

**Your Priorities for Texas Officials** 

### **Disability Policy is Not Partisan**

"Mr. President, my remarks today concern an exceptional group which I joined on April 14, twenty-four years ago, during WW II. It is a minority group whose existence affects every person in our society and the very fiber of our Nation.

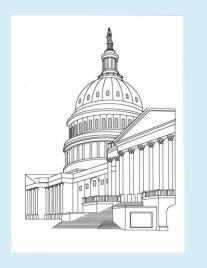
It is a group who no one joins by personal choice - a group whose requirements for membership are not based on age, sex, wealth, education, skin color, religious belief, political party, power or prestige."

U.S. Senator Robert Dole, April 14, 1969 (His first speech on the **U.S. Senate floor)** 

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Core Values, **Outcomes** and Guiding **Principles** within All **Disability Federal** Legislation Today!



### 1978: Independent Living Program

With principles founded on a "philosophy of consumer control, peer support, selfhelp, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals into the mainstream of American society."

Title VII, Rehab Act of 1973, as amended, Section 701

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### 1978 Amendments to DD Act (P.L. 95-602)

- Functional definition of developmental disabilities as having a life-long impact in 3 or more major areas
  - Self-care
  - Communication
  - Learning
  - Mobility
  - Self-choice
  - Independent living
  - Economic self-sufficiency

# **Developmental Disabilities Act** of 1984 (P.L. 98-527)

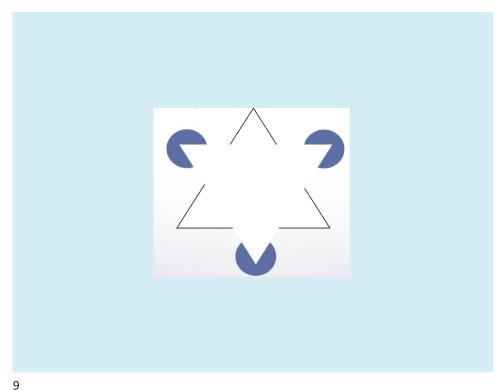
- Added new emphasis persons with developmental disabilities receive services to achieve their best through living and working in the community
- Independence, Productivity and Integration in the Community added as goals, with terms defined

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### **Policy of DD Act**

"(2) individuals with DD and their **families** have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique

strengths, resources, priorities, concerns, abilities and capabilities of such individuals..."



# **Perception is Reality**

What we believe to be true is the basis of our personal reality and the key to how we experience the world around us.

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# **Presumption of Employability and Competency:**

"Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."

Albert Einstein

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# **Arc of the United States** mission statement

"The Arc of the United States promotes and protects the human rights of persons with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetime."

# **United Cerebral Palsy**

The mission of UCP is to advance the independence, productivity and full citizenship of people with a spectrum of disabilities.

Life without limits for people with disabilities

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# **Autism Society of America**

- Vision: ...meaningful participation and self-determination in all aspects of life for individuals on the autism spectrum and their families;
- Advocating for inclusion, participation & self-determination in all aspects of life for individuals on the autism spectrum and their families.

#### **ALLIANCE FOR FULL PARTICIPATION, 2005**

- We want dignity and respect for all.
- We want full participation for all.

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### **ADA Findings P.L.101-336; 1990**

"The continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity."

# Goals of the Americans with Disabilities Act of 1990

- The nation's proper goals regarding individuals with disabilities are to assure:
  - Equality of Opportunity
  - Full Participation
  - Independent Living
  - Economic Self Sufficiency

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### **ADA INTEGRATION MANDATE**

"A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities "

28CFR section 35.130(D)

# **OLMSTEAD vs. L.C. & E.W.:** Supreme Court Decision (June 1999)

1. What Did the Supreme Court Say?

A. The ADA is a fundamental civil rights statute!

B. The Court acknowledged that Congress found that discrimination against people with disabilities includes segregation, isolation & institutionalization

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# Advocate / Artist Lois Curtis **Attorney Sue Jamieson** ALLAN I. BERGMAN High Impact Mission-based Consulting and Training

### DOJ on the ADA, June 22, 2011

The <u>"most integrated setting"</u> is defined as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."

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### Abraham Lincoln said:

"The people know their rights, and they are never slow to assert and maintain them when they are invaded."

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# Adapting to the "New Normal"

- ▶ Metrics and measurement; accountability
- ▶ All costs must produce clear measurable outcomes; cost effective
- ▶ Equity in resource allocation & incentives
- Pockets of excellence must be scalable
- Disparities in outcomes addressed
- Sustainable value that can be quantified
- ▶ Transformational policy across state agencies & in all community providers, infrastructure changes, and capacity building are essential in every state now!

Vision.....

# "The only thing that is constant is change.'

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Heraclitis

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"Suit the Actions to the Words" "Life is not a Program"

A Person is Not a Diagnostic Label

# Wisdom from President John F. Kennedy

"The great enemy of the truth is very often not the lie deliberate, contrived and dishonest but the myth persistent, persuasive, and unrealistic."

