

HOW TO OVERCOME ACCESS BARRIERS TO SGD FUNDING February 15, 2017, 7 p.m.

Presenter:

Lewis Golinker, Esq.
Director, Assistive Technology Law Center
USSAAC Advocacy Director
401 East State Street, Suite 300
Ithaca, New York 14850
607-277-7286 (v)

Igolinker@aol.com (e-mail)

"You know you've won when things become routine."

Gail Collins, NY Times, 5/21/2011

For SGD funding, *routine* means:

- Widespread coverage among funding programs
- Supported by professionally sound coverage guidelines
- That are reasonably interpreted and
- Consistently applied.

- "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 nothing' but cry, so don't mind her.'
- [This continued for *six years* until the client was approached by Arlene Kraat, who served in 1991-92 as the President of ISAAC. The following was reported about this encounter:]
- 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."

Generally accepted description of SGD medical need:

medical need for an SGD is established when an individual with complex communication needs is unable to meet daily communication needs using speech or other natural communication methods

Historic excuses: SGDs are not "medical:"

- SGDs don't treat a condition; only effects
- Speech is not "medical"
- Speech is a "convenience"
- Signing, writing, pointing is enough
- 24 hour staff is available to meet all medical needs

Historic excuses: content of speech or characteristics of partner:

- "medical words" only
- communicate health needs or to get health care
- communicate with care providers
- communicate to get basic needs met

Historic excuses: focus on place of use and evaluator:

- Educationally necessary, not medically necessary if used in school or if on IEP
- · Educationally necessary, not medically necessary if evaluator is school SLP

Andrew has a burn scar on his hand which occurred because he couldn't tell his attendants at school that they had pushed him up against a radiator and locked his wheels in a position where his hand was trapped to sear until the flesh melted off.

Affidavit of J. Frumkin, Feb. 11, 1995, para 80 submitted in *Myers v. State of Mississippi* No. 3:94-CV-185 LN (S.D. Miss. June 23, 1995)

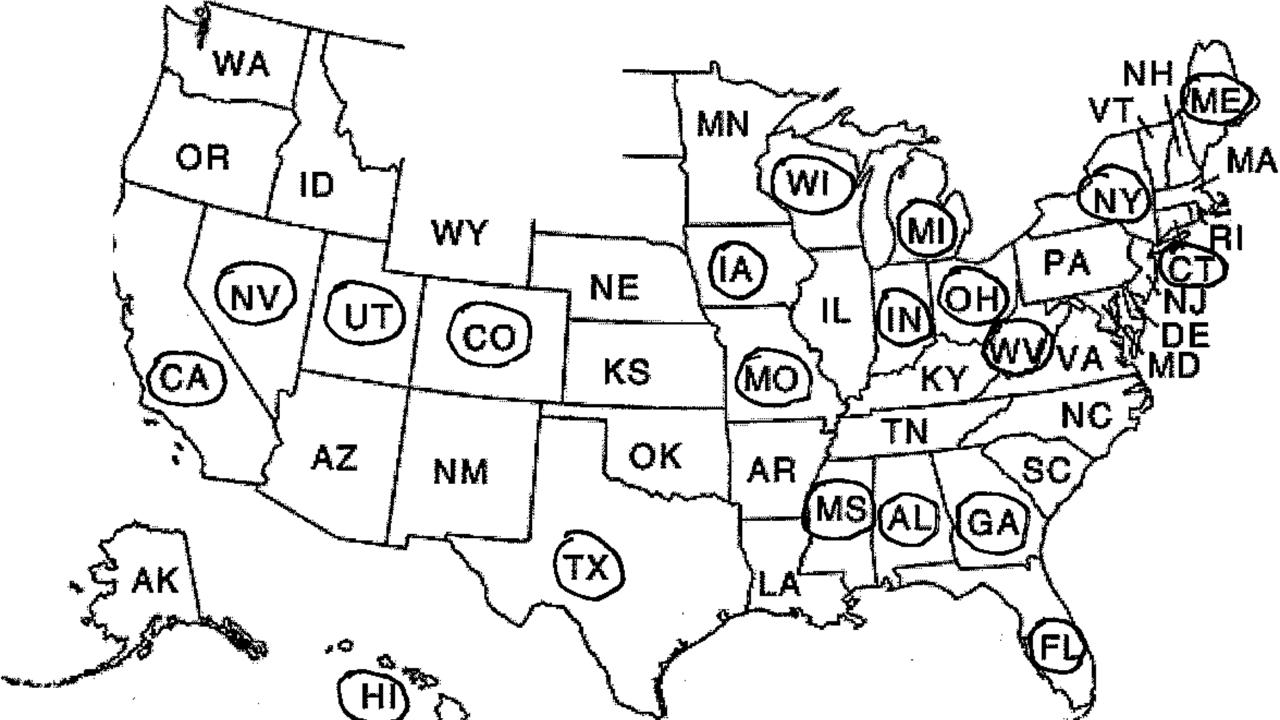
"Medical Need" for a speech prosthesis is not merely that need that results from, or relates to, the communication of symptoms or complaints of illness, or to the necessary treatment thereof. ...

