

Disclaimer: These notes were taken by Ruth Dameron at the LMBBS Conference in Houston, June 17, 2006. There has been no attempt to verify accuracy. Do not quote the speakers based on these notes!

Alice Brackett of Texas Children's Hospital – Speech Pathology and Therapy

[Note to reader: ignore annotations of the form "Axx" such as "A08".]

A08

See HANDOUT from Alice Brackett which summarized what can be wrong with speech and what can cause it.

Dr. Lewis cited a paper from 2005, Linguistic and Gait Disturbance in a Child with LMBS (from Formosa) that recommended early speech intervention. The last (only) paper before that was from many decades before.

Dr. Lewis asked the audience how many required speech intervention.

At least half with BBS who were in attendance required speech intervention and yet speech therapists have never heard about it and have nowhere to go to learn about it.

April Brackett:

[RHD note: There was an extensive handout listing definitions, categories of anomalies that affect speech; what can be done about them.]

She compiled information based on 22 years of speech language pathology. A lot of her talk is slanted from a pediatric standpoint.

Facial structure affects quality, pitch,

Fluency has to do with flow or smoothness

Motor speech disorders – affect respiration, articulation, resonance, ataxia, apraxia (volitional movement of articulators and inability to sequence those movements)

Rest postures – when the mouth is at rest, how do the jaws line up; does the lower jaw hang open; where is the tongue placed.

Swallowing

[I didn't catch the term for the] way the middle face grows, teeth erupt, the jaw grows

Language area (as opposed to "speech"):
vocabulary, following instructions, complexity

Phonology – combining sounds into words

Resonance – movement of soft palate function

hypernasality – too much of nasal quality – results in high-pitch, almost whiny sound

hyponasality – too little nasal quality – can sound rather flat.

Many other categories in handout.

Oral-motor – structure and function of each muscle and speech system – lips, tongue, rest positions

After initial assessment: parent education; parent role in stimulating language development

There are limitations to the services that can be offered. They may notice hoarseness, hypernasality, drooling, etc., these are not the area for a speech pathologist but might be referred to ENT.

Need to have some things corrected so that they can be able to build up pressure for consonants.

Dental anomalies may need to be corrected. (RHD note: dental anomalies are listed in the Beales paper on New Diagnostic Criteria. They include malocclusion [upper and lower teeth don't sit right], crowding, micrognathia [lower jaw is too small].)

Diagnostic Assessment

Swallow function – safety of oral feeding, rule out aspiration (food going into lungs), etc.

Hypernasality – may not be moving soft palate correctly.

Omitting final consonants – may not be using soft palate correctly.

Team approach – many related issues – may require speech pathologist, Ear-Nose-Throat doctor, Maxillofacial surgeon, orthodontist, occupational therapist.

If an individual has motor coordination and planning problems, there is an area of expertise where therapists can go through courses to maximize low muscle tone, manage high muscle tone (Neurodevelopmental Treatment Approach)

Web sites are provided in the handout for professional organizations.

Referral Criteria

Most of this information is geared for younger kids. [RHD note: That's exactly when BBS patients should be starting speech therapy so that's fine.]

See the list in the handout

Considerations for speech and language therapy – how to find a therapist – see handout

CCC = Certificate of Clinical Competency

There are specialty areas. But you want to be sure the therapist with a specialty can also cover all the basics. If you get a good generalist, s/he should have resources for advice in special areas.

Controversial area: sucking and blowing – those really don't address motor speech or airflow for speech.

Using sign-language to develop language and communication in absence of speech because of a motor problem. [RHD note: Joy began speech therapy at 11 months of age. She had such low facial muscle tone, poor motor planning ability with jaw, tongue, lips, plus other motor issues re the face AND a long delay before starting to attempt speech – they decided to work with me to attempt

to teach her some basic sign language signs so that she could enjoy communication without having to wait until she was able to speak. Of course, BBS children often have poor fine-motor coordination and have difficulty imitating motor actions so getting her to learn signs proved to be hopeless.]

Some kind of organized communication system – can be low tech (non computer) – is another way to help a child communicate. [RHD note: This is referring to things like making a poster of pictures of breakfast foods so your child can point to tell you what s/he wants for breakfast.]

Therapists need guidelines on BBS to know the breadth of what to explore. [RHD note: for starters, show them the table in Dr. Beales' New Diagnostic Criteria paper. It lists issues re speech, language, and dental anomalies.]