

ATiA 2021

AACREC: Assuring Access to Remote Services for Individuals with Severe Disabilities Session AACREC1281

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Learning Objectives

As a result of this session, participants will:

- Identify 3 resources that can assist in planning tele-practice services delivery.
- List 2 considerations when addressing services for individuals with complex communication needs.
- Describe roles of 2 members of the interprofessional team in planning effective remote services for individuals with severe disabilities.

Overview of Presentation

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- The NJC
- Tele-practice and its contemporary use
- What are the issues for individuals with severe disabilities?
- Communication Bill of Rights: Guiding Services for People with Severe Disabilities in the context of COVID-19 and systemic racism
- Tele-practice issues in educational settings
- Interprofessional collaboration: Related services and tele-practice
- Resources for practitioners and families

Purpose of the NJC







Advocate for individuals with significant communication support needs resulting from intellectual disability, that may coexist with autism, sensory and/or motor limitation.

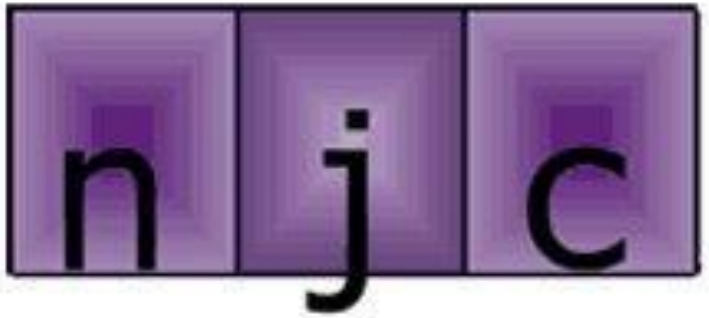
NJC Member Organizations

- American Association on Intellectual and Developmental Disabilities (AAIDD)
- American Occupational Therapy Association (AOTA)
- American Physical Therapy Association (APTA)
- American Speech-Language-Hearing Association (ASHA)
- Council for Exceptional Children/Division for Communicative Disabilities and Deafness (CDC/DCDD)
- TASH
- United State Society for Augmentative and Alternative Communication (USSACC)

History of the NJC

- Formed in 1986 by ASHA and TASH
- First guidelines with Communication Bill or Rights in 1992
- Celebrated 30th Anniversary in 2016





Communication Bill of Rights



National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC)

COMMUNICATION BILL OF RIGHTS

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. To participate fully in communication interactions, each person has these fundamental communication rights:

1. The right to interact socially, maintain social closeness, and build relationships
2. The right to request desired objects, actions, events, and people
3. The right to refuse or reject undesired objects, actions, events, or choices
4. The right to express personal preferences and feelings
5. The right to make choices from meaningful alternatives
6. The right to make comments and share opinions
7. The right to ask for and give information, including information about changes in routine and environment
8. The right to be informed about people and events in one's life
9. The right to access interventions and supports that improve communication
10. The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized
11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
12. The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers
13. The right to be treated with dignity and addressed with respect and courtesy
14. The right to be addressed directly and not be spoken for or talked about in the third person while present
15. The right to have clear, meaningful, and culturally and linguistically appropriate communications

For more information, go to the NJC website at: www.asha.org/njc

"All people with disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities."

www.asha.org/njc/communication-bill-of-rights

Guiding Services for People With Severe Disabilities in the Context of COVID-19 and Systemic Racism

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As systemic racism and COVID-19 influence lives, we are particularly concerned about their impact on persons with severe disabilities. Among the 15 rights in the Communication Bill of Rights are several that specifically address issues that we face today

- the right to establish and maintain social interactions during a time of isolation
- the right to be treated with dignity and respect
- the right to have culturally and linguistically appropriate communications
- the right to access information to address questions and concerns.



This we know…

- Many persons with severe disabilities have been cut off from friends and families as the facilities where they live have been locked down.
- There has been limited access to technologies and services that support communication, especially from a distance.
- Familiar care providers have not been able to provide ongoing services and supports.

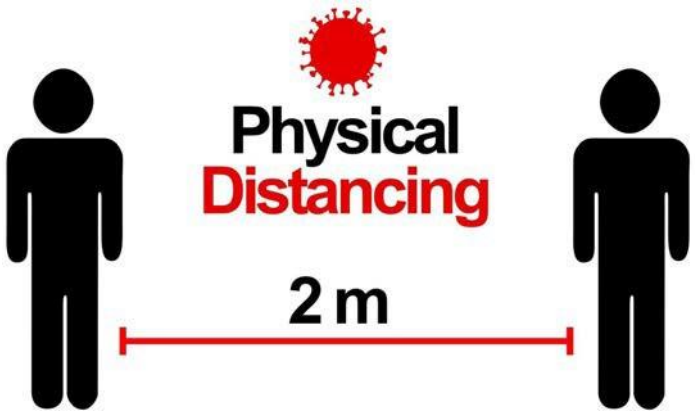
This we know…

- Masks alter communication and present barriers to communication success while feeling aversive to many persons with severe disabilities.



