

SLP Roles in AAC/SGD Advocacy

May 4th, 2021

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ASHA CEUs – live webcast

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AAC Disaster Relief

Community Admin



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I Have A Need

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posted 1 day ago by CERV from [Community Emergency Response Volunteers of the Monterey Peninsula](#)

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Individuals who use AAC and their family members can request help or sign...

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New Site added to address needs of people who use AAC and their family members impacted by Hurricane Irma [Edit](#)

SLP Roles in AAC/SGD Advocacy

Tuesday, May 4, 2021

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Advocacy: Definition

- the act or process of *supporting* or *recommending* a particular cause, proposal, or policy
- the act of *speaking* on the behalf of or in support of another person, place, or thing
- The act of *pleading* or *arguing* in favor of something, such as a cause, idea, or policy
- In health care, *pleading* or *representation* for a desired goal or interest group (e.g., patients, staff, providers, or biomedical researchers).
- The profession of an advocate.

SGD Advocacy Goals

To persuade decision-makers or policy-makers to do 3 things:

Individual Focused Outcomes: Say “yes” to an individual client’s request for a SGD

AND

Community Focused Outcomes: Change policies for a client community: e.g., change laws to require SGD coverage or to identify SGDs as example of covered benefits; change policies to accept SGDs as “covered benefits”; adopt standards related to “medical need”; remove SGD exclusions

AND

Procedural / Predictability Outcomes: Create pathways or procedures for SGD access: e.g., adopt guidelines describing required evaluations; trial periods; and reporting

SLP Advocacy Tools: Attitude -1

- *Why Me? Because Everyone Counts*

AAC strategies and tools enabled individuals with complex communication needs to be clients, not patients beyond help

Now I am horrified. . . . I know I have a throat and should be able to scream for someone to take me away. I realize there is no power in my legs, arms, hands, voice, body. I realize that I am paralyzed.

She [a nurse] doesn't speak to me or look me in the face to see if I'm alive, and I suddenly realize that I'm not going to get better. I'm just going to get worse. The nurse, ... is waiting for me to die.

She [the nurse] stops singing and calls another nurse into the room. ...
"This one doesn't got a brain. Can't do nothin' but cry, so don't mind her."

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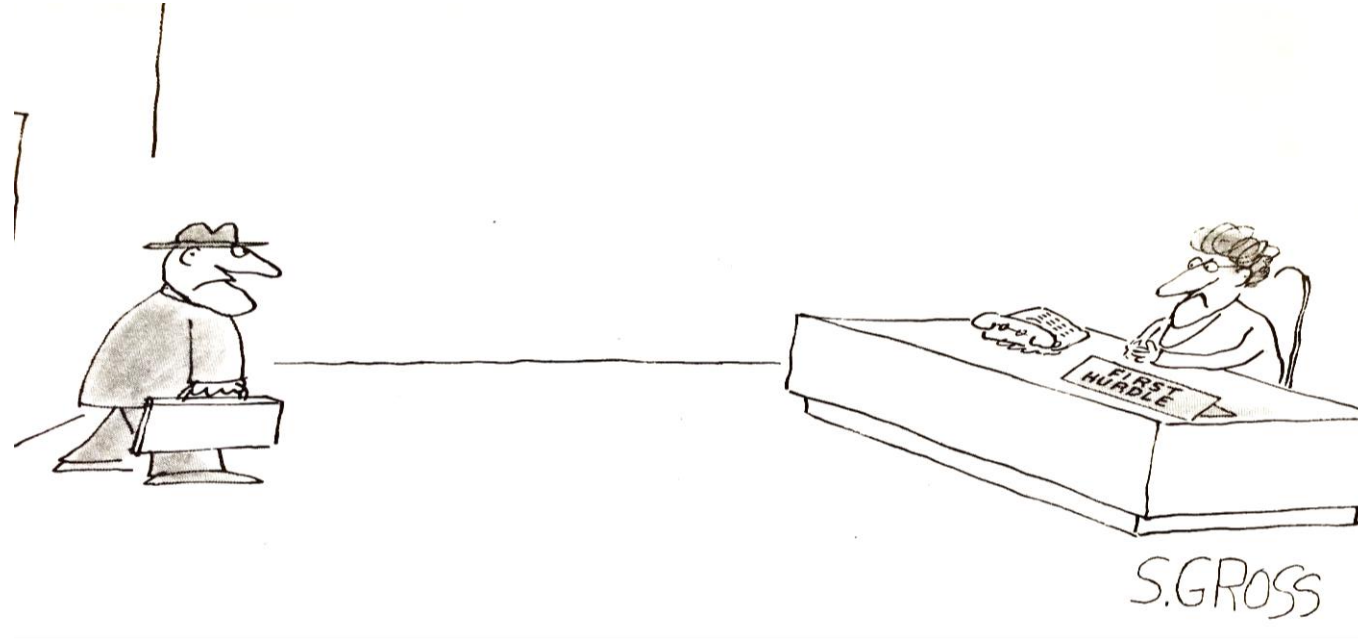
This is no dream: I'm actually being spoken *to*. . . . For the first time in six years, I feel whole. . . . I raise my eyes for *yes*, hardly able to believe that someone is asking permission before she does something to me.

