

An abstract graphic on the left side of the slide. It features several overlapping organic shapes in yellow, teal, and pink. Some shapes are filled with patterns of small white dashes or dots. The background is white. The right side of the slide has a purple-to-teal gradient background with a large, semi-transparent purple circle behind the title.

The Power Of Hybrid Therapies For Teens And Adults: *Themes For Independence*

Presenter: Jennifer Gray, MS, CCC-SLP

Co-presenter: Sarah Bookout, MA, CCC-SLP

HELLO!



Jennifer Gray, MS, CCC-SLP

jennifer@grayspeaktherapy.com

www.grayspeaktherapy.com

www.downsyndromespeech.com

@grayspeaktherapy

@downsyndromespeech



Sarah Bookout, MA,
CCC-SLP

sarah@grayspeaktherapy.com

www.grayspeaktherapy.com

@howdytexasslp

DISCLOSURE STATEMENTS

Jennifer Gray, MS, CCC-SLP

Financial:

- Self-employed and owner of Grays Peak Speech Service, LLC in Colorado
- Clinician, Speaker, Consultant, and Mentor
- Jennifer Gray receives consulting fees and a lecture honorarium from LSVT Global, Inc. KIDS training program, and receives compensation for presentations through SpeechTherapyPD and webinar for ASHA providing continuing education.
- She receives royalties for courses taught through PESI for recorded speaking events.

•Nonfinancial:

- Leads ST Group for the Down Syndrome Medical Interest Group (DSMIG)

Sarah Bookout, MA, CCC-SLP

Financial:

- Employed by Grays Peak Speech Service, LLC
- Clinician, Speaker, Student
- Sarah does not receive compensation for speaking events

•Nonfinancial:

- Leads ST Group for the Down Syndrome Medical Interest Group (DSMIG)

Summary

The ability to communicate with others is essential for building meaningful relationships and ensuring independent living success. As those with Down Syndrome age, social opportunities dwindle, and therapies become difficult to find and afford. This places teens and adults in jeopardy of losing previous skills and acquiring new ones if not maintained through active engagement and participation in daily activities. The tendency to turn inward when not engaged, combined with increased risks of regression, dementia, and Alzheimer's disease make prevention a priority. Therapies to address social skills such as perspective-taking and personal responsibility allows each person to achieve their dreams of the future. This presentation will provide a framework of intervention for individual and group practice based on shared experiences and common interests while building skills of independence such as cooking, scheduling, interest development, and goal setting. Demonstrations, attendee interaction, and resources will be provided for immediate implementation.

Objectives

1. Understand the importance of active engagement and continued speech and language practice for teens and adults to maintain and improve communication skills and independent-living success.
2. Learn how in-person and virtual social groups combine to improve interpersonal relationships and skill mastery for maximum impact.
3. Identify areas of concern and changes in behavior before loss of abilities are experienced.



- This may be the first time in history people with Down syndrome will collectively outlive their parents.
- Advocacy is rising as is visibility (commercials, advertising, tv, movies, etc.)
- Funding for research is also expanding rapidly

8 FACTS ABOUT DOWN SYNDROME

THERE ARE 3 TYPES OF TRISOMY

3 **21**

95% Trisomy 21 (nondisjunction) accounts for 95% of cases

4% Translocation
1% Mosaicism

400,000 People Live WITH DOWN SYNDROME IN THE UNITED STATES

1 in 691 Babies ARE BORN WITH DOWN SYNDROME IN THE US

80% of children born with it are born to women under 35 years of age

The incidence of births of children with the disease **increases with the age of the mother**

Life Expectancy

1983	Today
25	60






People with Down syndrome have increased risk for certain medical conditions including:

- Congenital heart defects
- Respiratory and hearing problems
- Thyroid conditions

Every person with Down syndrome experiences cognitive delays but this is not indicative of the many strengths and talents each individual possesses.

Many of these conditions are now treatable, so most people with Down syndrome live healthy lives

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Research, Medical Improvements, & Advocacy



- This is a very exciting time for Down syndrome research and acceptance.

Life expectancy:

- 1959 – 9 yrs
- 1983 - 25 yrs
- 2018 – 60+ yrs

Medical breakthroughs = Improve
quality of life But.....

Dementia & Alzheimer's Disease

- https://ndss.org/resources/alzheimers?gclid=Cj0KCQiA54KfBhCKARIsAJzSrdpbnlqaH_CAecym1Jl0QNON_Ktw4SBYRH3m0SUKnfsJiTYGwpq5cmIaAqfPEALw_wcB
- Most living with Down syndrome will experience signs and symptoms of dementia/Alzheimer's disease by the age of 40.
- This further demonstrates the importance of our role as SLPs who treat teens and adults.
- Little is known about prevention to prolong the onset of dementia and Alzheimer's disease in this population
- So we must assume the prevention suggestions of those without Down syndrome would still apply
 - Active physically and mentally, diet/nutrition, continuous learning, maintain social interactions, being busy, etc.

Advocacy is Working Now what?

- We must Assume Ability & Expect Competence
- **Prepare for the demands of participation**
- Independence requires continuous learning and the ability to communicate with others
- Teach the skills of independence
- **Practice Practice Practice**



PIVOT

We are used to preparing for the future for those with Down syndrome.

We now have a responsibility to ensure the person (with Down syndrome) is ready for their future.

Paradigm shift: barriers to success are speech therapy for teens and adults and therapy dosage.

Addressing speech clarity for those who choose speech should prepare individuals for contextual communication success to avoid frustration and failure.

Those living with DS are beginning to experience inclusion in schools, the workforce, and the entertainment industry but **ableism remains constant because we unknowingly place restrictions on even the most basic expectations of competence.**

Example: introducing oneself and being understood the first time.

Remember: Presume competence. Expect ability.

BE
a **VOICE**
not
an **ECHO**



“Communication disorders are common in DS. In particular, speech intelligibility is compromised in many individuals and can be a lifelong problem that seriously reduces quality of life (Kent & Vorperian, 2013;Kumin, 1994;Wild et al., 2018). A survey of 228 parents of individuals with DS revealed that speech was identified as being in the top four of 16 areas needing further investigation and as the second area of greatest parental interest, behind only cognition”

Research vs Practice for Adults

- Anonymous online survey about Speech and language therapy for adults with Down syndrome and their parents.
 - Adults with Down syndrome (n = 33)
 - Parents of adults with DS (n = 557)
- **We have evidence that more sessions per week equal better outcomes and skills attained.**
- 44% (n=253) were offered public SLT in 2019. Wait time for services was 1-2 years, and the average # of sessions received was **5/year**.
- Age and # of sessions revealed fewer sessions for older individuals with DS.
- Of the 40 individuals who participated in the study didn't receive **ANY** SLT in 2019.
- 40% of parents reported a **0 level in satisfaction for services available**.



Research shows better outcomes with more frequent sessions per week.

“Speech and language therapies for those with Down syndrome can be successful and benefit those of all ages.

However, the disparity between the availability of services, the quality of services (EBP), and the dosage of interventions negate all potential benefit.”

The average number of sessions reported, does not in any way approximate the intervention intensity specified in evidence-based interventions. Our limited service, at all ages, has detrimental implications for people with DS and our negligible adult service is in breach of human rights. Targeted, strategic investment is needed to allow practice to be aligned with best evidence; to support and treat people with DS effectively; to allow them to reach their maximum potential; and to exercise their right to communicate.

New Advocacy

DOSAGE

- Advocate for speech and language as the basis of learning, social participation, relationships, inhibition, neuroplasticity, resilience, & INDEPENDENCE



- Educating the public and professionals
- Insurance coverage
- School inclusion

Mastery

Practice Practice Practice Techniques

- Easy to employ
- Easy for others to understand
- May or may not be used at all times
- Use materials and targets that reflect the person's *need* for speech clarity (introducing oneself, address, phone #s, school and job lingo, specific events or lessons, etc.)
- Use interests and strengths of individual
- Can use to answer and ask questions
- Can use independently without cueing from others (most of the time)
- Can use with other communication strategies
- Can fix errors





SPEECH AND LANGUAGE SKILLS

- Are not like riding a bike.
- Skills attained when younger can regress when not practiced, maintained, and refined.
- Mastery is not developmental and does not require perfection

If We Know What To Do Why aren't we doing it?

Lack of resources

Lack of insurance coverage

Conflicting professional
opinions

- SLPs are not taught about Down syndrome in school.
- There are very few training opportunities for all allied health professionals
- Specialists are even less common
- Assessment and treatment materials and techniques are limited and difficult to find and apply without training
- Most therapies are provided by schools (that are bound by academic relevance)
- Even fewer resources for teens and adults
- Medical clinics open 1 day each week on average; remain state-specific
- Parents have tasked themselves with improving speech and language, nutrition, behavior, daily living skills, fine and gross motor practice, inclusion, job prep and seeking, and more.