This we know…

- Physical distancing is contrary to the types of supports and services that many persons with severe disabilities require.
- Information about precautionary measures and changes in routines is not being provided at all-or, if it is being provided, it is being done in ways that many persons with severe disabilities cannot fully understand.
- There is a history of systemic racism that has negatively impacted service delivery for persons with severe disabilities who are Black, Indigenous, and People of Color (BIPOC).



Tele-practice and its contemporary use

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- The COVID-19 virus has disrupted rehabilitation and education functioning of the United States.
- Speech-language pathologists, physical therapists, occupational therapists, and special educators have had to adjust how they deliver their assessment and intervention services.
- There has been a substantial increase in the use of tele-practice to provide communication services and supports.
- The quality of tele-practice has been evolving over the past year.



Tele-rehabilitation or tele-practice?

- The term tele-rehabilitation (American Telemedicine Association, 2010) encompasses services by speech-language pathologists, physical therapists, and occupational therapists.
- ASHA uses the term tele-practice to ensure services are not only in health care settings but also in schools, child care settings, group living situation and homes.
- Regardless of the term used, the quality of services provided must be equivalent to what would be provided face-to-face.



Types of tele-practice?

Three types of tele-practice services are:

- synchronous (interactive)
- asynchronous (stored and forward)
- hybrid (combination)



Individuals with severe disabilities and tele-practice

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- Individuals with severe disabilities and their families face unique challenges in participating in and benefiting from services delivered via tele-practice.
- The NJC advocates for the communication needs of individuals with severe disabilities. Part of our commitment involves highlighting that children and adults with severe disabilities can, and do, benefit from communication services and supports delivered through tele-practice.
- This presentation will highlight:
  - the need to ensure that children and adults with severe disabilities can benefit from tele-practice services and supports
  - provide examples of the use of tele-practice opportunities for the delivery of communication services and supports to both children and adults with severe disabilities
  - provide resources for practitioners and families

Considerations for tele-practice in Early Intervention, Preschool and School Age Children

- Parents and SLPs of children who use AAC have reported positive impacts of tele-practice on child outcomes (Therrien, Barton-Hulsey, Biggs & Romano, in prep)
- Parent Coaching and family centered practices are key to these successful child outcomes
- Recently, Barton-Hulsey, Therrien, Biggs & Romano (in prep) have explored contextual determinants that either facilitated or created barriers to successful parent - SLP partnerships during the COVID-19 pandemic for children who use AAC.
    - Facilitators: Parent active involvement during tele-practice sessions; opportunity for parents to contribute questions, ideas and insights; shared expectations between the SLP and parents regarding child's goals; consistent communication between the parent and SLP outside of therapy sessions
    - Barriers: Unequal opportunities for families to lead and participate; overwhelming pressure on families to juggle work responsibilities; poor or unreliable internet and other technology related factors; insurance reimbursement issues

Tele-practice considerations in the schools

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- Platform issues
- In-person vs. virtual scheduling
- Asynchronous vs. synchronous opportunities
- Virtual setting
- Availability of technology for modeling
- Family/caretaker participation
- lnterprofessional Practice and lnterprofessional Education (IPP & IPE)



Tele-practice considerations in the schools

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Platform Issues:

- Chosen by district
- HIPAA compliance
- Annotation
- Screen Sharing
- Device compatibility
- End user ability



GoToMeeting



Google Meet



TheraNest



AmplioSpeech®



zoom

Tele-practice considerations in the schools

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In person vs. virtual scheduling