Rather, [i]t is clear that the Appellant suffers from a permanent physical condition that totally interferes with his capacity for normal activity, and which handicaps him. The provision of the speech prosthesis is intended to correct the inability to speak, and thus, necessary to meet his medical need."

In re: Andrew S. No 1115201R (NY Dept. of Social Serv. Mar. 17, 1988)

"The Agency's contention that the Appellant's need for enhanced communication skills in employment and social settings is not medical in nature misses the mark since the communication skills themselves are medical in nature irrespective of the environment [in which] the Appellant is being asked to communicate."

In re: Melvin D. No. 4281016K (NY Dept of Health Sept. 26, 2005)



SGDs should be rented initially until such time the documentation establishes the coverage criteria for purchase of a device has [sic] been met. Documentation must include a detailed description of the beneficiary's trial of the SGD, addressing the ability to functionally communicate with the device while demonstrating proficiency in accessing and using the device to meet communication needs in all customary environments. Purchase should not be pursued until such time the documentation, including trial results, demonstrates functional and proficient use of the device in the beneficiary's customary environments....

NY Department of Health, Speech Generating Device Guidelines (Oct. 1, 2015)

The quality and quantity of data in current peer-reviewed scientific medical literature is inadequate to establish the clinical utility, safety, and efficacy of this device and [sic: as] treatment for your diagnosis. The requested service is therefore excluded under your medical benefit plan as experimental/investigational/unproven.

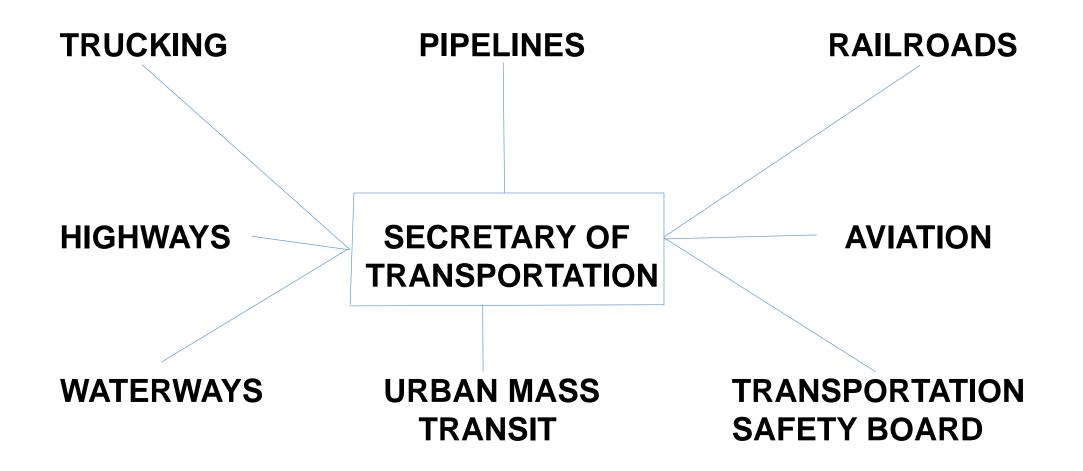
Letter dated April 19, 2011 to John C. from Charles Buttz, M.D., Medical Director, CIGNA Healthcare, relying on CIGNA Medical Coverage Policy, Autism Treatment Disorders/Pervasive Developmental Disorders: Assessment and Treatment, Coverage Policy No. 0447 (2010).