Teletherapy & Hybrid models

as a solution

The Research Says....

Teletherapy Outcomes are as good
or better than in-person services

To The Rescue:
We have a solution!

Teletherapy & Hybrid models provide a variety of *benefits*

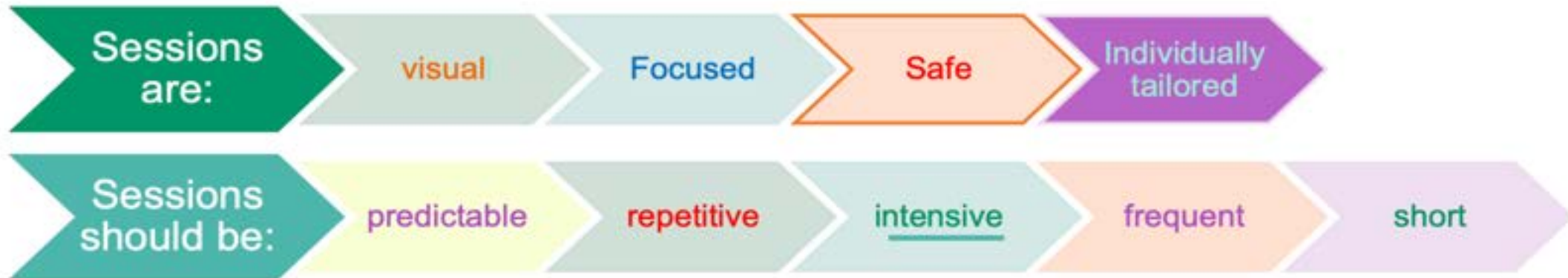
- ★ Independence
- ★ Flexibility
- ★ Opportunities for connection
- ★ State dependent Learning (learn in the environment used)
- ★ Ability to follow research recommendations for frequent and intense sessions

Why is Teletherapy So Effective?

- Lends to fewer cancelations, less distracted sessions, and faster progress!
- Access to specialists

Accessibility
isn't
restricted
due to:

health,
geography,
travel, time,
and weather.



Why is Teletherapy So Effective for Those with Complex Needs?

Many have specific learning strengths inherent to teletherapy (ability to remove other sensory distractions to focus better on visual information)

Dosage recommendations are more flexible (frequency, intensity, and duration of sessions per week) when travel is removed

Meaningful, contextual, and functional therapy activities are easier to access

Even group sessions are easier to use regularly due to HIPPA compliant platforms and social media sharing

Frequency of Therapy

Paul Yoder, Tiffany Woynaroski, Marc Fey, Steven Warren; Effects of Dose Frequency of Early Communication Intervention in Young Children With and Without Down Syndrome. *Am J Intellect Dev Disabil* 1 January 2014; 119 (1): 17–32.

doi: <https://doi.org/10.1352/1944-7558-119.1.17>

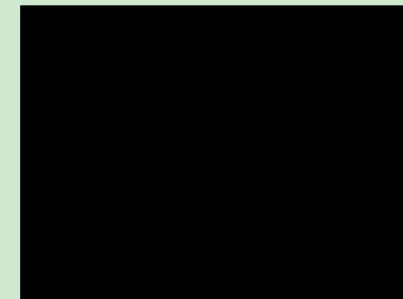
<https://blog.lsvtglobal.com/research/pediatric/>

- Clinical research has found shorter, more frequent and intense sessions yield better and faster speech outcomes for those with motor speech disorders like Childhood Apraxia of Speech, fluency disorders like stuttering, and voice and resonance disorders that require metalinguistic skills and good working memory.
- 1 hour, once per week or less may not provide improved speech outcomes. for those with moderate to severe speech disorders (along with language, cognitive, executive functioning, and feeding needs).
- Intense programs and frequent and short sessions provide recommended practice (e.g., 15 minutes, 3-4 times per week).
- Teletherapy is effective for visual learners and eliminates travel, cancelations, and allows for more flexible scheduling, leading to faster progress.
- This may mean seeing more than one speech-language pathologist to target the many needs

Salient and Meaningful Speech Therapy Case Example

- Frequent and consistent speech and language opportunities
- Speech teletherapy can address a variety of individualized needs beyond speech alone
 - active engagement, executive functioning, academic opportunities, perspective taking, social skills, self-awareness, empathy, personal responsibility, answering questions, use of technology, behavioral boundaries, relationships

1. video from January



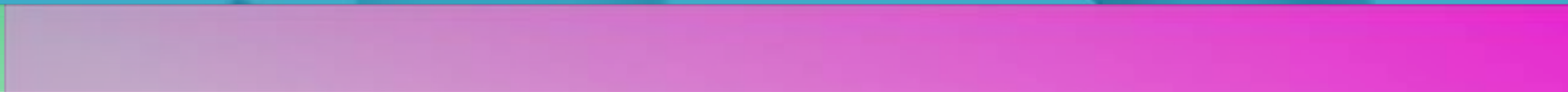
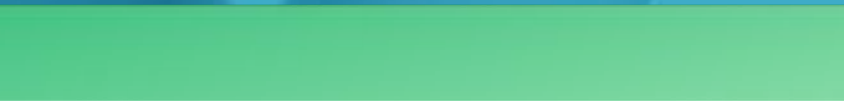
1. video from April



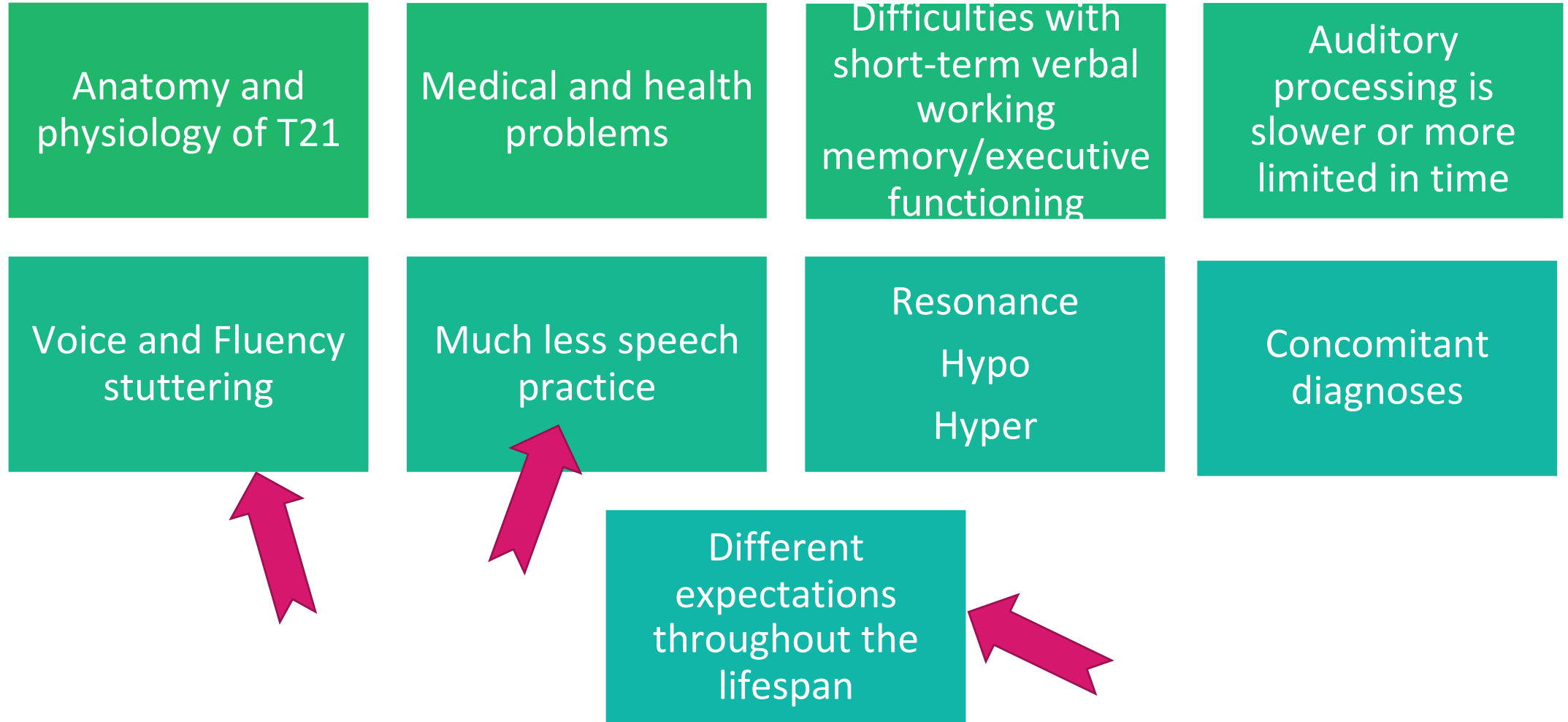
shared with parent permission

Humans produce up to 6
syllables or 14 distinct
sounds per second in
conversational speech.

