



**Friday, July 31, 2015
Breakout Session #14: 2:15 - 3:15pm
Schaumburg A-B**

**Identifying Effective Positive
Behavioral Supports for Young Adults
with CHARGE Syndrome**

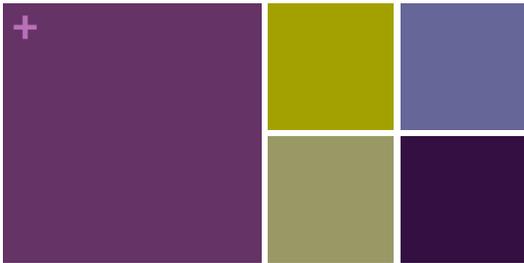
**Susan M. Bashinski, Ed.D.
Associate Professor, Special Education
Missouri Western State University
Susan M. Bruce, Ph.D.
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Presenter Information:

Susan M. Bashinski has 38 years' experience with learners who experience multiple disabilities. She has directed numerous federal and state grants in low-incidence disabilities and deaf-blindness, including: personnel preparation, research, model in-service training, and assistive technology. Dr. Bashinski has extensive experience in providing professional development and technical assistance nationally and internationally, particularly in the areas of augmentative and nonsymbolic communication for learners who have low-incidence disabilities, including deaf-blindness and CHARGE syndrome. Her research interests and areas of expertise include early communication and language development, augmentative communication, and cochlear implants, with numerous publications and presentations related to these topics. Dr. Bashinski authored the chapter on assessment of prelinguistic communication for the Hartshorne, Hefner, Davenport, and Thelin 2011 book, *CHARGE*. She has given both paper and platform presentations at the 2009 and 2011 CHARGE Conferences.

Presentation Abstract:

This presentation will share findings from an action research study that examined three elements of positive behavioral interventions & supports (PBIS): adult use of language, environmental arrangement, and sensory system sensitivities and needs. The presenters will utilize videos to demonstrate the application of proactive and reactive behavioral intervention strategies with five young adults who have CHARGE syndrome. Excerpts from profiles of these young adults will also be shared.



Strategies to Support Positive Behaviors in Students with CHARGE Syndrome

Susan M. Bashinski, Ed.D., Missouri Western State University
Susan M. Bruce, Ph.D., Boston College

+ Review of Literature: PBIS

Positive Behavior Intervention Supports apply behavioral principles to support emotional regulation

Learners with CHARGE syndrome:

- often have problems with emotional regulation (controlling one's emotions)
- usually have high anxiety levels

(Davenport & Hefner, 2010; Hartshorne & Salem-Hartshorne, 2010)

+ Review of Literature (con't.)

- PBIS is proactive rather than just reactive
- PBIS looks beyond the learner
 - Considers sensory integration needs
 - Considers environment
 - Uses information from Functional Behavior Assessment (FBA)-on purposes of behavior to build the Positive Behavior Intervention Support Plan
 - Cites alternative/replacement behaviors that must be taught (such as communication) (Homer, 2000)

+ Cognitive Behavior Therapy (CBT) Elements

- **Cognitive Behavior Therapy:** Action oriented form of psychosocial therapy-replacing maladaptive thinking and behavior with constructive thinking and behavior
- **We applied 10 elements of CBT:** Individual is active participant, implementation in familiar settings and activities, *cognitive rehearsal* through social stories, *role play*, reinforcement to condition positive responses, *systematic desensitization* through carefully controlled exposures, *cognitive restructuring*-choice making, labeling, redirection, & relaxation techniques

+ Action Research

- Recursive, problem solving form of research
- Cycles of action-reflection-action-reflection
- Four types: classroom, collaborative, critical, and participatory
- **OUR STUDY:** Collaborative action research with collective case study design
(Bruce & Pine, 2010; Hendricks, 2009)

+ Research Questions

- What positive behavior intervention (PBIS) supports are most effective with each of the young adults who are deafblind?
 - What language supports, especially adult use of sign language, will support positive behaviors in students?
 - How does environmental engineering support positive behavior in each student?
 - What sensory-motor integration strategies are helpful in promoting behavior in each student?
 - Which strategies are important to preventing a negative behavior and which are important to addressing a negative behavior?

