



Advance Your Advocacy: Techniques, Tips, and Technology

Dr. Melody Parsons, DNP, MS, RN, CNE Westminster, Colorado July 2024

# Dr. Melody Parsons

### Education:

Associate RN – 2000
BSN - 2009
MSN in Education 2012
DNP in Educational Leadership 2018 Certification:

•NLN  $CNE^{\bigcirc}$  2015

### Practice:

•Specialized in maternal newborn, mental health, and hospice. 25+ years of nursing practice

### Nurse Educator:

•18+ years of faculty experience in classroom, clinical, online.

•Current Roles:

-Content expert and developer at a national nursing education publishing firm.

-Online educator at SDSU (MSN courses)

### Personal Experience:

Primary Caregiver of an adult son with Sotos



### Goals

 Discuss advocacy as a way of life for those in the Sotos community

 Introduce tools to promote advocacy using a person-centered framework

• Offer tips for use of simple technology to advance your advocacy

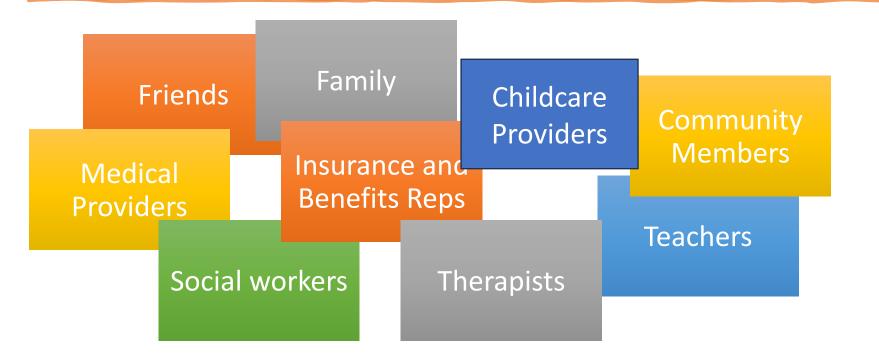




### Your Role as Advocate

Self Caregiver Friend Professional

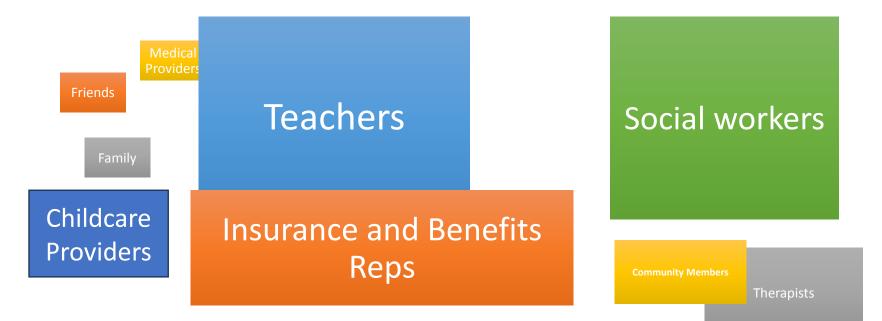
# Need to Know vs. Nice to Know



# Nice to Know

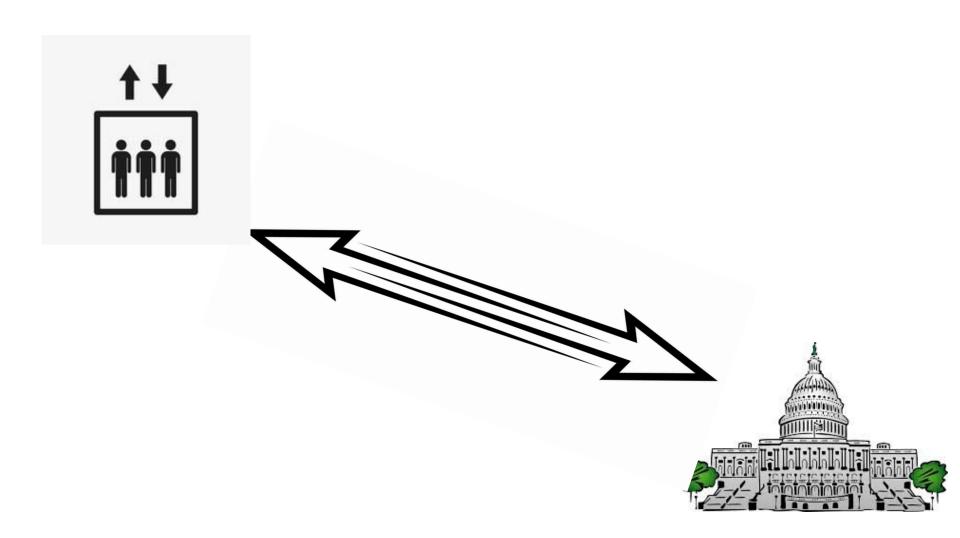


# Need to Know



# Need to Know





#### **PERSONAL STRENGTHS & ASSETS**

Skills, personal abilities, knowledge or life experiences; Strengths, things a person is good at or others like and admire; Assets, personal belongings and resources

#### TECHNOLOGY

Personal technology anyone uses; Assistive or adaptive technology with day to day tasks; Environmental technology designed to help with or adapt surroundings

#### RELATIONSHIPS

Family and others that love and care about each other; Friends that spend time together or have things in common; Acquaintances that come into frequent contact but don't know well

#### COMMUNITY BASED

Places such as businesses, parks, schools, faith-based communities, health care facilities; Groups or membership organizations; Local services or public resources everyone uses

#### ELIGIBILITY SPECIFIC

Needs based services based on age, geography, income level, or employment status; Government paid services based on disability or diagnosis, such as special education or Medicaid

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#### ersonal Strengths & Assets

