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Back to Basics: Down Syndrome

Theresa Bartolotta, PhD, CCC-SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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Back to Basics: Down Syndrome

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Learning Outcomes

After this course, participants will be able to:

- List the characteristic features of communication disorders in individuals with Down syndrome.
- Describe the influence of motor planning problems on speech acquisition.
- Identify effective treatments for speech and language disorders in children and adolescents with Down syndrome.

Basics

- Down syndrome (DS) is the most common genetic cause of Intellectual Disability (ID)
  - Cause – abnormal cell division results in extra material on Chromosome 21 – Trisomy 21
  - Prevalence: The estimated incidence of Down Syndrome is between 1 in 1,000 to 1 in 1,100 live births worldwide
  - Prevalence increases with maternal age; most notably over 34 years of age
  - Each year approximately 6,000 children are born in the US with DS
  - There are about 250,000 families in the US affected by DS

(Centers for Disease Control and Prevention)

Health and Wellness

- Life expectancy has increased dramatically. Most individuals with DS live into their 40's or 50's and beyond
- Approximately 50% of infants with DS are born with a Congenital Heart Defect. This increases mortality
- Risk of dementia is same as in general population; onset is 30-40 years earlier (early middle age)
- Many live independently or with some support
- Employment is common
- Many individuals have fulfilling personal relationships

(Down Syndrome International)

Communication Development: An Overview

- Literature is limited – see References pages at end for citations
- Significant variation among children with DS
  - For some, oral speech and language will come more easily
  - For others, oral communication will be very challenging so other options should be pursued – as early as possible
- Characteristic features:
  - Skills are acquired later
  - Children move through the developmental stages more slowly
  - Particular phonemes and language structures are problematic
  - Specific problems occur in voice, speech sound production, fluency & intelligibility

Voice

- Cries of babies with DS differ from typical infants
  - Likely due to abnormalities in respiratory & laryngeal function
- Dysphonia is a common feature of DS
  - Fundamental frequency is higher than age-matched controls
    - Secondary to a smaller larynx
  - Voice is typically judged as breathy & rough
- Resonance is altered – often hyponasal
- Nature of vocal problems not well understood
  - If laryngeal muscles are hypotonic, then a greater amount of energy is needed for phonation

Infant with DS

- Age 1 month
- High-pitched cry
- Highly responsive to Mom's voice

Speech

- Influenced by perceptual, motor and linguistic issues
  - Onset of babbling is likely delayed
  - Emergence and mastery of consonants is protracted – lingua-alveolar phonemes are particularly challenging and are more likely to be distorted
  - Midface (nose area, maxilla) tends to be small – affects resonance
  - Tongue is normal size – is not enlarged; may be large relative to the size of the oral cavity
  - Vowel errors are common

Speech (continued)

- Palate is high and shelf-like
- Rate of speech MAY be fast; challenge is likely the transition from sound to sound
- Speech may take more “energy” to produce
- Sound acquisition may not follow a developmental sequence
- Speech difficulties are likely due to impacts of:
  - anatomy
  - motor control
  - cognitive/linguistic challenges

Fluency

- Stuttering
  - Flow of speech is disrupted by repetitions, prolongations, or stoppages of sounds (blocks). May be accompanied by secondary symptoms
- Cluttering
  - Rapid and/or irregular speaking rate, excessive dysfluencies, often accompanied by language, phonological and attention problems. May accompany stuttering
- Fluency disorders occur in 10% - 45% of individuals with DS - a mean of 31% - (occurs in 1% in general population)
- Influenced by motor control and word finding or sentence formulation difficulties

Childhood Apraxia of Speech

- Diagnosis of CAS in DS is a diagnosis of exclusion
  - Because there are so many other fundamental issues to consider and rule out:
    - Respiration, phonation, fluency, cognition, dysarthria
- A diagnosis of CAS must consider:
  - The articulatory errors, abnormal muscle tone, and fluency problems that occur in this population
- Literature suggests that there are general difficulties in praxis skills in individuals with DS
  - Challenge with generating actions from memory
  - So this could be a central problem affecting all movements

Language

- Imitation and gesture use are strengths
- Vocabulary - onset and development are substantially delayed; and they may need more support and less complexity to fast-map. However, repeated practice can advance concrete receptive vocabulary to exceed NVMA.
- Phonological memory – short term memory of speech sound information - is a particular challenge and can impact acquisition of oral and written language.
- Syntax – particular challenges in learning to understand and use complex structures, e.g., passives, pronouns. Receptive syntax is a particular challenge.