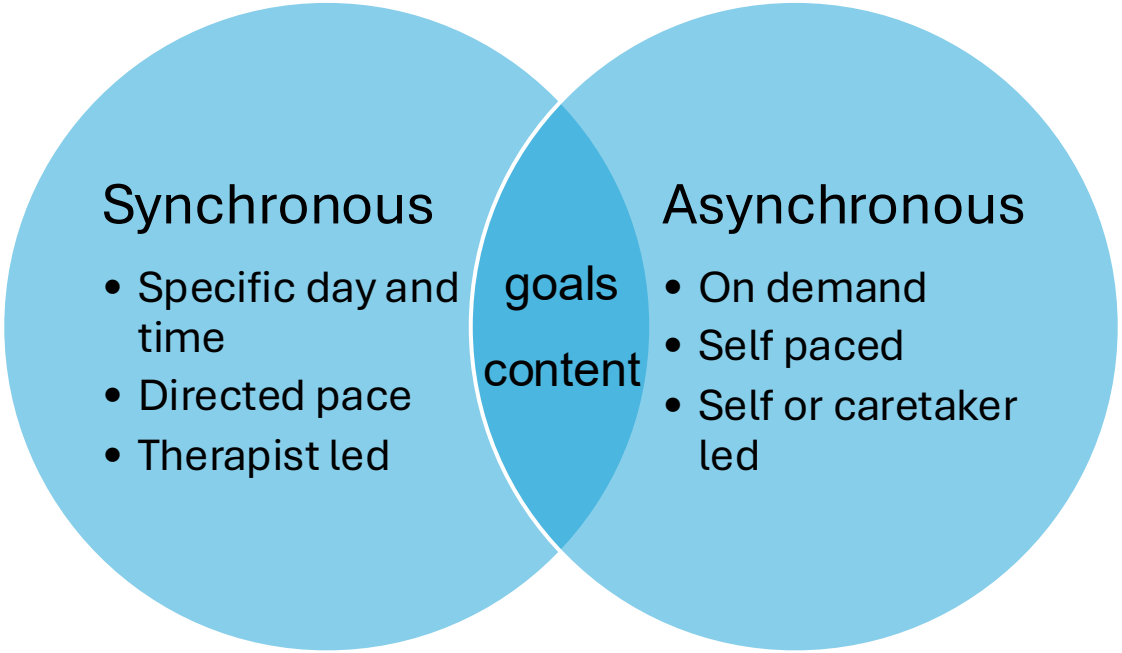
- Conflicts
- Groupings



Tele-practice considerations in the schools

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Synchronous vs. Asynchronous Opportunities



Tele-practice considerations in the schools

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Virtual setting

- Push in
- Pull out



Tele-practice considerations in the schools

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Availability of technology for modeling













Tele-practice considerations in the schools

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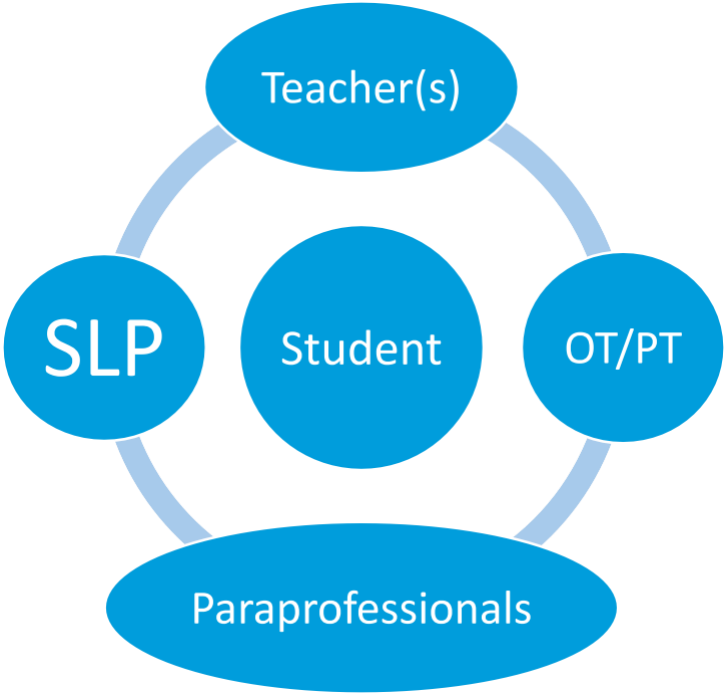
Family/caregiver participation



