



THE
LISTENING PROGRAM®

by ADVANCED BRAIN TECHNOLOGIES

CASE REPORT

DOWN SYNDROME

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SC

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ABOUT SC

Submitted: October 2017

Provider: Dr. Roger Dowis, OD FCOVD
Boulder, CO

Client: SC, Female, 17 years old

Clinical Diagnosis: Down syndrome, Sensory Processing Disorder, Social Anxiety Disorder, Unspecified Psychosis, Developmental Regression, Mixed receptive-expressive Language Disorder, Expressive Language Disorder, Lack of Coordination

BACKGROUND

The Jeyes and Newton (2010) study with the Down syndrome population addressed benefits of using the use of The Listening Program to achieve improvements in auditory processing and speech and language skills since children with Down syndrome are known to have auditory processing and language development difficulty (Jeyes and Newton, 2010).

The purpose of this case study is to describe the use of combining The Listening Program and vision therapy as an intervention for, or as a means of addressing the needs of SC, a teenager with Down syndrome, to overcome her sensory integration and processing deficits and social anxiety disorder.

SC was born with Down syndrome and congenital ASD/VSD heart defects, which were repaired at three months of age. SC later developed a heart block and required a pacemaker implant. SC has had four sets of ear tubes due to continual ear infections early on in her life. Due to sleep apnea, SC had her tonsils and adenoids removed.

Due to SC's Social Anxiety Disorder, SC would not generate an appropriate communication voice volume and needed much more time to warm up with people.

The discharge note from 06/09/2015 TCH Speech and Language Therapy gives an insight into SC's Social Anxiety Disorder: SC "has participated in nine sessions of short term, individual

speech-language therapy. During the first six weeks, SC's spoken language was minimal. She appeared highly anxious (i.e., keeping her head down, looking away from the therapist, disengaging in tasks) and spoke very little. When she did speak, her spoken output was very quiet and less than 40% intelligible to therapist in known context. During our 6th session of therapy, SC began to independently speak using full sentences. In addition, she did an excellent job increasing her voice volume when a visual "voice chart" reference was implemented.

Ongoing concerns remain regarding SC's ability to maintain a successful mode of communication in new environments and when engaged with unfamiliar communication partners. Because of this, SC's mother has been strongly encouraged to continue to explore use of the TouchChat or other ACC devices. SC was referred to a center where she could have longer term speech, occupational and physical therapy.

One of the congenital effects of Down syndrome is the musculoskeletal low or weak muscle tone, hypotonia, accompanied by ligaments that are too loose, ligament laxity (Down syndrome: Musculoskeletal Effects-OrthoInfo - AAO, n. d.). Since hypotonia and ligament laxity is common in Down syndrome, we should also pay attention to needed exercises to strengthen the muscles in the eye to assure visual input accuracy. In the case of SC, mom had strabismus which was corrected at a young age.

In the 2014 article Visual Status of Children with Down syndrome, Robert H. Duckman, OD, MA, of the College of Optometry of the State University of New York, indicates that some of the Visual Signs of Down syndrome are strabismus and cataracts, etc.

BEHAVIORAL HISTORY

At about three years of age, SC started hitting her peers at school. SC's cognitive teacher, a well-regarded professional from the community, would indicate that SC was exhibiting sensory integration issues, which was disregarded by the school psychologist. SC would be placed away, while being included, from the peer group in school.

At a later point, a behavioral expert SC's parents consulted with indicated that at three years old, there is an increase in academic demands; therefore, at that point SC, with her sensory integration and processing deficits, and her tactile defensiveness, etc., should have been placed in a one-to-four or two-to-six classroom placement.

The behavioral hitting continued in SC's schooling experiences. SC's tactile defensiveness would increase as her anxiety would increase, and SC's hitting would be harder, as the school year would progress. The mother took SC to the Boulder Community Hospital where the mother was informed that SC had sensory integration issues by the OT. Also, the parents took SC to the Star Center where the parents were informed that SC had Sensory Processing Disorder, a diagnosis which is yet to be recognized by the DSM. SC's parents decided to home school SC.

SC went for a short period of time to high school. This was the first time that SC was in a contained classroom, instead of being included. SC would appear to be very frustrated after school, and would at times do self-harming and other mal-adaptive behaviors like: hitting her forehead against the wood floor, slamming doors, tossing dining room chairs, hitting herself on the face until bleeding, etc. SC's parents decided to home school SC once again.

