

## Case Study – The Listening Program®

### Fragile X

Fragile X syndrome is a hereditary condition that causes a wide range of mental impairment, according to the National Fragile X Foundation, from mild learning disabilities to severe mental retardation. It is the most common cause of genetically-inherited mental impairment. In addition to mental impairment, Fragile X syndrome is associated with a number of physical and behavioral characteristics.

Sensory processing is a common issue for many diagnosed with Fragile X, with hypersensitivities to light, sounds, touch, and textures. Speech and language difficulties and cognitive weaknesses are especially common in males. The Listening Program can help address these areas.

### Case Study - using The Listening Program with Fragile X

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Name:  
Gender: R.C.  
Date of Birth: Male  
Chronological Age: April 10, 1989  
Clinical Diagnosis: 15 years old  
Fragile X Syndrome, Autism



Reason for Referral: R.C.'s parents were concerned that even with speech and occupational therapy, R.C. continued to make very slow improvements in functional skills in the areas of communication and living skills. They were excited at the reported changes seen with other children with Fragile X and Autism and wanted to attempt The Listening Program® with their son.

### BACKGROUND INFORMATION

R.C. is a 15 year old who has been diagnosed with Fragile X, with autistic characteristics. He was born at 8 months gestation and weighed 5 pounds at birth. He is the third of three brothers. His oldest brother has also been diagnosed with Fragile X. His middle brother is a college graduate with a degree in engineering. He also has a cousin with Fragile X. R.C. lives at home with his mother and father. His older brother lives in a nearby group home and is often present in the family home on weekends. R.C. currently attends a local middle school where he is placed in a trainable class.

R.C. has received therapy for many years. He began physical therapy at around age one. His therapist from that time remembers that he was slow to walk and mastered this around age three, was gravitationally insecure, and disliked putting his feet flat on the floor. He received services as an outpatient until he began school. He also was enrolled in the DCEC program as a preschooler. DCEC is a special needs daycare and infant stimulation program run by the South Carolina



Department of Special Needs. By at least age three, R.C. had started occupational therapy.

Developmental milestones were met as follows. R.C. never did crawl or creep. He was sitting independently at 18 months. He walked at age three. He was toilet trained at age ten. R.C. began babbling at age one, spoke his first word at age three, and combined two words at age seven. He began speaking in three and four word phrases when he was nine and continues to speak at this level. His early years were characterized by extreme sensory defensiveness, especially orally. He did not like his hands, face, feet, or hair to be washed.

## PRIOR TREATMENT

I first met R.C. during the 1998-1999 school year while he was a student at Whitehall Elementary School. He was placed in a Trainable Mentally Disabled classroom. At that time he was not receiving outpatient services, although he had in the past. He also received school based speech services. When I first met R.C. he was very echolalic. At that time he generally used only a few scripted phrases, such as "what a mess," "nose," and "knees". R.C. was very tactilely defensive. He refused to touch most objects with his hands and would not hold a pencil, crayon/marker, or a pair of scissors. R.C. moved slowly and was very gravitationally insecure. He clung to the therapist when sitting on a therapy ball, even when his feet were still touching the ground. He would bounce on a mini trampoline, but did not clear his feet from the surface. In the classroom R.C. preferred to spend his time at the computer watching preschool type computer programs.

Following the 1999-2000 school year, R.C. began outpatient occupational therapy again. His mother requested outpatient services to address his sensory integration dysfunction. Re-evaluation at that time indicated the following problem areas:

1. Extreme tactile defensiveness, unable to tolerate wet and/or gooey substances, and has difficulty tolerating soap while washing hands.
2. Significant gravitational insecurity.
3. Poor balance skills.
4. Delayed fine motor skills.
5. Does not visually attend to what his hands are doing.
6. Refuses all pencil and paper activities.
7. Significant difficulty with self-help skills:
  - o Does not pull up his pants when toileting.
  - o Does not know inside and outside of his clothing.
  - o Does not independently wash and dry his hands.
  - o Does not bathe himself independently.

R.C.'s initial goals addressed his sensory integration dysfunction and self-help skills. As school started, the decision was made to continue out patient services in addition to his school services. He continued with his sensory and "activities of daily living" type goals until November 2001. During this time increased tolerance of movement activities, especially swinging and jumping tasks, was noted. He began to assist more in dressing and bathing activities but was not independent with them. He did become independent in pulling up his pants, as long as he was wearing sweat pants. He was not able to put on a pair of shorts. He could take off a jacket, but not put it on. He could zip and unzip non-separating zippers on therapy equipment, but did not wear clothing with them. He was unable to fasten and unfasten a separating zipper. He could



not turn a sock right side out. He had learned to operate different types of switches to turn lamps on and off. He was matching socks with prompting and with significant differences between them, i.e. a pair of white socks, green socks, red socks, and black socks. He did not attend to details to differentiate two different pairs of red socks. R.C. began to tolerate vibration and shaving cream on his face for about 60 seconds. He continued to need help to wash and dry his hands, face and body.

