannot ignore or dismiss this mandate. However, the presence of a disability that impacts an individual's ability to demonstrate competence in these areas should not be

considered in isolation from the accommodations that can be used to compensate for a noted deficiency and, I would add, the setting where they intend to practice.

In the event a nurse or prospective nurse does have a disability that impacts performance of an essential core ability or attribute or of those that are specific to a position, role, or work setting, answers to the following set of questions is critical:

1. Can the individual, with or without reasonable accommodation, engage in the activities that are essential for the delivery of safe and effective nursing care?

2. In what clinical setting is the individual best suited for employment?

3. Does the individual have insight into the implications of his or her disability with regards to patient safety?

4. In the event of accommodation failure, does the individual with the disability have insight into potential consequences as they relate to patient safety?

Dr. Yocom continued: "Now, a comment on these four questions. Again, I think they're equal opportunity. For example, I haven't seen an OB unit since I graduated from nursing school in 1964. I am unsafe in any OB unit. I haven't been in clinical practice since 1985. So I'm probably unsafe across all clinical areas. When I applied for a position at Rutgers, after I left the National Council, I made it very clear to my potential employers that I had not worked in clinical practice for over 15 years. Therefore, I see these questions also applying to me."

"On that note, I hope that you all have a better understanding of the purposes of this study and how the results of it should be used. And my suggestion would be to focus on those core attributes that represent the higher cognitive skills, the psychosocial interaction and communication skills. Thank you."

Regulations, Licensure and Policy:
The functional abilities essential
for competent nursing practice
<u>Response</u>

Vickie Sheets, JD, RN, CAE[13]

This audience is quite stalwart to be hanging in here this late this afternoon. I'm very pleased that you're here and I'm very pleased for the opportunity to participate in this important discussion.

Whenever you deal with such an important issue, and one on which reasonable people may differ in their thinking, I think it's essential to try to understand the perspective of all positions.

Since this is a session on regulation, I will begin by sharing some considerations from the regulators' perspective.

First of all, the challenge to regulatory boards has always been maintaining the balance between an individual's desire to practice a chosen profession and the board's responsibility to protect the public from unsafe practitioners. Reasonable people can differ in how best to protect the public. And our boards vary in their approaches to a number of issues. I think many regulators recognize that providing access to nursing care is part of protecting the public.

In granting an initial license to practice, regulators are looking at a generalist practice, a nursing license grants practice authority at this

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[13] Vickie Sheets, JD, RN, CAE, is the Director of Practice and Regulation for the National Council of State Boards of Nursing. Some of her projects at the Council include the revision of National Council's *Model Nursing Administrative* Rules, Disciplinary Policy and Data Advisor for the Nurse Data Information System, and planning National Council's third *Investigator's Summit,* a two-day workshop for Boards of Nursing Investigators and Attorneys. Sheets has also been the staff support for National Committees addressing a variety of the regulatory topics such as continued competence, professional accountability, professional boundaries, use of criminal convictions and background checks, and other investigatory and disciplinary topics. Sheets received her JD from Hamlin University School of Law, St. Paul, Minnesota, and her BSN from Case Western Reserve University, Cleveland.

generalist level. Think of the nursing license as the key to any nursing role in any setting.

The burden of proving that an applicant meets all licensure requirements rests with the applicant. Remember that boards of nursing vary as to their structure and the level of discretion granted to them by the legislature.

Boards also vary in their philosophy and approach to regulation. The United States Constitution reserves police power to the state. Licensing authorities of states have traditionally been seen as part of that police power.

In considering applicants with disabilities, there are two distinct philosophies on how boards think and deal with these individuals. There are boards that have taken the position that the ADA is intended to "even the playing field" for applicants with disabilities. These boards ask few if any questions about functional abilities on their licensure applications. Their approach is to give the individual nurse an opportunity to self-limit his or her practice, if necessary, to make sure that any necessary accommodations are in place. The board would become involved only if there was a problem with practice reported. Other boards ask questions about functional abilities as one part of the information collected on licensure applications and use that information as part of the licensing decision.

I went to law school and can argue both of these positions. Besides disabilities, there are other ways practice can be self-limited. For example, I was a nurse before I attended law school. I practiced nursing in facilities and university hospital settings where either the resident or an IV team was responsible for venipuncture. While in law school, I worked for an agency that often sent me to various med-surg and critical care units. One of the first things I would do if a patient needed an IV restarted was to request assistance. I was not particularly interested in developing venipuncture skills because I was not going to be using them. I limited myself to situations where I could get the assistance I needed from other staff, or situations where I did not need the skill. I self-limited. Nurses with disabilities can similarly self-limit practice as needed and seek appropriate accommodations.

However, some boards believe that they are issuing a license that allows a nurse to practice in any role, any setting, the full range of nursing

practice; therefore the board has a responsibility to identify needs for accommodations or practice limitations and assure that this critical information is available to employers. Now, this may be counter to the beliefs of many of you here at the symposium and those involved in the disability movement. Try to think a little more about where the boards are coming from. You have to understand that boards have experience with individuals who haven't demonstrated insight into their situations. Boards take their responsibility very seriously, and they believe that they have the responsibility to evaluate all aspects of competence.

I think technical skills raise concerns for boards. I think another area that raises concerns is the so-called invisible disabilities. As Dr. Carole Anderson noted, faculty also found invisible disabilities problematic. For example, think about many of the accommodations granted, like having a quiet room to take an exam. That sounds pretty reasonable to take an exam. But how many of us work in a nursing environment where there is a quiet room? I think this illustrates the nature of concerns that board members may have.

The functional ability study that was described by Dr. Yocom is very important, cutting-edge work. A panel of nurses initially identified these abilities, and I recall that the panel included both nurses with disabilities and nurses who had worked with nurses with disabilities, who made recommendations for the survey questionnaire.

The subsequent survey of nurses really pinpointed a point in time (early 1990's). As Karen McCulloh, RN, pointed out earlier today, that was nine years ago, and we live in a different technological world today. That different techno world has to be taken into consideration when establishing functional ability lists.

The functions that were identified in the study, especially some of the physical functions, should be thought of as things that need to be done as part of the nursing service. They don't necessarily have to be done by the same person. Stacey Carroll, RN, gave us a nice example about how she traded — she would do some things and another nurse would pick up things that hearing was really needed for. I think this is a great approach.

I also agree with what Andy Imparato, JD, talked about — thinking in a broader concept about the ability to communicate. You might not be able to communicate in one way, but able in another. All the technical resources we

have now, should help — I have always thought nurses ought to be able to wear "star trek" devices so that they could record their nurse's notes as they are looking at a wound or doing an assessment.

The research that Dr. Yocom presented is about nine years old now and technology has changed dramatically in the last nine years.

Another thing to think about is that we are currently facing a nursing shortage of epic proportion. I realize that Dr. Goodman advised us to make changes because it is "the right thing to do." That's an important message, but politically speaking, I think this is an opportune time because we need nurses. I am not just talking about new nurses coming into the field, but nurses who have been working in the field and have developed some kind of problem that may be preventing them from doing the full scope of what they envision as a staff nurse role.

We have to be creative in how we think about making accommodations. It is important that nursing board members are educated about the ADA law and educated with examples in providing reasonable accommodations. Real stories like the ones given by the student panel earlier today help to demonstrate successful accomplishments. Studies like the one the board conducted did inform and influence decision-making. We need to update that study. We need to do other kinds of studies. I would love to have somebody look at sentinel events and determine what part, if any, nurses with disabilities had in them. Is it the same proportion of sentinel events as the general nursing population? My hypothesis would be it's probably so, but we can't just accept hypothesis, we need sound data to inform our decision-making. We need to look at whether we need the same functional abilities that were identified from the earlier work conducted in 1993-94.

I think one of the things that really jumps to mind is being able to write with pen and pencil. Now, there are voice-activated computers that we can talk to for things like change of shift report. There are a lot of technical solutions that we have to identify, and we have to demonstrate how they work.

We need to work to show how nurses with disabilities are effective. Currently, the National Council of State Boards of Nursing is working on a different study called an epidemiology of nursing error. The study is examining actual discipline cases, using a wonderful instrument that was

developed with the assistance of Dr. Patricia Benner from the University of California at San Francisco. All kinds of elements are tracked including demographic information, the environment where the problem practice occurred, the type of area where it occurred, system issues, and potential negative contributions from other healthcare team members, e.g., a new resident who may have contributed to the sentinel event due to lack of experience. We also track practitioner contributions, e.g., did the nurse have a functional ability deficiency or a drug-chemical problem? We are hoping that this study will show trends that can be used to make changes or corrections to improve practice.

There are four things that I hope you will take away from my comments today. First of all, remember that state boards have different philosophies about the regulatory management of nurses with disabilities. Remember, that as long as they can articulate a rational relationship between the intent of a regulation and the activity or requirement that's being used, they are likely to be supported by the courts.

The second thing to remember is that the ADA was passed to provide opportunity. It was not intended to place healthcare clients or students at risk of harm. Under the ADA you cannot discriminate against an individual simply because he or she has a disability. You can, however, keep someone from practicing a profession if allowing that person to practice puts patients at risk of harm. How boards do this is very important.

The third thing is that we need research, especially within the current practice context, in order to have informed analysis and informed decision-making. We need to have sound data available so that the boards of nursing can make evidence-based decisions. The functional abilities as identified in Dr. Yocom's study provide guidelines that can be used for informed decision-making, but they are just one piece. The context of the study was that it could be used as a resource for informed review and support decision-making regarding applicants and students with disabilities. It should be used in combination with other research and expert consultation. It represents what one group of professionals in one study recommended and what we validated at that point in time.

Finally, we need to be flexible, to be creative in accommodating individual challenges, to be open to new ways of practicing while maintaining patient safety.

At the same time, I think that educators have to reach a difficult balance. I don't think it is right to put unreasonable expectations in the mind of a student who may have significant problems becoming licensed to practice. Educators need to give students notice that there may be some speed bumps and barriers along the way. Once students are presented with this information then it becomes their informed decision to move forward — and it may be a good choice to become a nurse. Students with disabilities and colleges may devise some very innovative ways to accommodate students with disabilities.

We need to work with employers to show them the benefits of accommodations and to also encourage creativity in how work is done. Marca Bristo talked about how her nurse manager broke apart three job descriptions and reassembled the work to come up with a job that was very doable for a nurse in a wheelchair. That kind of job restructuring needs to be done more often. This is why we have to make sure that the employers buy into the idea because it won't matter if you get the education and license if you can't get a job.

We have to work together. The ADA created both opportunity and challenge: opportunity to work with prospective and current students to identify both alterations in their functional abilities and reasonable accommodations to support them in accomplishing their educational and career goals.

The challenge for educators is to provide opportunity and some creativity, but also maintain some reasonableness and provide notice to students of potential barriers.

The challenge for boards of nursing is to devise opportunity while maintaining standards for safe and effective nursing practice. Boards are accountable to the public first and then to the nurses.

I learned a lot today and I am going to take that knowledge back to the state board committees that I work with. I decided I really don't like the word disability. I think we're really talking about different abilities that can enable safe practice. Stacey Carroll, RN, who is able to lip-read and communicate that way has a different ability than others. I could have really used her in the ICU when I had patients with tracheostomies who were having difficulty communicating. We need data, we need to educate ourselves and we need to work with each other.

Again, thank you for the opportunity to participate today.

Audience Participation

Bobby Silverstein. I have a couple of questions. Vickie, I'm not sure I understand some of the information presented — maybe you could help. The second category type you described, the second approach that some state boards take in terms of re-licensure where the board says they re-license nurses if they can do everything nurses do, and you have Carolyn at this point in time in her career where she had not practiced clinical nursing for 15+ years and she is asking to be re-licensed but says, "Don't hire me to do clinical nursing because I can no longer do it, don't hire me to do this or that because I no longer do that type of nursing" — Would she fail the re-licensure?

Vickie Sheets. I hope not, because I'm in the same boat she is in.

Bobby Silverstein. I'm asking a conceptual question. Because if the answer is no, then it sounds more like a category 1 approach you described. Unless you're treating her experience different than the physical attribute.

Vickie Sheets. We're talking about the difference between initial licensure and re-licensure rules. The initial licensure is the point where those functional abilities are going to be evaluated. And there are a couple ways of doing this. In our Model Practice Act we have what is called a modified license, which is a non-disciplinary approach. Other boards have to use the disciplinary approach.

Bob Silverstein. Excuse me, I don't understand the rule and the differences if the ultimate goal, which we all agree, is protection of the public. Which absolutely is the bottom line, ADA and everything else. If the overarching policy objective of approach 1 and approach 2 is to protect the public, why is the re-licensure or initial licensure relevant at all if you're not now able to protect the public? For Carolyn if a board is using approach 2 — why should Carolyn be able to practice or be, quote, "certified"? I don't get it.

Vickie Sheets. Excuse me. I think the answer to the question is that it's different in different states. In other words, the rule is not different for initial licensure versus re-licensure; it's different by states depending on

whether the state uses the category 1 or 2 approach. In the states where our two colleagues are licensed, they use a type 1 approach. Period, whether you're initial or continuing. Whereas, in another state like Alaska, which was mentioned by Karen McCulloh, they use a type 2 approach. Which means that since your license allows you to do anything, it is the board's responsibility, as part of protecting the public, to limit your license related to your abilities. It's not initial licensure versus re-licensure; it's differences between states.

Bobby Silverstein. Then that's the follow-up to my question. If in fact I go to Rush University and I say I want to be the best researcher in the world in terms of issues affecting nursing, and I have no interest whatsoever in being in an ICU — what kind of license do I get if I cannot do three-quarters of the things a nurse usually does, but I'm the best damn researcher in the world? Do I get a qualified license or do I get no license?

Carolyn Yocom. It depends on the state in which you are applying for licensure. It all goes back to a phrase that Vicki had in her presentation that refers to the U.S. constitution — it gives the state the right to determine how it is going to approach licensure.

Bobby Silverstein. I understand.

Carolyn Yocom. Okay, but if I lived and worked in Alaska, I probably wouldn't get re-licensed. I have no intent of moving to Alaska. And because of the states' rights issue we have in this country, 61 Boards of Nursing and, therefore, 61 variations on a theme, any theme.