SLP Advocacy Tools: Attitude - 2

- *Why Me? Because you can.*



That's Easy for YOU to Say



- AAC devices often were NOT initially accepted by funding sources:
 - SLPs were new professionals to funding source staff responsible for “devices.”
 - AAC devices were new devices.
 - AAC devices were not curative: why was speech “medical;” what; how did devices “treat”?
 - AAC devices were expensive.

SLP Advocacy Tools: Attitude -2

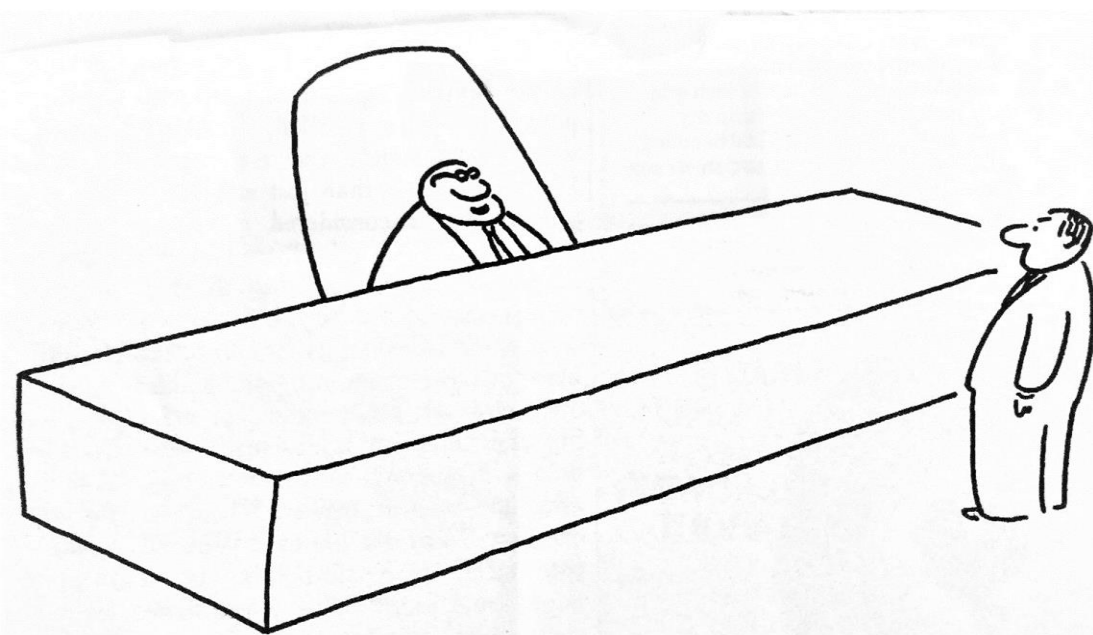
Why Me? Because you must, because you are right, and because most often, no one else is there to help.

