SOTOS SYNDROME SUPPORT ASSOCIATION

Advance Your Advocacy: Techniques, Tips, and Technology

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Westminster, Colorado
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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© 2015

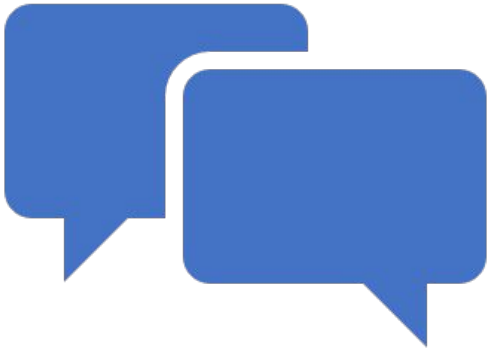
Practice:
•Specialized in maternal newborn, mental health, and hospice.
25+ years of nursing practice

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

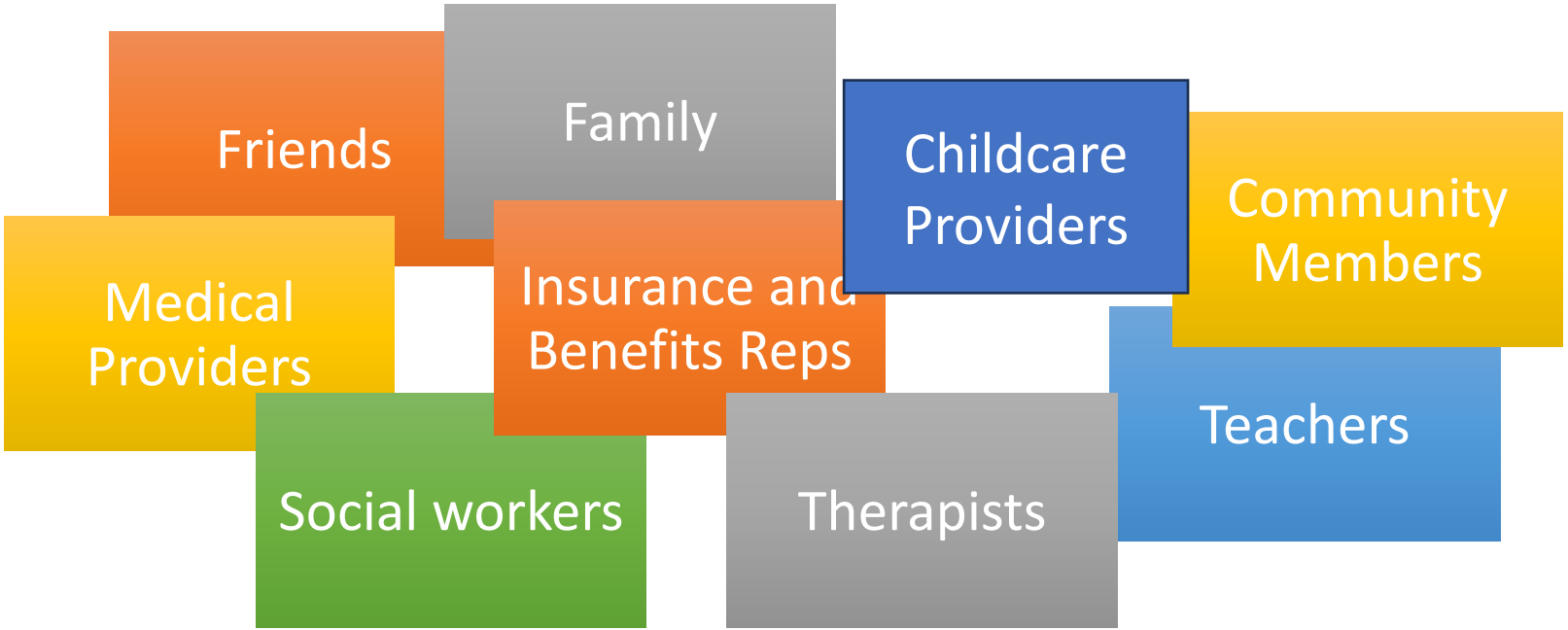
Self

Caregiver

Friend

Professional

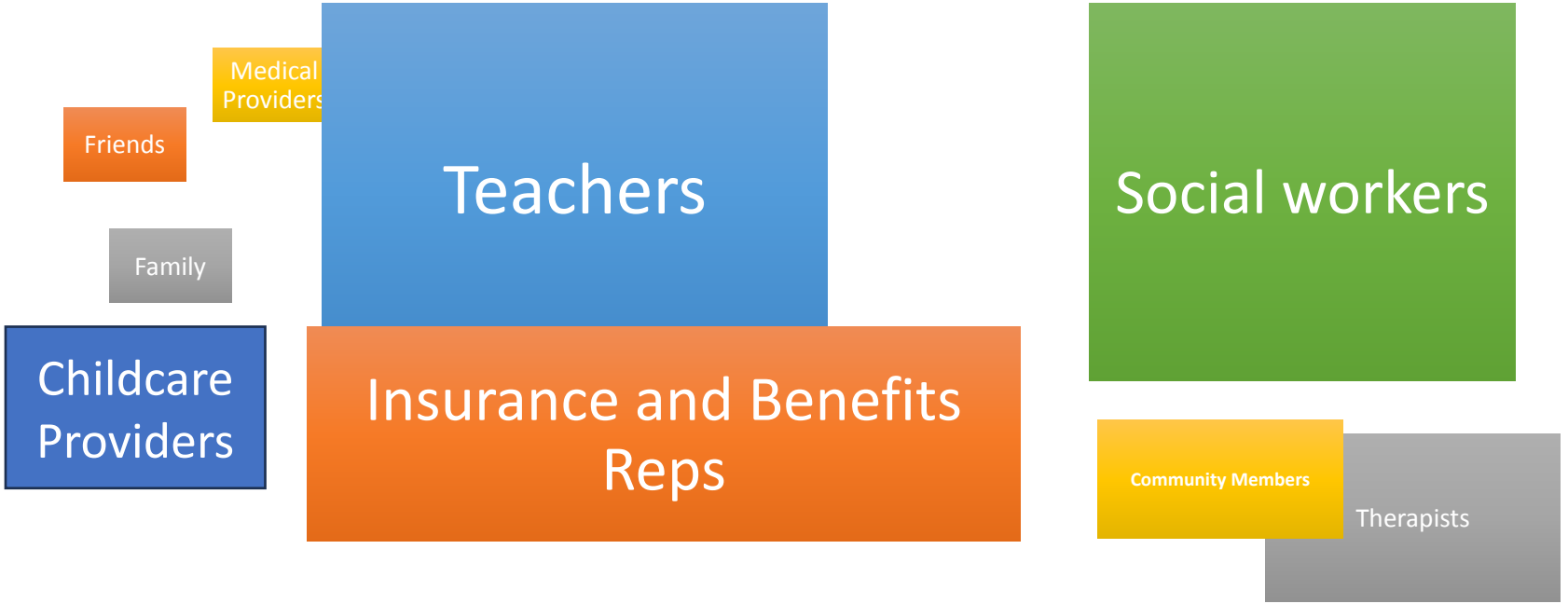
Need to Know vs. Nice to Know



Nice to Know

Friends
Community Members
Teachers
Insurance and Benefits Reps
Childcare Providers
Therapists
Social workers
Medical Providers
Family