Bobby Silverstein. But there is an organization or a group that probably provides advice to states. And rather than answer the question by saying that's the way it is, in Alaska versus another state, to me the issue for this symposium is a different question. It's not what is, it's what should be.

Carolyn Yocom. That organization is the National Council of State Boards of Nursing. I worked there for 15 years. The National Council's role is that of a service organization to the boards of nursing. Included in that is the provision of information regarding important issues in education, practice and regulation, not just with regard to nursing, but with many other professions. One of the points that was in Vicki's presentation, or in the introduction of Vicki, is that she works with various National Council committees on what's called the model nurse practice act and the model rules and regulations. It is through that type of activity, and the inclusion of

nursing board representatives on National Council's committees, that the Member Boards influence each other.

However, to paraphrase a common saying, you can lead a horse to water, but you cannot make them drink. This is because the National Council rather is a service organization. I think that's the piece that you have to remember. It can influence.

New Question. I am wondering, as a follow-up to that, how political or how arbitrary are the approaches and the determinations of whether Virginia does one thing and Illinois does another? I can understand the states' rights provision of the constitution, even as a non-lawyer I understand the states' rights provision. But I assume that it cannot be totally arbitrary. And so I am wondering who determines what the minimum standards are?

Vickie Sheets. The legislature. It is a totally political process.

Carolyn Yocom. Yes. Think about what you're dealing with here as public policy. In this case, it is much like for the nurses in the room, the whole issue of the minimal educational requirement for entry into licensure as a nurse. What the minimum education requirements are is in the law. If you don't like it, you then have to participate in the whole legislative change process. Because the board's responsibility is to implement the laws that have been passed by the legislatures.

Vickie Sheets. I think the most effective way to convince lawmakers is to have the data, to have evidence, not just the board's opinion on the basis of what they've seen in the past, not just your opinion on what you have experienced within this community. Have some facts. And I think that probably Rush College of Nursing could really help in this end in getting some research started in this area.

Beverly Huckman. I am a little concerned as I listen to this. As we have heard earlier today —and we know — Illinois has a pretty good ADA state law relative to people with disabilities. Then what you are saying to me is that that law should overarchingly govern what the Illinois board does. Is that correct? In other words, should that be as you said, the legislature. So I have to determine if the legislature doesn't establish the standards for nursing, organized medicine or anything else. In fact, we have someone here from the Illinois Department of Professional Regulation, maybe you can help.

What is the impact of the legislature in Illinois on the decisions that are made by the Board?

Vickie Sheets. The Legislature passed the law that gives the board the authority to function.

Pat Hughes. I'm actually the newly appointed general counsel for the Illinois Department of Professional Regulations (IDPR). And my predecessor, who was with the agency for eight years, Adrienne Hirsch, is here as well.

I have not as much history to answer some of the follow-up questions you may have; Adrienne is more in a position to answer than I. To answer your question directly —which is the interaction between the legislature and the agency — the legislature sets up for nursing in Illinois a nurse practice act, which covers how it sets up a structure. It sets up minimum qualifications.

Do you have to take a test? The statute says that you do. So you do. Do you have to go to school? The statute says you do, so you do. The overlay on that are the administrative rules, which sometimes get into a little bit more detail both on testing and discipline. If you really talk about it in terms of a "political process," whom do you talk to if you don't like the law? You have to answer in two areas, one being the legislature and the other the regulatory agency. The regulatory agency often has some ability to join in the discussion on what the statute is going to be. You're always talking to the right person if you're talking to us (IDPR). We're part of the solution, not part of the problem in everything we're talking about today. But ultimately if it's the practice act, we don't make the practice act — the legislature has to change it and the governor has to sign it.

Bobby Silverstein. The third is the American's with Disabilities Act and the second is 504. If the statute or regulation says, notwithstanding everything we said above, do not apply for a license or otherwise allow a person with a disability to participate in anything related to nursing, that statute or regulation would not be okay.

Vickie Sheets. I think it's a big challenge.

Howard Rosenblum. I have a question related to your study. With all due respect to Dr. Yocom, I think that the approach was to ask the questions of the nurses who were practicing at that time what they thought were the

essential duties. And I found that to be puzzling. And the reason is — I mean, that's just like asking in the old days if you were to ask a man if a woman could do a man's job. So naturally a man would say no. So if you ask a Caucasian person the same of a person of color, the person of color would also say the same thing. Before 1964. So to ask people without disabilities if it is really necessary to hear or to see or whatever, makes no sense. Because they have no concept of living with a disability, so I find the study to be flawed.

What we need to ask is if they can do the job with accommodations. And even asking that, you know, they still won't understand or get it. You have to look at it objectively, not subjectively.

Carolyn Yocom. First of all, there's a lot in the study that I didn't go into. But I do know that at least 10 percent of the participants did indicate that they possessed a disability. Many of them were visual, some were hearing problems, some were the usual array of musculoskeletal problems such as the bad backs, et cetera. So, there were some individuals with self-defined disabilities in the study. What we asked them was, for you to do your job yesterday, what did you need to be able to do. Now, that's the bottom line. What has to be done. The next question then in regards to the use of the study is how could it be done. And that's where the use of accommodations comes in.

We did ask those nurses who did self-disclose a disability what types of accommodations they used. The responses included things like having colleagues help do the heavy lifting or if they couldn't reach for something up high, to get someone to reach it for them. Or if they didn't understand what somebody was saying, to have them write it down. In the published study, there is a listing of those types of accommodations.

But that was seen as the second step. First, you have to identify what are the basic underlying abilities, the non-nursing specific functional abilities that you need to be able to perform given specific roles or functions or work settings. And then go from there with regard to how can that be accomplished in various and sundry creative ways.

New Speaker. I'd just like to point out that the definition of a disability is to be impaired substantially in something that most people find essential. Therefore, if you were to ask me what's essential to do my job as a lawyer, I would say walking, seeing, talking, hearing. Because I do all those things

because that's what people without disabilities or those particular disabilities do. So then you would think that my job could only be done by a person who could walk and see and talk and hear and touch because I bring all of those abilities to my job.

You never asked in your study could you have done this, without this or that; could you have used a typewriter? Well, if I knew how to type I could use one. Could you have done it with an audio devise? You asked them what they did do. And what they do is use what they have, not what they don't know about. If you ask a blind person if it's essential to see and they're leading a successful life, they're going to say no.

Carolyn Yocom. I don't disagree with you. I think you bring up a very good point. However, go back to my point that we had to identify what was baseline and go on from there. I understand completely where you're coming from. I have a disabled family member and this person's attitude is such that anything can be accomplished — it just takes longer, or in some cases it requires a different way of doing it. A person doesn't have to be able to clean the house in order to be a good wife — a housekeeper can be hired to do that kind of stuff.

New Speaker. I think the study questions didn't ask the able-bodied nurses/people functional questions — the study asked them what they did do, how they accomplished work. So naturally they responded by saying how they functioned at work.

Carolyn Yocom. Point taken. That was the purpose of the study.

New Speaker. I have a question. In regards to initial licensure, the scenario is a person has been in a nursing school and they are trying to complete an education. They want to become licensed and go to work. I'm interested in knowing if there's any data on how many people with disabilities go through the course work and are not licensed. I think this is the data we need to have. Also are they drummed out during the core courses, or do they go through all whole course work? I just want to know.

Carolyn Yocom. We do know by anecdotal information that most people who complete a nursing education program are declared eligible to take the licensure examination, NCLEX. Where we get into the whole issue regarding disabilities, is whether or not the board will certify them as eligible

to take the licensure examination. There are no hard and fast statistics that are collected on this that I am aware of.

Vickie Sheets. I think there might be a way to look at that type of information. And, there might be a way that we could look into collecting the information. I think the next step is even more important. Does the person who's able to get through school and get licensed, are they able to get a job? Each piece is very important.

New Speaker. I have a question. And first of all I want to thank you for being here. I feel like we're in the meat of the subject now. So whatever our questions are, we love you, Okay?

Carolyn Yocom. I don't take any of this personally.

Speaker Continues. I have two questions. Number one, do you have any nurses with disabilities on your Board? Number two, do you have any statistics, any case studies, across the Board nationally where you know that nurses with disabilities have caused public harm?

Vickie Sheets. That's what we're hoping to find out in our epidemiology study. I'm not aware of any. There are some other regulatory people in the room. If any of you know of particular cases in your state, please speak up. I think that's a very good question. One of the things that kept going through my mind in this discussion today, is that some things that you view as prejudices, some regulators would view as serious concerns. I think that's why it's so important that we have this dialogue. And that we inform each other. I think that people disagree. I think people can disagree as to one of the challenges with the ADA being some of the terminology in defining it. Let me give you an example as to what we as a regulatory board see. A nurse who is hearing impaired, what would that nurse do if a patient calls for help and you can't see the call light? I can think of lots of ways you can work around it. You simply don't have the person work by themselves. It's that kind of thing. But it's important that the board review this type of issue and think it through because it is part of their responsibility.

Speaker's Second Question. What about membership of people?

Answer. Let me give you some help too. One of the things I would recommend is that you look at the EEOC guidelines on what is called an essential function. Because I wouldn't have thought of it the way that you

defined it in terms of a dictionary view of it. Where you're going to be licensing people to go is into workplaces, in essence what the EEOC is going to look at are things like job descriptions that probably should or should not have in them things like needing to see, hear, walk. I don't think of those as essential functions. That's not why I went to school - to see, hear and walk. Those are things that I think of when you say definition of terms. That's where EEOC is coming from because that's the guidance we're getting on the workplace. You'd think they'd all kind of come together at some point.

Vickie Sheets. Like I say, we need more work on them.

New Speaker. Two comments. First to the gentleman down here who said he didn't know how you got to your survey. And he was saying it's not the job. Well, you have to define the job first and then that's what you were doing.

Carolyn Yocom. That's correct!

Speaker Continues. When you ask 5,000 people what did you do yesterday at work, that is defining the job. And it's true that there are parts of the job that may be accommodated. But it is the job of nursing. Because if 95 percent of those working nurses said that's what I must do on my job as a nurse, that's a pretty good definition of what nurses do. It's just a comment.

And a comment to the first gentlemen asking questions (Bobby Silverstein) - when you asked whether Dr. Yocom should be licensed continuously, I will tell you that in today's nursing shortage, I graduated very similar to you -- and I'm really good at what I do. And my job is nursing. But if I were to go back to work in an ICU tomorrow, I would be quite dangerous, I think. I could fix that in about a month. I have an active license and they would hire me if I walked in the door. So there is a question. And I have a continuing concern about that.

So do all of us in the nursing profession know how to demonstrate continuing, general competence in nursing? Because I too would not work in an OB unit if you paid me because I would be down right dangerous. I don't try to work in areas like that because I monitor myself. Not because my Board of Nursing says I can't, because in this shortage environment I could work there.

Carolyn Yocom. If would like to make another comment. As I mentioned previously, the study used what's referred to as a job analysis methodology. This is a methodology that's been developed and used within the field of industrial psychology. The National Council uses this method as a way of identifying what is the nursing content and knowledge that a nurse needs to possess. It serves as the underlying mechanism for establishing the content validity for the licensure examinations. This study then used an extension of that process, one that is more commonly used in fields outside of health professions.

For example, if you have a new company that is going to make widgets; in order for them to screen and hire individuals into positions who are competent to make the widgets, they need to be able to describe what it is that the individual needs to be able to do. That information underlies the job descriptions that are developed. So, if you go out into industry and you look at those job descriptions for a machinist, for example, it talks about being able to lift X amount of weight or pick up a piece of metal and be able to twist it, to turn it, to manipulate it, to turn this crank and so forth and so on. Those are skills that underlie the performance of that job.

In nursing, the knowledge base that you needed to possess is an important component of competence. However, there was nothing in the literature or anywhere else that described the other skills and abilities that a nurse needs to possess in order to perform their job safely and effectively. That was the basis for the study.

New Speaker. You mentioned that 10 percent, 300 of the nurses...

Carolyn Yocom. About 200 of them had disabilities.

Speaker Continues. The question then is, were the answers of those nurses different from the rest? Did they look at it from a different perspective?

Carolyn Yocom. That's a very good question, and I don't remember if we looked at it or not. It's been a number of years and I'm no longer at the Council. Therefore, I don't have the data. I just can't remember. Maybe we could look it up.

Vickie Sheets. I'm sure we still have it and I will take that question back.

New Speaker. What was just asked, in going back to sampling you had mentioned that disabled nurses participated, but we already know that disabled nurses are underrepresented. So we don't have a good sample to which we can say that nurses with disabilities said that they can or cannot do X, Y, Z. And they may have a bachelor's degree, or be someone with a hearing impairment or hearing disability. Like me, I may say I don't need to hear, because I already know I can do the job with my hearing impairment — it's not the same. Just because you have disabled people, not all disabilities are the same and you're missing a whole layer of applicants.

Carolyn Yocom. I understand completely what you're saying. It's the same point as some of the other individuals have brought up. I said that we had, at one point convened focus groups composed of both individuals with disabilities and those without disabilities and others who had worked with nurses who had a disability of some sort or another. It was very, very difficult to identify individuals who had a disability so that we could invite them to participate in the focus group. This is because the Boards didn't have the information.

Remember, it was back in the early '90s when we did this study. To this day I'm sure there are Boards that ask on the application forms, "Do you have a disability?" Others don't. And if they don't ask, they're not going to know. So it was very difficult.

Nancy Spector. I'm told we're running out of time. Is there is one more burning question or remark?

Jean Bartels. I am from Georgia Southern University and the president-elect of the American Association of Colleges of Nursing. We're talking about a study that is dated and was pressuring job performance, expectations in acute care settings, which is pretty much where the majority of nurses worked in that time. We're in a different era. Moving out of an industrial age into a different one and we have an opportunity to recreate. Regulation will follow practice. I think we really need to look at the fact that the expectations for nurses today are far different and the nurse that we create for the future will look far different. That's the moment we are in. Again, no longer industrial age, we're just where Florence Nightingale was when she started her work and moving into the industrial age. I think we need to keep that in mind. The practice of nursing needs to change because a system in which these studies were done is broken. And there isn't a soul

around who doesn't understand that from any of the medical professions. We're all going to be seeing revolution and change. And this gathering has an opportunity to look at the place for all nurses in that situation.

