

## The CAPD Model and Kabuki Syndrome

Theresa Cinotti, M.A., CCC-SLP

Kim Tillery, Ph.D., CCC-A

### What is Central Auditory Processing Disorder (CAPD)?

CAPD is not how one hears, but rather “what one does with what they hear”. Clients with a CAPD display a wide range of functional behavioral limitations: difficulty understanding or remembering auditory information, weak phonemic skills, intolerance to noise, difficulty understanding speech in background noise, frequently require directions to be repeated, substitute improper speech sounds, display weak reading, spelling, organization and comprehension skills, and often act as if they have a hearing loss.

There are different types of CAPD that dictate specific therapy regimens. Decoding type of CAPD involves a breakdown at the phonemic level where the client struggles in understanding each sound, displays weak reading and spelling skills and requires a long time to respond. A second type of CAPD is known as Tolerance-Fading Memory (TFM) which involves weak short-term memory resulting in poor reading comprehension and weak expressive language skills. Often those with TFM forget the first set of information verses the final set. A third type of CAPD is known as Organization, as weak sequencing and organization abilities are characteristic of this type. A fourth CAPD subtype is Integration, involving poor language and phonemic ability and severe reading and spelling delays.

While an audiologist is the professional who diagnosis the types of CAPD, it is usually the speech-language pathologist who provides therapy and who also evaluates language skills. Most individuals with a CAPD exhibit normal hearing. The etiology is unknown although it is speculated that a history of ear infections and genetic links may be related.

### LIZ

Liz was first diagnosed at 14 years of age with Kabuki Syndrome. Currently at age 22 years, she presents with several characteristics related to the syndrome, such as a submucous cleft of the palate, hypotonia, visual perceptual difficulty and mild-to-moderate cognitive challenges. Hearing problems include sensorineural (inner ear) and conductive (middle ear) hearing impairment with recurrent bouts of ear infections. In addition she exhibits speech-language delays and increased nasality of speech.

Liz was first referred for a CAPD evaluation at 16 years of age by a reading specialist as Liz could write the grapheme (letters), but was unable to make the sound-symbol relationship. For example, Liz was able to write her name, but did not understand the



**Theresa Cinotti, Liz S. and Dr. Kim Tillery (left to right)**

relationship of the sounds to the letters, an essential precursor to reading, rhyming and spelling. The reading teacher reported a lack of understanding of left to right scanning of words across the page and also noted that Liz was unable to perform on preschool literacy testing.

The CAPD evaluation indicated two subtypes of CAPD: TFM and Decoding and Liz was referred for CAPD therapy. She received two 50-minute therapy sessions, per week for one and half years, targeting the Decoding CAPD subtype. Therapy consisted of Phonemic Synthesis Training Program (Katz and Fletcher, 1982), Visual-Rhyming Therapy, and general auditory training exercises.

Phonemic Synthesis Training Program consists of 15 lessons to expose the client to the concept of sounds in words by auditorily presenting one sound at a time for which the client is instructed to properly blend the sounds into the target word. For example, the client hears: “b-oa-t” and should respond “boat” without any form of delay or struggle. The goal of this program is to enhance the client’s ability to properly perceive sounds in words and utilize that skill in higher level of comprehension, reading and spelling tasks.

Visual-Rhyming Therapy is a technique derived from Soundabet, a training activity in the Processing Power program (Ferre, 1997), which assists the client to recognize sounds and sound patterns represented by all graphemes (letters), thus enhancing rhyming skill. For example the client is presented a target pattern such as “at” and must rhyme this provided word or nonsense word using all probable consonant sounds. The client would respond

with, “bat, dat, fat, gat, hat, jat, kat, lat, mat”, etc. with the visual cue provided in left-to-right format.

b	d	f	g	h	j	k	l	m
n	p	r	s	t	v	w	y	z

Upon the success of accurately blending the above consonants with the target pattern, the chart is expanded to include consonant blends, such as br, bl, dr, fl, fr, and st, etc.