In November 2015, SC was formally diagnosed with Unspecified Psychosis and Developmental Regression. SC qualified for the Children's Extended Services (CES) waiver. From that point on, mom was primarily working, with the help of support from the CES waiver, on: getting SC's speech back after her self-advocacy had regressed (as if she felt silenced and could no longer advocate for herself); keep SC busy so that she doesn't drift into her own world; challenge SC's fears; get SC back to her morning, pre-bed time, and night-time routines with accommodations, and modifications (not her normal way); etc.

By the summer of 2016, SC was doing much better with her fears: sleeping in her room upstairs, with mom sleeping in the trundle bed; mom did not have to be within her eyesight all the time like before; decline in panic attacks, no longer having the extreme panic attacks she used to have; and working well with the respite provider.

During the summer of 2016, with much reservation from mom, SC went to summer camp with prevention/handling strategies to deal with mal-adaptive behaviors while in Camp. For precaution purposes, due to her history of aggression towards young children, mom proposed the protocol of including SC in camp with the older campers, and avoiding exposure to young children as much as possible. A few incidents happened at camp, but the overall experience was positive.

In July 2016, SC went to Orlando with her mom and older sister to the 2016 National Down syndrome Congress Convention. Her mother still was apprehensive, not knowing how SC would behave.

During the conference, mom learned from a speaker at the conference, a psychologist from Barcelona, that it is very important to work on one's self-concept and the identity from very early in life. Flórez et al. (2015) indicate that crises of identity in adolescence are frequent and that can lead to psychotic outbreaks or decompensation followed by loss of contact with reality; this is why it is so important to work on the identity from a young age. In the adult world, the identity is tightly linked to responsibility, to greater autonomy, and making decisions (each one according with their possibilities). The role of labor is important as well, as entering the labor world means entering in the adult world (Montobbio, 1995).

Again, a few incidents happened during that Orlando trip, even with all the precautions that were in place, but the overall experience was positive.

TREATMENT

Prior treatment, since early intervention, consisted of speech therapy, occupational therapy, physical therapy, music therapy, tutoring interventions, some vision therapy, etc. which did not appear to impact SC's need for overcoming her sensory integration and processing deficits and her need to overcome her social anxiety disorder.

SC has been receiving psychological help for her social anxiety disorder from the SIE Center for Down syndrome at The Children's Hospital. SC would have problems and react, her fear response, mostly in a fight mode, versus a flight mode, to her fight or flight triggers such as:

- When SC feels that someone is staring at her fixedly with a neutral face or not smiling (SC calls this a "mean mad face")
- When someone doesn't want to play with her or when SC is trying to connect/communicate with the other child or when SC is feeling jealous when the other child is giving the attention to another child and not to her.
- Coming from behind, without warning. For example, children approaching in a group from behind after recess.
- You have to verbally ask for permission before kissing or hugging her. You have to ask for permission before doing anything that touches some part of her body, by example, brushing her hair, brushing her teeth, etc.

Other triggers are found:

- Children (boys rough play) hitting and yelling to each other
- Yelling and staring at her
- When SC feels that the work is hard when she is tired, or has not been introduced several times to the task. Note that she has lost the love for learning since the last elementary public school she was in.
- When she doesn't want to work (e.g. academic work) or wants to leave classes (e.g. music and art classes at school). Note that the classes might be boring or not interesting to her.
- When going from a lighted area into a shaded area has been found to be another trigger (e.g. In the Museum of Natural History in a setting where they had the children going into a cave-like situation; e.g. when going hiking when entering the wooded area where there is more shadows.) - Note that for this trigger, SC reacts in a flight mode.

SC's social anxiety disorder, not able to verbalize, needing to overcome her sensory integration and processing deficits and visual impediments (not reading visual information properly) caused SC to misread many visual cues, and resort to maladaptive behaviors.

After her unspecified psychosis manifested itself as SC being afraid of monsters following her, and attacking her from behind; having terrible panic attacks where SC would run frantically from one side of the house to the other, from upstairs to downstairs, looking for her mom for protection; and after losing a front tooth from tripping after a panic attack, SC's parents had no choice but to consult with a psychiatrist and start SC on psychosis medication. Together with medication, there was a need to work with the psychologist to help SC conquer her fears, such as getting into the shower, going upstairs in the house (where her bedroom happens to be), falling asleep, etc. Slow, incremental exposures to her fears were done with big rewards after satisfactory completion of the given exposures.