Tele-practice considerations in the schools

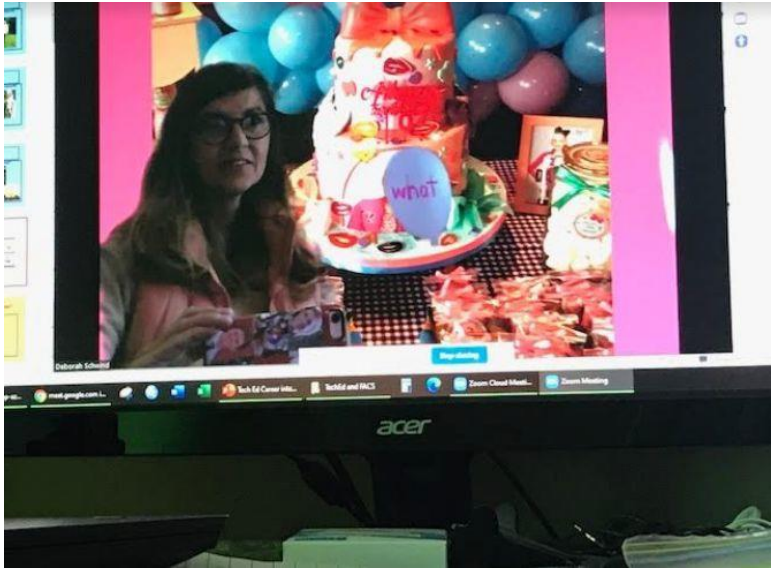
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Interprofessional practice and interprofessional education



Interprofessional collaborations and tele-practice

As with other professions, occupational therapists can use tele-practice to deliver many of the same services they provide in-person allowing for services to occur where the client lives, works, learns, and plays.



Occupational therapy services and tele-practice

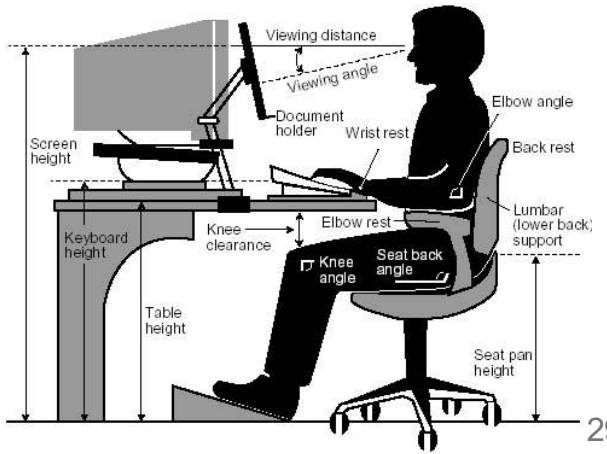
Interventions include assessment, activities, coaching, and collaboration with other professionals to address:

- Fine motor skills (such as using buttons, manipulating scissors, or holding a pencil)
- Writing, reading, or learning
- Gross motor skills (such as using muscles in the neck, arms, hands, and torso)
- Assisting with self-care, such as dressing, eating, and grooming
- Managing emotions or behaviors
- Playing or engaging in leisure activities
- Organizing, planning, and completing tasks
- Interacting or communicating with others

Ergonomics and tele-practice

Occupational therapists can educate clients, parents, guardians, and educators about the type of environment that is most conducive to success in tele-practice. Considerations include:

- Positioning of the the clients and the device(s) being used for the delivery of teletherapy
- Lighting
- Noise
- Time spent in front of screen
- Hydration



Accessibility during tele-practice



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- Change contrast or backgrounds of screen or documents/slides on screen (ex: blue with white text)
- Reduce onscreen distractions (simplify displays)
- Adjust mouse cursors as needed (enlarge, invert, change color, and/or with trails)
- Consider blue filters (low or high tech) or
- Change display properties (increase the resolution or text size system wide)
- Take advantage of ease of access features

Assistive technology devices and services

During COVID-19, individuals who rely on assistive technology for their activities and participation have been particularly affected:

- care and support services (for example AT services, special education, peer support groups, mobility services) may have been reduced or stopped
- accessible information may not be available
- on line participation in social or classroom activities is more difficult
- factors such as accessibility, providing AT in the new environment, type and quality of materials, and the duration of distance learning may be considered by support staff as they develop individualized proposals for IEP implementation or services, including how AT devices and/or services may be delivered during virtual and/or distance sessions
- Care and maintenance of assistive technology including keeping devices clean