Need to Know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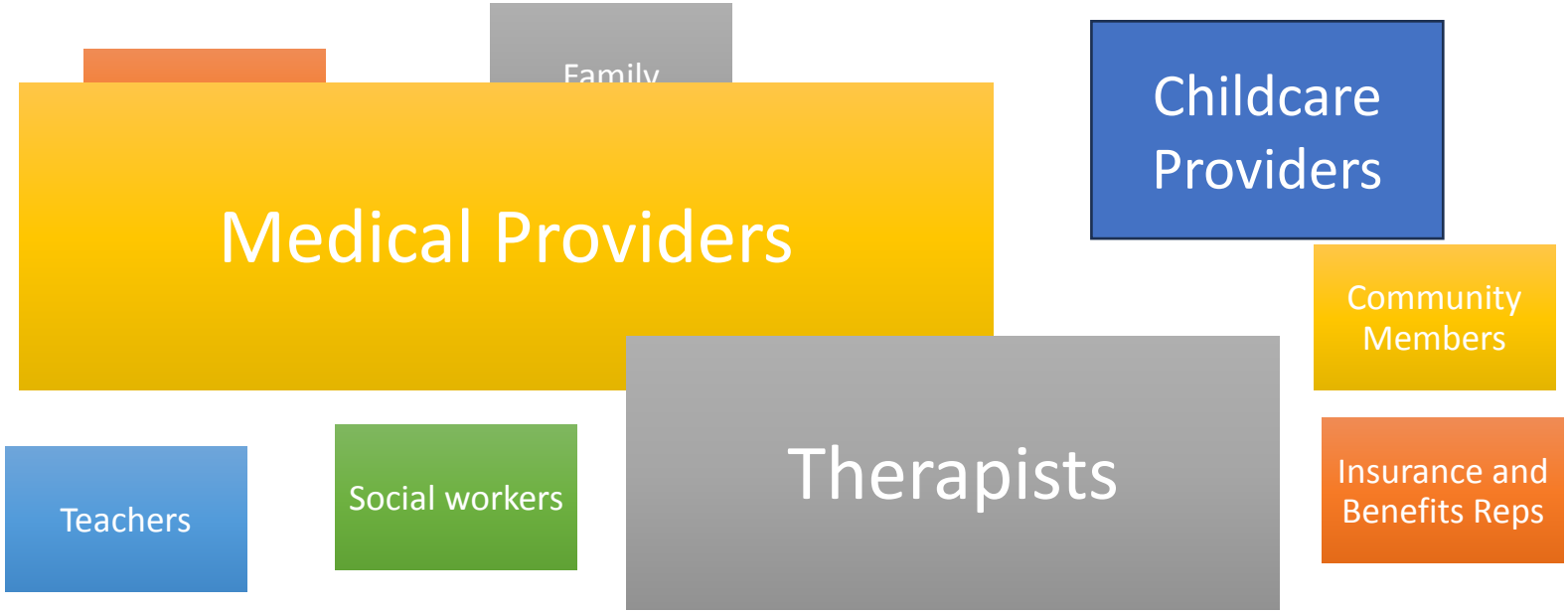
Need to Know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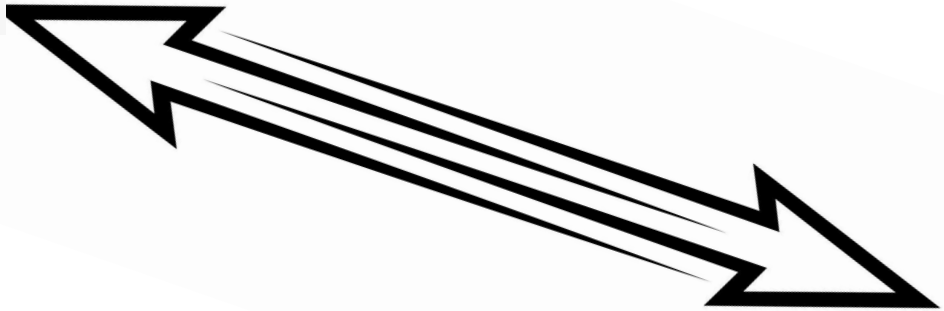