Since SC's psychosis and regression were diagnosed, SC's family started getting more help thanks to the Children Extensive Services waiver, which covered behavioral help from The Brain Center. The Brain Center, among other parts in the treatment, used The Listening Program® (TLP) Spectrum and Brain Builder® products from Advanced Brain Technologies. SC's vision therapy sessions were also covered by the CES waiver.

The Brain Center Executive Director facilitated having mom's training and the TLP SPECTRUM being covered by the CES Waiver. Therefore, mom became a TLP provider.

SC began the sound stimulation program TLP Spectrum with the WAVES bone-conduction headphones at home almost concurrently to starting her vision therapy program. SC started with TLP at home, listening to only one module daily for a while. Mom re-started the TLP program completely, on 09/18/2016, since mom did not know which the last module SC listened at The Brain Center was. SC is now in TLP's Condensed Schedule Cycle 4. Mom is planning to continue using The Listening Program indefinitely.

SC's ability to acquire visual information accurately was evaluated on 08/22/2016 by Dr. Jen Simonson, OD, FCOVD. Clear eyesight, focusing ability, eye alignment, and tracking skills are all important to acquire visual information and are called "acquisition skills". These skills require the efficient use of our eye muscles (six extra-ocular muscles surround each eye to control eye movement, two muscles regulate the amount of light entering the eye, and one muscle adjusts the focusing lens inside the eye). Proper coordination of these skills is necessary to see something clearly, easily, accurately, and as a single image. SC's abilities in these areas were:

VISUAL ACUITY (clarity of eyesight) Distance visual acuity was 20/30, reduced in ability. Near visual acuity was 20/20, adequate.

FOCUSING ABILITY The eyes must use a different set of abilities to focus on objects nearby than they use to see clearly at a distance. A muscle inside the eye (ciliary body muscle) must constrict so that the lens inside the eye bends the appropriate amount. If this focus cannot be maintained for any length of time, words will become blurry, loss of place may occur, and visual discomfort may be noticed. The ability to maintain focus for near work, the ability to relax focus to see clearly at distance, and the ability to change focus easily from far to near were all reduced.

BINOCULAR STATUS (eye teaming ability) The human visual system is designed so that the two eyes work as a team. The accuracy of clear, single vision and the presence of depth perception depend on a person having these skills. If the information from the two eyes does not match, the brain may ignore the information coming into one eye (suppression), or experience double vision. Depth perception, although present, was considerably reduced when compared to expected norms. Suppression and instability of the left eye were present. Eye alignment testing showed exotropia - a type of strabismus

(eye turn) where one eye turns outward toward the ear. Convergence, the ability to turn the eyes inward the appropriate amount, was also reduced.

EYE MOVEMENT ABILITY (eye tracking skills) To accurately and quickly obtain information with the least amount of effort, the eyes must be able to scan with speed and control. When these eye movements are slow, clumsy, or uncoordinated, the amount of information obtained will be reduced. The types of tracking skills evaluated were: FIXATIONS – the ability to keep the eyes steady on a target; PURSUITS – slow smooth eye movements used when following an object like an airplane across the sky or following the ball in sports; SACCADES – the eye movements used while reading. They require small voluntary jumps from word to word easily without making extra eye movements. Each of these tracking skills were reduced in ability.

A program of vision therapy was recommended, which included weekly office sessions, and home exercises to be performed daily.

On 09/01/2016 was SC's first vision therapy session. Starting on 09/18/2016, with TLP at home, and vision therapy, we were combining the two strongest senses, hearing and vision, which give input to our bodies from our outside world, developing and enhancing them simultaneously.

SUMMARY OF CHANGES

After starting The Listening Program and vision therapy, in September 2016, by the November 2016 to December 2016 timeframe, SC exhibited a more grounded and stable sensory integration and processing ability. She was able to brush her hair twice daily (in her morning and nighttime routines), expressed less tactile defensiveness, and showed a decline in maladaptive behaviors like hitting. Mom started noticing an increase in verbalization and personal confidence, and a decline in social anxiety. For example, when ordering food at a restaurant before, with much anxiety, SC could only point to the items she wanted, whereas now she can order each item she wants with confidence, with the right tone of voice and much more understandable. Now mom is more concerned with issues around SC's psychosis, her period (affecting her psychosis), her regression, other medical issues, side effects of the psychosis medication like weight gain, her willingness to be present, and her fear of falling asleep among others.