Speech Clarity



Contributors to Poor Speech Clarity & Expressive Language



Speech Clarity

► Segmental

- ❑ Articulation: sound production
- ❑ Phonology: systems and patterns of sounds to convey meaning
- ❑ Motor Planning: imprecise timing of coordinated movements

► Suprasegmental (quality)

- ❑ Prosody: Intonation, rhythm, rate
- ❑ Voice: pitch and loudness
- ❑ Syllable and word Stress
- ❑ Resonance: hypernasal, hyponasal
- ❑ Fluency



We
treat
these



&
ignore
these

Which Speech Characteristic Is Preventing Clarity

The Most?



It's probably **NOT**
Specific Sound errors

It is usually a
combination of:

- rate (too fast or slow)
- Loudness (too loud or quiet)
 - Missing words
 - Stuttering
- Voice and Resonance
- Prosody – Rhythm, syllable
or word stress

Voice therapy for people with Down syndrome

There is, as yet, little work being done to remediate the voices of people with down syndrome. Speech and language therapists have focused their attention on the need to develop the language skills of children with down syndrome who, undoubtedly, require skilled input in this area (jenkins, 1991, [cunningham et al., 1985](#) etc).

The poor articulation of this group of people has also been recognized and programs are frequently devised to assist in improving this ([hamilton, 1993](#)). However, the current research suggests that **far** more emphasis needs to be placed on the problems of **initiating voice**. Ideally, this should be incorporated into early therapy packages so that an awareness of the problem and procedures to remediate it can be started - almost from birth.

Voice therapy techniques have traditionally developed from the strategies used by singing teachers to promote vocal control and to eliminate straining and vocal abuse. Very few people with down syndrome can sing at all. **Therapy techniques for increasing vocal efficiency need to be devised.**

<https://library.Down-syndrome.Org/en-us/research-practice/02/3/voice-people-down-syndrome-emg-biofeedback#:~:text=very%20few%20people%20with%20down,tension%20in%20their%20own%20muscles.>

LSVT LOUD

LSVT LOUD for KIDS

- Intensive voice treatment: 4 one-hour sessions 4 days a week for 4 weeks. 16 sessions.
 - Originally developed for those with Parkinson's disease
 - Uses simple cues and hierarchy of complexity
 - Frequent sessions and intense repetition allow patients to take back control of their speech
 - New research shows promise for pediatric populations with CP and Down syndrome, but other motor speech disorders also respond well, (childhood apraxia of speech, fluency/stuttering/cluttering)
- <https://blog.lsvtglobal.com/intensive-speech-therapy-lsvt-loud-for-clients-with-down-syndrome-one-clinicians-experience/>



Use your LOUD voice

Say it like I do

Simple cueing
system

caters to
STRENGTHS

to DIMINISH
weaknesses

Salient

Carry-over
effect

Improves
Executive
Functioning
skills

POSITIVE Outcomes

- One or 2 cues for all speaking events
- Instant speech clarity
- Fits in perfectly with techniques used for motor planning and fluency:
 - High intensity and frequency of actual speech practice
 - Dosage is the same as recommended for CAS

- Fits perfectly with the need for executive functioning and short-term verbal memory goals
- **Self-confidence** (from high frequency and intensity of repetition). They quickly learned each session was the same and change was gradual. There are no surprises. We use what we know they like and are good at (visual stimuli; Pictures, words, music).
- Builds self-awareness and promotes self-correction.
- Participants are able to handle the frequency and duration of sessions (4x -hour sessions each week, for 4 weeks).

Intensive Voice Treatment (Lee Silverman Voice Treatment [LSVT LOUD]) for Children With Down Syndrome: Phase I Outcomes. Carol A. Boliek , Angela Halpern , Keren Hernandez , Cynthia M. Fox and Lorraine Ramig

FLUENCY/STUTTERING

- Very common
 - Will wax and wane
- Don't ignore
- Mention speech difference then model how to say it again (bumpy speech, tough, etc.)
- **Practice saying common words and phrases using a technique that works and is incompatible with dysfluencies**
 - Melodic intonation
 - Imitate a better rate or rhythm
 - Clapping, tapping, pointing to pacing board
 - Visual representations of stretching, slower rate, and rhythm



BEST SPEECH TECHNIQUES

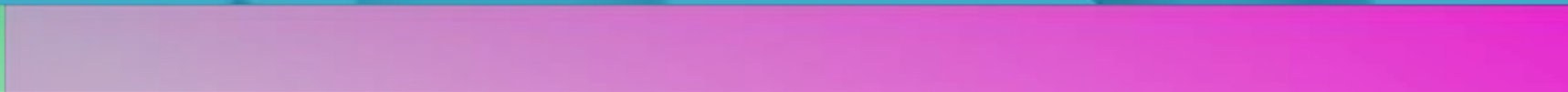
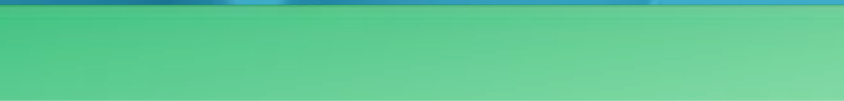
THERE'S ONLY 3!

1. Manner of speaking that is incompatible with habits of poor clarity – Melodic Intonation Therapy, LSVT LOUD, Reading for Speech
2. Short, frequent, and intense practice
3. Reduction and elimination of dysfunctional speaking habits

Practice, Practice, Practice!



Functional & Salient Practice





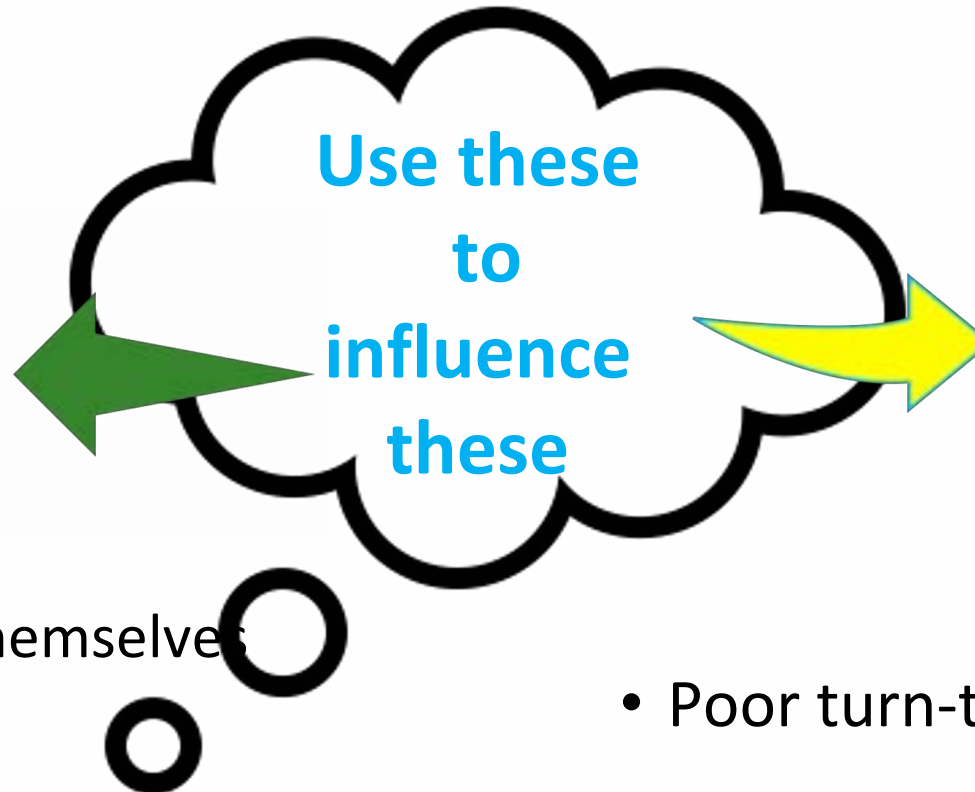
Meaningful Examples of Practice for Independence