In November of 2001, R.C.'s goals were changed to address more pre-vocational tasks and instrumental daily living skills. He began to address activities such as household cleaning tasks (for example cleaning off table tops, washing windows and mirrors), putting clothes on a hanger, sorting dishes and silverware, setting a table, and pouring liquid into a glass. During that school year he also began working on pre-vocational shoebox tasks. R.C. made good progress on these goals, although he never became independent with them. He continued to use very poor visual attention skills while performing the tasks. During this time he began outpatient speech services with Sharon Steed. Ms. Steed addressed augmentative communication, introducing picture symbols and devices such as a touch talker to promote effective expressive communication. At this time his verbal communication continued to be very scripted and echolalic. His receptive skills were stronger than his expressive skills.

During the summer of 2002 the occupational therapist began co-treating with his speech therapist. Goals emphasized functioning in the community and most sessions were held outside of the therapy center. We worked in the hospital cafeteria, a laundry mat, and a fast food restaurant. We addressed increasing his tolerance to doctor visit activities such as being weighed and having his temperature and blood pressure taken.

He also participated in an aquatic therapy program. Goals for that program included pouring water over his arms, shoulders and chest, pouring water over his head, throwing a ball to the therapist, and engaging in water play activities with other children. R.C. did well in the pool, mastering three of four goals. He needed cueing to interact with other children appropriately. Progress on the community goals was slower. He needed more repetitions of each activity than were possible during the summer sessions. R.C. began using a dynamo as a communication device during the summer and this was incorporated into all his activities. His community goals were continued during the school year but addressed in the clinic. He made slow but steady progress on these goals. His greatest gains were in his tolerance for doctor visits. He was getting on and off a scale with assistance and allowing his blood pressure to be taken. He still had difficulty holding still for his temperature, using an ear thermometer, to be taken. Visual attention to task continued to be poor and tactile properties of the items continued to be an issue. He was becoming more dexterous with handling coins, but was not able to identify them.

During the next summer, 2003, R.C. again participated in an aquatics program and his occupational therapy and speech sessions were again community based. This summer he was better able to manage money to make purchases, although he had a lot of difficulty getting his wallet in and out of his pocket. He was opening loose screw top containers, sorting items into three containers, and pushing a shopping cart with moderate assistance. He needed much prompting to visually watch where he was going and to actively steer the cart around obstacles and people in the aisles.

During the fall of 2003 R.C.'s mother asked that we help him to tolerate a new face washing and acne treatment routine. He was extremely defensive to this activity. The use of his dynamo, a social story picture book and picture symbols for sequencing the task were used in addition to sensory activities and skill practice. His family re-instated the Wilbarger brushing/compression program prior to face washing. The use of vibration to the face and terry cloth rubbing was also used. Very slowly R.C. began to first accept the procedure and then to assist with it. He tolerated the soap much better than the lotions and creams that were used after his face was washed. He also tolerated the procedure better in the therapy room than at home with his mother. When he was actually starting to show decreased hypersensitivity to the procedure, the regimen needed to be changed because his skin was becoming too dry with the first products. With the change in products, the entire procedure had to be restarted. R.C. seemed to be negatively reacting to the

new feel and smell of the products. During the fall/winter of 2003 the therapist introduced The Listening Program to R.C.'s mother and suggested that it might be beneficial for him. However, at that time his mother was not interested in pursuing the program.

In the spring of 2004, after being shown a report in the TLP Provider newsletter PPOV of a man with Fragile X using The Listening Program successfully, R.C.'s mother became very excited about the program and wanted R.C. to participate in it. A case history form and listening checklist were filled out and the Sensorimotor Performance Analysis and the Visual Motor Integration tests were given.

## PROGRAM IMPLEMENTATION

R.C. started The Listening Program in March 2004. He began by listening to the Sensory Integration (SI) Classic 1 CD and then Sensory Integration Kids 1, listening for two weeks to each CD 2 X 15 minutes a day. He then started the TLP Classic Kit, CDs 1-8. R.C. followed the Base schedule and listened twice a day for 15 minutes each session. He uses Grado SR-125 headphones.

## GOALS FOR INTERVENTION

Ultimately R.C.'s parents want him to be able to function in a group home living environment. When given the form for TLP Listening Goals and Results, they were able to articulate many specific goals for R.C.. These include:

- Increase concentration, attention, and memory skills.
- Improve communication, the use of words, and voice tone.
- Improve self-expression.
- Be able to listen to someone over the telephone and answer their questions appropriately.
- Improve time and quality of listening skills.
- Stop inappropriate and impulsive behaviors such as throwing, pinching, hitting, wadding paper, etc.
- Develop the ability to run and work towards aerobic conditioning.
- Improve eye contact.
- Greet people appropriately.
- Develop pre-vocational skills.
- Be able to sing, hum, or whistle simple songs.
- Learn to play a keyboard or guitar.
- Learn to play simple card games.
- Learn typing skills.
- Be able to work puzzles, draw, paint, and participate in pretend play

## PRE/POST TLP

### Visual Motor Integration Test

#### *Pre-test:*

Raw Score = 3

Age Equivalent = 2 years 9 months

R.C. was able to imitate a horizontal line and to copy a vertical and horizontal line. He made random marks for other figures.