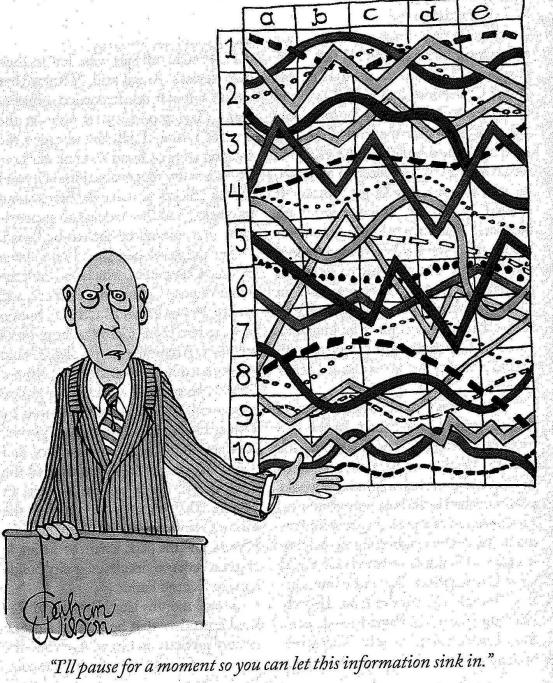
A covered health service must meet each of the following criteria:

- It is supported by national medical standards of practice;
- It is consistent with conclusions of prevailing medical research that demonstrate that the A health service has a beneficial effect on health outcomes and is based on trials that meet the following designs:
- Well-conducted randomized controlled trials. (Two or more treatments are compared to each other, and the patient is not allowed to choose which treatment is received); or
- Well-conducted cohort studies. (Patients who receive study treatment are compared to a group of patients who receive standard therapy. The comparison group must be nearly identical to the study treatment group);
- It is the most cost-effective method and yields a similar outcome to other available alternatives; and It is a health service or supply that is described in the plan documents, and that is not excluded under general exclusions.
- Decisions about whether to cover new technologies, procedures and treatments will be consistent with conclusions of prevailing medical research, based on well-conducted randomized trials or cohort studies, as described.

United Healthcare Choice Plus Plan

- Clinical Scenario 1 of 3
- Choose one:
- 1. initial request
- Diagnosed with severe expressive speech impairment:
- 1. yes
- Formal evaluation of cognitive and communication abilities has been completed by a [SLP]:
- 1. yes
- Documentation supports, choose all that apply:
- 1. detailed communication impairment (type, severity, language skills, cognition, anticipated duration)
- 2. exclusion of other forms of treatment including natural modes of communication to improve intelligibility;
- 3. functional communication goals;
- 4. treatment options and rationale for specific device;
- 5. cognitive and physical abilities appropriate to specific device;
- 6. treatment plan and training schedule
- Choose all that apply:
- 1. speech impairment will benefit from [SGD] ordered
- 2. [SLP's] written evaluation sent to treating physician prior to ordering device
- Choose one:
- 1. extensive core vocabulary necessary
- Choose one:
- 1. multiple modes of access and methods of message formulation necessary.
- Source: InterQual 2016 Durable Medical Equipment Criteria: Speech Generating Devices: SGD, synthesized speech, permitting multiple methods of message formulation and mutlple methods of device access.





Follow Up Information

- Join USSAAC! http://www.ussaac.org/memberships.cfm
- Go to https://www.isaac-online.org/english/news/upcoming-events/webinars/ for CE information, webinar materials, and the evaluation
- Let us know what you think and ideas for future topics and events
- Thank you!



Upcoming

USSAAC Webinar

April 5th at 7 p.m. EDT

Emergent Symbolic Language in Autism Spectrum Disorders

Presenter: Lucas Steuber, SLP

Facilitator: Lisa Timm, SLP

USSAAC Twitter Chat

March 9th at 8 p.m. EST

Follow up conversation about Webinar on Advocacy