- Name (first & first and last). Spell it too.
- Greetings and Goodbyes
 - (“Hi, thank you for coming in” vs “Hi”)
- City, state, addresses, phone numbers
- Practice using and referring to calendars
- Ordering own food at restaurants
- Shopping
- Upcoming events (graduation, employment, special gatherings, etc.)
- Texting
 - Talk-to-Text
- Siri & Alexa
- Speaking on the phone
- Teletherapy

Know & Use Strengths And Needs

Strengths

- Social and emotional
- Visual learning
- Long-term memory
- Music
- Can focus if interested
- Proud confidence in themselves



Relative

Weaknesses/Needs

- Empathy and affect
 - Auditory learning
- Short-term memory
 - Rhythm
- Meta skills and rigidity
- Poor turn-taking and reciprocal skills

Virtual Cooking Classes

Targets:

- Independence
- Planning
- Sequencing
- Social Communication
- Use of Technology
- Practice of functional skill
(cooking)

Modifications:

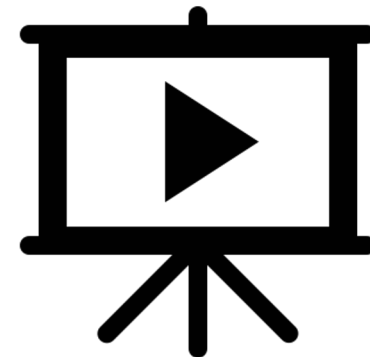
- More or less parent support
- Ingredient substitutions
- Additional assistance:
occupational therapist, ABA,
sibling, etc.

**Teaching Authentic
Cooking Skills to Adults
With Intellectual and
Developmental Disabilities:
*Active Engagement***



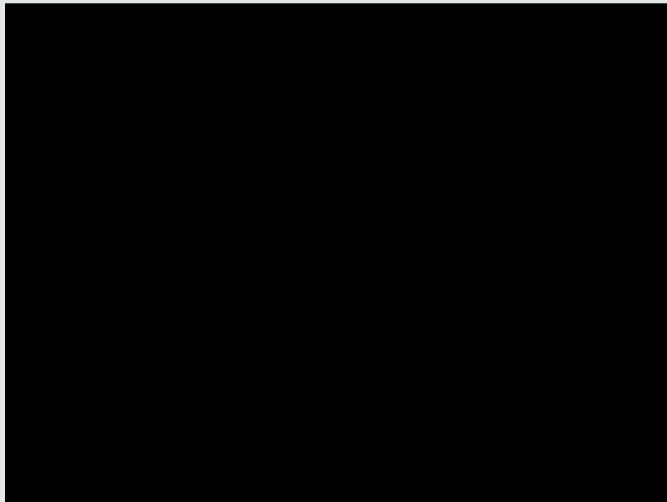
Janice Goldschmidt

[https://www.aaid.org/education/education-
archive/2019/02/07/default-
calendar/active-engagement-
resolving-common-problems-for-
individuals-with-idd-in-learning-
to-cook](https://www.aaid.org/education/education-archive/2019/02/07/default-calendar/active-engagement-resolving-common-problems-for-individuals-with-idd-in-learning-to-cook)



Virtual Cooking Class

We made **quesadillas**!



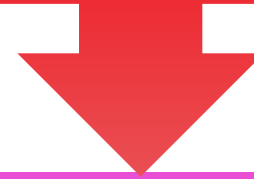
Cooking Sequence

Nearly every speech and language goal can be targeted through cooking

- What do I like to eat?
- What do I want to learn to make for myself and others?
- Where do I get ideas (cookbooks, Pinterest, magazines, etc.)
- Shopping list and finding items in store
- Buying
- Unpacking
- Preparing ingredients and kitchen supplies
- Following a recipe, etc.
- Safety
- Serving
- Eating
- Cleanup
- Discussions about the cooking and eating process
- Repeat



A combination of physical skills, sensory feedback, and self-awareness
for social participation



MESSINESS

Common culprits:

poor motor control	Poor body awareness	Unstable movements, stability movements, erratic movements, grandiose movements, faster and slower movements than necessary.	Unstable seating	Stuffing	Lack of utensil use = messy hands that touch and grab other things (cups, etc.).
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Online & Visual Recipes at Home

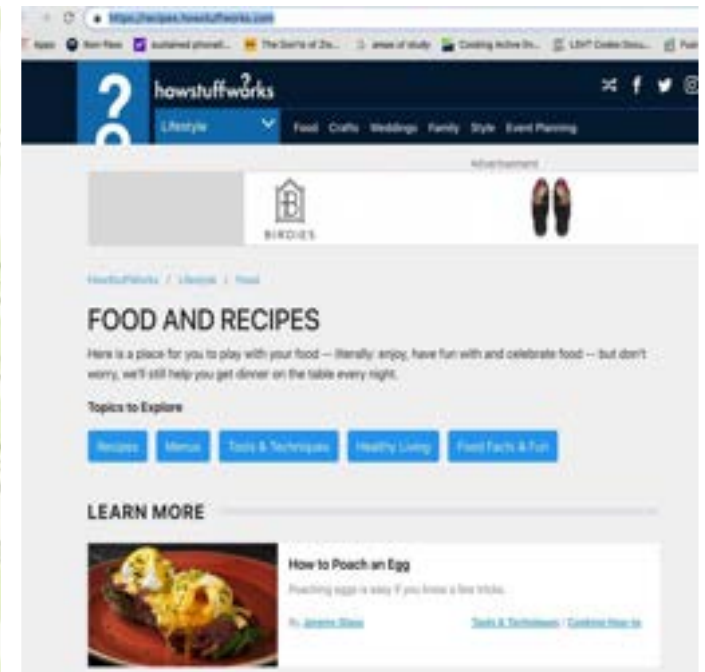
<https://recipes.howstuffworks.com/>



The screenshot shows the 'dr.yumrecipes' website. At the top, there are navigation links for 'recipes', 'meal-o-matic', 'meal planner', 'print recipes', and 'SIGN UP TODAY'. Below the navigation is a search bar and a 'YOUR SHOP LIST & MENU PLANNER' button. The main heading is 'meal-o-matic' in green. Below it, a paragraph explains the tool: 'Here at the Doctor-Yum Project we believe that cooking does not have to be complicated in order to be healthy and delicious. That's why we have designed meal-o-matic to help you make a few basic recipes with the ingredients you love. Design your own personalized meals based on the ingredients you have on hand, your favorite flavors, or your own dietary needs. No matter what your skill level is in the kitchen, using the meal-o-matic is easy and fun for the whole family!'. To the right of the text is a colorful gear icon. Below the text are seven recipe cards with icons: 'stir-fry maker', 'curry in a hurry', 'super soup maker', 'busy night bake', and three more cards. At the bottom right, there is a 'meal-o-matic app!' logo with an 'Available on the App Store' badge.



The screenshot shows the 'ACCESSIBLE CHEF' website. The top navigation bar includes 'Home', 'Recipes', 'Recipe Cards', 'Resources', 'About', 'Blog', and 'My Profile'. The main image is a young girl with glasses, smiling and holding up two pieces of paper. Below the image is a '5.0' star rating. The page has two columns: 'INTRODUCTION' and 'MEET THE TEAM'. The 'INTRODUCTION' section is titled 'Welcome To Accessible Chef' and contains the text: 'Accessible Chef is a collection of free visual recipes and other resources to help teach cooking skills to individuals with disabilities. Looking for Your Special Chef? You're in the right place! We changed our name and look to better represent our goal of making cooking accessible to everyone.' The 'MEET THE TEAM' section features a photo of two men, one in a blue shirt and one in a blue shirt and a yellow hat.



The screenshot shows the 'howstuffworks.com' website. The top navigation bar includes 'Lifestyle', 'Food', 'Crafts', 'Weddings', 'Family', 'Style', and 'Event Planning'. Below the navigation is a search bar and a 'howstuffworks' logo. The main heading is 'FOOD AND RECIPES'. Below it, a paragraph explains the site: 'Here is a place for you to play with your food — literally, enjoy, have fun with and celebrate food — but don't worry, we'll still help you get dinner on the table every night.' Below the paragraph is a 'Topics to Explore' section with buttons for 'Recipes', 'Meal', 'Tools & Techniques', 'Healthy Living', and 'Food Facts & Fun'. The 'LEARN MORE' section features a photo of a poached egg and a recipe card titled 'How to Poach an Egg' with the text: 'Poaching eggs is easy if you know a few tricks.' Below the recipe card are links for 'In: Appetizers', 'Dishes & Dinnertime', and 'Cooking How-to'.

