

1999

**GOVERNOR'S PREVENTION CONFERENCE SPEECH
TRANSITIONS ACROSS A LIFESPAN
FOR DISABLED AND ELDERLY VERMONTERS**

Thank you so very much for the opportunity to speak before you today. After I was told it was time for the Department of Aging and Disabilities to host the Prevention Conference, I learned that it was customary for the Commissioner of the host department to speak and highlight the work his or her Department was doing. Perhaps to the chagrin of my staff I have chosen not to do that today. At least I do not want to highlight, in a methodical sort of way, program by program, the accomplishments we've made or goals we have charted for the future.

Instead I simply want to talk to you from the heart.

I want to talk to you in part about the values that I believe must guide us as those with disabilities and older people transition across the lifespan. I want to talk to you about the challenges we face, and those we will overcome. I am not sure I have solutions or suggestions that will change the future, but I do have some observations.

It has been said that we are all - Temporarily Abled Bodied – otherwise known as TAB's.

This condition of wellness we enjoy, some more so than others, is not a permanent condition. Our time will come when we too will have to reach out to others - to family, friends, neighbors, strangers, government - for a helping hand as we cope to perform the activities of daily living many take for granted – the ability to move about from bed to chair, to dress and bathe and feed ourselves. For some, the moment they enter this life they will face years of disability. For others, they may live a long and full life free of restrictions until the very end. Others will face a limited period of disability.

The research says approximately 3% of all children born in this country today will be uniquely different - born to this world challenged in extraordinary ways - and that one out of five adults between the ages of 45 and 65 will experience some form of disability for an extended period, and that 43 % of those over age 65 will spend a portion of their life in a nursing home.

Let me share with you some of the stories of some Vermonters I have come to know.

This is Darren and these are the words of his parents.

Darren is a 9-year-old with a degenerative neuromuscular disorder. He is in a wheelchair full-time and needs help with basic living skills. Darren's room and bathroom are very small. There is no space for a Hoyer lift. A PC-2 track lift, mounted in the ceiling would be our only option, but is difficult to obtain funding for. It takes two people to lift Darren from bed to toilet; dressing him on his bed, then lifting him into his chair. We have a personal care attendant for one hour in the morning to help us.

My husband and I work full time jobs. A personal care attendant comes in the afternoon to meet Darren's bus. She also helps with his bath and exercises; which must be done at least four days a week to help slow the progression of the disorder. This gives us time to unwind after work.

This is Derek. This is his story.

My name is Derek. I am 10 years old. I look like all the other boys at school but I'm not. I have ADHD, Tourettes Syndrome, Anxiety Disorder, Obsessive Compulsive Disorder and Dysgraphia.

School is hard for me because I can't do my work very well. I guess I'm not very good. Sometimes the words don't stick in my head when I am reading so I have to read it again and everyone else is done and I'm still doing it. Sometimes teachers think I am being rude when I'm not because of the faces I make from the Tourettes. I say things before I think and they don't come out right. I get bored at school a lot.

I use a word processor called a Dream Writer because I have trouble writing. I have trouble writing because my hands don't work the way I want them to. I feel like I am the only one in class who can't write in cursive. I have to print and my printing is hard to read. I get real upset when I have to write and can't.

At home I get in trouble because I can't stick to what I am supposed to do. Sometimes so many things are in my head that I can't think of what I need to do. I have a lot of fears and because of them I can't do things I want to do. I love to shoot baskets but I am afraid to go outside unless someone is with me so I don't do it much anymore. Sometimes I get really worried about things. My parents tell me not to worry so much but I can't help it. I try really hard but sometimes people don't think so and it makes me feel bad. I am proud of being really good at spelling, computers, reading and playing video games.

Who will stand by these boys and their families to assure their self-esteem grows, and they live with dignity and independence? What will happen as they mature and seek employment, as we all do as we reach adulthood?

