



# Advance Your Advocacy: Techniques, Tips, and Technology

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# Dr. Melody Parsons

## Education:

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

## Certification:

- NLN CNE<sup>©</sup> 2015

## Practice:

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



## Nurse Educator:

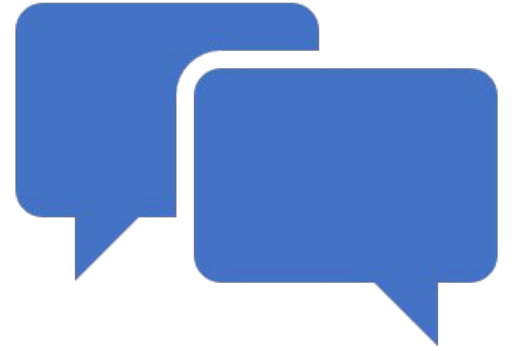
- 18+ years of faculty experience in classroom, clinical, online.
- Current Roles:
  - Content expert and developer at a national nursing education publishing firm.
  - Online educator at SDSU (MSN courses)

## 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

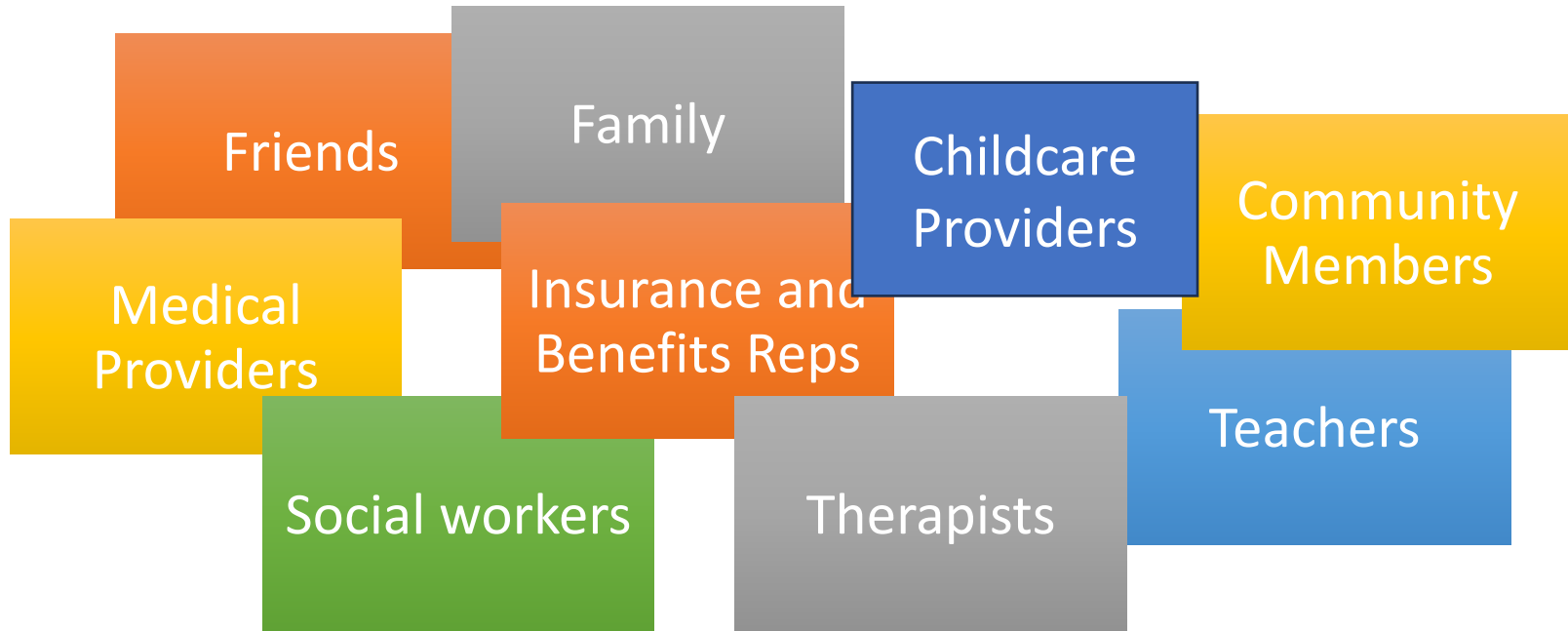
Caregiver

Friend

Professional

# Need to Know vs. Nice to Know

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# Nice to Know

Friends

Community Members

Childcare  
Providers

Insurance  
and Benefits  
Reps

Teachers

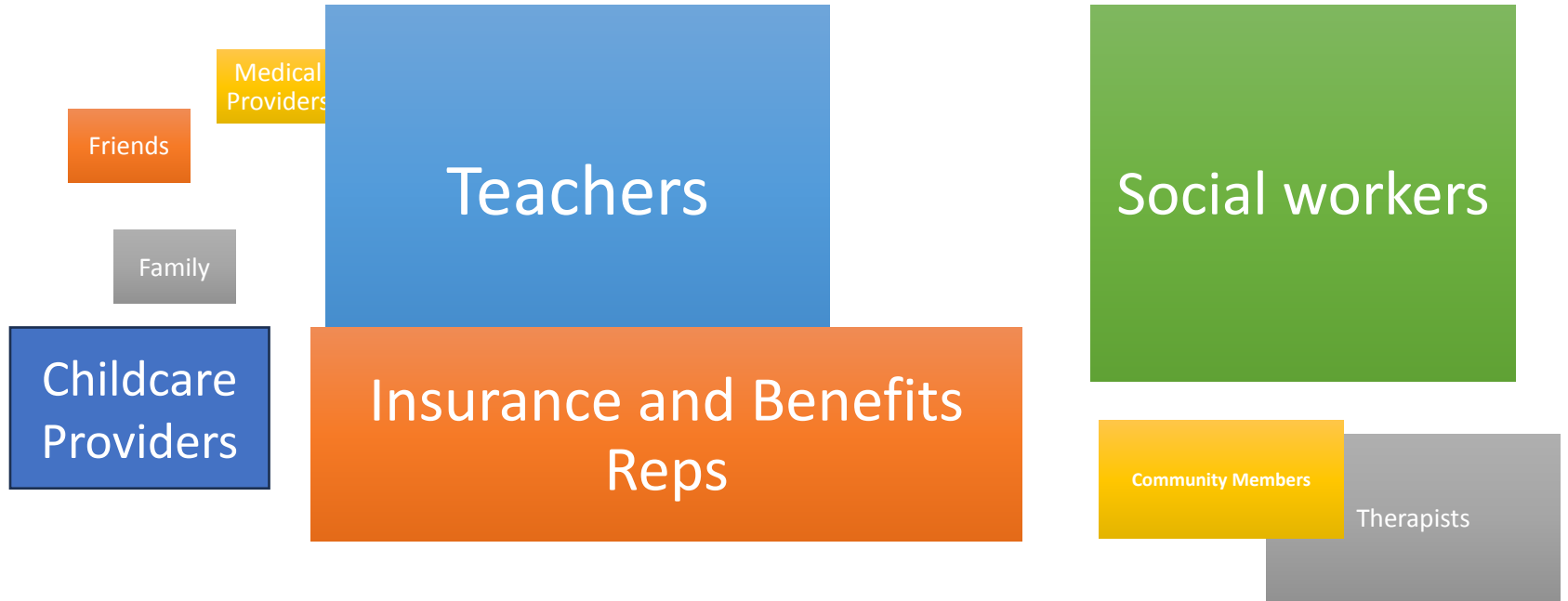
Therapists