EXECUTIVE FUNCTIONING



WHAT IF.....

- Utterance length/MLU/# of words said at a time is not a language problem but a memory sequencing Problem (# of words, word order, how to correctly say the sounds of each word, breathing, not breathing, rate, loudness, rhythm, etc.) and other motor speech movements?
 - How would that change our approach to improving this skill?



EXECUTIVE FUNCTIONING

Executive functioning is the part of the brain that manages the skills we need to complete tasks in our daily lives.



mindfulrambles.blogspot.com

is responsible
for learning
new skills

- ❑ Necessary for all successful speech and language skills
- ❑ Very closely tied to language as the basis of cognition.

Tera Sumpter, Sarah Ward

- ❑ Working memory/Short-term verbal memory
- ❑ Inhibition
- ❑ Flexibility – modify thinking and doing
- ❑ inhibition / self regulation
- ❑ Perception of time (past, present, future)

Beware: Helpful practices can become liabilities if rigidity is allowed to dominate

- Schedules, eating, being late, cancellations, unforeseen circumstances

Retrieval not Knowledge

We know you Know

- While memory is a concern that demands interventions, retrieval of knowledge to immediately act upon the world may be more to blame than acquiring knowledge or learning.
- This is the gap between receptive and expressive language skills
- The speed of retrieving knowledge is the problem; not knowledge itself
- Allow the person time to retrieve what they know and practice reciprocal cueing
- We rarely have to teach the knowledge, Instead, we should help speed up retrieval
- Impacts:
 - Answering questions accurately, participating in conversations, and remembering the many speech and language techniques taught over the years (in the span of seconds)



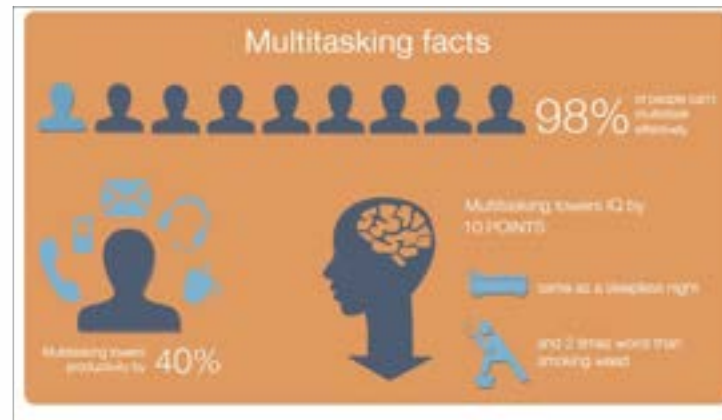
Practice talking about special events and milestones prepares the mind and body for upcoming events

These same preparation skills will continue to help with future event

Executive Functioning **and** Independence

- **Executive function and self-regulation** skills are the mental processes that enable us to plan, focus attention, remember instructions, and juggle multiple tasks successfully (Harvard University <https://developingchild.harvard.edu/science/key-concepts/executive-function/>)

Multitasking Doesn't work {well}



...**because**

Multiple speech delays and disorders simultaneously

Concomitant disorders of language, hearing, vision, dysarthria, hypotonicity, voice, resonance, stuttering...

Anatomical and physiological impacts

Executive functioning needs: working memory and short-term verbal memory

Language targets get more attention, especially at school

AAC assessment and use is very time consuming (if done right)

Technology can prepare those for opportunities after high school

- Transition Programs
- Local day programs
- College courses
- Volunteer opportunities
- Jobs
 - Companies specifically hiring people with disabilities (Bitty & Beau's, Howdy's Ice Cream)
 - Known inclusive companies (chick-fil-a, Lowe's, Walmart)
 - or any employment of choice!

How we get there:

- Resume building
- Online job search
- Identifying strengths and weaknesses
- Identifying interests for job satisfaction
- Preparation with transition programs or college based programs

High Repetition Of Meaningful Upcoming Events

Prom is May 14th

When:
May 14th

Who:

Rachel
Rachel is my sister
She's my sister

I will graduate on May 18th

May 2022						
Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

©Michel Zlotnik / Calendar 48MB

LOUD Voice

- I'm a Senior
- I'm a Senior
- I'm a Senior
- I'm a Senior
- I'm a Senior

Prom

- Are you going to Prom **Yes, I am.**
- When is Prom? **On May 14th**
- Who are you taking to Prom? **Rachel**
- Who is Rachel? **She's my sister**
- Will you take her to dinner? **Yes**
- Where will you have dinner? **The Bonefish**



“Hey Siri
play Folsom Prison
Blues”

“Hey Siri
play A boy Named
Sue”

Hey Siri, play Ring of
Fire.”

- ★ volunteering
- ♥ graduation parties
- swim team

JUNE 2023

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1 ★	2 ♥	3 ♥
4	5 ●	6 ●	7 ●	8 ★	9 ♥	10
11	12	13 ●	14 ●	15 ★	16	17
18	19 ●	20 ●	21 ●	22 ★	23	24
25	26 ●	27 ●	28 ●	29 ★	30	

www.a-printable-calendar.com

First

Piper and I walked to get coffee in the morning

Mom and I rode bikes together to middle school.

Monday, softball was cancelled because of the weather so I watched tv.

Next

I ate a chicken salad sandwich for lunch

I came home to see the puppy and I pet her.

Today, I rode bikes to school with mom.

Last

I read my book outside before making dinner

After speech, I want to play on my iPad.

Friday, I want to go fishing with my dad.



Technology and Teletherapy

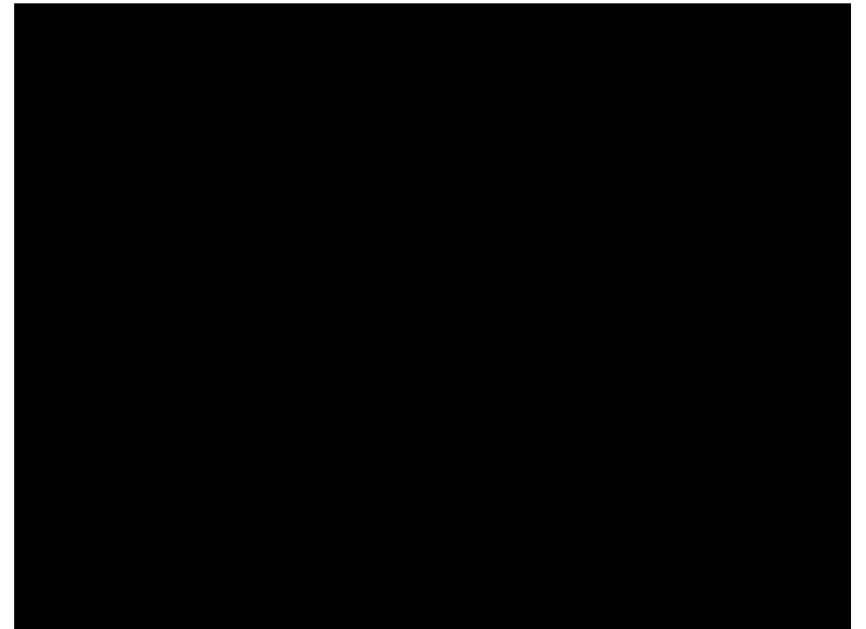


- ★ Texting and email skills
- ★ Group messages
- ★ Google calendars and personal planning

All of these translate into skills for *jobs* and *school*



People with Down syndrome and other motor speech disorders want to be understood by others and will continue to use verbal communication even in the absence of success.