Assistive technology devices and services

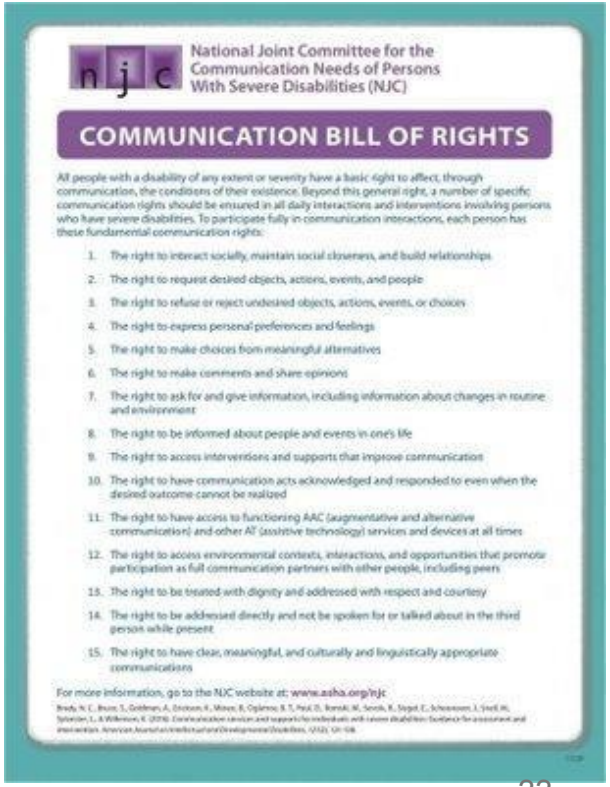
- Many advocacy groups continue to compile resources to help people with severe disabilities, their families, and service providers to understand this global pandemic and its impact on the devices and services they need to communicate.
- It is important to apply what we have learned about what is working and what is not to plan for the future. In the wake of this health emergency and economic crisis, it is essential to organize and advocate more than ever before.



Moving forward-

Some steps that we can take to promote the communication rights of all persons with severe disabilities in this moment and moving forward include:

- Review the Communication Bill of Rights and distribute it widely.
  - Post it on social media outlets.
  - Draw attention to it when it is posted in common areas.
  - Share it with families, caregivers, and service providers.



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Moving forward-

- Help persons with severe disabilities understand and advocate for their communication rights.
  - Talk about communication rights using systems that best support comprehension.
  - Provide specific examples that are relevant to the lives of the individual.
  - Become so familiar with the rights that you can explain them and relate to them in the moment.

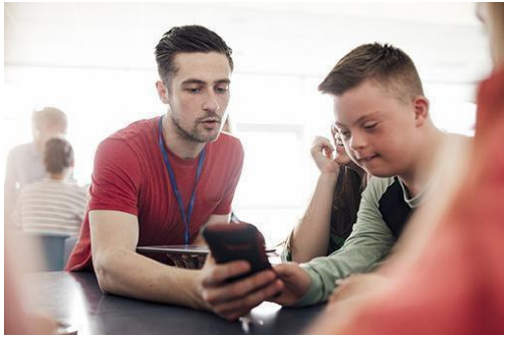


Use the Communication Bill of Rights to:

- Guide respectful interactions and advocacy.
  - Ensure that all communication partners are aware of the Communication Bill of Rights.
  - Assess your own interactions relative to the rights.
- Provide culturally responsive supports and services for persons with severe disabilities.
  - Ensure that symbols used in interactions with persons with severe disabilities reflect cultural and linguistic diversity.
  - Create and share personalized materials reflective of the individual's lived experience.

Use the Communication Bill of Rights to:

- Evaluate existing and new programs and actions regarding programs and services for persons with severe disabilities.
  - Assess your program's policies, practices, and actions related to supporting the communication needs of persons with severe disabilities.
- Amplify the voices of persons with severe disabilities who are BIPOC.
  - Support individuals with severe disabilities in sharing about their lived experience-and, with permission, share it with others.





NJC COVID-19 Resources

The NJC expresses our support for access to communication, communication-related services, and all other therapeutic/medical assessments/interventions for persons with disabilities during the current global COVID-19 pandemic. The NJC and related organizations have information for providers and others caring for individuals with severe disabilities during the coronavirus/COVID-19 pandemic. These resources can be found at:

https://www.asha.org/njc/njc-covid-19-resources/

https://www.atia.org/covid 19-resources/

"Thank you for including the resources on COVID-19! We recently used these to support our related service providers to receive N95s when working with students who are exempt from wearing masks/face coverings in school. This was a critical issue for us and really appreciate the support of the NJC!"
NJC Network Member

References

- Brady, N. C., Bruce, S., Goldman, A., Erickson, K. A., Mineo, B., Ogletree, B.T., Paul, D., Romski, M. A., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication supports and services for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities, 121*(2), 121-138. https://www.tandfonline.com/doi/ref/10.1352/1944-7558-121.2.121
- Madel, R. (2020). Supporting children with complex communication needs through telepractice. www.docs.google.com/presentation/d/1h_zpvhENx7Ja1cHcOQLetlEEhusPNXlRBMVUMJKM40/edit#slide=id.g4e633c5442_2_72
- https://www.asha.org/About/Telepractice-Resources-During-COVID-19/
- http://www.aaidd.org/docs/default-source/default-document-library/4-8-20-powerpoint.pdf

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