It is estimated that there are roughly 3,000 children with needs similar to Darren's and Derek's in our Vermont schools. Will the pervasive pattern of dependency, and a lifetime of unemployment face these children? What can we do to break the cycle? The unemployment rate of the disabled, according to the Harris poll is 72%, and yet we know those with disabilities, profound disabilities, given the opportunity can and do work, and contribute richly to our Vermont way. To get started however, some folks need a little help like vocational rehabilitation or transportation. Yet, the federal government's policy that says if you earn one penny over \$500 in a month you will lose your Medicare coverage, puts the disabled into an all or nothing situation. This is not a kinder and gentler policy. It is not the message we seek to send.

Let me share with you the story of a friend of mine in my hometown .

Stricken in his prime with MS, he first lost his business, then he lost his wife, then he lost his ability to function completely, and now can only move his eyebrows, and his mouth, but he has found a renewed inner spirit. He adds his voice to the Vermont landscape we love and his vibrant soul is an example of faith for all to point to.

The family members who care for disabled Vermonters and all the Darrens and Dereks in our state are indeed the backbone of our long-term care system.

While children's services have dramatically improved over the years, most of the federal resources for these Vermonters are not designed to keep families intact but instead only fund services for institutional care after family caregivers have burned out.

We ought not to need a special waiver from the government to receive help to stay in our home while at the same time we are entitled to open access to a nursing home bed. It is time to reverse this backward policy. It is time to stop "Government by Waiver" and to embed as policy the belief that people should be supported to live with dignity and independence in settings they prefer.

The challenges and blessings that have been bestowed on these extraordinary families can extract a heavy toll from their spirit and from their capacity to remain solvent.

These families call out for respite care, not because they crave access to a government program but because they have nowhere else to turn. Today many of these families face a two-year wait for services before they can get help.

These family caregivers, who endure sleepless nights, chronic backaches and a stunning incidence of depression some six times the rate of the rest of the population - do not have access to paid professional lobbyists.

They do not have the guile and savvy or time to establish political action committees.

They are not armed with fax machines, or cell phones, or laptops that they can use to mobilize support for their cause.

All they have is a devotion to family, a deep anxiety of what the future holds, and the hope, the sincere hope, that when they do have to reach out to government for help someone, somewhere, will reach back.

For a moment, let's measure just how far we have come.

In the days of the last century disabled children were written off as pitiful, without hope or help. In the 1800s, churches routinely published stories of moral instruction, with titles such as The Patient Cripple, The Deaf Boy's Triumph, The Happy Mute, Witless Willie: The Idiot Boy. All were tales that stressed only God could be a comfort, that these lives could be nothing but examples of faith. Those with disabilities were without value, except as short-lived symbols for the able bodied to learn from. Today we work not to pity the disabled or to give them charity but to give them rights so they can integrate their lives with ours so there is no them and us but we.

Does anyone remember the first Eugenics Survey, in 1931? Have you heard of this state government activity to cleanse Vermont communities of individuals considered "unacceptable degenerates." In all, 254 Vermonters were sterilized before this law was repealed in 1966.

Yes, just 58 years ago, those in power, those who felt they Knew Better, sanctioned and supported such heinous practices. But what is past is past, there is no way to undo it or change it.

Like other groups of oppressed people, we cannot afford to dwell on past injustices or live with anger; we must heal and move forward. Anger and cynicism are easy, a lot easier than understanding, forgiving and growing. Anger is freeing, it frees us of responsibility, it permits us the powerless role of victim, busy defining the wrongs, not defying them.

And yet, if we don't step up and speak up, who will?

For too long, oppressed people, and perhaps particularly those with disabilities, have felt they were the only ones hurt through their silence and invisibility. And the twisted thinking was "Well, I don't matter so it doesn't matter."

But as we are reminded of the efforts by all great crusaders against oppression and for human rights, we see the beneficiaries of their missions number in the millions, across time and space.

By not taking a leadership role, in the front row of the march for human equality, we not only deny ourselves opportunities for self-expression and full lives, but we discount the lives of others, as well. By pulling our voices out of the song, the chorus we call community lacks color, harmony, volume. When one of us is silent, we are all diminished. When one of us is invisible, we are overlooked.

Perhaps one of the most startling results of the Harris study I mentioned earlier, is the data on the workforce and those with disabilities. The research showed only 28 percent of disabled persons of working age (18-64) work full or part time.