Social  
workers

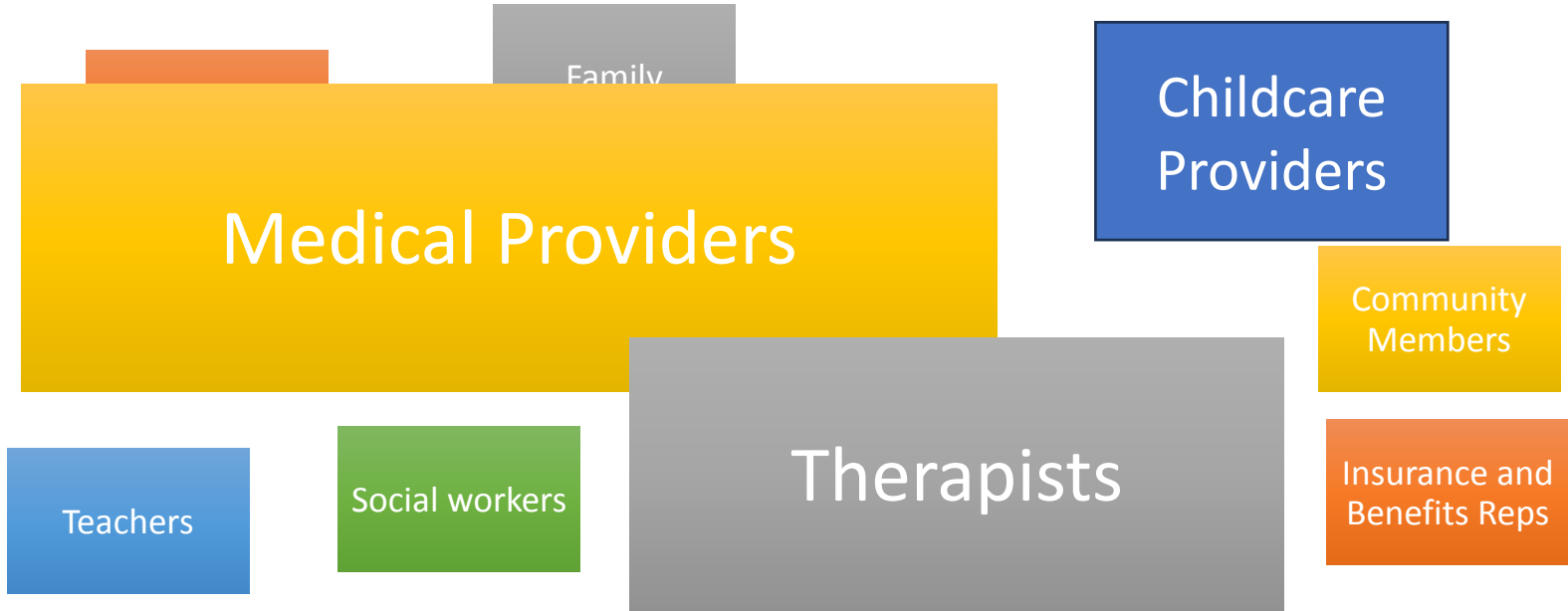
Medical  
Providers

Family

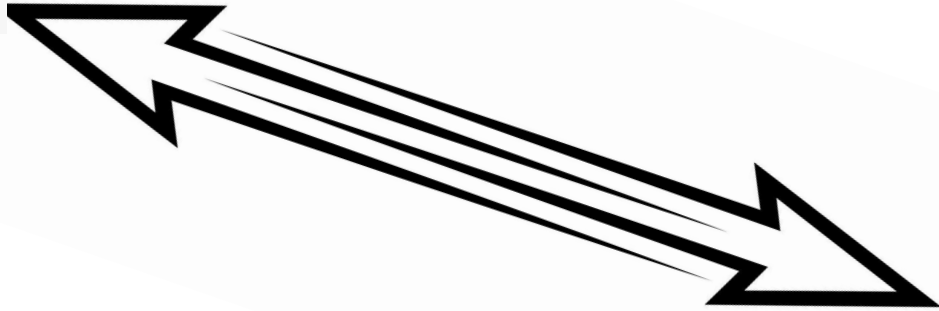
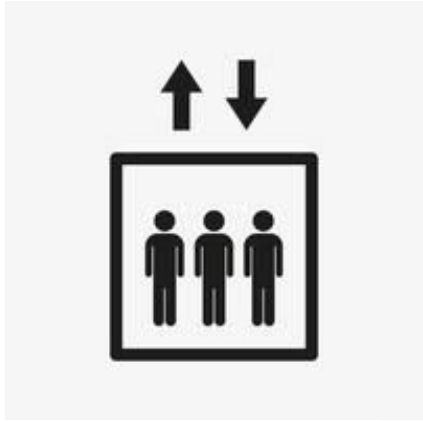
# Need to Know



# Need to Know











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

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**

Needs support for community involvement.

No respite available.

Many requirements (unable to do without support).

Complex health care needs.

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?

Technology

Relationships

Need: Job Coach and  
Vocational Rehab

Goal: Competitive  
Employment?

Now:  
Mom and Dad  
Medicaid/Medicare  
SSI and ABLE

Future: Guardian  
planning (Siblings or  
Residential?)

Community Based

Eligibility Specific



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# How do you keep it all straight?

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Phone calls

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Appointments

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Records

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Photos

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Medications

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Specialists

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Multiple Diagnoses and Therapies

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Financial support

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Insurance

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Individualized Education Plans (IEPs)

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Transition



Step 1







## Medical Records and Patient Portals

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



MyChart

# Multipage Document Scanner





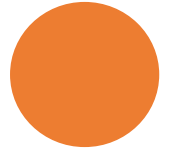
External Hard Drive



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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