The Right to Communicate: Putting theory into practice

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ASAN
AUTISTIC SELF ADVOCACY NETWORK

Who Are We?

- Nation's largest advocacy group by and for autistic people ourselves
- All-Autistic leadership, plus majority of Board is autistic – including people with significant communication and support needs
- 21 Chapters Nationwide, plus international affiliates and partners

Communication and SDM

- Understanding information
- Expressing preferences, desires, feelings, decisions
- Putting decisions into practice (e.g., financial transactions, consent forms)

Effective Communication Rights

- IDEA: Right to “Free Appropriate Public Education”

- ADA Titles II and III: “Auxiliary Aids and Services”
  - Communication must be as effective as with people without disabilities
  - Includes receptive and expressive
  - Focus on preferred form of effective communication
  - Different terminology – e.g., translators, interpreters, communication support persons, etc.
  - “Fundamental alteration” and “undue burden” defenses
- ACA (right to habilitative services)
- Medicaid (EPSDT, adaptive equipment)
- Guardianship law (right to less restrictive alternatives)

“Everyone Communicates” Toolkit

http://odpc.ucsf.edu/communications-paper

Assessments

- Useful for establishing need for communication supports and, sometimes, for figuring out which supports will work

- Competent assessment must:
  - Evaluate sensory, motor impairments – not just cognitive
  - Identify which forms of communication a person already uses
    - Person must be able to *use* these forms of communication during assessment
  - Make recommendations for effective communication supports
  - Involve a credentialed professional with a background in communication – *not* in behavior modification

Choosing Communication Methods

- Match supports to communication needs
- Prioritize **open-ended communication** over pre-selected word/phrase options
- Pay attention to **training requirements** – both for the individual and the supporters. It may take significant time to learn to use supports effectively
- May need to use multiple different communication methods for different situations (nondisabled people do this too!)

Addressing "Supporter Influence"

- Influence is **not restricted to certain kinds of communication supports!**

- People who use speech often are influenced by supporter body language and expectations of what they think supporters want to hear

- Be careful of supporters who
  - Insist they are the only person who can communicate with the individual
  - Don't want to train others to assist with communication
  - "Correct" the people they support
  - Believe that their method works for everyone
  - Discredits all of a person's attempts to communicate through other methods

Sources of Communication Supports Funding

- Private health insurance
- Medicaid EPSDT
- IDEA
- State-level agencies (e.g., Regional Centers in California)
- Vocational Rehabilitation
- Americans with Disabilities Act

Private Health Insurance

- May cover physical, occupational, or speech-language therapy
- Some plans cover durable medical equipment, such as speech-generating devices
- May be required to prove that services are “medically necessary”
- All plans have appeals processes – different regulations apply to different plans
- See toolkit for sample letters

Medicaid (under 21)

- EPSDT: requires Medicaid to provide medically necessary services to people under age 21, *even if they are not include in the state plan.* This can include:
  - Evaluations
  - OT, PT, Speech
  - AAC devices and training in how to use them
  - Other communication interventions
- Medicaid agency must provide process for requesting EPSDT service not covered by state plan
- Toolkit discusses Medi-Cal, but the legal requirements for EPSDT are consistent across states

Medicaid (adults)

- Adults may be entitled to:
  - Evaluations
  - OT, PT, Speech therapy
  - Assistive devices
- Fewer protections for those who need services not covered by the state plan
- Appeals Process available

IDEA

- Covers people between 0-21 who have not graduated high school
- Requires school districts to provide:
  - Evaluations
  - Related services, including speech, OT, PT
  - Assistive Communication technology + training on how to use it
  - Special Education Services and Individualized Education Plan for students over 3

Vocational Rehabilitation

- VR offices serve adults and transition-age youth who have “substantial barriers” to employment due to disability and need VR services to help achieve employment
- Communication supports and assistive tech may be covered if a person needs them to work
- “Payer of last resort” – will not cover needs that can be paid through Medicaid

ADA

- Covers public accommodations, state programs, and employers
- Similar law (Rehabilitation Act) covers federal government programs and contractors
- In some situations, ADA requires entities to pay for interpreters or other related services for effective communication. Entities cannot discriminate against people with communication disabilities
- Time-limited – e.g., an employer doesn't have to provide service to someone when they are not on the job or at a work-related event

ASAN DOJ Complaint

- Five Arlington, VA students (two minors, three adults)
- All spell to communicate
- Focusing on ADA Effective Communication Claim
- Possible impact: Guidance to states?
- Complaint online: http://autisticadvocacy.org/2016/03/asan-files-ada-complaint-on-communication-access-in-schools/

ASAN DOJ Complaint

“I am in my last year of high school. I have been in autism classrooms all my years of school. I have never been instructed beyond a second grade level. Stop treating autistics like they can’t learn. Speech is not a sign of intelligence. Everyone needs to be educated. This is my challenge to you—find a way to include nonspeaking autistics.”

“I am clearly capable of learning, yet no school will teach me. This must stop. I am not alone. There are so many like me who do not speak who are being robbed of an education. This is an atrocity that our education system must stop.”

“Nonspeaking autistics like me that want you to know how much they want to learn. I am asking on behalf of those who do not have a voice to hear our plea to teach us.”

Open Discussion