When I read this statistic, I thought, "What literature am I not reading because someone isn't writing? What pictures aren't being painted? What cures aren't being invented? What loving relationships aren't occurring?"

There is no survey, no study, or report, by Harris or Gallup or anyone else, that can measure what we are all missing because a large number of Americans aren't fully franchised, aren't all invited to the table.

Imagine with me for a minute if those leaders, who opened the New York Institute for the Blind in 1847, America's first school for the visually impaired, hadn't followed their call? What if they had felt overwhelmed and defeated by the powers that be?

One consequence is that Fanny Crosby, the American hymn writer and poet who wrote over 9,000 hymns, could have died without writing, could have died with every song and verse in her head. Why?

Blinded at a young age, Fanny entered the NY Institute at the age of 15, and afterward taught English and history. As a pupil and as a teacher, Fanny spent 35 years at the school. Her first book of poems was published in 1844 and was called *The Blind Girl and Other Poems*.

One biographer wrote of her,

"...in her day, she was considered by most people to be the greatest songwriter in America. As Johann Strauss reigned in Vienna as the Waltz King, and John Phillip Sousa in Washington as the March King, so Fanny Crosby reigned in New York in the later nineteenth and early twentieth century as the "Hymn Queen;. " (Have some fun this Sunday, look at the index of authors in your church hymnbook! But remember, like all devalued people, Fanny had to play the game. She often used pseudonyms, particularly of men, as she found the publishing houses more eager to buy the work of a sighted white man than a blind woman! So much of her work is still invisible.)

For the sake of the healing of ourselves and for all those who come after us, we simply cannot accept this invisibility any longer.

In a small Vermont town, recently a woman aged 88, died peacefully in her sleep. For most of us, hers is our desired way of leaving this world. Peacefully, without pain, quickly, in our own beds.

But for the townspeople, their thoughts and worries were not about the aged neighbor they would soon bury. All eyes and hearts were on her daughter, a woman in her fifties, with disabilities. "What will happen to Marybelle? Who will care for her?" was heard round the stores and churches.

Marybelle and her mother belonged to an era, a generation, in which people with disabilities were invisible, hidden from view, isolated.

We cannot afford to raise another invisible generation; we cannot ask another aging mother to be the solo caregiver to her isolated daughter. We cannot leave families to cope alone with their children who are blessed in different ways. We cannot leave people with disabilities out of the workforce, our communities, our lives.

Nor can we cry out in anger at the circumstances that brought us to this point. Our challenge, knowing what we do, is to make the quality of life better for all Vermonters.

How many of you were born at home? If I asked that question of a group this size 75 to 100 years ago virtually every hand would go up.

But throughout the century, waves of cultural transformations and technology have swept us all into a >sea of vast changes. If I asked that hypothetical group of the past, how many women voted in the last election, none could have raised her hand. And the number of car owners would have been small, as the automobile, known then as "a devil catcher" or "the iron cage," was just beginning to chase horses off the highways.

When the great, late-blooming painter Grandma Moses was a girl, living in the Cambridge Valley of Washington County, New York, just across the state line from North Bennington, VT, she went by buggy to visit her grandmother, a few villages away.

Stopping in the little town of Cambridge, NY, she noticed everything was trimmed in black. In her autobiography, Grandma Moses writes, "I remember my mother asking 'Oh, what has happened?' The pillars of the store were all wrapped in black bunting. And this man told her that President Lincoln was shot the night before. And I remember her coming back to the buggy and she said, 'Oh, what will become of us now?'"

Well, much has happened since the days of Grandma Moses. We live in a world of constant change – change we cannot always comprehend. We are connected in ways we never imagined. Today when we learn of tragic occurrences, like the one in Colorado recently, international internet chat rooms are set up and the world is instantly fixated on the latest breaking news.

When we throw away a musical greeting card today we discard more computer power than existed in the entire world before 1948, let alone the days of Grandma Moses.

Automobiles come with computer mapping devices installed to help us find our way and medical breakthroughs have dramatically extended our life span – from 48 years at the turn of the century to 75 years today - and tested our ethical capacity to adapt to these changes.