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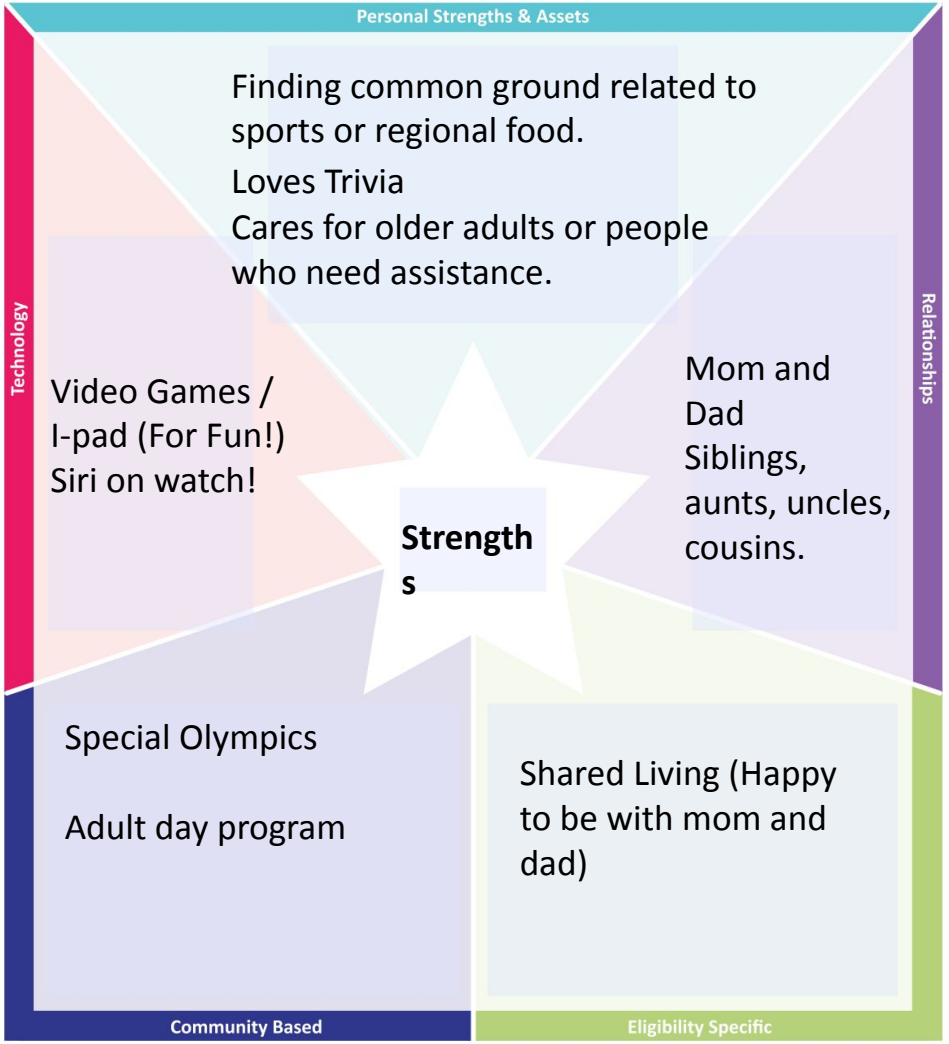

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How do you keep it all straight?

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

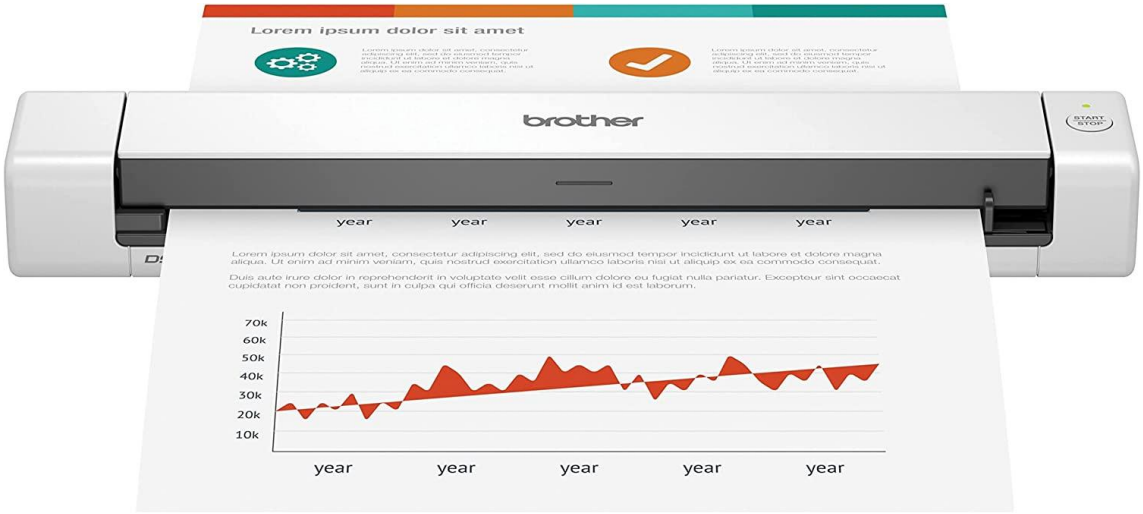
Step 1

Medical Records and Patient Portals

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

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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