Lois Halstead. A number of issues were presented and discussed today. Tomorrow after Bobby Silverstein presents insights into legislative change, we will break into three smaller groups: education, employment and regulations. During those sessions, with the help of a group leader, the groups will come up with recommendations, as specifically as possible, for change, ways to enact the recommendations, and potential barriers. The recommendations should be as pragmatic and realistic as possible in order to develop "next steps." We should be able to leave the symposium with next-steps ideas.

All of you were invited to the symposium because of expertise in your area and because you represent change agents. You have the ability to take what we're all learning here and to make a difference in different arenas of practice, education, employment and licensure/regulations. So tonight, please think about what we need to communicate to others, where we want to go and how we're going to get there. Thank you.

CHAPTER 8

Tips For Being an Effective Disability Policy Change Agent

Robert Silverstein, JD[1]

As a congressional committee staffer for more than a decade (1985-1997), I played a role in the enactment of over 20 bills related to disability policy. The process of making policy includes formulating solutions to problems of general concern and transforming these solutions into policy. Disability policy includes those policies specially targeted to addressing the needs of persons with disabilities and generic policies that address issues and concerns affecting non-disabled persons as well as persons with disabilities. There is a need for people to get involved in the policy-making process, becoming disability policy change agents — to ensure that our policies foster the inclusion, independence and empowerment of people with disabilities.

Changing policy is not an easy task. There are certain lessons that I've learned over time in how to maximize the likelihood that you will be successful. This paper describes ten tips for disability policy change agents on how to influence policymakers.

[1] Robert Silverstein, JD, is the director of Center for the Study and Advancement of Disability Policy (CSADP). In this capacity, he conducts action research, provides policy guidance to policymakers at the federal, state and local levels, and conducts advocacy training to disability policy change agents. Silverstein's areas of focus include civil rights, education, work incentives, workforce investment, and welfare reform from a disability perspective. From 1987 to 1997, Silverstein served as the principal advisor to Senator Tom Harkin, (Chair of the Senate Subcommittee on Disability Policy). Silverstein played a central role in all important disability policy legislation produced between 1985 and 1997, including the landmark Americans with Disabilities Act, along with numerous other pieces of legislation, and numerous disabilities-related amendments to bills concerning health, civil rights, education and job training. He received his baccalaureate in science from The Wharton School at the University of Pennsylvania and his JD from Georgetown University Law Center.

Understand Historical and Policy Context

The first tip is to "understand the historical and policy context in which you are operating. You need to be able to describe the nature of the problem you are trying to fix." If you believe there is something inappropriate, illegal, or unfair that needs to be changed, you just don't say it's bad and expect that it will be changed. You must be able to justify why change is necessary. This process requires research and surveys. For example, you may want to research the treatment of persons with disabilities (e.g., data on the numbers of persons with disabilities employed in nursing-related positions or accepted into nursing schools; possible reasons explaining the data, such as the use of criteria or methods of administration that have the effect of excluding or denying effective opportunities to qualified applicants with disabilities).

The second point is the importance of understanding current policy (e.g., model policies developed by associations or governing boards, state laws or regulations). Start with current policy, not with the policy you are trying to get adopted. A key aspect of serving as a change agent is to possess as much knowledge about current policy as those who developed it. It is important to understand why and how current policy was developed; the extent to which specific efforts were made to include policies relating to people with disabilities, good and bad; what issues and concerns did the policymakers attempt to address; what were the basic precepts that formed the basis for the policy. In sum, when you want to bring about change in policy, a key strategy is to explain why change is necessary and the nature and scope of the change that you're trying to bring about.

Values, Principles, and Goals of Disability Policy

Tip number two. Change agents' actions must be guided by a set of agreed-upon principles. The guiding principles are the values that underpin what it is you're trying to accomplish. Too often change agents are overly anxious to start negotiations over what changes to policy must be made. As a change agent, you must be able to articulate the principles that will guide your actions. For the disability community, it is important to understand the old and the new paradigms of disability policy. The old paradigm views people with disabilities as "defective and in need of fixing," "incompetent," "vulnerable," and "dependent." People with disabilities are patients who need professionals to tell them what they need.

The new paradigm of disability policy rejects this old approach; instead, it views disability as a natural and normal part of the human experience that in no way diminishes a person's right to fully participate in all aspects of society, commensurate with his or her abilities and disabilities. The focus should be on fixing the environment, rather than on "fixing" the person.

There are four goals of disability policy:
1) Equality of opportunity;
2) Full participation;
3) Independent living; and
4) Economic self-sufficiency.

Equality of Opportunity

There are three aspects of "equality of opportunity." First, treat a person as an individual based on facts, objective evidence, and science. Do not treat a person based on presumptions, stereotypes, fear, ignorance and prejudice.

Second, ensure each person an effective and meaningful opportunity to participate. For the "average" employer this may mean, for example, providing a computer with certain software, a desk, a chair, lights, physical access to and from the work site. For the "average" nursing student this might entail the provision of seats in the lecture hall, a lighted room, and amplification. These are all reasonable accommodations and auxiliary aids and services provided to the "average" person (although we rarely, if ever, refer to these goods and services as such). Similarly, people with disabilities are also entitled to effective and meaningful opportunity. But what works for the "average" person may not work for a person with a disability. It may be necessary to provide reasonable accommodations, auxiliary aids and services or make reasonable modifications to policies, practices and procedures that are unique to the individual. Third, people with disabilities should participate in the most integrated setting appropriate — it is unacceptable to unnecessarily isolate and segregate people based on disability.

Full Participation

The second goal of disability policy is the concept of full participation. What this means, as noted by disability activists, is "Nothing about us without us." That says a lot. If you are going to be making policy, people with disabilities must be at the table as active participants. There is nothing better than having people with disabilities at the table, in order to avoid the adoption of policy that has the unintended consequence of denying equal opportunity to all. The disability community describes the goal of full participation in terms of "self-determination," "empowerment," and "self-advocacy."

Independent Living and Economic Self-Sufficiency

The third goal of disability policy is independent living. The fourth goal is economic self-sufficiency. The promotion of independent living and employment is a legitimate outcome of policy.

In sum, these four goals of disability policy can serve as the guiding principles for the disability policy change agents. These guiding principles can be used to help change agents determine when to compromise and when to persist in their advocacy.

Policy is Made In a "Political" Context

The third tip is to understand that policy is made in a political context. I am not just talking about bills enacted by the legislative branch or regulations promulgated by executive agencies. Whether you're talking about universities, admissions criteria, or licensure, policy is made in a political context, in a political environment. If you are a change agent, you need to understand the tools of the trade — politics, power, self-interest, and compromise. **Politics** is <u>not</u> a dirty word; it is defined in the dictionary as the art of governing. **Power** sounds bad. Well, it is bad when you don't have it. It's good when you do. Power is what you need to effect change. **Self-interest** is also very important. Finding and realizing a policymaker's self interest is key to affecting change. We **compromise** positions all the time. But we try not to compromise principles.

Needs of Policy Makers and Staff

Tips four and five consist of understanding the needs of policy makers and the needs of staff. And here is where understanding a person's self-interest is really important. The discussion yesterday was about altruism — doing the right thing for the right reasons. We heard quotes from Martin Luther King, Jr., and quotes about "glory" and "love." As a change agent I don't focus on whether or not the policymaker I am trying to influence has lofty ideals. What I care about is identifying somebody's self-interest, because at the end of the day altruism does not control a person's behavior. That's just a hard reality. If you find someone who is with you based on altruism on Monday and they find it is not in their self-interest on Tuesday, they won't be with you in the end. They will find an excuse or rationale or justification to change their minds.

It is also important to understand that policymakers and their staff need help in carrying out their various responsibilities associated with adopting policy. They are dependent on others for information. That's where change agents come in. Change agents can provide data, they can provide information, and they can provide anecdotes. Additionally, they can help do the research and help develop the policies. In sum, policymakers and staff need input. The better and the more effective your input, the better chance of success.

Organized Coalitions in Exercising Power over the Policymaking Process

The sixth tip requires an understanding of the need for and role of organized coalitions. In my opinion, nothing happens in terms of change unless there is an effective coalition and the broader the coalition, the better. And, if coalition members can "duke it out" behind closed doors and then go public with a unified, cohesive message, you have a better chance of winning in the end. Again, the broader the coalition the better.

Let me highlight some of the key aspects of an effective coalition. The first point is leadership. Sometimes in the literature we call leaders in the policy context "policy entrepreneurs." We can also call them brigadier generals. Without a leader, an idea usually goes nowhere. Because it is hard work, starting by identifying a problem, then getting on the policy agenda for

consideration, and finally actually securing positive action. It may require someone working on the issue seven days a week, eighteen hours a day. This is what it takes to effect significant change. Change does not happen because it's the right thing to do. Without a leader, somebody who is saying, "This is my mission," it's just not going to happen.

Another important aspect of a coalition is synergy — the bringing together of a number of persons who together can perform the functions essential to bring about change. Any significant change effort will need persons competent in performing such roles as visionaries, researchers, fiscal analysts, drafters, political strategists, lobbyists, grass roots advocates and media experts.

Strategic Plan

Tip number seven addresses the need for a strategic plan. I call this "planned spontaneity." The more spontaneous an action appears, the better. But the best spontaneous action is the result of exhaustive planning. That's the reality in terms of change and politics.

One key aspect of a strategic plan is carrying out a reality check. When we worked to enact the Americans with Disabilities Act, I was the staff director and chief counsel of the Senate Subcommittee on Disability Policy. I insisted on behalf of Senators Tom Harkin and Ted Kennedy that the disability community come up with answers to the following 250 hardest issues and questions we thought others might raise and ask. We played devil's advocate, we asked the hardest questions you could imagine.

If you are a change agent, you have to know the current law and you have to be able to anticipate what policymakers and opponents are saying and why. And, you have to develop answers to those issues and concerns that you know will be raised. This process is not simple, but it pays dividends in the end.

This leads to the next set of issues: How do we frame the issue and what is the message? How you frame an issue can be the difference between winning and losing.

How do you frame the issue so that you are going to maximize the likelihood that, at the end of the day, you will be able to foster a consensus

and move things in the right direction? As an example of the difference between one message versus another, if you are trying to get more community-based services and support for people with disabilities, one way of doing it is to say "Free our people, close institutions." Another way is to say, "People with disabilities should have choice, the opportunity to live and work and pray with their families. Let's keep families together." If you are trying to organize the disability community, "Free our people" is perfectly appropriate. But if you are trying to convince policymakers, market-based solutions, real choice, keeping families together is a whole lot more powerful message to policy makers. How you frame your message depends on who is the audience. Moreover, when you are developing viable solutions, they need to be based on research. They have to be able to withstand scrutiny.

The Power of Personal Stories Tied to Policy Objectives

The eighth tip is realizing the power of personal stories tied to policy objectives. Personal stories themselves do not really resonate when it comes to bringing about change. Figure out the policy objective. For example, I'm a nurse, I'm working, and I'm effective. That's the message and you have personal stories tied to that policy objective. Personal stories are extraordinarily powerful, because we know that policymakers are bombarded with issues and they can't focus on everything. However, if you can get to their heart first, to their soul, so they understand deeply what this is all about, then all of a sudden the mind opens up to information. That is why personal stories tied to policies are so critical.

Long-Term Relationships and Who Delivers the Message

Tip nine addresses the importance of long-term relationships, along with the idea that who delivers the message is more important than the message itself. Points one through eight are insignificant in comparison to tip nine. If you do not have a relationship with the policy makers, if you do not have trust, if you do not have the right people who are in the policy-making position with you, or the right people to convince the policy makers, it doesn't matter what you do, you will not win.

Finding the right person to deliver the message is almost always the difference between success and failure. Developing trust relationships is the difference between winning and losing. It is as simple as that. No matter what you do otherwise, if those two are not there —if you do not find the right people and develop a trusting relationships — you will not win.

Strengths and Limitations

The last point is tip number ten, know your strengths and limitations. Do not speak for people whom you don't represent, don't give answers when you don't know what you are talking about. Be willing to say I will get back to you, I need to do more research, I need more information.

Mr. Silverstein's Handouts Follow.

Handouts

Tips for Disability Policy Change Agents on How to Influence Policymakers

1. **Understand Historical and Policy Context**

   - Research treatment of persons with disabilities (such as use of criteria or methods of administration that have the effect of excluding or denying effective opportunity to qualified applicants with disabilities).
   - Become knowledgeable about current policy and its strengths and inadequacies from a disability perspective.
   - Use understanding of historical and policy context to explain why change is necessary and the nature and scope of needed changes to current policy.

2. **Articulate Values, Principles, and Goals of Disability Policy**

   - Recognize the difference between the old versus the new paradigm of disability policy (old paradigm -- need to "fix" "defective" disabled person versus new paradigm — recognize that disability is a natural

part of the human experience and the responsibility of society to fix the natural, built, social and political environment by providing necessary supports, services, and accommodations).

- Recognize the goals of disability policy — equality of opportunity, full participation, independent living, and economic self-sufficiency.
    - Equality of opportunity (individualization, inclusion, meaningful opportunity).
    - Full participation (empowerment, self-determination, informed choice at individual and systems level).
    - Independent living (skills, services, and supports).
    - Economic self-sufficiency (training, education, assistance and supports).

3. Understand That Policy is Made In a "Political" Context

- Policy is proposed, debated, modified and adopted in a "political" environment (whether the focus is public policy or policy governing a profession or organization).
- Tools of the trade include use of:
    - Politics
    - Power
    - Self-interest
    - Compromise of Positions, Not Principles

4. Understand the Needs of Policymakers

- Self-interest (re-election/appointment, power/status among peers or interest groups).
- Balancing priorities (Time pressures).
- Dependent on others for advice.