But with all this progress, has the life of the average older Vermonter changed that much? What can we say about growing old in Vermont in 1999?

- We know that about half of all seniors live alone, and that 1 in 5 of those over 85 live in a nursing home.
- We know that 1 in 3 earn less than \$10,000 a year and that, on average, senior citizens spend one fifth of all their income on health care.
- We know that 1 in 5 are blind or otherwise chronically disabled.
- And sadly, we know that 1 out of 5 of all suicides are committed by senior citizens and the rate of suicide of men over age 85 is 6 times the rate of the rest of the population.

The economic and medical challenges of old age that I have detailed are not experienced in a vacuum. Let's look at the environment and systems older Americans must adapt to:

- If they are in an HMO, their health will be worse than their counterparts who have standard insurance plans.
- More than 3/4's of the nurses who work as nurses in this country don't want to remain in their careers and two out of five would not even recommend their place of employment to a loved one.
- More than 37 percent of all health care expenditures are spent on older Americans, even though they make up only 12 percent of the total population. And they account for nearly half of all the days of care provided by our hospitals.
- More than 80 percent of the long term care dollars spent in this country are spent in nursing homes, though more than 80 percent of the patients who need such care live at home.
- And to expose just how morally void our federal policies on long term care are today - if you are a senior citizen in need of home health services but you leave your home 4-5 times a month for more than 10 hours – In other words you go to church- you will be told you are ineligible for services because you are not "homebound", even if it took 2 people to lift you in and out of the car to get you into church!

Government policies must support our value systems. We must be sure they do not act to isolate, to deny senior citizens and others their right to a full and meaningful life.

Yet in the quest for a balanced budget Congress has in the words of some "decimated" our home health agencies – 2000 have closed nationwide over the last year. Right here in Vermont revenues are down 18% and utilization is down 25% statewide. This quest comes at a time when our society spends \$370 billion a year on recreation - everything from movies to books, to billiards, to bowling. It comes in a country that spent \$58 billion on beer and whiskey, another \$31 billion on cigarettes, and \$500 billion on gambling, in one year! But our answer to balancing a budget in a country with the riches we have is to cut home health?

How do we change this picture, make change occur within our culture? Can we accelerate it in any way?

I think we can. I think in our little State there is a strong and lasting commitment to helping those in need. The notion of Abraham Lincoln when he said "The legitimate object of Government is to do for a community of people whatever it is they need to have done, but cannot do at all in their individual and separate capacity" is deeply embedded I think, in our Vermont culture.

The belief that we should help elders to live in settings they prefer with dignity and independence is a long held tradition in this country – I quote the following:

"As having their own way is one of the greatest comforts of life to old people, I think their friends should endeavor to accommodate them in that as well as anything else. When they have lived long in a house it becomes natural to them; they are almost as connected with it as a tortoise with its shell; old folks and old trees, if you remove them, it is ten to one that you will kill them."

Benjamin Franklin had a lot to say over 200 years ago.

I see evidence of this spirit all over our State. With the Dean Administration leading the way with initiatives in Fiscal year 2000 that will bring over \$9 million to help address issues of senior citizens and disabled Vermonters, **Communities** are coming together in powerful ways to help their neighbors. For sure, we are challenged by painful Medicare cutbacks but despite this our resolve is strong.

In Brattleboro and Rutland, Hope in Housing initiatives are being piloted to test ways to help elders in congregate housing sites so they can "age in place".

In Morrisville and Randolph, local hospitals are closing nursing homes and rebuilding assisted living opportunities and providing other community based options.

Adult day care centers throughout the State are expanding their hours and days of service and serving more people.

We are just beginning to drive reform for older and disabled Vermonters by shifting our focus from illness to wellness by working with elders to maintain their nutrition, mobility and social interaction with others for as long as possible. If we increase their health span, we will not only reduce the consumption of services and drive a reduction in spending, we will improve their quality of life.

