

## Case Study – The Listening Program®

### Anna-Michael, Age 17 Mos, Cerebral Palsy, et al

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**Name:** Anna-Michael

**Gender:** Female

**Chronological Age:** 17 months

**Clinical Diagnosis:** Cerebral Palsy, Dandy Walker Variant, Seizure Disorder, Swallowing Disorder, and Cortical visual impairment

#### **BACKGROUND INFORMATION:**

As far as we know, Anna-Michael was born full-term without any complications. Her birth parents were aware of her disabilities prior to her birth and decided to put her up for adoption. Shortly after she was released from the hospital, she went into Foster care with a couple who are Cottage Parents, at a local Baptist children's home. She was in foster-care for three months, when we found about her through an intake coordinator for Early Steps (an Early Intervention program that I work with). I was initially contacted because she was in need of services, but because of her special needs and not being adopted, yet, she was going to be turned over to the state for foster care and possible adoption. Her family service coordinator asked if I would be her mother instead of her therapist and in less than 3 weeks, we were a family.

While in foster care for the first two months she cried and screamed unceasingly. This gradually decreased to 8-10 hours and by the time we adopted her it was from 4:00 pm to 11:00 pm. It continued to decrease, until now it is only when she is hungry, sleepy, fighting sleep, or not wanted to do therapy (wanting to be held and bounced, instead).

Medically, Anna-Michael presents with Dandy Walker Variant (missing part of her cerebellum), two different types of seizure disorders, and agenesis of the corpus callosum. Her diagnoses are Cerebral Palsy, Failure to Thrive Syndrome, GERD, and Epilepsy. We were seen by a Neurosurgeon, because our pediatrician was concerned about hydrocephaly as she is very microcephalic and her fontanelles were closing rapidly. She was found to also be micro-enchaphalic, and therefore there was no pressure on her brain. The Neurosurgeon told us that she would "NEVER be more than a two-year old, she would not grow, she would never know that we are her parents, she would be in a wheelchair and orthotics, and would be a vegetable." He also told me that I "adopted the wrong baby". That response put me in gear to prove that man WRONG! We began aggressively treating her seizures and enrolled her in Early Intervention.

Since that initial visit, we have had many ups and downs. It took a long time and many trials of medications and dosages to finally get her seizures relatively under control. (She was having seizures almost constantly on some days and very frequently on others – but only while she was awake) 24-hour Video EEGs noted that she had only minimal seizures while sleeping. Once her seizures were under control, she quit eating and in a less than 20 days lost 3 pounds (she went from 17'8" to 14'8"). She began gagging on all foods with any texture or thickness and choking on everything thin. In October, 2004, she had a GI-tube placement and a Nissen Fundoplication to assist with feeding, weight gain and decrease reflux. Also in October, she was diagnosed with cortical visual impairment. According to the swallow study performed in December, 2004, Anna-Michael aspirates on all thicknesses and demonstrates a very delayed swallow. Since this study, it has also been noted that Anna-Michael aspirates on her saliva or any fluids/mucous from her mouth or nose and fluids refluxed. She is now requiring daily breathing treatments of Pulmocort and adding Zopenex as needed when respiratory irritation is increased. She was hospitalized in December with RSV and pneumonia.

**TREATMENT:**

At present, she is receiving OT 3x/week, PT 2x/week, ST 2x/week, and Special Instruction 1x/week. She has participated in 2 cycles of TLP, and also receives OT 1x/week from my students in our on-campus clinic and receives additional OT from mom and all her OT friends whenever any of us are around. She attends an Infant development program/school during weekdays from ~ 9:00 to 3:00. Her therapists see her in this environment at least one time a week. Otherwise she receives therapy within the home or at the clinic. Seizure medications have been adjusted. TLP has been ongoing.

**PROGRAM IMPLEMENTATION:**

Anna-Michael started the first cycle of The Listening Program in June, 2004. She began using the TLP Classic Kit following the Extended schedule, listening to 1 module per day for 5 days per week. Because she was unable to sit unsupported and was so small, she was placed in supine with the headphones positioned to play into her ears.