LIVING WITH DOWN SYNDROME



57% of adults with Down syndrome were employed

Of that 57%, only **3%** were full-time paid employees

26% were volunteers

Almost **3%** were self-employed

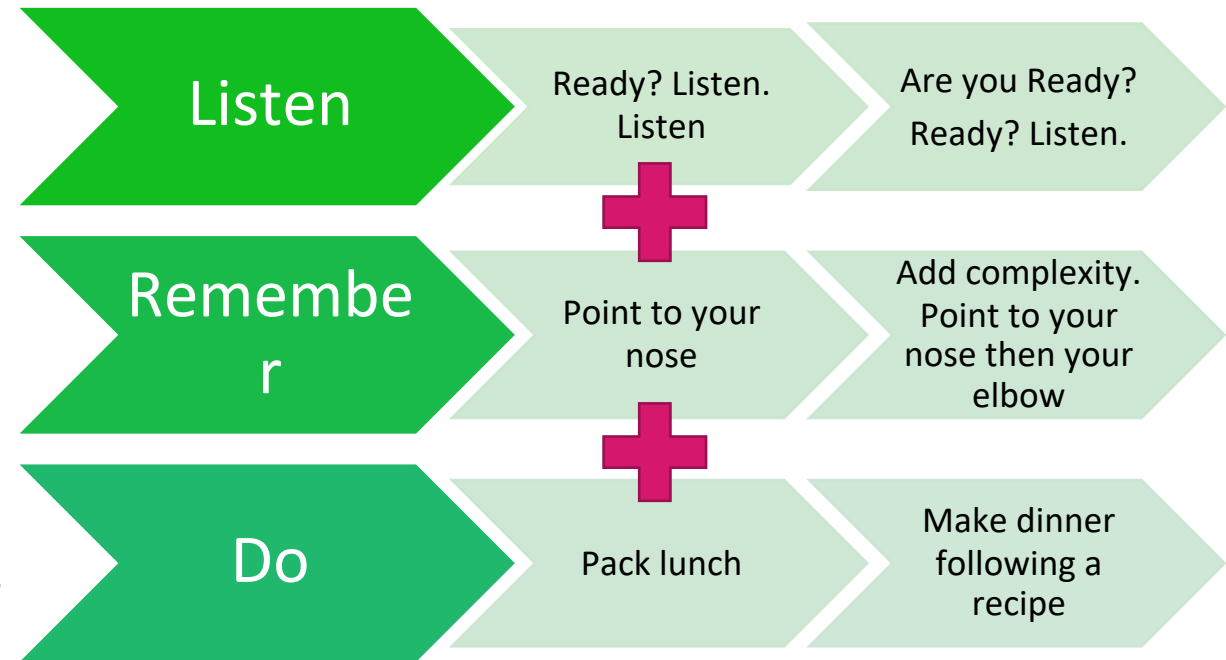
Source: National Center on Health, Physical Activity and Disability (NCHPAD)

healthline

Memory Techniques

Focus on Retrieval

- Matching games
- Memory games
- Multiple direction activities
- Following 1-2 step directions : “touch your nose and then your tummy.”
- Increase complexity with “before, after, then, etc.”
- Verbal games like “I went to the store and bought...”
- Actual independence skills



EXECUTIVE FUNCTIONING RESOURCES

Sequence & Visualize:

- **Get Ready Do Done** (examples: <https://www.slpcorner.com/therapy-ideas/clinical-model-for-developing-executive-function-skills-get-ready-do-done>)
- Ward, S., & Jacobsen, K. (2014). A clinical model for developing executive function skills. *Perspectives on Language Learning and Education*, 21(2), 72-84.

Same but different: Sarah Ward, MS, CCC-SLP

- Scaffolding skills slowly
- Expand boundaries for less rigid routines

Benefits of Being Busy: Stacy Taylor, MA, B.C.B.A.

- being active and involved
- reduces time spent self soothing or worrying

**ADDITIONAL
RESOURCES**

Canadian Down
Syndrome video
series – (YouTube)

Adult Down
Syndrome Center

Perspective Taking & Relationships

Sense of self
→
independence

All teenagers, especially those with Down Syndrome, have difficulty with perspective taking, internal motivation, and goal setting for their future selves.

Active Engagement

Active listening

- ❑ Requires Executive functioning skills and awareness of others and various settings
- ❑ This is not listening, but actively participating.
- ❑ Extended periods of time alone or engaging in routine behaviors hinders active engagement and growth.
- ❑ Over time, a lack of active engagement can lead to regression
- ❑ Important implications for breaks (summer break), holidays, transitional times in life (graduating from high school)

Conversation
Joint attention
Socializing
Phone, texting,
email

Cooking
Chores
Helping others
Sports
Ordering & paying for own
items, food, etc.

Watching Cinderella multiple times each day

Benefits of a strong **sense of self**:

- ★ Emotional awareness and regulation
- ★ Perspective taking and consideration of peers
- ★ Internal motivation and planning for the future
- ★ Getting out of their “bubble”
- ★ Ability to develop meaningful relationships

How can we work on sense of self??

Internal Motivation: creativity, planning, the “want”

- identify interests
- visualizing future self
- set goals

Perspective Taking: emotional intelligence, awareness, inhibition

- name personal feelings
- identify appropriate comments
- role play

Recovery from Regression

There are little to no therapeutic resources for those experiencing and recovering from Down Syndrome Regression Disorder (DSRD)

Techniques in the areas of Dementia and Alzheimer's disease can be used and adapted for habilitative and rehabilitative therapy

Many speech and language skills are intact in recovery; some emerge with better language skills observed prior to initial symptoms

Speech Therapy Pre and Post Recovery

- Giving >1 sentence or question choices on the screen to read
 - Remove cognitive load to reduce anxiety about speaking or remembering
 - Using reading aloud to recover the feeling (e.g., like muscle memory) and control of using longer utterances (because language may not be the problem)
 - Voice techniques to strengthen the initiation of voice and speaking endurance
 - Video modeling is very effective
 - Begin with videos of others and ease into self modeling videos if anxious
-

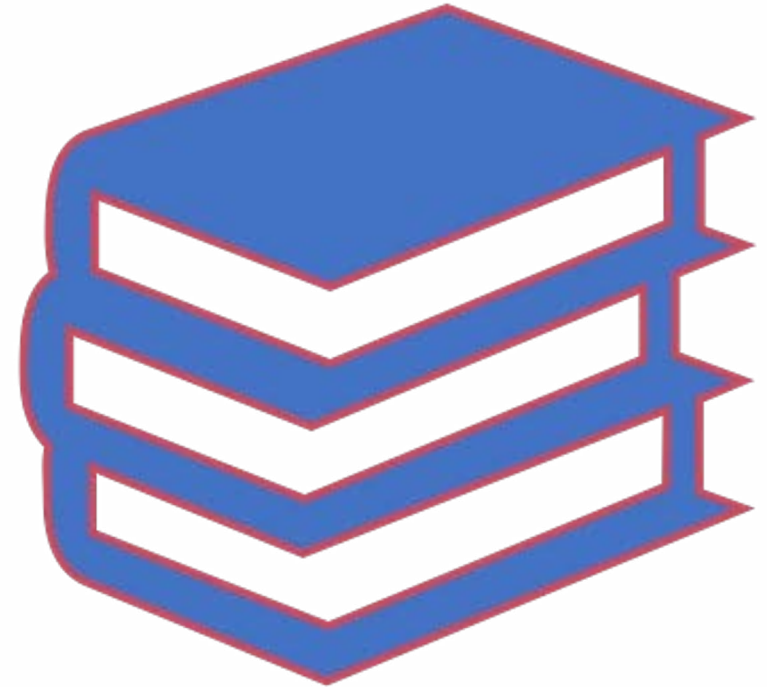
VISUAL PACING



Reading

FOR SPEECH

- ▶ Reading may be introduced prior to longer MLUs are mastered.
- ▶ Reduces the cognitive load of spontaneous speech.
- ▶ Can act as a pacing board
- ▶ Reading aloud gives the feeling of speech, motor memory, controlled breath support for longer utterances, visual support, etc.
- ▶ Use speech techniques such as loudness, appropriate rate, and punctuation as cues for prosody.
- ▶ Focus on whole words, then fluency, then decoding.
 - ▶ Then comprehension, but not as a part of speech



- Common phrases used at work
- Daily schedules
- Retelling past events
- Rehearsing future events
- Personal and safety information

Shutterfly

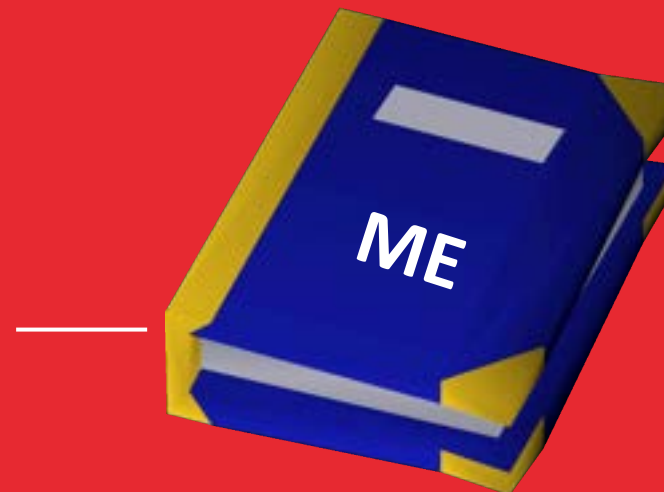
Walgreens (has same day pickup)

Apps: (e.g., Pictello)

videos

PERSONAL BOOKS

- Physical
- Digital
- Make them accessible at home
- Use them in Teletherapy sessions