Finding common ground related to sports or regional food. Loves Trivia Cares for older adults or people who need assistance.

Video Games / I-pad (For Fun!) Siri on watch!

Strength

S

Mom and Dad Siblings, aunts, uncles, cousins.

**Special Olympics** 

Adult day program

**Community Based** 

Shared Living (Happy to be with mom and dad)

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#### Personal Strengths & Assets

Sports talk: Doesn't pick up on subtle social cues Trivia: Has trouble following rules for structured games Physical limitations: balance, coordination, stamina.

Needs

Risky online content (not a great filter).

Doesn't use tech as a tool for independence. Doesn't facilitate friendships or social events.

Can lack boundaries.

Needs support for community involvement.

No respite available.

Many requirements (unable to do without support).

Complex health care needs.

**Community Based** 

Eligibility Specif

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**Personal Strengths & Assets** 

#### Strength: Talking with others (not shy)

#### **Need: Tires Easily**

Tool: Talk to text with Mom and Dad on apple watch

Goal: Doesn't **Navigate Money** without help (debit card someday?)

Current: Facilitated Day Group, or family connections.

Dreams: Independent Friends?

Now:

Mom and Dad Medicaid/Medicare SSI and ABLE

Future: Guardian planning (Siblings or Residential?)

Relationship

Need: Job Coach and Vocational Rehab

Goal: Competitive Employment?

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**Community Based** 

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# How do you keep it all straight?

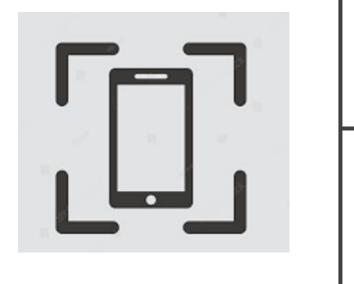
Phone calls
Appointments
Records
Photos
Medications
Specialists
Multiple Diagnoses and Therapies
Financial support
Insurance
Individualized Education Plans (IEPs)

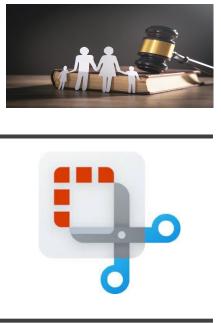
Transition



### Step 1







Medical Records and Patient Portals

- •Legal Rights
- •HIPAA
- •Guardianship
- •Responsible Use
- •Practical Tips





### <u>Multipage</u> <u>Document</u> <u>Scanner</u>





### **External Hard Drive**



Using the cloud for storage and communication

### Why We Advocate



- Understanding, Inclusion, and Acceptance
- A Full Life Experience
- Future Planning

# **Discussion**

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