5. Understand the Needs of Staff

- Help in sorting through avalanche of inputs to determine what is real and what is posturing.
- Help develop assumptions and present implications (fiscal and program).
- Help in identifying key players.
- Help in researching and crafting viable policy options.

- **Help in developing strategy for effecting desired change.**

6. Understand the Need for and Role of An Organized Coalition in Exercising Power Over the Policymaking Process

- **Need for a coalition (source of power, and helps provide support/assistance to policymakers and their staff).**
- **Composition of the coalition (include as many stakeholders as possible).**
- **Cohesion (power of consensus).**
- **Leadership (policy entrepreneur).**
- **Synergy.**
- **Responsibility (carrying out agreed-on tasks).**

7. Understand the Need for A Strategic Plan

- **Planned spontaneity (need to think strategically and act on basis of a plan).**
- **Reality Check (macro issues, past advocacy efforts and why change now possible, constraints on achieving success, capacities of coalition, and degree of opposition).**
- **Identify the prize (focus on principles and major concerns, not positions).**
- **Decide on overall strategy:**
    - **Determine the nature and degree of controversy/opposition.**
- **Decide on appropriate vehicle, such as modifying a policy, practice, or procedure.**
    - **Identify the key policymakers who will assume leadership roles.**
    - **Frame the issue and decide on the message.**
    - **Control the dynamics of the debate to create an aura of inevitability.**
    - **Determine how a particular tactic (such as direct action or a meeting with a policy maker) fits in.**
    - **Develop favorable program and fiscal estimates.**
    - **Present viable policy options based on research and program and fiscal estimates.**
- **Assess effectiveness of strategies.**

8. **Understand the Power of Personal Stories Tied to Policy Objectives**

- Telling personal stories in isolation doesn't work.
- Need to decide policy objective and how to frame the issue and then tie personal story to policy objectives and policy options.
- Best personal stories demonstrate positive impact of proposed intervention/change in policy (describe circumstances before and after intervention).

9. **Understand the importance of Long-Term Relationships and that Who Delivers the Message Is Often More Important Than the Message**

- Develop long-term trust relationships to maximize influence.
- Strategically select the spokespersons who will have maximum influence over policymakers.
- Ensure that message is presented in manner that recognizes the needs of particular policymakers/staff.

10. **Recognize Your Strengths and Limitations**

- Keep your eye on the prize — put ego aside.
- Don't agree to a policy option when not fully knowledgeable.
- Don't agree to a policy option on behalf of others whom you don't represent.

Audience Participation

Marca Bristo. My question comes up more than any other issue in all the work I have done with change. Illustrate the difference between a principle and a position. Give an example if you want.

Bobby Silverstein. Let me paraphrase the question – "What IS the difference between a principle and a position?" For example, one of the issues was in a psychiatric situation. One of the necessary skills was to get away quickly. One needs to be able to move quickly, along with being able to walk to do this. We need to ask what is the principle, that is, what is the issue and concern in the discussion? In this situation, the principle, which is what we are talking about, is safety, the safety of and concern for others in

the environment. Now, the position would be ultimately whether you had to be able to walk.

Or the question is: Are there different ways in which we could address the issue? A change agent may insist that certain words used in a position are unacceptable. The issue consists of what is the concern, what is the issue, and what is the principle? Moreover, can we find different ways of addressing that issue or concern? So, the critical importance is not that the focus be on walking. The critical importance is to say: What is the purpose, and issue, and function, and concern of walking? Make sure that when you articulate those, the answers are based on a set of values. Then together you can try to come up with a solution.

What is the purpose and function or the concern that is driving you? When you ask WHY, you find out that you often share the same principle and concern. In turn, you are more likely to have a better sense of what the real issues are and to reach a consensus. Typically, in negotiation that is why we discuss principle versus position. Typically you look to split differences and things like that rather than truly find out what is behind it. What is the purpose, what is the function, what is the issue?

When you are challenging current policy, ask WHY over and over again. If you have a common set of principles in the negotiation, you're more apt to get to "yes" at the end of the day. My experience in negotiation is that when you sit down and focus on values, there are a lot of shared values. And in this group — no matter what your positions were that we talked about yesterday (day 1 of symposium), I know that in 45 minutes we could come up with a set of principles that everybody would agree on.

When we deal with walking versus getting away quickly, I know we could reach a consensus on a position. I think the point I am trying to make is that it's the shared values that you have to achieve. You have to get to those shared values. You share the value of safety and I share the value of safety. You might say in the beginning, well I value escaping on foot. And I say, I value just escaping. But the reality is, the value is safety. That is exactly the point! With change, take the time to start off with trying to find those shared values. Don't skip that step.

Thank you and good luck for the rest of your day.

CHAPTER 9

Recommendations

Nursing Education and Accommodations

<u>Introduction</u>

Discussion leader – Nancy Hogan PhD, RN[1]. This is a key time in the history of nursing. It is a time of redefinition of what nursing is and what nurses do. We can take advantage of this time of transition, of change, to craft a definition of nursing that is inclusive —to provide access to qualified people who wish to enter nursing.

We looked at barriers and stigma as a barrier. We discussed technical competencies as a barrier. The key issue is not that it can't be done, but rather, why can't it be changed? Why should we open nursing education to people with disabilities? The answer is simple — nursing and society need them! Why haven't we changed our educational system before now? Educators take their role seriously and feel a strong responsibility to prepare a competent practitioner able to deliver safe, effective nursing care. The problem has been that as educators, we have thought there was only one road to take, only one way to educate nurses. We are beginning to see that there may be many roads that lead to the same destination.

There was much discussion about the issue of safety. Nursing is a practice discipline and much of that practice deals with physical skills. However, there is concern about defining nursing using assessment and evaluation criteria based on rigid definitions of technical and physical competencies. Schools can do much to reduce barriers and make accommodations to students.

Certainly one of the major factors to be considered is who should decide? Persons with disabilities have to be represented in the groups having the discussions and making the recommendations. They need to be on the committees to help guide and direct the recommendations.

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[1] Nancy Hogan, Ph.D., RN, is a Professor, at the University of Miami School of Nursing, Miami, FL.

Recommendations

1. **Educate the stakeholders.**
   a. **Nursing is a viable career choice to many more people than those currently considering nursing. Increase public awareness of the opportunities that a nursing career affords. Stories of successful students with disabilities need to be made known.**
   b. **Nursing organizations should promote nursing as a career open to a diverse population, including people with disabilities.**
   c. **Research the real cost of accommodations so as to dispel myths about prohibitive educational expenses to colleges and universities.**
   d. **Inform potential employers of benefits of hiring people with disabilities.**
   e. **Educate faculty on the rights of people with disabilities.**

2. **Define nursing in terms that fit the modern practice of nursing.**
   a. **Eliminate the definition of nursing as a list of technical, physical competencies.**
   b. **Utilize criteria such as the *Essentials of Baccalaureate Education for Professional Nursing Practice* by the American Association of Colleges of Nursing (AACN) to define nursing practice.**

3. **Redefine the educational process to make it inclusive and accessible.**
   a. **Define curriculum according to outcomes not process.**
   b. **Promote facility designs that promote access to schools and clinical sites.**
   c. **Partner with assistive technology providers to improve access to nursing education.**
   d. **Insist on alternative formats for continuing educational programs.**
   e. **Include students with disabilities in curriculum planning and development of evaluation criteria.**
   f. **Hire faculty with disabilities to serve as role models.**

4. **Provide access to resources.**
   a. Target loan and scholarship programs for students with disabilities.
   b. Develop mentoring programs for students with disabilities.
   c. Create clearinghouse for resources.
   d. Partner with disability awareness organizations and specialized job placement services.
   e. Encourage development of demonstration projects and grant efforts.

Addendum: In September, 2003, the National Organization of Nurses with Disabilities (NOND) sent recommendations to the AACN "Disability Policy" Review Committee in regard to their review. The following are NOND's recommendations:

1. The National Organization of Nurses with Disabilities (NOND) respectfully recommends that the AACN Review Committee include qualified, experienced representatives with expertise in disability issues in this review process. NOND believes that AACN should include experts from a variety of fields who can speak to the efficacy of adaptive technology and adaptive devices in the work lives of nurses and the role of reasonable accommodations in assisting students with disabilities to successfully complete nursing programs.

2. In addition, NOND advocates that AACN include disability policy experts and legal representatives who work in the disability rights arena as members of, or consultants to, the Review Committee. These experts should include those individuals who are familiar with the legal implications of the Americans with Disabilities Act (1990) and Section 504. In this way, AACN can be provided with information related to including students with disabilities in accordance with existing laws so that access can be provided to a wide diversity of nurses. NOND believes that the inclusion of these experts to the review Committee would assist AACN in its exploration of the ethical and legal issues surrounding AACN's "Disability Policy" review.

NOND recommended six individuals, all experts with different disabilities, to AACN's "Disability Policy" Review Committee.

Discussion

Nancy Hogan: One of the members of the breakout session had some interesting things to say. I would like for Dr. Robert Levin, faculty from the College of Medicine, to give us an overview of the things he reported to us.

Robert Levin: There are two points that I would like to bring up speaking from my outsider perspective. First, as in medical education, one of the greatest barriers to making nursing education more inclusive is the use of technical standards or guidelines as a way of determining who may or may not participate. From our experience in the medical school, no list of technical competencies will ever be completely appropriate and complete. They always change. So, list of competencies need to be created from a perspective of inclusion, not exclusion. They need to be defined in a way that will permit accommodations.

The second point has to do with the linking of employment of the graduate to accreditation. I do not see that one always needs to assume that because one is going through the educational program in nursing that assumes that a person is going to work in nursing. Education belongs to the person being educated. What they do with it is up to them.

Nancy Hogan: This is really the time to ask lots of hard questions — to raise issues and question what we are doing and why.

Recommendations

Nursing Employment and Accommodations

Introduction

Discussion Leader - Robyn Jones, MS[2]. **The end goal of this discussion is for people with disabilities who choose nursing careers and successfully complete nursing education to become employed as nurses. The same is true for nurses who develop disabilities after they are nurses — they want to be able to continue working as nurses.**

We examined the employment issue of nurses with disabilities from four different perspectives:
1. **those who are exploring the possibility of nursing as a career;**
2. **those who are completing a nursing education and are seeking employment;**
3. **those who began their nursing careers with a disability and then the disability exacerbated itself to the point that the current position is difficult to maintain; and**
4. **those who began nursing careers with no disability but acquired a disability sometime after becoming nurses.**

The first step for someone considering a career in nursing starts early in the education process. Somewhere in either elementary, secondary or post-secondary education the idea of nursing as a career needs to be promoted and encouraged. People with disabilities need to be given access to view nursing as a viable career and employment choice. An initial barrier is the perception of nursing — what a nurse is, what a nurse does and the physical nature of the job. Most persons with disabilities do not even realize that nursing may be a viable career choice for them.

One of the biggest barriers to employment for persons with disabilities is attitude and misconceptions from employers. A lengthy discussion ensued regarding employer attitudes towards persons with disabilities. It is critical for upper management to establish a supportive tone and policies in regard

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[2] Robyn Jones, MS, is the Director of the Great Lakes ADA and Accessible IT Center, Chicago, IL.

to hiring persons with disabilities. A supportive attitude creates a work environment that welcomes these employees for the added value they bring to the job. Institutional policies must foster a supportive work environment; that supportive "attitude" will filter to middle managers, to supervisors and to staff. Attitude is reflected in one's knowledge of the ADA law, in one's understanding of the cost of accommodations, where to get resources to help with some of those costs, and in knowing what adaptive technology is available to assist in helping people to do their jobs.

Whether they realize it or not, national organizations are part of the employment process. Professional nursing organizations, healthcare organizations, state nursing boards, and disability organizations need to be supportive of employing nurses with disabilities because their attitudes and policies help set the tone for acceptance into a workforce that can utilize their knowledge and expertise. These organizations discuss the issues, they promote opinions and rules, they help educate people in the profession, and in this way influence hiring policies and employer attitudes.

Recommendations

Recommendations were made from the perspective for the four different groups involved in the employment process.

1. **Educate employers** on:

    a. the law,
    b. the benefits of hiring persons with disabilities, especially in nursing because of the perspective they offer to patients and fellow workers,
    c. evaluating a realistic, bottom-line financial forecast of cost for accommodations,
    d. understanding tax credits for accommodations,
    e. matching employee skills with employer needs,
    f. reviewing job descriptions and essential functions of the job,
    g. working with front-line managers and supervisors when hiring a person with an accommodation need,
    h. partnering with existing disability work agencies and programs to promote a smooth transition into the workplace through education and support services for both the employer and employee.
    i. involving organizations that understand nursing.

2. <u>Colleges' and Universities' roles in supporting transition to work</u>:
      a. **Educate students with disabilities on the job search process;**
      b. **Coach and mentor students and potential employers on working together to oroceed from education to employment;**
      c. **Use former disabled students' success stories in the education process;**
      d. **Forge linkages with the disabilities community.**

3. <u>Community assistance in supporting employment success:</u>
      a. **Communities need to support affordable and accessible housing near high-volume employment areas;**
      b. **Accessible transportation needs to be made available for employees to get to and from work.**

4. <u>Prospective employee's responsibilities</u>; **the prospective employee must be prepared to problem solve during the employment process:**
      a. **Translate job descriptions into functional language;**
      b. **Know that employee skills will meet employer needs;**
      c. **Know that employment is an interactive process between the employer and employee;**
      d. **Contact and use existing models and networks;**
      e. **Know where the employee's assets lie.**

<u>Next Steps Suggestions</u>:

1. **Develop a pilot program. It was suggested that the next step should be to develop a demonstration pilot project between a nursing education program and clinical sites (hospital or medical center) to develop a model of recruitment, nursing curricula and clinical relationships associated with the education program. The pilot program would document and publish the barriers, successes and failures so that other institutions could model the pilot's best practices.**

2. **Maintain a dialogue. Develop an e-mail list of the core group of people present at this conference who are invested in the issues to keep the dialogue and problem-solving going.**

3. **Establish a conference every year or every other year to help measure progress. Review what has happened, what progress has been made and bring the best practices back to the forum and share them. Progress would happen at a faster rate this way.**

4. **Make nursing career fairs accessible.** A minimum of 1,000 people usually attend large nursing career fairs. If these fairs were accessible, nurses with disabilities would be able to attend and speak with potential employers about matching their skills with available jobs.