BE YOUR OWN IEP

**Using melodic intonation, reading,
personal choices without correction,
video modeling, speech practice, using
writing as communication**



VIDEO MODELING

- Use pictures and videos of self doing a desired skill. Cell phones are cameras and video recorders!
 - Helps with memory, recall, sequencing, and predicting
 - Pics of day to show others at the end of the day or a later time.
 - Retell events: the zoo (first we saw the elephants, then the giraffes and they had long tongues, etc.
 - Personal books
- Videos of self and others (other children): Copy-Kids, YouTube
(Discrete Video modeling: Gemiini <https://gemiini.org/solutions/down-syndrome#/get-started>)





SHARED VIDEOS OF INDEPENDENCE

***With permission I show this to my
other teens***

ADD Pearl Smoothie video

INTERVENTIONS

for answering questions



- Teach how to answer 1st
 - Modeling and gaining full attention
- Practice answering common questions: name, age, grade, etc.
- Rapid drill: objects, pictures, people
- Retelling recent past, relevant present, and near future.
 - This is also the best strategy for **memory**
- Teach the task, not the answer.
- **Being able to answer common questions with ease using clear speech sets the expectation of ability and confidence in the speaker by listeners.**

TEACH THE TASK, NOT THE ANSWER

TEACH DON'T TEST

Teach & cultivate EMPATHY & CURIOSITY

- Possible culprits to a lack of interest in others
 - All about them from birth (medical needs and concomitant difficulties delay typical interactions)
 - Few opportunities to help others early in life
 - Fewer opportunities to practice social communication (regardless of type)
 - More time with music and movies than exploring life with peers/friends
 - Few opportunities to self-monitor and self-correct (others do it for them and may not notice or worry about own errors)
 - Rigid preferences and empathy get worse with age if allowed
 - Fewer corrections from others, especially if negative reactions persist

INTERVENTIONS TO CULTIVATE EMPATHY AND SOCIAL RELATIONSHIPS

- Monitor medical concerns (hearing, vision, cardiac and pulmonary interactions, GI and inflammatory flareups, etc.)
- Visual strategies (video modeling, AAC, role playing, observation followed by interaction with peers)
- Practice opportunities in real groups with mediators
- Peer mentors
- Less time alone and/or watching familiar entertainment
- Staying busy as part of a family, exercise, work or chores, school activities, etc.

Active Engagement

Teletherapy And Digital Materials And Homework

Materials

Creation of individualized PowerPoints for structured coaching

Reports of the past or planning for future events through pictures, notes, and AAC

Texting or email correspondence between sessions



Metalinguistic Awareness

self-correction, joking & pretending

Problem

- Many meta-skills are absent or minimal
- Working memory must be able to hold: what I heard, retrieve vocab and knowledge, think of answer, how to say it (sounds, syllables, words, syntax, grammar, connected speech for phrases), , make any corrections
- Not aware of own errors
- Will persist through communication struggles without attempts to say it differently
- Fluency/stuttering emerge
- But ALL can be taught and improved!

Intervention - Strengths

- Repeat their error with descriptive language (that sounded bumpy, let's try that again)
- Then offer a way of speaking to imitate, hear, and see (biofeedback)
- Use strengths of enjoying repetition and sameness for intense practice
- Play with different voices – actors, youtube, etc.
- Fluency shaping with high repetition then then stuttering modification

LEARNING THE HARD WAY

Wishart JG. Learning the hard way: Avoidance strategies in young children with Down syndrome. Down Syndrome Research and Practice. 1993;1(2);47-55. <https://library.down-syndrome.org/reviews/10/>

If these behaviors are extreme and prevent learning, we must work on these first by making learning easy, short, and enjoyable.

Only consistent and deliberate practice can help move away from this tendency.

This will lead to Perseverance

Another common parallel trait is the lack of internal motivation to learn or change. This is where we come in.

Poor speech clarity persists into adulthood and continues to fluctuate despite improved speech and language development.



ENHANCE
SKILL LEVEL

Behavioral Phenotypes

That Lead To Signs Of Struggle

Be Vigilant

- Avoidance and opting out
- Lashing out
- Self-isolation
- Self soothing or stimming behaviors increase in frequency and severity
- Impact ability to learn, transition, negotiate varying environments, develop relationships and friends
- Seek professional help when undesired behaviors become problematic: interfere with daily life activities and relationships with others

Intervene

- Include in household responsibilities
- Be busy
- Reduce time left alone (yes, when they prefer it)
- Can attempt to replace with more appropriate actions
- Build awareness of self and others
 - Emotional training, modeling, video modeling, retelling of day & planning tomorrow

**** Work of Deborah Fidler

<https://www.globaldownsyndrome.org/our-story/leadership/adults-with-down-syndrome-task-force/deborah-fidler-phd/>

BEGIN THE TRANSFER:

Independence And Ownership

Familiar

- **Choices: clothing, snacks,**
- **Responsibilities: pack lunch, make breakfast, clean**
- **Chores**
- **Homework (checklists)**

Maybe Less Familiar

- **Digital communication (using the phone, texting, email).**
- **Presentations to peers**
- **Conduct own IEP**
- **Peer modeling**

What can I help you with?

Talk To Text
&
Siri/Alexa

Meaningful &
Empowering



Teaching/Training

the Task 1st

- **Demonstrate it yourself**
- **Write down the steps**
- **Take pictures of the steps**
- **YouTube Videos**
- **Videos of a peer setting up the device**
- **Many exposures**
- **Make it highly desirable (music, friend contact, family contact, etc.)**

Hey Siri

(5 times)

Best text ever from teen client:

- Hi. Can we meet now instead of later?
I'm bored.
- Therapist reports:
 - “She asks me before every session between 5-15 mins to send the go to meeting.”



SIRI

- “Send a message”
- “How’s the weather today?”
- “Set a timer for 3 minutes”
- “Play some music”



Talk-To-Text

- To text family and friends
- To call mom or dad
- To begin doing own scheduling
- Self-Reminders
- If the Phone does not transcribe the message correctly...
 - Try your voice again
- Type
 - Use emojis or photos or GIPHS

Intense and Frequent Therapy

More powerful than lower dose therapies

Successful speech clarity is achieved when others listen to what you say, not how you say it.

Where do we start?

Speech Clarity should be the first step if poor comprehensibility is preventing him/her from participating and learning

- Speech clarity – What about his/her speech is causing the message to be misunderstood?
 - Sounds?
 - Rate/Speed
 - Voice: breathy, hoarse, strained
 - Resonance: like he/she has a cold, hearing loss, or strain
 - Rhythm/Prosody: syllable and word stress is different than _____ expected.

Where do we start?

Active Listening and Engagement is
the first step to better Executive
Functioning skills and learning

- Difficulty answering easy questions he/she knows the answers to
- Replies with rote/scripted answers regardless of setting or topic (“I don’t know, oh great, yes/no, etc.”)
- Difficulty with topics of Recent Past, Present, and Near Future
- Can ignore useless information or distractions (air conditioner turning on, lawn mower, etc.)
- Difficulty describing things beyond nouns
- Notice things that seem strange or different and commenting on them
- Reciprocal interactions with others or monologues only