- Classic CD 1 (weeks 1 & 2): The first night, Anna-Michael began making consonant sounds, which she had not done before. She repeated "dddd". As she listened to the CD's her eyes would move to the right and left sides. Previously, she would not look to the right at all. By the second week of CD 1, if placed in carrier or other supported seating system; Anna-Michael would bob or rock her head side to side while listening.
- Classic CD 2 (weeks 3 & 4): Anna-Michael continued to move her head and eyes while listening, which was really exciting. However, this did not carry over throughout the day when she was not listening.
- Classic CD 3 (weeks 5 & 6): Anna-Michael began holding her hands together in midline as if praying. She would also maintain her head and eyes in midline while the CD was playing. For several minutes up to 20 minutes after listening, she would bang her hands together in midline and move her head from the left to midline more often.
- Classic CD 4 (weeks 7 & 8): During these weeks, Anna-Michael began falling asleep during the last few minutes of the modules. I had to bounce her while listening to keep her awake. When completed listening each day, she would take a 20-30 minute nap. Nights became less fussy. She would only cry/scream for about 3 hours, rather than 6-7.
- Classic CD 5 (weeks 9 & 10): Anna-Michael started cooing and making sounds more throughout the day. She also began copying lip smacks at times and "singing" all vowel sounds. She would also "sing"/ make sounds while listening to TLP.
- Classic CD 6 (weeks 11 & 12): Fussy outbursts at night began lessening more, only about 2 hours now. She still has great difficulty sleeping at night. However, babysitters report her taking up to 45 minute naps during the day. She will now roll from side-lying to back and is really lifting her head to look up when placed in prone.
- Classic CD 7 (weeks 13 & 14): During the 14th week, she started crying a lot more during mealtime, becoming very agitated and refusing to allow spoon or bottle in mouth at times. She would be difficult to calm and even fussed and squirmed during her TLP times. (Later we found out that her reflux was much worse and that she was aspirating) Her weight really started declining around this time.
- Classic CD 8 (weeks 15 & 16): By the 16th week Anna-Michael was not fussing as much while listening and started chewing on her fingers and making grunting sounds while listening to TLP.

Sleeping behaviors, which consisted of a few very short naps during the day and 1-2 hour intervals of sleeping at night, did not change. However, starting ~ the 7th week, she did start taking 20-30 minute naps after her listening session.

Approximately during the 9th week, we started the Music for Babies™ which helped to calm her when riding in the car. She responded best to the Peaceful Baby and Playful Baby CD's. When we used Sleepy Baby, she would quiet down while listening, but did not go to sleep or sleep better at night. We also listened to these during meal times to calm her, as meal times were so upsetting to her.

We took two weeks off from TLP prior to beginning Anna-Michael's second cycle of her listening schedule. This coincided with my beginning distance training as a TLP Provider.

We decided on two weeks of the SI-Kids 1 CD because Anna-Michael is so young and there is no research to support her age using this program and we didn't want to over-stimulate her system. I chose the Extended schedule because I felt that we need to slowly introduce the sensory input and vestibular stimulation that are provided by the SI CD. Following the two weeks of SI Kids 1 CD, we began the second cycle of an Extended schedule of TLP using the Classic Kit.