5. **Be sure that e-recruiting is accessible.**

6. **Enhance and promote a career mentoring program. Link with the National Disability Mentoring Day (NDMD) program, sponsored by the American Association of People with Disabilities. NDMD is a national effort to promote the employment of students with disabilities through the experience of personal mentoring.**

7. **Develop a media campaign and market the information learned at the symposium to the broad, mainstream employment groups to educate them on the fact that nurses with disabilities can be valuable, contributing employees.**

Discussion

A point made several times in the discussion was that employers are under enormous pressure to meet their bottom-line financials. However, there are misconceptions about the costs of accommodations, especially that accommodations cost a lot of money; employers then feel they cannot afford to make the accommodation. Accommodation costs must be viewed from a "bigger-picture" perspective — look at what it costs to recruit and train someone who will be a good, loyal and valuable employee. Many times recruitment and training costs are negated if an employer looks only at a strict bottom line.

There is a tremendous need to teach soft skills as well as nursing skills to prepare nurses with disabilities to market themselves to employers. These nurses need to know what is expected of them and what is expected of the employer to be able to "match" their skills with what the job requires. This is a huge promotional issue — to first be able to get the job experience, then to demonstrate how nurses with disabilities can work as nurses.

Nursing schools should consider hiring faculty with disabilities. A faculty member with a disability would be key in modeling his or her experiences and bringing those experiences into the classroom.

The clinical relationships a nursing student has at his or her clinical sites will help potential employers understand how people with disabilities can be employed in their setting. Use these positive, eye-opening experiences as a bridge to help change employer and staff attitudes and perceptions. Colleges need to be part of the solution for creative options for accommodations in nursing education at the clinical sites. Schools can help the employer at clinical sites to identify an accommodation and learn how some can be acquired for little cost. The interaction between the school and the clinical setting becomes a critical issue for future employment for disabled students in nursing programs.

A disability can be acquired at any time, especially as we age, so nurses need to understand how they can continue working in their profession if they develop disabilities. These discussions should start in nursing education programs and continue through professional development programs. Organizations that can assist with this understanding are disability groups, vocational counseling programs, training programs, rehab services, placement services, and ADA compliance officers at each institution.

There needs to be a marketing campaign that shows that a nurse who has a disability can continue to work as a nurse. Nursing organizations and those who promote the image of nursing need to encourage images of people who are working nurses who have disabilities. Assistive technology and information technology organizations need to promote their products and make employers aware that they are part of the employment answer.

Recommendations

Nursing Regulation, Licensure, Policy

<u>Introduction</u>

Discussion Leader - Nancy Spector, DNSc, RN[3]. **The goal of this discussion was to recommend strategies for enabling nurses with disabilities to practice nursing while also protecting public safety. Several participants thought that public safety is not a unique factor in any kind of a disability, and they did not think that we need to frame it differently. Nevertheless, we need more data on public safety and disabled caregivers. Actually, this is an issue for the other disciplines as well.**

Some people in this group said that they had never understood regulation until coming to this conference. Students need to understand licensure and the issues related to it. For example, students need to understand the nurse practice act, how it is developed, and how changes are made.

The stakeholders in the world of people with disabilities delivering health care are legislators, policy makers, lawyers, educators as well as people with disabilities. People with disabilities should not be labeled; for example, it is not appropriate for nurses with disabilities to have to check a box that designates that they are disabled, if they are applying to take the nursing licensure examination. It was pointed out that people with disabilities are ill at ease in living with screening mechanisms. They feel like they are always being screened out. [note: if people with disabilities want special accommodations for taking the NCLEX, wouldn't they need to check a box in order to get them? If someone is disabled, but doesn't need special accommodations for taking the NCLEX, they don't have to check anything. I would think this comment more effectively applies to one's license through the boards of nursing.]

The group addressed the importance of not just considering nurses with disabilities at this time because of the nursing shortage. Yet, this crisis

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[3] Nancy Spector, DNSc, RN, is the Director of Education for the National Council of State Boards of Nursing, Chicago, IL.

does provide a ripe opportunity for us to explore all options of adding qualified people to the nursing workforce. Moreover, the public might become more interested in the subject at this time.

The group focused on the essential skills of nursing, especially critical thinking. The ADA law should be explored with respect to its inclusion of critical thinking as an important skill for those seeking practice roles in health care or other domains. Caution was recommended concerning avoiding communities that are now in a state of unrest about other issues regarding people with disabilities. Involving ourselves here might cause more friction.

Recommendations

#1 The first step is to determine a definition of the term disability that is mutually agreeable to all the stakeholders. Using the ADA definition should be acceptable.

#2 More data are needed. There should be a follow-up study on the research done at the National Council of State Boards of Nursing (NCSBN) with a broad coalition supporting it. Define the essentials of nursing. Clearly, critical thinking is at the head of the list. Gather more reality information from practicing nurses with disabilities with respect to the essence of role, tasks, etc. Judgments must be based on objective evidence.

The next step under data needed would be to explore the different models used by state boards of nursing to license and relicense nurses and to determine the best model to include in NCSBN's Model Practice Act and Model Rules. The National Council of State Boards of Nursing offered to do this study. This would be a good next step. We also need information regarding nurses with disabilities. We don't even know how many nurses there are because, again, people are afraid to disclose and label themselves. We need to gather more data on the professional regulation laws in health care. We need to see how the current laws are being interpreted.

Regulators need to educate the profession and public on the state's role, the role of the boards of nursing, and NCSBN's role. People with disabilities should also become members of boards of nursing. The latter is essential. This is where people with disabilities can really make differences.

#3 There needs to be dialogue in the healthcare arena among people with disabilities, policy makers and legislators. The latter two groups can influence and make regulatory changes. This might start as a national roundtable, including the appropriate people; there could then be discussions in each state because states are regulated differently. Next, dialogue must be initiated with nursing programs, and that can occur at the same time.

#4 When we have the national dialogue we must include our shared principles and values. That was very obvious in our group because we had regulators and people with disabilities in the group. Barriers to success were identified and included limited resources, lack of opportunity, licensure restrictions, and needing more data.

Discussion

Question. Why did you advocate a national roundtable without the colleges of nursing?

Answer. If I remember correctly, that discussion was to include NCSBN, AACN, as well as policy makers, legislators, and people with disabilities. The dialogue with nurse educators will help us to come to consensus about what are the essentials of nursing. Because as we've learned over the past couple days, there does not appear to be uniformity of understanding in this area.

Tony Burda, RPh. I'm a blind pharmacist here in Illinois and I want to share a little bit about my experience with licensure. I agree about everything said by you and the gentleman this morning, Mr. Silverstein. We need research and data. But the absence of that can become a barrier. I wanted to become a licensed pharmacist in 1978. There was a reason for not licensing me because there was quote, no precedent, unquote.

So we have to be careful of that. I talked with Mr. Dale Atkinson who was here yesterday, representing the National Board of Pharmacy. I said, "How many folks have you licensed as pharmacists since I broke the mold back in 1978, which was 25 years ago?" He's not aware of any. So if I depended on research and data I would still be waiting for my license.

So, you nursing movers and shakers in this room, pursue the research, pursue the data, but don't rely on that. You're going to have to make some gutsy, cutting-edge decisions and you may have to do that quickly. Do

what's right and what's cutting edge, but don't let the absence of that information serve as a barrier.

Question. I wasn't able to participate in your break-out group, but a question that I have to ask is what about the licensing of facilities as well, in terms of whom they're employing? Is there any intersect between that and accreditation in terms of what they require of facilities to then bring in employees? The intersect has to do with physician groups, JCAHO, licensed nurses, physicians, but they don't dictate what the license is. That's the regulator, the State Board or Medical Board. I think in the education group that I was in, there was at least one comment that nursing has been sort of looking at its navel for many years trying to decide what it is. Right?

And part of the issue seems to be that the time is now to try to get rid of the barriers to nursing education for people with disabilities. It's time to get rid of the barriers that exist, and to let people in. And that will itself force some of the changes in regulations and force some of the changes in education. And so forth. Because if you — again, I would agree with Tony Burda, if you wait around for the data, it's not going to happen.

Nancy Hogan. Part of the data are going to be programs that have success with this. We talked a lot about the importance of looking at administration. We had deans in our group who were willing to take that challenge and move forward and those are the data that will result in practice that changes licensure. Remember that licensure follows practice. Then what we need to do is look at administrations that will take a chance and faculty who want to be on board and make this an exciting adventure. Here everybody wins. And ultimately then we make legitimate changes that are based on reality. Right?

Comment. I want to make a comment about the word safety, which you started with and then came back to. I think that nursing is the only profession that tends to talk about our practice as it relates to safety. I don't really hear physicians or pharmacists or dentists talk about safety. I think of licensure, as, you know, ensuring that there's a basic level of competence, ensuring that somebody is competent to practice in that particular field. I would encourage us to stop using the word "safety." I don't think that that is an appropriate word when it comes to licensure. I think licensure is really established in terms of having that basic level of competence. When I go to the dentist or I get my hair cut I want to make sure those people are

competent, not safe. Competent practice ensures safety; that is, they go hand in hand.

Nancy Spector. This is the conclusion of the report for this breakout session.

CHAPTER 10

Symposium Summary

Katherine A. Pischke-Winn, MBA, RN[1]

One hundred and seventeen invited national and state experts on nursing education, licensure/regulations, employment, health policy, disability rights, and legal aspects of the ADA and disability law attended this groundbreaking symposium. For one and one-half days this group assessed, discussed and debated nursing curricula, educational and employment accommodations, and the implications of regulation and licensure for persons with disabilities who are academically qualified and wish to enter and/or remain in the nursing profession. The result was an informative, eye-opening experience for all attendees.

We learned from the keynote speaker, Marca Bristo, that "disability" is everyone's issue. The disabilities community is the largest minority group in the United States and the only minority group that every single person who attended the symposium can and probably will join sometime in their lives. We need to throw out the disease model, which sees the person as being "sick," and change to the sociopolitical model in which persons with disabilities are viewed as competent, contributing members of society, capable of professional careers. Nursing lends itself to accommodations because no nurse does everything; there are hundreds of different jobs in nursing. People with disabilities add value to the healthcare system because they add diversity, the dimension of a successful role model, and are navigators of health care systems.

We learned from the student and faculty panel presentations that students needing accommodations must have a supportive faculty and educational environment in order to be successful. Faculty attitudes towards accepting and working with qualified students with disabilities can be the greatest barrier. In many cases, necessary accommodations don't go beyond accepting, open-minded attitudes by college faculty and clinical sites. A

major concern of employers and state regulators is that persons with disabilities may be "unsafe" in certain areas due to their disability. We learned from practicing nurses with disabilities that they do not choose practice areas where their disability would keep them from doing their job safely. They want to be successful in their careers and in order to accomplish that, they self-regulate their practice.

We learned about the ADA law and legal aspects of accommodations. Once a qualified student with a disability discloses the existence of the disability and requests accommodation(s), colleges will usually request reasonable documentation of the disability from the student. Once the college receives the documentation, the college is required to make an accommodation that will be <u>effective</u> in ensuring that the student has equal access to the program. Colleges are not required to lower standards or substantially modify essential program requirements or make modifications that would fundamentally alter the nature of a service, program or activity. What is most important is that colleges work with the student in an individualized manner to develop an effective and meaningful accommodation that will give the student equal opportunity. The ADA was written to be deliberately flexible. What is "reasonable" is different for each school and is dependent on variances such as geographic areas, budgets, size of faculty, etc. Colleges need to think about going beyond federal compliance and make sure doors are opened as wide as possible to qualified persons with disabilities.

Under the topic of education, Carole Anderson presented standards that guide nursing curricula. Discussions revolved around the issue of whether or not a student with a disability can be accommodated without compromising academic and professional standards. The first professional standard is the requirement for licensure, the NCLEX exam, which is a cognitive test. Students who have successfully completed a nursing program may need an accommodation from state licensing agencies to take the exam. The challenge for faculty is to open up their minds and shake off old prejudgments of what it takes to be a nurse and determine how and if a student with a disability can be successful in the program. Faculty struggle with discerning whether giving an accommodation means the student is receiving an advantage over other students. Beth Marks discussed how nurses with disabilities have the potential to improve nursing care and to advance culturally relevant care due to their unique understanding of disability issues. Students should be able to use a range of technologies to

perform the essential functions of their learning experience and subsequent work.

Once a person with a disability completes his or her nursing education and successfully passes their NCLEX exam, the person seeks employment. Karen Wolffe emphasized that colleges that have prepared these nurses with disabilities need to help bridge the road to employment. Most likely, faculty members have already worked on accommodation needs and relationship building with clinical sites for the student during their education. This relationship building and observation of clinical competence can lead to letters of recommendation or direct employment for some students. Managers of patient care areas where disabled students are placed have been eyewitnesses to the students' knowledge, skill and competence. Martha Younger-White spoke to the issue that employment for qualified persons with disabilities is a matter of civil rights. Hiring practices as well as training and compensation must be nondiscriminatory and accessible. Nurses with disabilities need to be educated on how to package and present themselves to employers and on how and when to discuss their disability and accommodation needs.

The passage of the ADA law has raised a number of issues within the nursing community, especially for the regulators of professional practice. What specific functional abilities must a nurse possess to provide safe, effective nursing care? To address these functional abilities, the National Council of State Boards of Nursing undertook a series of job analysis studies that resulted in the now controversial 1996 publication, *"Validations study: Functional abilities essential for nursing practice."* This paper lists what are considered the 21 core attributes that a nurse must possess in order to provide safe and effective care. Carolyn Yocom spoke at length on the purpose of the study and emphasized that the 21 core attributes are not "THE" list that one has to possess in order to be a nurse. The list is representative of the skills and abilities that nurses may possess (as described by practicing nurses who completed the survey at that time; 10% of them indicated they had a disability when they responded to the questionnaire). Vickie Sheets described the challenge to regulatory boards — maintaining the balance between an individual's desire to practice a chosen profession and the board's responsibility to protect the public from unsafe practitioners. Boards vary from state to state in their philosophy and approach to protecting the public. She noted that the results of the functional abilities study is already nine years old and we live in a different world today with adaptive technology. The list, while providing a model, must

be reexamined for its relevance. Regulation will follow practice and the practice of nursing is evolving as technology evolves and medicine changes.