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### The Fringe Benefits of Failure and the Importance of Imagination

"IT IS IMPOSSIBLE TO LIVE WITHOUT FAILING AT SOMETHING, UNLESS YOU LIVE SO CAUTIOUSLY THAT YOU MIGHT AS WELL NOT HAE LIVED AT ALL - IN WHICH CASE, YOU FAIL BY DEFAULT."

> J.K. Rowling, Commencement Address, Harvard University, June 5, 2008

# THE ULTIMATE TEST OF POLICY IS YOUR BUDGET

- Many words of law represent hollow promises for individuals with disabilities;
- No incentives or accountability for valued outcomes and results; must develop outcomes and incentives!
- We need to talk about ROI?
  - A return on investment to the government and, thus, the tax payer?

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### Words That Work: It's Not What You Say, It's What People Hear by Frank Luntz

"You can have the best message in the world, but the person on the receiving end will always understand it through the prism of his or her own emotions, preconceptions, prejudices, and preexisting beliefs...The key to successful communication is to take the imaginative leap of stuffing yourself into your listener's shoes to know what they are thinking and feeling in the deepest recesses of their mind and heart. How that person perceives what you say is even more real, at least in a practical sense, than how you perceive yourself." 2007

# The Power of Language

- Words create images
- Values are formed early in life
- Stereotypes, stigma and prejudice are learned behaviors
- Use terms of dignity and respect to promote citizenship
- Watch your language.....pity and charity
  - Handicapped; Wheelchair Bound;
  - Most Vulnerable; SpecialNeed; Meltdown
  - High Functioning- Low Functioning
  - Mental age of a ...... Year old
  - Compassion

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### **DISABILITY CONSTRUCT IN MULTIPLE FEDERAL LAWS**

- "Disability is a natural part of the human experience and in no way diminishes the right of individuals to:
  - Live independently
  - Enjoy self determination
  - Make choices
  - Contribute to society
  - Pursue meaningful careers
  - Enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.



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# How you can help?

Reach out and begin to develop (or continue to develop) relationships with Members and their staff and educate them about what issues are important for them to learn about and help address today and the rest of this year!!!

### **ALL MEMBERS VOTE AND THEY WORK FOR YOU!**

Members need to hear both the data, and the stories that demonstrate both the problem and if known, a proposed solution.

Continue to be in touch with staff in the offices throughout the year by sharing information about what is happening in Minnesota.

### **Protecting Medicaid: Our Message**

- Medicaid helps a wide cross-section of Americans
  - Largest payer of long-term supports and services
  - Supports seniors and people with disabilities to have valued roles and to live, learn, work and play in the community
  - · Helps kids and working families stay healthy
- Medicaid works. It's efficient and has improved people's health and their lives.
- Cutting Medicaid at the federal level hurts states
- Cutting Medicaid doesn't make health care needs go away – it just passes on the costs
- Do NOT use the terms "Entitlement" or "Welfare" as these have negative meaning to many Americans

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### **Creating Your Personal Message** about Medical Assistance

- Individuals with disabilities of all ages & families have to be mobilized
  - Need to understand that everyone is impacted
  - Need to think about what role Medicaid has played and is playing in early intervention, preschool and K-12 IEPs
  - Need to think about what role Medicaid has played and is playing in your access to affordable health and mental health care
  - Need to think about what role Medicaid HCBS waivers or state plan services, Money Follows the Person and Medicaid Personal Care Services have played and are playing in your life as an integrated member of your community
  - Need to think about what the loss of any of these protections and services will mean to your current quality of life and what that means for your future!

### Call To Action!!!

"The strength of our democracy depends on citizens getting involved and engaging our government."

League of Women Voters of the United States

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**Quote from Nelson Mandela,** Activist...

"Education is the most powerful weapon which you can use to change the world."

Motivation from U.S. Supreme Court Justice, **Ruth Bader Ginsburg** Fight for the things you care about but do it in a way that will lead others to join you."

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**Authentic Leadership, Bill George** 

" Authenticity has become the gold standard for leadership."

Harvard Business Review, 2015

### **Authentic Leaders, defined, 2003**

People of the highest integrity, committed to building enduring organizations...who have a deep sense of purpose and are true to their core values who have the courage to build their companies to meet the needs of all their stakeholders, and who recognize the importance of their service to society."

**Bill George** 

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# **Authentic Leadership: Qualities**

- Built on your character, not your style; flexible to meet situations; coach, mentor, dismissals in difficult situations
- Real and genuine; can't fake it; trustworthy and willing to learn
- Constantly growing from experiences
- Match behaviors to their context; selfmonitoring; use EQ to communicate
- Not perfect nor do they try to be; make mistakes, admit them & learn from them
- Sensitive to the needs of others

"Let the shameful walls of exclusion finally come tumbling down." President George H.W. Bush, July 26,1990



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# "Equal Justice Under the Law"



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### FOR ADDITIONAL INFORMATION

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