Language

- Morphology – use of morphemes is delayed and problems can persist well into adolescence
- Pragmatics – a strength – convey same basic functions as typical children; however nuances of messages are missed because their messages are often incomplete. Challenged to make corrections/clarifications
- Literacy – many acquire reading and writing skills

Interventions

- There is a need for evidence-based interventions for persons with DS
- Literature is limited – we can use evidence from other populations with similar challenges
- Many families feel service provision is inadequate – expectations may be low

Interventions: Basic Principles

- Consider HEARING – fundamental to learning spoken language
  - Babies and children with DS have high incidence of otitis media (middle ear infections) which impacts hearing
  - Be vigilant about making sure that fluid does not remain in the middle ear space after an ear infection has resolved
- Tongue position will be affected by size of oral cavity
- Breathing should be a primary concern
- If the tongue is low and forward, find out WHY? Consult an ENT – make sure tonsils/adenoids are not an issue
- Provide multimodal stimulation and repetition of input and output
- Early use of AAC can help acquisition of verbal speech – we must convey that message to other providers and to families

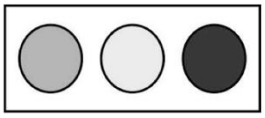
Language

- Do not delay AAC – there is no harm to verbal language by introducing AAC early – it can always be faded/discontinued as verbal language grows
- Types of AAC
  - Aided or unaided
    - Unaided – using gestures or sign to communicate
      - Baby sign, Signed English
    - Aided – using some type of external system (low tech to high tech)
      - Communication board
      - PECS – consider motor skills
      - iPAD apps
      - Electronic dedicated AAC devices with speech output

Things to remember about AAC

- Include training on how to use AAC for meaningful communication
- AAC is not about touching icons or signing –it's about interaction
- We all communicate using multiple modalities – don't just rely on just one
- Consider Communication Partner Instruction to enhance interactions
  - AAC programs that include partner instruction are highly effective, particularly in children with developmental delays such as ASD or ID.
- Meta-analysis (Kent-Walsh et al., 2015) found these skills were most frequently targeted:
  - Aided AAC modelling, expectant delay, open-ended questioning

Speech



- There is no ceiling on improvement – skills may likely continue to improve over the lifetime
- Self-monitoring is required – will emerge as children get older
- Techniques
  - Begin with single syllable or syllable approximations; move to rote phrases that can be repeated in multiple contexts; carrier phrases can help
  - For motor learning to occur – repeated practice is essential
  - Drills are critical - in young children begin with contexts that occur frequently; then move to drill practice as they get older
  - Pacing – use techniques like a pacing board or tapping or counting on fingers

Speech (continued)

- Techniques that provide tactile input may assist with sensory feedback (e.g. PROMPT)
- CAS interventions – e.g. small core of syllable types, repetition, may help motor learning
- Integral stimulation – combines motor learning and sensory feedback. Begin with small units and increase in complexity
- High intensity practice of nonsense targets paired with real-world referents may result in improvement in speech control (Rvachew & Folden, 2017)

Language

- Vocabulary and sentence structure can continue to improve over time
  - Early language stimulation –
    - Milieu communication training
    - Hanen programs
    - Functional communication training
  - Aspects of grammar are challenging, e.g. proper tense, plurals, use of “and”, “because”, “so”
- Explicit teaching using repetition and multisensory input
- Use reading and writing as a tool to improve language
  - Introduce print early
  - Use preliteracy strategies used with individuals with developmental language disorders

Language (continued)

- Address phonological memory directly
  - Songs, early vocalizations, imitation of sounds
  - Introduce drills early to address short-term memory
  - Increase complexity over time
- Cognition –
  - Ideas can be "literal" – play and language develop hand-in-hand
  - Work to advance logical, abstract thinking
  - Consider use of Floortime and DIR
    - A relationship-based therapy based on emotional engagement and relationships

Case Study - Jordan

- Age 19 years
- Speech and language therapy since age 12 months
- Multiple interventions
  - Began with sign language
  - Exposed to multiple videos for word learning, alphabet, signs, songs
  - Transitioned away from sign as she began to form 2-3 word utterances (age 5)
  - Continual focus on improving word knowledge, comprehension, and clarity and complexity of spoken language