Our aim is not to simply (there is nothing simple about it of course) shorten the stay in a hospital for a broken hip from seven to five or even three days. We're trying to prevent the broken hip from ever happening. We know that 40% of seniors who fall and go to the hospital never go home again. We can change this, and in Burlington a group has started a fall prevention program and aims to save over \$200,000 in avoided hospital costs next year.

We know that older people who are not socially connected, who lack a social convoy, are two to four times more likely to die when faced with an illness than those who are connected to their community. Neighbor to Neighbor and Senior Companion programs across our state are helping to assure that older Vermonters are not abandoned.

We know nearly half of all older people admitted to our hospitals are malnourished and we know malnourished patients take 40% longer to recover and their average length of stay is 90% longer than average. We know we can change this and throughout Vermont community groups are coming together to do just that.

Yes, when I look over our green mountains I see Vermonters coming together in ways that are most exciting. But to be sure there still remains much to do.

Well into her nineties, Grandma Moses reflected on 'progress.' Born Anna Mary Robertson in 1860, she was "discovered" as a primitive artist by a NYC art collector when she was over 80 years of age. Grandma Moses wrote, "Things have changed greatly and still are changing, can they change much more? Can you think of any more improvements? I would not be surprised, when the younger generation gets old, when people of coming generations, a hundred years from now, will look back upon us as primitives. And yet I wonder sometimes whether we are progressing. In my childhood days, life was different. In many ways, we were slower, still we had a good and happy life, people lived life more in their way, at least they seemed happier, they don't take time to be happy nowadays."

But I don't want to romanticize the old days. That's not the message I carry. I am looking for a balance in our delivery of long term care services, one that preserves the goodness of the past and encourages improvements in the future.

Earlier today, I asked how many were born at home. I bet if I asked how many want to die at home, all hands would go up. That is what Gallup and AARP surveys tell us.

But I don't want to romanticize death at home, either. My grandfather died at home, but it was not a heartwarming scene. It was by his own hand, and that vicious grip of depression. I seek to loosen that grip on the lives of all older Vermonters, and I seek your help to assure a standard of living, a quality of life, that preserves independence and dignity, and gives Vermonters real choices when their time of need comes.

Am I hopeful? Am I optimistic? Do I believe we can succeed? Yes.

Trusting in the Greater Good, I say let's push on, believing in a society based on mutualization; giving and receiving.

I believe in a "caring community". A community where each of us is responsible for all of us.

A community that works to enable those of us who can, to do for ourselves, and serves those among us who cannot, with dignity and grace.

Perhaps the community I speak of was best characterized by John Winthrop who when addressing his fellow colonists said:

We must delight in each other.

Make others' conditions our own.

Rejoice together.

Mourn together.

Labor and suffer together.

Always having before our eyes our community as members of the "same body".

A community that shares is a community that cares. This testament to serving others resonates throughout our small state as community partnerships and coalitions come together to serve others.

- In Randolph loggers and locals came together with chain saws and trucks to split, stack and deliver 75 cords of wood for area shut ins.
- In Westminster, the spirit of neighbor to neighbor came together as Mothers and daughters, Fathers and sons, united to provide over 7000 hours of care to a local woman to help her remain in her home.
- Over 100 food shelves, most operated through churches, helped feed over 8600 children last year.
- Volunteers came together all throughout Vermont last year, to deliver meals to over 3600 homebound seniors.

All across our State, Vermonters come together not because they have to but because they want to.

No, the constitution never said we had an obligation to feed the hungry or clothe the poor. There is no law that compels us to house those who have no shelter, or keep warm those who are cold.

We do these things not because we have to. We do these things because we believe in the Vermont spirit. It is this community spirit that I believe will help us carry on during these challenging times.

Perhaps what is called for, as we approach the next century, is a renewal of our vows of service to one another, to restore the lost happiness Grandma Moses mentioned.

I want to thank you for being a gracious and tolerant audience today. I leave you with the wisdom of English clergyman Augustus Hare, who wrote in the early 1800s:

"We need not be afraid that we shall go too far in serving others. There is no danger that any of us will ever go too far in the work of active love. There is no likelihood that any of us will become too bountiful, too kind, too helpful to his neighbor."