Changing policy is not easy. Change agents have to justify the need for change and then be able to articulate the principles that will guide those changes. Bobby Silverstein presented his "ten tips" on how to successfully influence policy makers. The four goals of disability policy— equality of opportunity, full participation, independent living, and economic self-sufficiency — should serve as guiding principles for disability policy change. Persons with disabilities must have full participation as active members in any policy change. Know the politics behind policy changes because political power is necessary to effect change. Change agents can do the research, provide data, information and anecdotes to policymakers to help develop policies — the better the input, the better the chance of success. Know the needs and self-interests of the policymakers — help them, so that at the end of the day you will help each other be successful. Organized broad-based coalitions, with an identified strong leader who is committed to the cause, are the key to success. A strategic plan that appears spontaneous is the result of exhaustive planning and will pay off in the end. Frame the issue to maximize the likelihood of fostering a consensus with politicians — it may mean the difference between winning and losing. Personal stories tied to policy objectives can be powerful because they get to the hearts and souls of policymakers so they understand deeply what the issues are. Develop long-term relationships with the policy makers based on trust, because finding the right person to deliver the message is almost always the difference between success and failure.

Symposium participants divided into small group breakout sessions to brainstorm recommendations for three areas: nursing education and accommodations, nursing employment and accommodations, and nursing regulation, licensure and policy. The recommendations from all three groups are detailed in the preceding chapter. There were some common themes generated from all three groups:

- Persons with disabilities have to be part of the process and work groups discussions, decisions and recommendations.
- Educators, employers, legislators and state boards all need education on the ADA law and the added value that a person with a disability brings to any environment.
- More data are needed with follow-up studies as to what the current essential functions of a nurse are.

- There must be continual dialogue between groups representing nursing education, employment and regulation to make some cutting-edge decisions for change.

A few noteworthy outcomes of the Symposium include the following:

- **Education.** Jean Bartels, PhD, RN, President-Elect of the American Association of Colleges of Nursing (AACN) will appoint a Task Force to update AACN's position paper, "*Guidelines for Accommodating Students with Disabilities in Schools of Nursing*". AACN has been asked to appoint persons with different disabilities to the task force.

- **Employment.** Create a national data bank, which lists resources (laws, education, support, employment, adaptive technology, etc.) that will assist persons with disabilities that want to become a nurse or continue working as a nurse if a disability arises. This data bank must have the ability to link with the organizations they list.

- **Regulations and Licensure.** The National Council of State Boards of Nursing (NCSBN) will survey nursing state boards to identify models that states use to license nurses who are disabled. With input from the disabilities community, one of these models will be incorporated into NCSBN's Administrative Rules. The ultimate goal is to promote a best practice model among all nursing boards.

- **National Organization.** Birth of the National Organization of Nurses with Disabilities (NOND). NOND mission statement reads: "The National Organization of Nurses with Disabilities is an open membership, cross-disability and advocacy organization that works to promote the full inclusion and acceptance of people with disabilities and chronic health conditions into nursing careers." NOND's Board of Directors includes legal experts on ADA and civil rights laws, nurse educators, nurses with disabilities, a nurse from the National Council of State Boards of Nursing, the disability community, and employment agencies.

Symposium Chairperson, Lois Kazmier Halstead, summed up the symposium with these remarks: "This symposium is just a first step. If everyone goes home and does nothing, then all that we learned here will be just an exercise. We all have a responsibility to continue these discussions in arenas where we work or professional organizations we represent. All of you are encouraged to become actively involved in the

next steps of supporting career opportunities for qualified nursing students and nurses who are also persons with disabilities. Don't lose this energy."

Along with the disability community and nurses, identify milestones that can be measured and evaluated within a few years. How will qualified nurses with disabilities be able to remain practicing nurses and how will barriers be knocked down for acceptance into nursing school programs? We look towards the newly formed National Organization of Nurses with Disabilities to lead this charge.

CHAPTER 11

Appendix

Speaker and Attendee Information

Name	Break-out Session
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Name	Break-out Session

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CHAPTER 12

National Organization of Nurses with Disabilities (NOND)

Resources for Nurses with Disabilities

NOND was founded on April 10, 2003, during the Rush University College of Nursing Symposium on Students with Disabilities: Nursing Education and Practice. NOND's mission reads: The National Organization of Nurses with Disabilities is an open membership, cross-disability, public education, and advocacy organization that works to promote the full inclusion and acceptance of people with disabilities and chronic health conditions into nursing careers.

EDUCATION   ADVOCACY   FULL INCLUSION

Please note that telephone numbers and resources change and may be discontinued without notice. All resource lists must be updated on a regular basis in order to ensure accuracy. NOND has attempted to include and categorize resources to address some of the informational needs and requests from the participants who attended the Symposium, April 2003. This resource list does not include all resources that are available. NOND would like to update this list over time, as well as to add missing resources, as this list is a "work in progress." Please email resource names, contact information, and description to NOND Corresponding Secretary, Stacey Carroll, at stacey@carroll88.com and c.c. Karen McCulloh at KJMcCulloh@aol.com, President of NOND.

General Disability Resources:

American Association of Colleges of Nursing (AACN)
http://www.aacn.nche.edu
Jean Bartels, PhD, President-elect
National voice for America's baccalaureate- and higher-degree nursing education programs. AACN's educational, research, governmental advocacy, data collection, publications, and other programs work to establish quality

standards for bachelor's and graduate degree nursing education, assist deans and directors to implement those standards, influence the nursing profession to improve health care, and promote public support of baccalaureate and graduate education, research, and practice in nursing.

American Association of People with Disabilities (AAPD)

http://www.aapd.com/

AADP Main Office: Member Services:

1629 K Street NW, Suite 503   258 Main Street, Suite 203

Washington, DC 20006   Milford, MA 01757

V/TTY: 202-457-0046   V/TTY: 508-634-3200

800-840-8844   Toll Free: 866-241-3200

President: Andrew Imparato, JD

AAPD is a cross-disability member organization that works in coalition with other disability organizations for the full implementation and enforcement of disability nondiscrimination laws, particularly the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973.

American Nurses Association (ANA)

www.nursingworld.org

The American Nurses Association is a full-service professional organization representing the nation's 2.6 million Registered Nurses through its 54 constituent state associations and 13 organizational affiliate members. ANA advances the nursing profession by fostering high standards of nursing practice, promoting the economic and general welfare of nurses in the workplace, projecting a positive and realistic view of nursing, and by lobbying the Congress and regulatory agencies on healthcare issues affecting nurses and the public.

AskAble

http://askable.askvrd.org

Personal online disability resource.

Association for Higher Education Access and Disability (AHEAD)

www.ahead.ie

Newman House

86 Saint Stephen's Green

Dublin 2 Ireland 01-4752386

Fax: 01-4752387

Email: ahead@iol.ie

Organization based in Ireland that works to promote full access and participation in education for students with disabilities.

David Wright's Pages
http://www.shef.ac.uk/~md1djw/
This site provides a wealth of information for students and nurses with various disabilities. The site originates in the United Kingdom. It offers information helpful to nurses worldwide. Also provides instructions for signing up for a disability newsletter.

Disability Central
www.disabilitycentral.org
Online community of people who spread and share helpful and relevant information to people with disabilities. It is committed to providing a world of resources to anyone, disabled or not, who needs information, in a hassle-free environment.

Disabled and Injured Healthcare Workers
http://groups.yahoo.com/group/DisabledAndInjuredHealthcareWorkers/
This group was started by RNs who live with disabilities, but want to remain as active members of the healthcare community. They are continuously making efforts to increase the awareness of the healthcare community as to their desire to return and continue working with accommodations.

Exceptionalnurse.com
www.exceptionalnurse.com
Exceptionalnurse is committed to inclusion of more people with disabilities in the nursing profession. The Website includes many useful links for nurses with various disabilities.

George Washington University Health Resource Center
http://www.heath.gwu.edu/
National clearinghouse on postsecondary education for individuals with disabilities. Support from the U.S. Department of Education enables the clearinghouse to serve as an information exchange about educational support services, policies, procedures, adaptations, and opportunities at American campuses, vocational-technical schools, and other postsecondary training entities.

Global Organization of Feminists with Disabilities
www.gofwd.org

900 N. Stafford Street
Suite 2322
Arlington, VA 22203-1851
Tel.: 703-309-8601
Fax: 703-528-0079
Email rciotti@gofwd.org
This organization's goal is: working together, worldwide, toward the social and economic empowerment of women and girls with disabilities, regardless of borders.

Health Sciences Faculty Education Project

http://www.healthsciencefaculty.org/

The Health Sciences Faculty Education Project has developed, implemented, and evaluated approaches aimed at enhancing the capacity of Postsecondary health science education programs and their faculty to teach and accommodate students with disabilities. The project has developed several resources to assist faculty and institutions to more effectively teach and accommodate students with disabilities in health sciences programs:
1. A faculty in service training curriculum, "A Day in the Life of a Health Science Student" which provides specific information about how health science students with various disabilities can be successfully supervised, taught and accommodated in clinical settings.
2. A videotape series: "Profiles of Health Science Professionals with Disabilities." These videotapes highlight the stories of health science professionals (nurses, physicians, dentists) who experience various disabilities and the strategies and accommodations they used in school, during clinical rotations and as successful practitioners in their various professions.
Articles on exemplary health science professionals who happen to experience disabilities can be found at
http://www.healthsciencefaculty.org/profile_gallery/profile_index.html

MinorityNurse.com

www.minoritynurse.com

Career and educational online resource for minority nursing professionals, including those with disabilities.

National Council of State Boards of Nursing (NCSBN)
Education web page:

http://www.ncsbn.org/public/regulation/nursing_education.htm

There is information on our various educational tactics at NCSBN, including

our work with transition programs, approval of nursing programs, distance learning, and our ongoing initiative of developing evidence-based indicators of nursing education programs. There are also a number of relevant links, and there is a section on nursing issues, which will periodically change.

NCSBN also distributes a "Profiles of Member Boards 2002" (new issue due July 2003 for about $25). It has a small section about nurses with disabilities. It is a comprehensive review of the regulations of all the boards of nursing on various issues. The "Profiles of Member Boards" can be purchased by calling Sue Shephard at NCSBN at 312-525-3677. It can also be ordered, along with other resources, from the Internet at: http://www.ncsbn.org/public/resources/resources_publication.htm

National Council on Disability
http:www.ncd.gov
1331 F Street NW, Ste. 850
Washington, DC 20004
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202-272-2074 (TTY)
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The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate. A series of reports are listed on the Website. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. The organization monitors the effects of the Americans with Disabilities Act and influences policy development for people with disabilities on a federal level. It offers a variety of publications about the ADA and ADA implementation, available in alternate formats. Monthly newsletter free. Recent publication: *Equality of Opportunity: The Making of The Americans with Disabilities Act*, July 1997.

National Council on Independent Living (NCIL)
www.ncil.org
Voice: 703-525-3406

TTY: 703-525-4153

Fax: 703-525-3409

A membership organization that advances the independent living philosophy and advocates for the human rights of, and services for, people with disabilities to further their full integration and participation in society. Contact to find out what services are provided and to locate a Center of Independent Living in your area.

National League for Nursing

www.nln.org

Ruth Corcoran, EdD, RN, Chief Executive Officer

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Founded in 1893, the National League for Nursing champions the pursuit of quality nursing education. It is the professional association of faculty and nursing education leaders, education agencies, healthcare agencies, allied/public agencies and public members. NLN's mission is to advance quality nursing education that prepares the nursing workforce to meet the needs of diverse populations in an ever-changing health care environment. NLN serves as the primary source of information about all types of nursing education – from the LVN and LPN to the EdD and PhD. NLN affiliated Constituent Leagues provide a local forum for members. NLN's bi-monthly *UPDATE* is available free of charge on the NLN Website and via email.

National Organization on Disability

910 Sixteenth Street, Suite 600

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ability@nod.org

http:www.nod.org

The mission of the National Organization on Disability (NOD) is to expand the participation and contribution of America's 54 million men, women and children with disabilities in all aspects of life. By raising disability awareness through programs and information, together we can work toward closing the participation gaps.

National Rehabilitation Information Center

1-800-346-2742

Offers information about rehabilitation services and resources across the USA.

The Nurse Friendly
http://www.nursingexperts.com/directpatientcare/disabled.nurses.disability.htm
National resource Website with section on nurses with disabilities.

NursesHouse
http://www.nurseshouse.org/
To help nurses in need, Nurses House extends short-term financial assistance to registered nurses in difficulty as a result of injury, illness, or disability.

Research and Training Center on Independent living

University of Kansas	Voice: (785) 864-4095
Room 4089 Dole Center	TTY: (785) 864-0706
1000 Sunnyside Avenue	FAX: (785) 864-5063
Lawrence, KS 66045-7555	email: RTCIL@ku.edu

Their strategic mission is to enhance Independent Living (IL) for all by working with consumers, providing quality research, and widely disseminating effective and relevant products. Guidelines for reporting and writing about people with disabilities can be found on their website.

Social Security
www.ssa.gov/work
Work related benefits for people with disabilities.

Teaching College Students with Disabilities
http://www.udel.edu/cte/disabilities.htm
University of Delaware Center for Teaching Effectiveness website has a section on teaching students with disabilities. Resource for faculty.