- **ASHA Code of Ethics:** SLPs have an affirmative obligation to “hold paramount the welfare of persons they service professionally” and must “use every resource ... to ensure quality service is provided.” [Principle 1; Rule B]
- **Professional pride:** to develop competence in SGD evaluation and treatment, SLPs must elect to pursue additional training, clinical experience and continuing professional education. That investment matters. Clinical judgments and recommendations should be relied on and not challenged or rejected by funding source staff who intentionally disregard good clinical practice or who cannot tell the difference between good and poor clinical practice.



SLP Advocacy Tools: Attitude -3

- As a matter of principle, SLPs rejected “Learned Helplessness”
- Definition [Martin Seligman]: “Learned helplessness is the giving up reaction, the quitting response that follows from the belief that whatever you does not matter.”



Charvotti

“Don’t fight the system, Jessup. The system is good.”



SLP Advocacy Tools: Attitude -4

- SLPs' Respect for Code of Ethics, Professional Pride, and Rejection of Learned Helplessness leads to:
- Refusal to accept “no:”
 - not covered
 - not medically necessary
 - not least costly
 - not effectiveas a final decision.
- Refusal to accept “exclusions” as a final decision.

SLP Advocacy Tools: Knowledge

- To develop competence in SGD evaluation and treatment, SLPs must elect to pursue additional training, clinical experience and continuing professional education.
- SLPs know more about their clients; their conditions; their abilities and limitations; the range of treatment options; how to select among those options; and how to implement these options, than any funding source staff member.
- SLPs also know from experience how this and other funding sources have reviewed requests in prior cases
- Overall, we have far greater knowledge and control of the facts and if we use this advantage wisely, we should control the outcome of funding requests.
- Advocacy is a process of persuasion. Persuasion is not achieved by “declarations” e.g., “you must do something or agree because I am”

SLP Advocacy Roles

Primary Focus		Advocacy Activity
Individual Benefit	Community; Consistency	
✓		Learn key funding program principles and procedures.
✓		Respond persuasively to requests for clarification or for additional information from prior authorization reviewer.
✓		Provide direct representation in appeals.
✓	✓	Establish relationships with and tutor professional advocates about AAC/SGDs.
✓	✓	Collaborate with professional advocates to develop appeal strategies.
✓	✓	Serve as expert witnesses in appeals.
✓	✓	Provide second opinions for appeals for other SLPs' clients.
	✓	Conduct Research.
	✓	Conduct Literature Reviews.
	✓	Join Advocacy Organizations such as USSAAC.

Individual Client Focused Advocacy

SLPs' primary *clinical* role will be identifying treatment needs and recommending most appropriate treatment options for individual clients. Accessing funding assistance for treatment options will be the clinician's primary *advocacy* role.

1 x 1 x 1 = "Rogaine Strategy:" Individual requests and appeals also can be a systemic strategy, but like Rogaine, it ensures SGD access only if it is used again and again, forever. It was applied successfully against NY Medicaid in the 1980s, with 4 professional advocates. But it is almost impossible to maintain over time.

Medicare: Rogaine strategy was tried in 1990s before petition for policy change was filed. Achieved 20 client wins in 7 years. Estimated 60 in 20 years. By contrast, policy change has resulted in 60,250 SGD approvals in 18 years.