This therapy enhances knowledge of left-to-right reading, phonemic and phonological awareness, rhyming, and sound-symbol awareness, again all skills needed for comprehension, reading and spelling. General auditory training exercises were used to supplement the above therapies. Therapies utilized would be considered aural rehabilitation (AR) therapies, although the impact is often seen in language and written language development.

After completing the above therapies, Liz demonstrated progress in the areas of focus. On the Phonemic Synthesis Test (Katz and Fletcher, 1981), a measure of Liz’s sound blending skills, Liz’s progress was follows:

**Pre Therapy:**

4 accurate responses

**1 year later:**

19 accurate responses

Lesson 12 of the Phonemic Synthesis Training Program was administered as a baseline measure prior to beginning the entire Phonemic Synthesis Program (lessons 1 through 15). On Lesson 12 Liz performed as follows:

**Pre Therapy:**

2 accurate responses

**3 months later:**

21 proper responses

**1 year later:**

39 proper responses

In August of 2002, at 19 years of age, Liz entered a therapy program which focused on further enhancing auditory decoding and phonological awareness skills while concurrently fostering language abilities, in essence combining aural rehabilitation and language therapy techniques for functional generalization of skills learned.

With this new therapy program, sound blending was a continued focus with sound segmentation added to the challenge. Sound segmenting tasks involve an individual hearing a word, perceiving the sounds in the word, and then being able to identify the sounds individually and in sequence, the inverse of a blending task. For example, if

asked to segment the word “tent” the individual would be verbally presented with the word and then required to say the sounds “t-e-n-t”.

Being able to perceive the sounds in a word is a precursor to actual spelling abilities and an aid to fluent reading. As segmenting skills develop, an individual is then challenged to represent sounds with symbols. At first arbitrary symbols such as blocks may be used and, later, the actual graphemes (letters) will be added. As an example, when segmenting the word “ten” an individual may verbally respond “t-e-n” and place three different colored blocks on the table, representing the three different sounds heard. They then could assign letters to correspond to the blocks to actually spell the word. As segmenting skills and sound symbol association skills increase, an individual’s spelling as well as reading skills should subsequently improve. The aforementioned methodology is similar to that advocated in programs such as the Lindamood Phoneme Sequencing Program (Lindamood and Lindamood, 1998), the Phonological Awareness Kit (Robertson and Salter, 1997), and the Ortan Gillingham Program (Institute for Multi-sensory Education), to name a few.

When Liz first began attempting segmenting tasks she required maximal support to separate the sounds in two phoneme (sound) words (ie. no = n-o). As therapy progressed, she was able to consistently identify the sounds in two sound words and also represent the number of sounds heard using arbitrary symbols (colored blocks). Liz continued to progress in segmenting and is currently able to segment four phoneme words using colored blocks and match blocks to appropriate letters with some consistency. Liz is able to match sounds to corresponding consonants approximately 90% of the time with less consistency with matching vowel sounds to letters. However, using this structured system with a speech-language pathologist to guide her through the process, Liz is able to spell two, three, and four sound words with minimal error. Some carryover is seen in spontaneous spelling of words outside of the clinic setting, however, Liz has not fully generalized her skills and continues to work toward independence in this area.

Given that the development of decoding and phonological awareness skills begins in infancy and continues through a child’s school years, LS has made remarkable progress in “catching up” over the last six years of her life to reach a level of phonological processing consistent with early readers. Her most recent testing, using the Phonological Awareness Test (Roberson and Salter, 1997) revealed rhyming skills to be at a 5 year 2 month level and segmentation skills to be at a 5 year, 4 month level. Liz’s ability to isolate sounds in words (determining what sound was heard at the beginning, middle, or end of the word) was found to be at a 6 year, 0 month level, and her deletion skills (ability to determine what the remaining sounds in a word are when a sound or set of sounds are deleted – say “bat”, say “bat” again without the “b”) were found to be at a 5 year, 10 month level.