#### *Post-test:*

It is too soon to re-test using this test.

Observation of his drawing skills while performing items on the SPA indicate that his imitation of

lines is more accurate and that he is using more circular strokes. He has not mastered forming any new shapes.

Sensorimotor Performance Analysis

Performance Area	Pre-TLP	Post-TLP
1. ATNR	74.3%	82.9%
2. STNR	33.3%	46.7%
3. Anti-gravity Extension	74.3%	82.9%
4. Anti-gravity Flexion	83.3%	96.7%
5. Body Righting/Trunk Flexibility	47.5%	62.5%
6. Head Righting	74.3%	94.3%
7. Equilibrium/Protective Reactions	46.0%	72.0%
8. Vestibular Function	40.0%	69.3%
9. Tactile Processing	52.5%	72.5%
10. Visual Processing	54.3%	60.0%
11. Bilateral Integration	33.9%	46.1%
12. Motor Planning	50.4%	53.6%
13. Tone and Strength	60.0%	75.5%
14. Stability/Mobility	47.1%	62.9%
15. Neuro Status	73.8%	75.0%
16. Developmental Level	57.9%	70.0%
<b>TOTAL TEST</b>	<b>54.4%</b>	<b>84%</b>

R.C. began showing changes after one week of listening to the Sensory Integration CDs. He shows marked increase in tolerance of vestibular activity. He is now walking up and down steps independently. He goes up using an alternating step pattern and down with a step to pattern. He tries activities that challenge his balance such as climbing the foam steps to jump into the pillows. He is now able to get onto the top step with a hand held, but does not jump from there. When the steps are reversed, he will fall off the lowest step into the pillows but does not jump. He is getting onto a bolster swing with minimal assistance and off with the swing held but no assistance to move his leg over the bolster. On the bolster swing and frog swing he will initiate movement at a moderate rate, initiate rotation, aim to move in a particular direction, and push off the wall with his feet. He also enjoyed bouncing into the therapist to produce a quick jarring movement. After two weeks of listening (he was now listening to SI Kids I), his classroom teacher reported that he had started applying deodorant, and that he was talking more in class.

April 7: R.C.'s mother reported that he was starting to help dress his lower extremities.

April 14: R.C. participated in Special Olympics and had a great time.

May 5: R.C.'s mother reported that he is beginning to eat new foods, specifically melons, and that he was now going up and down flights of steps in a hotel where they were staying.

May 12: R.C. is now listening to CD 7 in the TLP Classic Kit. R.C. is more curious, especially with things that have buttons to push. He is sometimes turning the TV and video on by himself in the mornings when he awakens before his parents. He continues to speak more to people at school and actually greeted people in the waiting room at the clinic today. He started using the phrase "love you" to his parents and teacher. At school a new student entered the class and R.C. is getting along well with her. She often hugs him in the morning when she first sees him. R.C. still shies away from that slightly.

May 19: R.C. is now listening to CD 8. He shook hands with the new speech therapy student when introduced to her. He has shown increased eye contact with the therapists during treatment. He also showed amusement when the occupational therapist modeled movement activities for him.

#### FOLLOW-UP RECOMMENDATIONS

R.C. will begin listening to the Speech and Language Classic 1 CD the week of May 24 and the Speech and Language Kids 1 CD the following week. He will then start his second cycle of the TLP Classic Kit immediately, listening for 2 weeks each to the Sensory Integration CDs and one week to the other CDs. He will continue to follow the Base schedule.

#### DISCUSSION

R.C. has made significant gains in sensory functioning during his first listening cycle. He is demonstrating less tactile defensiveness, less gravitational insecurity, and has increased his social and communication skills.

R.C.'s control with a pencil has improved although he is not forming any new shapes. He is, however, more sure of the line direction and utilizes appropriate pressure to form the line. He is also beginning to make a circular scribble motion, although it cannot yet be called a circle. R.C. is still very impulsive with cutting, taking a few snips and then ripping the paper.

R.C. is now participating in many pre-vocational tasks. One of the biggest changes I have noticed is that he is now able to pick up one sheet of paper when asked to collate papers. This was impossible for him prior to The Listening Program. He is also able to stuff envelopes with a pre-folded paper. He is visually attending to the task and able to problem solve when the envelope flap does not close appropriately. He is able to sort silverware, but still has some difficulty placing it in the correct place when setting a table while using a placemat jig. He has also worked on rolling silverware into a napkin and applying a paper fastener. He still requires a good deal of physical assistance to perform this task, especially to roll the items into the napkin.

His parents have been very pleased with his results so far and are excited to have a new option for treatment of individuals with Fragile X.

NOTE: Kathy Bostater presented this case study with video documentation of R.C.'s progress, at the 2004 International Provider Conference in Park City. This video will be available online in the coming weeks. We will send an email announcement when it is ready.

End of Case Study  
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