Join Advocacy Organizations: USSAAC -1

- JFK: *Ask not* what advocacy organizations can do for you; *ask* what your membership and participation in advocacy organizations can do for your clients and for the AAC community.
- **Advocacy Role # 1:** develop policy or position statements about professional practice: provide reinforcement for SLP actions in evaluation and clinical decision making. Examples:
 - ASHA: SGD use is within the scope of SLP services; SGD use by clients with autism is both effective and evidence-based; AAC treatment goal is for clients to communicate as independently as possible, but not necessarily without assistance from others; if a trial is to be conducted as part of an evaluation, 1 trial not multiple trials
 - NJC: no condition or diagnosis based eligibility criteria
 - USSAAC: professional purpose of SGD trial is to confirm client interest; understanding of SGD operation; ability to use SGD; and benefit from use – it is NOT a performance test; SGDs are not convenience items; SGDs are appropriately covered as DME; framework for requesting employer sponsored health plans to remove SGD exclusions

Join Advocacy Organizations: USSAAC -2

- **Advocacy Role # 2:** Advocacy organizations can participate in proceedings (appeals, rulemakings, petitions, court actions) to establish, expand or protect SGD coverage and access Examples:
 - **Court Challenges:**
 - Nevada Medicaid – USSAAC was a party in successful court challenge to decision by Medicaid to drop SGD coverage
 - Michigan Medicaid – USSAAC was a party in successful court challenge to refusal by Medicaid to cover SGDs for “habilitative purposes” for adults
 - New York Medicaid – USSAAC was a party in successful court challenge to Medicaid demand that clients show “proficiency” or “competency” in SGD use to be eligible for device purchase
 - Medical Mutual of Ohio – USSAAC was a party in successful court challenge to insurer’s use of SGD coverage guideline that authorized SGD-type by client vocabulary size
 - **Rulemaking Proceedings:**
 - California Telecommunication Equipment Distribution Program – USSAAC is a party in ongoing rulemaking proceeding before CA Public Utilities Commission to develop coverage criteria for SGD coverage
 - Medicare: USSAAC was a party in all Medicare proceedings related to SGD access: development of coverage policy (2001); expansion of SGD coverage (2001; 2015); authorization of telepractice delivery of SGD evaluation and treatment (2021).