Speech-language therapy

- Goals: improve her speech intelligibility; improve her ability to communicate in conversation; improve her syntax (grammar), vocabulary, and ability to answer complex questions (why, how)
- Use specific strategies
  - Pacing board
  - Cues for speech – slow, loud, clear
- Additional areas to address:
  - problem solving, struggling with having deeper, more complex conversations about new topics, advancing play, expressing range of ideas and emotions

Video clip one

- Goals of the session: providing reasons for actions, sharing complex and new ideas, asking for information to solve problems
- Context – Jordan has prepared a list of questions about my recent trip

Typical session

Enter DIR…

- Strategy – participate with her in play scenarios; she chose the topic, the characters, the events.
  - My goal – to begin to assess and then advance her play and her social-emotional skills, and her complex thinking and ideas

DIR /Floortime intervention

- Strategies
  - Pull back, wait
  - Say less, giver her time and space to develop the complexity of the play and the situation
  - Go with the affect of the situation and stay there – push her through it
  - When she is stuck, give her choices
  - Work to try to expand her emotional range
  - Introduce conflict into the stories she knows

Clip number two

- Context – we play with dolls who are going to school. My doll has been bullied by Jordan's doll. My doll is so sad – Jordan wants to have the dolls be friends and continue on as if nothing has happened. My doll refuses to do that...
- I protest and Jordan finally "gets it" and her doll has a very appropriate response – feels sad and rejected and apologizes.

Transition Planning

- Remaining in high school
- Job sampling: sorting/delivering mail at a corporate park; serving as a hostess at a restaurant
- Therapy goals: expanding vocabulary based on job needs; reading comprehension; writing narratives and editing her work; clarity of speech

Jordan at 19

Summary

- Intervention should begin early and continue well into adolescence and young adulthood
- AAC should be introduced early
- Drill and practice are key fundamental principles of intervention
- Teamwork is critical – SLP can focus on vocabulary and other skills that can assist school/work performance

CONTINUED

References

- Abbeduto, L. Warren, S. F. Conners, F. A. (2007). Language development in Down syndrome: From the prelinguistic period to the acquisition of literacy. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*, 247–261.
- Centers for Disease Control and Prevention (n.d.). Data and statistics on Down syndrome. Retrieved from https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html
- Down Syndrome International (n.d.). Down syndrome explained. Retrieved from https://www.ds-int.org/Pages/FAQs/Category/adult-health/Tag/adult-health
- Faught, G. G., Conners, F. A., Barber, A. B., & Price, H. R. (2016). Addressing phonological memory in language therapy with clients who have Down syndrome: Perspectives of speech–language pathologists. *International Journal of Language & Communication Disorders*, *51*(6), 703-714.
- Kent, R.D., Vorperian, H.K. (2013) Speech impairment in Down syndrome: A review. *Journal of Speech, Language, and Hearing Research, 57,* 178-210
- Kent-Walsh, J., Murza, K. A., Malani, M. D., & Binger, C. (2015). Effects of communication partner instruction on the communication of individuals using AAC: A meta-analysis. *Augmentative and Alternative Communication*, *31*(4), 271-284.
- Meyer, C., Theodoros, D., & Hickson, L. (2017). Management of swallowing and communication difficulties in Down syndrome: A survey of speech-language pathologists. *International journal of speech-language pathology*, *19*(1), 87-98.

CONTINUED

- Nass, K. A. B., Lervag, A., Lyster, S. A. H., & Hulme, C. (2015). Longitudinal relationships between language and verbal short-term memory skills in children with Down syndrome. *Journal of Experimental Child Psychology*, *135*, 43-55.
- Romski, M. A. Sevcik, R. A. Adamson, L. B. Cheslock, M. Smith, A. Barker, R. A. Bakeman, R. (2010). Randomized comparison of augmented and nonaugmented language interventions for toddlers with developmental delays and their parents. *Journal of Speech, Language, and Hearing Research*, *53*, 350–364.
- Rvachew, S., & Folden, M. (2018). Speech therapy in adolescents with Down syndrome: In pursuit of communication as a fundamental human right. *International journal of speech-language pathology*, *20*(1), 75-83.
- Sanoudaki, E., Variokosta, S. (2014) Pronoun comprehension in individuals with Down syndrome: Deviance or delay? *Journal of Speech, Language, and Hearing Research, 57,* 1442-1452.
- Thiemann-Bourque, K.S., Warren, S.F., Brady, N., Gilkerson, J., Richards, J.A. (2014). Vocal interaction between children with Down syndrome and their parents. *American Journal of Speech-Language Pathology, 23,* 474-485.

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