As Liz continues on her journey toward enhanced skills it is a goal to have her consistently make sound symbol associations for functional vocabulary that she will encounter in her environment or during her daily routine. In addition to using decoding therapies to enhance spelling and reading ability, sight word reading is also a focus to

enhance comprehension and use of written words pertinent to Liz's vocational, academic, and personal life. Visualization, association, and first letter cuing strategies are currently utilized to develop Liz's recognition of words. Although Liz requires several weeks for the establishment of each new set of sight word vocabulary, this practice has allowed Liz to use, recognize, and read words too complex at this point in her development to sound out independently. Recently, in addition to sight word recognition, common phrases have been targeted for recognition. The goal is to have Liz recognize common phrases from a list of phrases that she will use as a cue to independently create appropriate written language, particularly targeting e-mail communication with friends and relatives.

In addition to written language (spelling, reading, and writing), Liz's understanding and use of language has been targeted through the years. Particularly, Liz has made outstanding progress in compensating for auditory comprehension issues resulting from language delay and hearing loss and compounded by her auditory recall difficulty and perception related to her auditory processing disorder. Liz has developed and frequently utilizes strategies such as attending to visual cues (body language and lip reading), recognizing comprehension breakdowns, and repairing breakdowns through asking for repetition or clarification.

Liz's expressive language has continued to blossom with therapy targeting expansion of simple utterances to form complex. In addition, pragmatic skills, which are interaction abilities have flourished as Liz's practice and maturity have resulted in improved conversational abilities. As language and auditory processing skills have developed, Liz has been able partake in functional activities geared to enhance daily living through improved organization and problem solving. For example, medication recognition and organization, calendar planning, event planning, and situational problem solving and role-playing have contributed to enhancement of Liz's overall independence.

Liz has made outstanding progress through the years in all aspects of her communication and overall development. Liz's successes are likely a function of her positive attitude and the outstanding support that she receives from each of her family members. Liz consistently attends and participates in scheduled sessions, and carryover of skills is facilitated by family as her mother regularly attends sessions and continually communicates with Liz's speech-pathologist, audiologist, and ENT to optimize care. Continued success is projected for Liz's future. Liz's story has been shared at numerous conferences and serves as an inspiration to professionals, conveying the message that those with multiple challenges can achieve amazing feats with the appropriate therapies and supports. Central auditory processing therapies have been integral in Liz's skill development, particularly related to her comprehension skills and her reading, writing, and spelling development. The first step in proper treatment planning is appropriate evaluation. Those suspecting an auditory processing disorder, should consult a qualified audiologist with verbal and written language skills assessed by a speech-language pathologist. It has been an honor to work with Liz and her family. They are truly an inspiration to all.

## **About The Authors**

### **Theresa M. Cinotti, M.A., CCC-SLP**

***Clinical Assistant Professor at the University at Buffalo***

Theresa is currently the Speech-Language Coordinator and one of the clinical supervisors at the University at Buffalo Speech-Language and Hearing Clinic, a training clinic for graduate students pursuing their master's degree in speech-language pathology. Theresa runs the Intensive Language and Auditory Processing Program at the University, an intensive summer program which addresses the language and auditory processing needs of children ages 5 years and older. In addition, Theresa coordinates the adult language and auditory processing program at the University, a program which focuses on optimizing processing skills and functional communication for adults with auditory processing and related issues.

### **Kim L. Tillery, Ph.D., CCC-A**

***Associate Professor and Chairperson of the Speech  
Department at SUNY of Fredonia***

Dr. Kim Tillery has authored one chapter and co-authored four chapters and several peer-reviewed journal publications regarding Auditory Processing Disorders (APDs) and its relationship with Attention Deficit Hyperactivity Disorders (ADHD). Invited international, national and state presentations include her research of 1) Ritalin's effects on APD, 2) therapeutic measures for Decoding and Integration types of ADP, 3) the comorbidity of attention, learning and auditory processing deficits, and 4) how reliable differential diagnosis improves effective management of ADHD, LD and APD. Besides her teaching and research Dr. Tillery maintains a private practice, has served as the Co-President of the Speech-Language and Hearing Association of Western NY (SHAWNY) for two-years, received the 2003 SHAWNY Award for her dedication and service to the communicatively disabled of WNY, and serves on other Professional Advisory Boards and Committees.