Join Advocacy Organizations: USSAAC - 3

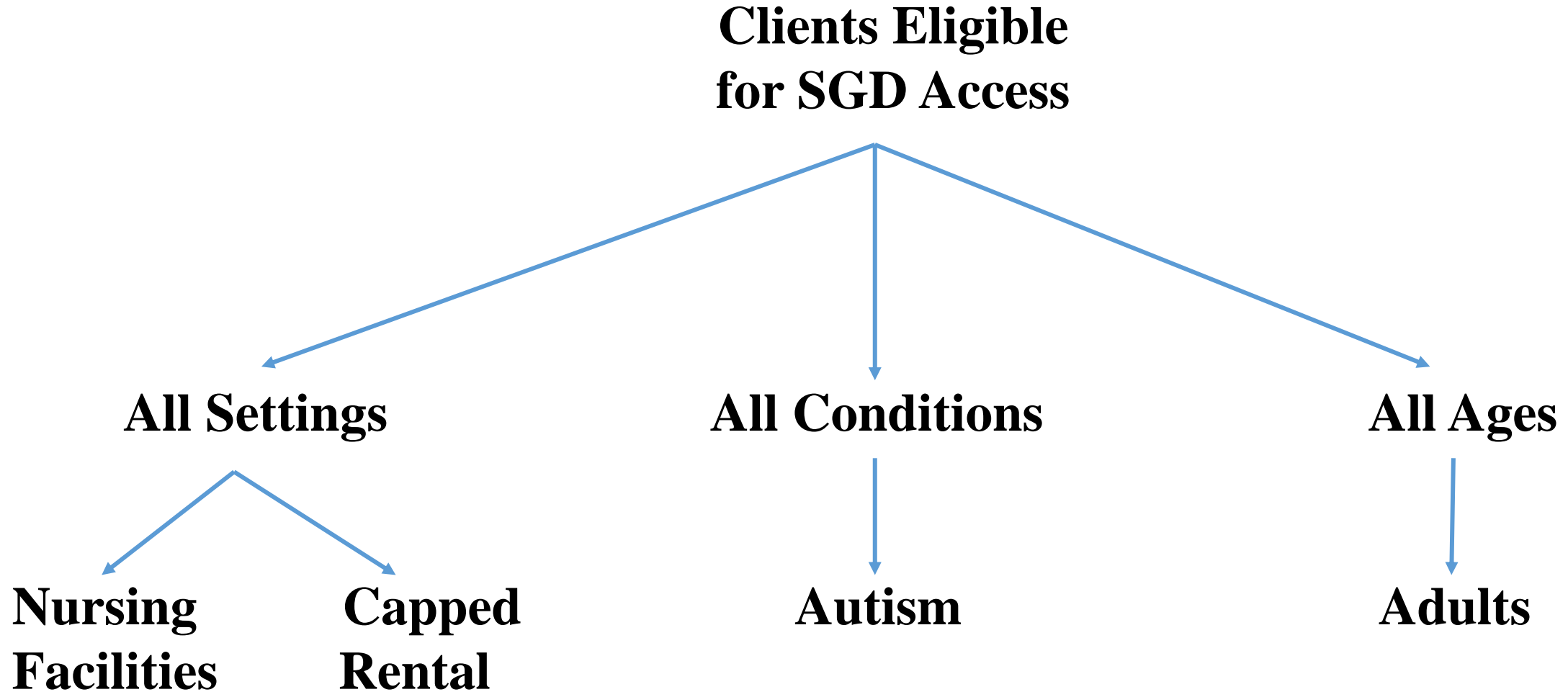
- **Advocacy Role # 3: Institutional Memory**
 - Examples related to SGD funding practices: USSAAC maintains records of all court actions and decisions related to SGD coverage; partial database of insurer and health plan SGD coverage; records of all efforts to remove employer sponsored health plan SGD exclusions; actuarial report of costs of SGD coverage in group health insurance; records of insurer coverage of SGD for individual with autism because state autism treatment mandate statute pre-empted SGD exclusion in insurance policy;
 - Examples related to Professional literature reviews: USSAAC maintains and updates a database of published peer-reviewed professional literature that supports the conclusion that SGD use by individuals with autism is effective. This resource has been used to challenge insurer guidelines that state SGD use by individuals with autism is investigational.

Join Advocacy Organizations: USSAAC – 4

- **Advocacy Role # 4:** Change funding sources structurally to establish, expand or protect SGD access; develop pathways & frameworks for professionally sound, predictable and consistent SGD funding decision making.
Examples:
 - Autism Speaks persuaded almost every state to enact autism treatment mandate laws. Team Gleason persuaded Congress to Protect Medicare recipients from loss of SGD access if they require nursing home care.
 - USSAAC negotiated with Michigan and New York Medicaid and Medical Mutual of Ohio to change their SGD guidelines to expand SGD access.
 - USSAAC petitioned Medicare to adopt and then expand its SGD coverage guidelines (2001) and to authorize telepractice delivery of SGD evaluation and treatment (2021); and provided comments to support Medicare's reconsideration of its SGD guidance (2015).
 - USSAAC persuaded employers covering more than 2.5 *million* workers and family members to remove SGD exclusions from their health benefits plans.