Legal/ Employment Resources:

Access Currents
www.access-board.gov
202-272-0800
TTY: 202-272-0082
Fax: 202-272-0081
An independent government agency. Ensures access for people with disabilities in telecommunications, transit, and architecture. Provides a newsletter of the US Architecture and Transportation Compliance board. Free Braille, cassette, large-print copy. Write to: US Architecture and

Transportation Compliance Board, 1331 F Street, NW. Suite 1000, Washington, DC 20004-1111

ADAPT
www.adapt.org
Nationally ADAPT focuses on promoting services in the community instead of warehousing people with disabilities in institutions and nursing homes. Attendant services (help with things like eating, dressing, toileting, moving from wheelchair to bed, etc.) are the cornerstone to community-based services for people with severe disabilities. ADAPT is working to get 25% of the Medicaid long-term care funds redirected to pay for a national, mandated attendant services program.

Americans with Disabilities (ADA) information line and connection to Department of Justice:
http://www.usdoj.gov/crt/ada/adahom1.htm
Voice: 1-800-514-0301
TTY: 1-800-514-0383
Electronic bulletin board: 202-514-6193

The Bazelon Center for Mental Health Law
http://www.bazelon.org
National legal advocate for people with mental illnesses or mental retardation. Through precedent-setting litigation and in the public policy arena, the Bazelon Center works to advance and preserve the rights of people with mental illnesses and developmental disabilities*.*

Civil Rights (U.S. Department of Health and Human Services Office for Civil Rights)
www.hhs.gov/ocr
Hot line: 1-800-368-1019, voice. TDD: 1-800-5377697 (National)
Ensures that federally funded programs that are funded through HHS are available to everyone regardless of race, national origin, disability, or color. Can inquire about section 504 violations and/ or discrimination. Enforces HIPAA (Health Insurance Portability and Accountability Act); this health information privacy law protects an individual's health history and states that it should be kept confidential and not disclosed unless it is to health insurance plans, health care providers, and to health care planners.

Commission on Mental and Physical Disability Law

www.abanet.org/disability

Since 1973 the Commission has been the primary entity within the American Bar Association focusing on the law-related concerns of persons with mental and physical disabilities. Its mission is "to promote the ABA's commitment to justice and the rule of law for persons with mental, physical, and sensory disabilities and their full and equal participation in the legal profession." The Commission's members include lawyers and other professionals, many of whom have disabilities. For more than 20 years, the Commission has published the Mental & Physical Disability Law Reporter, which provides analyses of key disability law developments and trends, and coverage of leading state and federal court decisions, legislations, and regulations. The Commission also publishes a variety of timely books and articles relating to mental and physical disability law.

Community Options

www.comop.org/rrtc

Rehabilitation Research and Training Center on Workforce Investment and Employment Policy for Persons with Disabilities. The mission is to expand knowledge that improves and modifies disability and generic policy that impacts positively the employment status and economic independence of Americans with disabilities. Funded by the U.S. Department of Education.

Consumer Action of Illinois

Tel: 1-800-472-6640

Largest public interest organization in US. Works on state and national level to ensure safety for consumer products and on environmental issues.

Disabilityinfo.gov Website

www.disabilityinfo.gov

The New Freedom's Initiative online resource for Americans with disabilities. This Website is a one-stop interagency Web portal for people with disabilities, their families, employers, service providers, and other community members. It is a comprehensive online resource specifically designed to provide people with disabilities with the information they need to know quickly.

Disability Rights Education and Defense Fund

www.dredf.org

Founded in 1979 by people with disabilities and parents of children with disabilities, the Disability Rights Education and Defense Fund, Inc. (DREDF) is a national law and policy center dedicated to protecting and advancing the

civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities.

Equal Employment Opportunity Commission (EEOC)
www.eeoc.gov
The EEOC coordinates all federal equal employment opportunity regulations, practices, and policies. The Commission interprets employment discrimination laws, monitors the federal sector employment discrimination program, provides funding and support to state and local Fair Employment Practices Agencies (FEPAs), and sponsors outreach and technical assistance programs. Any individual who believes he or she has been discriminated against in employment may file an administrative charge with the EEOC. After investigating the charge, the EEOC determines if there is "reasonable cause" to believe discrimination has occurred. If "reasonable cause" is found, the EEOC attempts to conciliate the charge by reaching a voluntary resolution between the charging party and the respondent. If conciliation is not successful, the Commission may bring suit in federal court. As part of the administrative process, the EEOC may also issue a Right-to-Sue-Notice to the charging party, allowing the charging party to file an individual action in court without the Agency's involvement.

Federal Government (USA)
www.firstgov.gov
Tel: 1-800-688-9889
Federal government citizen information center.

Find Law
www.findlaw.com
Search for specific legal cases.

Justice For All Email Network
www.jfanow.org
Justice for All was formed to defend and advance disability rights and programs in the 104th Congress. One JFA goal is to work with national and state organizations of people with disabilities to get the word from Washington D.C. out to the grassroots.

Legal Engine
www.legalengine.com
Search for legal information.

National Association of Protection and Advocacy Systems, Inc.

www.protectionandadvocacy.com

The Protection and Advocacy (P&As) Systems and Client Assistance Programs (CAPs) comprise the nationwide network of congressionally mandated, legally-based disability rights agencies. The National Association of Protection and Advocacy Systems, Inc. (NAPAS) is the voluntary national membership association of the P&As and CAPs, and it assumes leadership in promoting and strengthening the role and performance of its members in providing quality legally based advocacy services. NAPAS has a vision of a society where people with disabilities exercise self-determination and choice and have equality of opportunity and full participation. NAPAS believes this vision will be realized through the enactment and vigorous enforcement of laws protecting civil and human rights.

Rehabilitation Institute of Chicago

lifecenter@rehabchicago.org

326 W. Illinois

Chicago, IL 60610

312=238-6810

Vocational Rehabilitation Services

Employment of People with Disabilities (2003).

Career Candidates Seeking Employment

Rush College of Nursing

A. Beverly B Huckman

Associate Vice President for Equal Opportunity

Equal Opportunity Affairs

Rush University Medical Center

Rush University

Chair, Americans with Disabilities Act Task Force

Rush University Medical Center

Rush University

312-942-7093

Beverly_B_Huckman@rush.edu

B. College Admission Services

600 S. Pauline Suite 440 AAC Chicago, IL

Phone: 312-942-7100

E-Mail: rush_admissions@rush.edu

www.rush.rushedu/nursing/admission

C. **Dean's Office**
   c/o Kathy Pischke-Winn, MBA, RN
   600 S. Paulina - Suite 1080 AAC Chicago, IL
   Phone: 312-942-2318
   E-Mail: kathy_a_pischke-winn@rush.edu

Supreme Court Collection
http://supct.law.cornell.edu/supct
Search for Supreme Court cases.
United States Department of Education
www.adagreatlakes.org to find your regional contact
1-800-949-4232 (voice/ tty)
Provides general ADA technical assistance through 10 regional disability and technical assistance information centers.

United States Department of Labor
www.dol.gov/odep
Provides the following publications:
Attitudinal Barriers.
Making Management Decisions about Accommodations.
Americans with Disabilities Act Focus on Employment.
Employing People with Disabilities Q&A.
Employment Checklist For Hiring Persons With Disabilities.
Affirmative Action and People with Disabilities.
Facilitating Return-to-Work For Ill or Injured Employees.
Also includes information on the Family Medical Leave Act, OSHA, and the Workforce Investment Act.
The Office of Disability Employment Policy (part of the U.S. Department of Labor) offers the Job Accommodation Network
www.jan.wvu.edu
The Job Accommodation Network (JAN) is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities.

Adaptive Technology/ Devices/ Services:

Abledata
www.abledata.com
1-800-227-0216
Fax: 301-608-8958

Database of assistive technology. Provides information exchange, publications, national associations, rehabilitation center resource information and information for independence and user services. Operated by the National Institute on Disability.

Acu-Life Products
www.healthenterprises.com
(800) 633-4243
Provider of home care products

AiSquared
www.aisquared.com
Tel: 802-362-3612
A Vermont company that sells two magnification software products for the computer. Zoomtext, Version 8 is now available. Magnification of this program goes up to 16X and has a voice reader. Also sells a 2X magnification software program called Big Shot for $99.00.

American Printing House for the Blind (APH)
www.aph.org
1-800-223-1839 (Kentucky)
Direct line: 1-502-895-2405
Fax: 1-502-895-1509
Sells 4-track tape recorder/ players, other adaptive equipment, large print and Braille materials, catalogue of instructional aids, and tools. Supplies and provides free ADA information in large print and on cassette.

Americans with Disabilities Act Technical Assistance Center
www.adata.org
Information on accessible information technology and the ADA.

Ann Morris Enterprises, Inc.
http://tribeca.ios.com/~annm2
1-800-454-3175 (New York)
Email: annmor@netcom.com
Catalogue of innovative products dedicated to people with vision loss.
Available in large print, cassette, IBM format disk, and Braille edition. $6.00.

Aware Center
http://aware.hwg.org
Internet accessibility.

Bobby
http://bobby.cast.org/bobby/html/en/index.jsp
WWW accessibility.

Carolyn's Products for Enhanced Living
1-800-648-2266 (Florida)
Fax: 1-941-761-8306
Direct line: 1-941-795-8932
Offers free catalog listing adaptive equipment for people who are visually impaired.

Chicago Lighthouse for People who are Blind and Visually Impaired
www.chicagolighthouse.org
1850 West Roosevelt Rd.
Chicago, Illinois 60608-1298
312-666-1331
TTY: 312-666-8874
The only comprehensive private rehabilitation agency in the state of Illinois whose primary target population is children and adults who are blind, visually impaired, deaf-blind and blind with additional disabilities. The Lighthouse serves people from across the Chicago metropolitan area, throughout Illinois and the surrounding states.

Diabetes Home Care
www.diabetespartners.com
(800) 544-5433
Supplies for people with diabetes

Disability Specialtys
www.disabilityspecialtys.com
(888) 892-7878
Offers broad range of adaptive equipment and instructional tutorials for individuals with disabilities, educators, rehabilitation professionals, and professionals working in the private sector.

Diabetes-Supply
www.diabetes-supply.com
(800) 779-3374
Supplies for people with diabetes

Dynamic Living
www.dynamic-living.com
(888) 940-0605
Offers hundreds of kitchen products, bathroom helpers and unique daily living aids that promote a convenient, comfortable and safe home environment for people of all ages and with various disabilities.

Educational Teaching Aids
1-800-549-6999 (CALIFORNIA)
Catalog of teaching aids for rehabilitation specialists and teachers who work with children and adults who are visually impaired.

Federal Communications Commission
www.fcc.gov/cib/dro
The Federal Communications Commission (FCC) is an independent United States government agency, directly responsible to Congress. The FCC was established by the Communications Act of 1934 and is charged with regulating interstate and international communications by radio, television, wire, satellite and cable.

Freedom Scientific
www.hj.com or www.freedomscientific.com
Tel.: 727-803-8600
This company sells many adaptive products including Braille printers. JAWS: (Job Access with Speech) A voice synthesizer screen reading program. Sells MiAGic a screen magnifying software program.

Independent Living Aids, Inc. (ILA)
1-800-537-2118
Fax: 1-516-752-3135
Catalog available in regular print and on cassette. Sells a wide variety of watches, magnifiers, games, kitchen products for activities of daily living, etc.

Learning, Sight, and Sound Made Easier (LS&S)
www.lssgroup.com
1-800-468-4789 (Illinois)
Fax: 1-516-752-3135
TTY: 1-800-317-8533
E-mail: issgrp@aol.com

Catalog that specializes in products for people who are visually and hearing impaired.

Life Solutions
www.lifesolutionsplus.com
(877) 785-8326
Products for independent living.

The Lighthouse, Inc.
1-800-829-0500 (New York)
Consumer products catalog available in Braille, cassette, or large print.

MaxiAids
www.MaxiAids.com
1-800-522-6294
TTY: 631-752-0738
Fax: 631-752-0738
E-mail: sales@maxiaids.com
Aids and appliances for independent living. Products designed for those who are/ have low vision, blind, hard of hearing, deaf, deaf-blind, mobility impairments, etc. Catalog available on cd-rom and audiocassette.

The Medical Supply Company
www.medsupplyco.com
(888) 633-8282
Directory of medical supplies.

National Assistive Device Center
www.hitec.com/nadcenter.html
Assistive devices for people with various disabilities.

National Library Services (NLS): Library of Congress
1-800-424-9100 (English)
1-800-345-8901 (Spanish)
A national regional library service referral line. Leave your name, telephone number, address, city, state, and zip on recording. The regional library service provider in your area will contact you so that you may register for equipment and book programs offered to people who are visually impaired, physically disabled, or dyslexic. No fee.

Recording for the Blind and Dyslexic (RFB&D)

www.rfbd.org

1-800-221-4792

20 Roszel Rd

Princeton, NJ 08540

Records textbooks and maintains lending library. Must be registered for service. Has thousands of textbooks already on tape.

Registry of Interpreters for the Deaf, Inc.

www.rid.org

Interpreter directory, online store, workshop information, and chapter locator.

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) Technical Assistance Project

www.resna.org/taproject

1700 North Moore Street, Suite 1540

Arlington, VA 22209-1903

703-524-6686 Phone

703-524-6639 TTY

703-524-6630 Fax

 resnaTA@resna.org E-mail

Provides technical assistance to the 56 states and territory assistive technology programs as authorized under the Assistive Technology Act of 1998.

Science Products for the Blind

(800) 888-7400

Section 508 (U.S. Department of Justice)

www.usdoj.gov/crt/508/508home.html

Section 508 requires that Federal agencies' electronic and information technology is accessible to people with disabilities, including employees and members of the public.

Speak-to-me

www.speaktomecatalog.com

(800) 248-9965

Catalog of talking products.

Stethoscope information

See AMPHL under "hearing loss" section.

Structure Probe, Incorporated (SPI) Supplies
www.2spi.com
(800) 242-4774
Source for microscope laboratory supplies and equipment.

U.S. Department of Transportation
www.dot.gov/accessibility
For the 54 million Americans with disabilities, access means simply being able to use, enjoy and participate in the many aspects of society, including work, commerce and leisure activities. Transportation is a vital link that allows full participation. The Department is committed to building a transportation system that provides equal access for all Americans. With the advent of accessibility standards for electronic and information technology under Section 508 of the Rehabilitation Act of 1973, DOT is endeavoring to be at the forefront in ensuring accessibility to technology used by the Department to accomplish its vital mission.