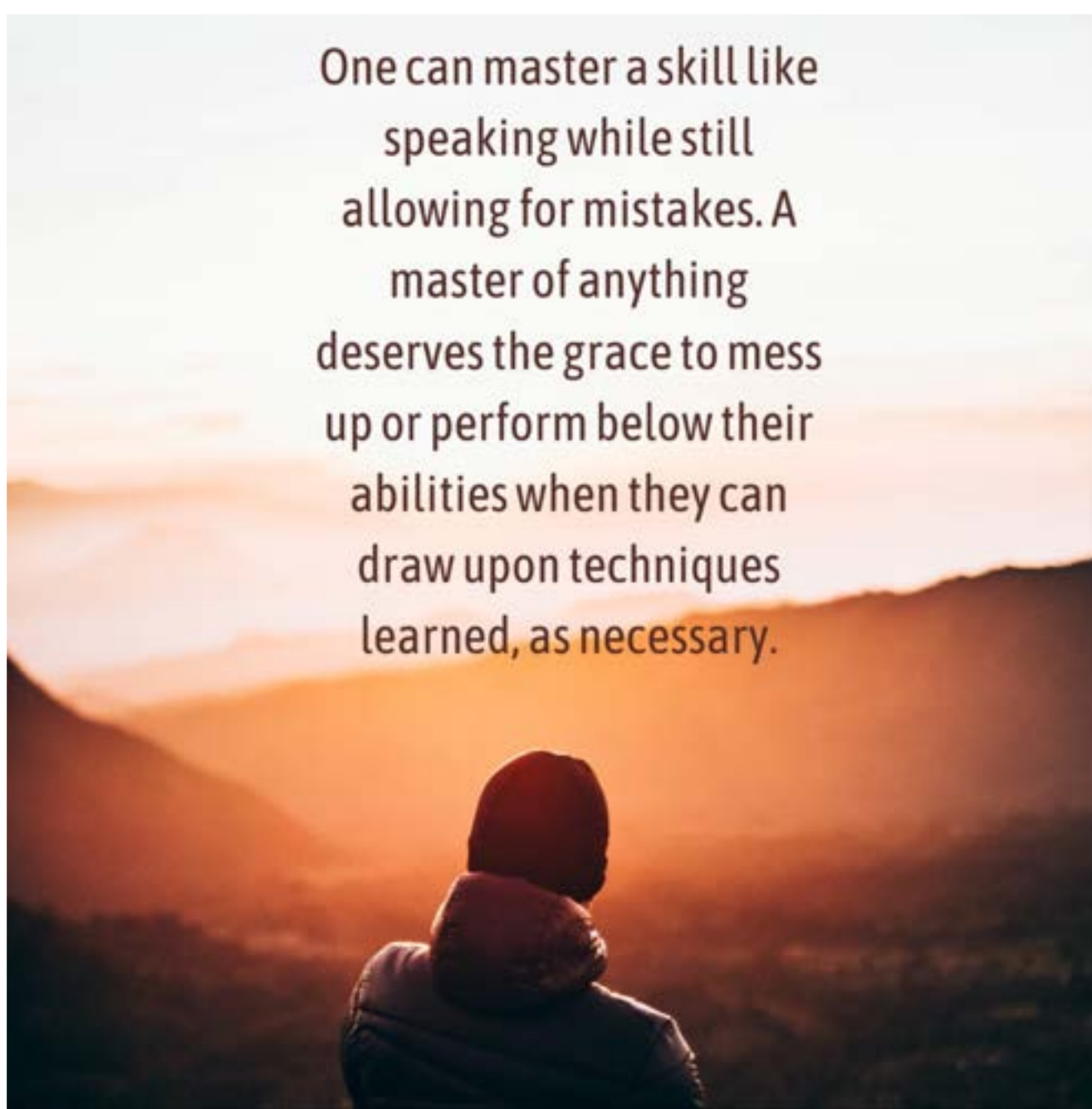
THE IMPROVANEERS

"PIONEERING NEW REALMS OF IMPROVISATION"

"Using improvisation to build skills that will greatly improve social, workplace and lifetime opportunities in those with developmental disabilities."

Authentic And Purposeful Engagement

One can master a skill like
speaking while still
allowing for mistakes. A
master of anything
deserves the grace to mess
up or perform below their
abilities when they can
draw upon techniques
learned, as necessary.



SPEECH & LANGUAGE SKILLS

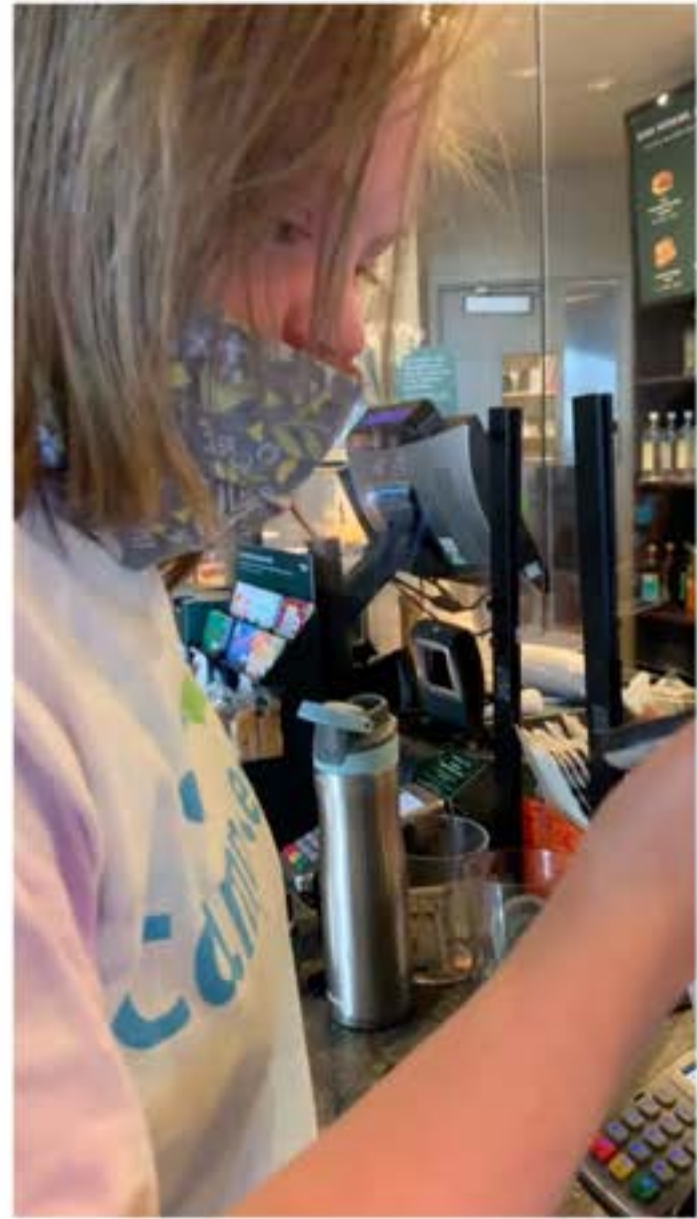
Will open doors for all opportunities. They will enable relationships, employment, health, help prevent regression, and prolong dementia and Alzheimer's disease.

ALL SKILLS CAN BE LEARNED AND IMPROVED AS ADULTS

REGARDLESS OF DISABILITY

PRIDE & CONFIDENCE

**Using a technique then no longer
needing the support**



Thank You!



Jennifer Gray, MS, CCC-SLP

jennifer@grayspeaktherapy.com

www.grayspeaktherapy.com

www.downsyndromespeech.com

@grayspeaktherapy

@downsyndromespeech



Sarah Bookout, MA,
CCC-SLP

sarah@grayspeaktherapy.com

www.grayspeaktherapy.com

@howdytexasslp

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•Vani Rupela, Shelley L. Velleman, Mary V. Andrianopoulos. *Motor speech skills in children with Down syndrome: A descriptive study. International Journal of Speech-Language Pathology*, 2016; 1 DOI: [10.3109/17549507.2015.1112836](https://doi.org/10.3109/17549507.2015.1112836)

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Resources

Health & Medical Co-Occurring Conditions: National Down Syndrome Society

--<https://www.ndss.org/resources/cooccurring-conditions/>

Dr. Kishore Vellody, Medical Director, Down Syndrome Center of Western PA, www.ndsc.org

Down syndrome research and practice

--<https://www.down-syndrome.org/en-us/>

Down syndrome Education

--<https://www.dseinternational.org/en-us/>

Dosage

--<https://doi.org/10.1352/1944-7558-119.1.17>

Comprehensive motor speech Reference list (in the citations of this article):

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6604063/>

Myths of Down syndrome

--<https://www.ndss.org/wp-content/uploads/2017/08/NDSS-Myths-and-Truths-2015.pdf>

Executive Functioning/Cognition/working memory/verbal short-term memory

https://www.researchgate.net/publication/41759591_Executive_function_in_adolescents_with_Down_Syndrome

Learning: Reading, Writing, and Math:

--<https://www.sohappytolearn.com/>

--<https://www.seeandlearn.org/en-us/>

Video modeling:

--<https://www.copy-kids.com/>

--<https://gemiini.org/#/get-started>

Active Engagement:

--<https://www.electronic-therapy.com/category/e-therapists/>

Feeding/Eating/Cooking:

--<https://www.mymunchbug.com>

--<http://www.talktools.com>

--<https://www.aaid.org/education/education-archive/2019/02/07/default-calendar/active-engagement-resolving-common-problems-for-individuals-with-idd-in-learning-to-cook>

-- <https://accessiblechef.com/>

--<https://recipes.doctoryum.org/en/makers>

Voice

--<https://www.lsvtglobal.com/>

--<https://downsyndrome-voice.weebly.com/down-syndrome-research.html>

--<https://blog.lsvtglobal.com/intensive-speech-therapy-lsvt-loud-for-clients-with-down-syndrome-one-clinicians-experience/>