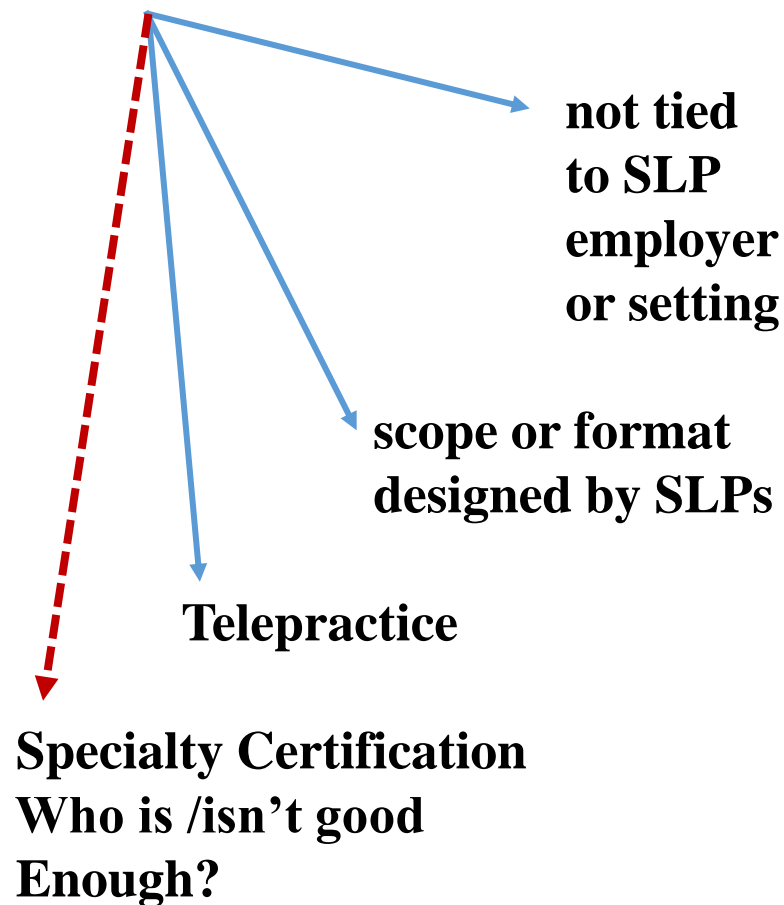


SLPs as Catalysts for Issue Resolution

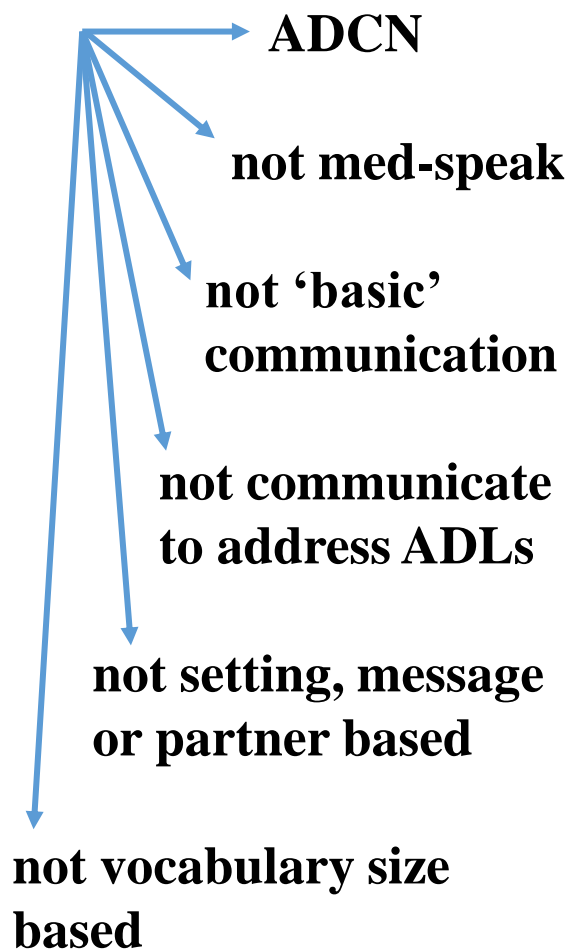


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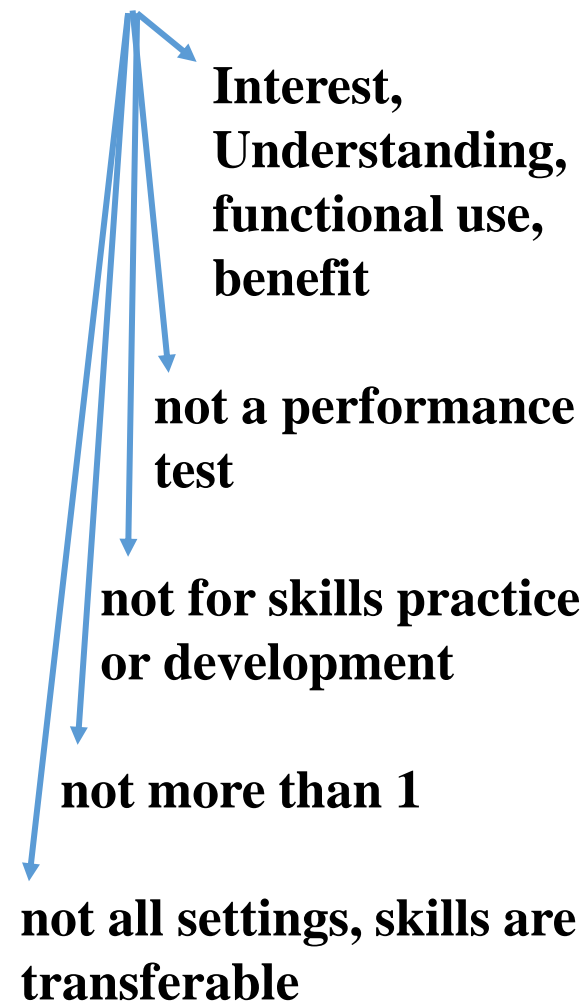
Evaluation



Standard of Need



Trials



Remove Exclusions



SLP Advocacy in Context

	SLP says “yes”	Funding source representative says “no”	
	Who is the Decision-Maker or Policy-Maker to rely on? What does the funding source representative bring to the table?		
1	SLP – education, CCC	Maybe	Maybe not
2	Individual training, clinical practice, continuing education	Maybe	Definitely not
3	Research; Presentations; Courses about AAC/SGDs	Unlikely	Definitely not
4	State employee (e.g., university faculty)	If Medicaid, yes, but not professor	
5	Funding experience: same condition; same SGD; same funding source; other funding sources	Maybe	Definitely not
6	Evaluation and recommendation consistent with professional practice standards	Unlikely to have basis to contradict	
7	Evaluation and recommendation consistent with professional literature	Unlikely to have basis to contradict	
8	Evaluation and recommendation consistent with funding source guidelines (or Medicare)	Maybe claimed; question of fact whether true	
9	Evaluation and recommendation consistent with past practice of same funding source	Maybe claimed; question of fact whether true	
10	Evaluation and recommendation consistent with past practice of other funding sources	No	
11	Evaluation and recommendation supported by second opinion of other SLP(s)	No	

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Why AAC/SGD Advocacy Matters

- “Without a doubt, my inability to speak has been the single most devastating aspect of my handicap. If I were granted one wish and one wish only, I would not hesitate for an instant to request that I be able to talk, if only for one day, or even one hour.”
- ‘On June 8, it will be six months since my new life began.’ . . . Those were the first words of the first mailing of my monthly letter . . . [T]hat first bulletin caused a mild stir and repaired some damage caused by rumor The gossipers [in Paris had] left no doubt that henceforth I belonged on a vegetable stall and not to the human race. . . . [In response,] I would have to rely on myself if I wanted to prove that my IQ was still higher than a turnip’s.
- Will was, is, and always will be my son, and regardless of his disabilities and his needs, I have tried and will continue to try to satisfy them. But Will knows first and best when he has needs, what he wants help with, and whether the help he gets is on target. With his SGD he can tell us all of these things. Without it, he cannot. And, with this device he can be so much more than a little boy with needs -- he can just be a little boy.
- The day Will got his communication device was as important as the day he was born: one gave him life; on the other, he became a whole person.



"Not only have my eyes glazed over—they have turned completely into cinnamon rolls."



"I'm glad you said that."



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Next webinar:

September 15th, 2021

Vicki Clarke





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