W3C WorldWide Web Consortium what is this?-

Student Resources:

College/ University Disabled Students Union
Many colleges and universities in the US have Disabled Students Unions or Associations. Often information about these organizations can be found online or by calling the campus office of student organizations.

College/ University Office for Students with Disabilities.
Each college or university should have an office that serves students with disabilities. The name varies from school to school, but examples are: Disability Services, Disabled Student Services, or Office for Disabled Students. Information about each school's office should be available on the school's Website and by calling the main campus phone number or directory. Services provided in these offices will also vary by school.

ELA Scholarship
www.ela.org
info@ela.org
The ELA (Ethel Louise Armstrong) Scholarship provides financial assistance to women with physical disabilities who are enrolled in a college or

university graduate program in the United States.

Healthy and Ready to Work (HRTW) National Center
www.hrtw.org
Academy for Educational Development
Disability Studies and Services Center
1825 Connecticut Ave. NW
Washington, DC 20009
info@hrtw.org
Patti Hacket, Co-Director and Team Leader
Ocala, FL
352-207-6808
The Center's mission is to promote positive changes in policy, programs and practices that support youth with special health care needs, to allow them to transition into adult health care.

Kids as Self Advocates (KASA)
www.fvkasa.org
1400 West Devon #423
Chicago, IL 60660
773-465-3200
773-465-3693 (fax)
Julie@fvkasa.org
National, grassroots network of youth with special needs and our friends, speaking on behalf of ourselves.
Naomi Ortiz, Board Chair
Julie Sipchen, Project Director

National Center on Secondary Education and Transition (NCSET)
www.ncset@umn.edu
Institute on Community Integration
University of Minnesota
6 Pattee Hall
150 Pillsbury Drive SE
Minneapolis MN 55455
612-624-2097 (phone)
612-624-9344 (fax)
Coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve

successful futures. David Johnson, Director

National Collaborative on Workforce and Disability for Youth (NCWD/YOUTH)

www.ncwd-youth.info
C/o Institute for Educational Leadership
1001 Connecticut Ave., NW, Suite 310
Washington, DC 20036
(877)871-0744 (Toll Free)
Youth/Family Contact Person: cscott@aed.org
Source for information about employment and youth [and students] with disabilities. Our partners — experts in disability, education, employment, and workforce development — strive to ensure you will be provided with the highest quality, most relevant information available.

National Council on Disability Youth Advisory Committee (NCD-YAC)

http://www.ncd.gov/newsroom/advisory/youth/youth.html
The Committee provides advice to the National Council on Disability on various issues such as NCD's planning and priorities. NCD is seeking this type of input in order to make sure NCD's activities and policy recommendations respond to the needs of youth with disabilities.
Christina Mills, 2003 Chair
Gerrie Drake Hawkins, Designated Federal Official
ghawkins@ncd.gov

National Disabled Students Union (NDSU)

www.disabledstudents.org
National Disabled Students Union
430 Northeast 16th Avenue
Portland, OR 97343
803-524-6029
ndsu@disabledstudents.org
Nationwide, cross-disability, student organization concerned with civil rights. The organization works to ensure that all disabled students have the opportunities they need to learn, the opportunities they need to live and work, and the opportunities they need to be full participants in their communities and full members of American society.

National Youth Leadership Network (NYLN)

www.nyln.org

Mission is to promote leadership development and education that ensures all youth with disabilities have the opportunity to attain their maximum, unique, personal potential.
Marissa Johnson, 2003 Chair
Kristen Jones, 2003 Co-Chair
Alison Turner, NYLN Coordinator

Vocational Rehabilitation Services

Vocational Rehabilitation, a state-supported division of services, assists individuals with disabilities who are pursuing meaningful careers. VR assists those individuals to secure gainful employment commensurate with their abilities and capabilities through local job searches and awareness of self-employment and telecommuting opportunities. Each state has its own office for Vocational Rehabilitation. A list of state offices can be found on the Rehabilitation Services Administration's Website at
www.jan.wvu.edu/SBSES/VOCREHAB.HTM

Hearing Loss Resources:

Alexander Graham Bell Association for the Deaf and Hard of Hearing
www.agbell.org
Organization that advocates independence through listening and talking. Has a Deaf and Hard of Hearing Section (DHHS). Many resources related to hearing loss are available through the organization. Also offers academic scholarships.

Association of Medical Professionals with Hearing Losses
www.amphl.org
Provides information, promotes advocacy and mentorship, and creates a network for individuals with hearing losses interested in or working in health care fields.
AMPHL has comprehensive links for:
stethoscopes adapted for those with hearing loss; disability law; assistive listening devices/paging systems/ interpreters/ real time captioning. AMPHL has a listserv called NOISE (Network for Overcoming Increased Silence Effectively), an international support forum for discussion of topics relevant to medical professionals with hearing loss.

PepNet Online
www.pepnet.org

PEPNet, the Postsecondary Education Programs Network, is the national collaboration of the four Regional Postsecondary Education Centers for Individuals who are Deaf and Hard of Hearing. The goal of PepNet is to assist postsecondary institutions across the nation to attract and effectively serve individuals who are Deaf and Hard of Hearing.

NETAC (Northeast Technical Assistance Center) is part of PepNet and its website http://www.netac.rit.edu/ has a section profiling healthcare professionals, including nurses, with hearing loss.

Promoting Awareness in Healthcare, Medical and Deaf (PAH, MD)

http://www.urmc.rochester.edu/smd/stdnt/pahmd/welcome.htm

PAH, MD works to improve the quality of healthcare offered to deaf and hard of hearing individuals through education of consumers and healthcare providers. They also encourage deaf and hard of hearing individuals to pursue careers in healthcare delivery.

PAH, MD website has many useful links to resources for those with hearing loss.

Self-Help for Hard of Hearing People

www.shhh.org

Self Help for Hard of Hearing People is the nation's largest organization for people with hearing loss. It exists to open the world of communication for people with hearing loss through information, education, advocacy and support.

Vision Loss Resources:

American Council of the Blind (ACB)

www.acb.org

1-800-424-8666 or 202-467-5081

Washington, D.C. ACB chapters in all states

National membership organization established to promote the independence, dignity, and well-being of people who are visually impaired and blind. Provides numerous programs and services.

Organization has a job bank (1-800-424-8666/ Sarah DeYoung) that provides electronic listings for jobs and other appropriate listings sent to ACB and available on the Internet. Can be accessed by clicking on ACB job bank link on the website.

American Foundation for the Blind (AFB)

www.afb.org

Since 1921, the American Foundation for the Blind—to which Helen Keller devoted her life—has been eliminating barriers that prevent the ten million Americans who are blind or visually impaired from reaching their potential. AFB is dedicated to addressing the most critical issues facing this growing population: independent living, literacy, employment, and technology.

CareerConnect (American Foundation for the Blind)
www.afb.org/careerconnect
A free on-line resource for blind or visually impaired job seekers and students to learn about the range and diversity of jobs performed by blind/visually impaired adults throughout the US & Canada (including nursing, medicine, and other health care professions). Database includes information on jobs being performed by people in the AFB. Includes nurse mentors.

Council of Citizens with Low Vision International (CCLVI)
www.cclvi.org
1-800-733-2258
Fax 813-443-1040
International organization that provides newsletter, speakers, networking, conferences, and scholarships to students. Membership fee.

EnableLink: (Canadian)
www.enablelink.com
Online community for visually impaired adults and their families, based in Canada. Includes breaking news, music reviews, lifestyle articles, technology features and more.

Hadley School for the Blind
www.hadley-school.org
1-800-323-4238 or 847-446-8111
700 Elm Street
Winnetka, IL 60093
Provides accredited and non-accredited correspondence courses nationally, which are on the high school and college level, and provides other courses for personal growth and learning. Provides an extensive course listing available on cassette, large print, in Braille, or on disk. No fee.

Musculoskeletal/ Neurological Disability Resources:

American Association of Spinal Cord Injury Nurses
www.aascin.org

The American Association of Spinal Cord Injury Nurses (AASCIN) is dedicated to promoting quality care for individuals with spinal cord impairment (SCI). This is achieved by advancing nursing practice through education, research, advocacy, health care policy, and collaboration with consumers and health care delivery systems. Founded in 1983, AASCIN is the only nursing organization devoted exclusively to promoting excellence in meeting the nursing care needs of individuals with SCI.

International Organization of MS Nurses

www.iomsn.org

The IOMSN is the first and only international organization focused solely on the need and goals of professional nurses, anywhere in the world, who care for people with multiple sclerosis. Mentoring, educating, networking, and sharing, the IOMSN supports nurses in their continuing effort to offer hope.

National Amputation Foundation

www.nationalamputation.org

Organization provides resources to those who have amputations. Also provides a list of support groups for every state.

National Multiple Sclerosis Society

www.nationalmssociety.org

The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS. The Society and its network of chapters nationwide promote research, educate, advocate on critical issues, and organize a wide range of programs — including support for the newly diagnosed and those living with MS over time. A section of the website is devoted to being employed while having MS.

National Spinal Cord Injury Association

www.spinalcord.org

At NSCIA, we educate and empower survivors of spinal cord injury and disease to achieve and maintain the highest levels of independence, health and personal fulfillment. We fulfill this mission by providing an innovative Peer Support Network and by raising awareness about spinal cord injury and disease through education. Our education programs are developed to address information and issues important to our constituency, policy makers, the general public, and the media, and including injury prevention, improvements in medical, rehabilitative and supportive services, research and public policy formulation.

Spinal Cord Injury Law

http://www.spinal-cord-injuries.com

Spinal Cord Injury Lawyers is intended to provide up-to-date references and resources for spinal cord injury law. The links and resources are provided as a public service for attorneys and consumers.

Spinal Cord Injury Support Network

http://www.brainlink.com/~phil

The Spinal Cord Injury Support Network is a volunteer organization of people living with a spinal cord injury. Our purpose is to help others with a SCI toward independent lives through the sharing of information. Our goals are: to create programs that help newly injured individuals re-integrate into their communities, to maintain an information network that will provide answers to practical questions, as well as advocacy on issues of common concern. Our philosophy is based on an independent living, self-help model. While our primary focus is to help people with spinal cord injuries, we will never lose our recognition that we are a part of a larger community of people with disabilities.

Mental Illness Resources:

Boston University

http://www.bu.edu/cpr/reasaccom/index.html

Online resource for employers and educators about reasonable accommodations for people with psychiatric disabilities.

National Alliance for the Mentally Ill

www.nami.org

NAMI is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses. Founded in 1979, NAMI today works to achieve equitable services and treatment for more than 15 million Americans and their families who are living with severe mental illnesses. Hundreds of thousands of volunteers participate in more than 1,000 local affiliates and fifty state organizations to provide education and support, combat stigma, support increased funding for research, and advocate for adequate health insurance, housing, rehabilitation, and jobs for people with mental illnesses and their families.

Learning Disability Resources:

Learning Disabilities Association of America

www.ldanatl.org

The Learning Disabilities Association of America (LDA) is a nonprofit grassroots organization whose members are individuals with learning disabilities, their families, and the professionals who work with them. LDA strives to advance the education and general welfare of children and adults with learning disabilities.

Chronic Illness Resources:

American Diabetes Association

www.diabetes.org

The mission of the organization is to prevent and cure diabetes and to improve the lives of all people affected by diabetes. To fulfill this mission, the American Diabetes Association funds research, publishes scientific findings, provides information and other services to people with diabetes, their families, health care professionals and the public. The Association is also actively involved in advocating for scientific research and for the rights of people with diabetes.

Chronic Ill Net

http://www.chronicillnet.org

Provides a forum in which the facts about chronic illnesses are examined closely, providing a new scrutiny of age-old problems.

Fibromyalgia Employment Resources

http://www.coloradohealthsite.org/fibro/fms_career.html

Disability Careers, Inc. provides employment resources for those who have fibromyalgia.

Immunesupport.com

www.immunesupport.com

World's largest fibromyalgia and chronic fatigue syndrome site. Offers many resources.

The Pediatric Network

http://www.pediatricnetwork.org/independence/working-index.htm

Provides internship and career resources for young adults with chronic illness.

Journal Articles/ Books/ Online articles of Interest:

Americans with Disabilities Act of 1990, 42 U.S.C. §12101 et seq.

Bryere, S. (no date). *A human resource perspective on implementing the ADA,* Cornell University. www.ilr.cornell.edu/ped/ada

Bryere, S. (2001). *The ADA and personnel training.* Cornell University. www.ilr.cornell.edu/ped/ada
Carol, R. (2003). *Nurses with disabilities.* http://www.minoritynurse.com/features/nurse_emp/01-27-02h.html

Charlton, J. L. (1998). *Nothing about us, without us.* University of California Press.
A social theory book about disability oppression and empowerment set in an international context. Available at Borders and on Amazon.com

Christensen, R. (1998). Nurse educators' attitudes toward and decision-making related to applicants with physical disabilities. *Journal of Nursing Education, 37*(7), 311-314.
In this study, decision-making responses of nurse educators do not correspond with ADA. Additional awareness and education is needed.

Coates, K. J. (2002). *Up to the challenge: Nurses with disabilities overcome legal, social and mental hurdles to flourish in their careers.* http://www.nurseweek.com/news/features/02-03/disabilities_print.html

Computer Center for Visually Impaired People, Division of Continuing and Professional Studies Baruch College, City University of New York (2002). *A practical guide to accommodating people with visual impairments in the workplace.*

Duston, S. (2001). *Definition of disability under the ADA: A practical overview and update.* Cornell University. www.ilr.cornell.edu/ped/ada

Harkins, D., Kirchner, C., Esposito, R., Chandu, F., & Istanbouli, M. (1991). *Report from a study of issues and strategies toward improving employment of blind or visually impaired persons in Illinois.* New York: American Foundation for the Blind.

Harris, L. (2001). *N.O.D./Harris 2000 survey of Americans with disabilities.* New York: Harris Interactive.

Hartman, D., & Asbell, B. (1978). *White coat, white cane.* New York: Simon and Schuster.

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