Nevertheless, for precaution purposes due to her history of behavior, mom will continue with the protocol of including SC in adult or senior classes, and avoiding exposure to young children as much as possible.

Other examples of changes observed are:

- At the therapy center where SC receives her therapy, instead of hitting a little boy when she was upset, she instead would tell the Speech Therapist that she is sad that the boy doesn't want to play with her.
- At Boulder Valley vision therapy, Thursday 12/08/2016, SC read at the 3rd grade level and answered the reading comprehension questions with 80% accuracy. The therapist used the neurological impress method.
- On Thursday 12/29/2016, SC earned some headbands at vision therapy, and she has been using them in her own hair ever since. This could be an indication of how much sensory integration improvement she has made, and how much her "fight or flight" system has tapered down. SC can now brush her hair twice a day, as part of her daily morning and nighttime routines, and wear headbands and ponytails the whole day, without any problems.

SC's psychologist commented on 04/20/2017, concerning SC's social anxiety disorder issues, and other behavioral issues, that SC was showing "Improved nonverbal and verbal communications when in social settings; increased volume when talking and better eye contact; decreased aggression towards herself and objects; decreased refusal to complete activities of daily living; more independent with daily living skills (requiring less prompting); drastic improvement in clarity of thinking; much better able to answer questions when asked; content of response also matches content of question better; decrease in processing time, can answer questions much more quickly when asked; more motivated to participate in group activities."

As a result, her psychologist sessions were reduced from weekly to bi-weekly sessions.

SUMMARY OF PRE AND POST TEST SCORES

The changes seen on SC in this case study are similar to the changes seen by Jeyes and Newton (2010) in their study where, after using The Listening Program with Sennheiser Headphones for two 15-min sessions, five days a week, over a ten-week period, children with Down syndrome exhibited clearer speech, more extensive vocabulary, and they were using greater number of words more

effectively sequenced. This was coupled with a greater attention span, improved communication with peers and others, and overall reduced frustration felt by all parties (Jeyes and Newton, 2010).

Furthermore, after combining TLP with vision therapy in September 2016, only a few months later SC exhibited more grounded and stable sensory integration and processing. She could brush her hair twice daily and exhibited less tactile defensiveness and maladaptive behaviors. Mom started noticing an increase in verbalization and personal confidence and a decline in social anxiety in public situations. Also, see SC's psychologist comments of 04/20/2017.

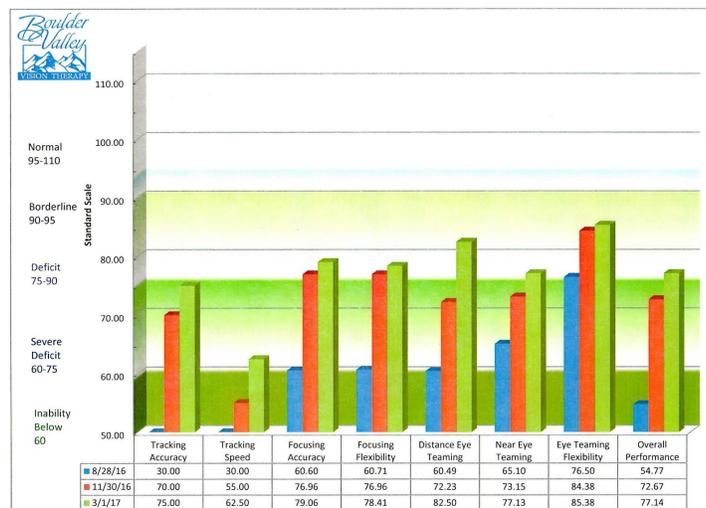
From previous clinical experience, it has been observed that combining vision therapy with The Listening Program enhances and speeds up the therapy program. As seen in the results displayed on the appended graph, SC's visual acquisition skills have improved greatly. To see this amount of improvement in a six-month period demonstrates the power of a combined visual and music listening therapy program.

FOLLOW-UP RECOMMENDATIONS

SC will continue with The Listening Program Spectrum with the Waves multi-sensory bone-conduction headphones at home, combined with vision therapy.

Mom agrees with the recommendations from Jeyes and Newton (2010), and would like to point some of them, like:

- The fact that more appropriate tests need to be developed for children with Down syndrome for pre- and post-study testing
- More extensive and larger formal study is recommended to confirm the findings of the 2010 study,
- Video evidence would be a useful addition



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