- SI Kids 1 CD (weeks 1 & 2): During the early part of the first week Anna-Michael would cry while listening, but by the end of the week, she was cooing while listening. Her sleep lessened at night during the first week, but by the second week, she would sleep 2 hours and sometimes longer before waking up.
- Classic CD 1 (weeks 3 & 4): Back to her head bobbing/rocking while listening and eyes moving left and right while listening. Because Anna-Michael continued to have significant swallowing problems and weight loss, surgery was scheduled for the next week to place a GI tube and a Nissen Fundoplication.
- Classic CD 2 (weeks 5 & 6): Since Anna-Michael was doing well with TLP; we decided not to stop it while she was in the hospital in Little Rock, Arkansas (Arkansas Children's Hospital) undergoing surgery and testing. The listening schedule time had to be frequently changed because of items scheduled during hospitalization. During the 6th week, Anna-Michael became very ill with Rotavirus and had to be put back into the hospital locally. We continued TLP while in the hospital, although due to her illness very little changes were noted.
- Classic CD 3 (weeks 7 & 8): During the 7th week, Anna-Michael was still in the hospital at the first of the week and continued to feel ill the rest of the week. By week 8, she was more active while listening returned to banging her hands together and "signing" along with the CD.
- Classic CD 4 (weeks 9 & 10): Anna-Michael began kicking her legs while listening to the CD's which was new. At times prior to this, she would kick her left leg, but not her right leg until around this time. She also started kicking when she wasn't listening to the CD's. With her food intake improved and her medications being tolerated better, her seizures have lessened significantly.
- Classic CD 5 (weeks 11 & 12): Not many changes this week. Anna-Michael continued to sing along with the CD's and bang hands and kicking legs. She began having respiratory problems related to reflux and aspiration of secretions during the 12th week.
- Classic CD 6 (weeks 13 & 14): Anna-Michael developed RSV (Respiratory virus). Her pediatrician tried to keep her out of the hospital because of her extremely poor immune system and the fact that she usually gets worse in the hospital than at home. However, her breathing became so labored and her oxygen levels were so low that she needed to be put on oxygen and have intense breathing treatments. We continued TLP during the week and a half that she was in the hospital, but she was not very active. She tended to be extremely fussy

throughout the day and night while she was sick, however, while listening she would calm down and lay quietly.

- Classic CD 7 (weeks 15 & 16): This week, Anna-Michael started clearly saying “da-da” on her own and at times repeat it when we would say it to her. She also would smack her lips in response to us making noises to her and really started looking to the right more often. The looking to the right continued even when not listening to TLP. She began making eye-contact at times and was tracking lighted/colorful objects across midline, briefly.
- Classic CD 8 (weeks 17 & 18): Anna-Michael’s health was improving; she was gaining weight well and was much more attentive to her environment and to us. She looks around when she hears us talking and smiles when I sing to her. She continued to do the things identified with the previous CD including saying “da-da” and looking to the right.

### **SUMMARY OF CHANGES:**

Anna-Michael will inconsistently roll over from prone to supine, and will now roll from supine to side-lying and back, and is working on supported sitting. She will maintain propped sitting, for up to one minute, although she is unable to move in and out of sitting.

She will now attend to and look toward the right side and even maintain her head and eyes in this direction. Amazingly, she now looks in the direction of sounds. She brings her hands together at midline and will bring them to her mouth and at times can isolate her thumb or finger to place in mouth. When a Z-vibe or vibrating toy is placed on her stomach or chest, she will put both hands on it and attempt to bring to her mouth.

Since we have participated in TLP, she is now saying “da-da” (although not in response to her daddy), smacks her lips, make all vowel sounds and “maaaaaaa” sounds. She continues to have the most beautiful laugh and smile in the world!

### **FOLLOW-UP RECOMMENDATIONS:**

We have taken a short break from TLP, as Anna-Michael has since had more medical complications requiring medical attention and hospitalization, but she hopefully, is on the mend. We plan for TLP to be an ongoing part of Anna-Michael’s therapy as we have seen her make such magnificent gains. As her health improves, we can only expect her to respond even better to TLP.

I recommend that she begin the SI Kids 1 CD again for two weeks Extended schedule (1 module per day) followed by the TLP Classic Kit Base schedule with two modules per day for eight weeks. I feel that since she has gone through two cycles of the Extended listening schedule of TLP, that she should now be ready to begin the Base schedule and experience TLP at a slightly more intense rate than previously. If, however, this seems to be too much for Anna-Michael, we can revert to the Extended schedule.

### **DISCUSSION:**

Anna-Michael has had many medical complications that have interfered with her therapy and progress. I don’t feel like she has gotten to receive full benefit of the TLP during the second cycle, however, she did continue to make significant gains. I really feel that now that her seizures are under control and that she is no longer so malnourished that her body has to use all her energy to function, that she will really be able to benefit more from TLP. She has been a lot more active and continues to incorporate her right side more into her normal activities. We have been very pleased and continue to expect great outcomes from TLP with Anna-Michael.