+ Young Adult Student Participants



- 7 young adult students*
- 5 with CHARGE syndrome (4 who are deafblind, one who is deaf with additional disabilities)
- Ages: 18-22 years
- 3 males, 2 females
- *This presentation will focus on the 5 students have CHARGE syndrome: Joe, Jon, Gail, and Nathan, and Renee

+ Five Students with CHARGE Syndrome



- **Joe:** Profound bilateral hearing loss, 20/900, right field restriction, severe delays, expresses in signs and sign combinations
- **Jon:** moderate bilateral hearing loss, left eye-20/300, right eye-20/30, superior field restriction, moderate delays, expresses in sign language
- **Gail:** Severe bilateral hearing loss, 20/360, superior & inferior left and lateral left field losses, moderate delays, expresses in speech, sign language as back-up (especially receptive)

+ Five Students with CHARGE Syndrome (con't.)



- **Nathan:** Moderate-severe hearing loss, left eye-20/70, right eye-20/800, moderate delays, expresses in sign language
- **Renee:** Profound hearing loss, normal vision, severe delays, expresses in pictures/line drawings, body language, some signs/gestures

+ Adult Participant/Co-Researchers



- 3 classroom teachers with expertise in deafblindness
- 1 teacher liaison
- 1 psychologist with expertise in Cognitive Behavior Therapy (including adaptations for those with developmental delays)
- 6 paraprofessionals
- 1 university faculty member

+ The Intervention



Our study focused on three areas of PBIS:

- Adult use of language
- Sensory needs of the learners
- Environmental engineering/arrangement

+ The Intervention (con't.)



- Teachers recorded data on behavior
- Teachers videotaped at times that were often problematic for each student (specific transitions and activities)
- Teacher and psychologists discussed data
- All research team members discussed a focus student each month and generated a PBIS Profile
- Students participated for 6-9 months, depending on their graduation date

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Data Sources

- Behavior chart addressing our 3 areas of focus
- Some students had additional behavior sheets provided by the psychologist
- Classroom journals (for teachers and paraprofessionals to record ideas about each student's behavior)
- Videotaped observations that captured proactive and reactive strategies (transcribed)
- Ongoing development of Positive Behavior Intervention Support Profile for each learner. Completed profiles were member checked by teachers.

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Data Analysis

- Constant comparative, elements of grounded theory
- During data collection-observing for themes for each student/case with influence on teaching (action cycles)
- After data collection-identification of themes that cut across cases (collective case analysis)
- Open coding (capturing the specific) and axial coding (identifying families or categories of data)

(McHatton, 2009)

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Environmental Engineering & Sensory Sensitivity: Sample Flip Chart Data from Meeting re: **Joe**

Asking him: "it's going to be really loud - do you want to leave?"

Designated area that is his area - showing him how much space he has - what space is "his"

last year - sitting @ desk and/or doing his schedule were triggers

being "jostled" by others

being active - likes making backpack heavier (sensory)

discontinued "signing in" for waterroom - trigger - begins crying

Sensory

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Findings

8 Major Themes/Super-Categories

- Provide structure
- Support students to cope with anxiety
- Address students' sensory needs
- Support on task behavior
- Support transitions between activities & environments
- Support mature behavior (cooperating & adult-like)
- Establish & maintain positive climate
- Adult language supports positive behavior

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Theme #1: Provide structure

- Directly teach rules, practice, remind, have learner restate the rule
 - Individual nuance: Give **Nathan** the direction, step back to allow him time to process, don't repeat the direction. At times, remind him that everyone has rules to follow.
- Use schedules & calendars(relates to learning routines)
 - Individual nuances: **Joe** needs novelty built into schedule; **Jon** requires that the entire schedule is reviewed whenever an activity is canceled; **Renee** needs first/then language (work first, then computer)

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Provide structure (con't.)

- Establish & teach routines (within & between activities)
- Structured physical spaces
 - Well defined workspace essential for staying calm (**all students**)
 - Secure place to leave unfinished work (**Jon**)
 - Chill out space (when overwhelmed/stressed) (**Joe**)

+ Theme #2: Support students to cope with anxiety

- Structure (Theme #1) helps
- Keep students informed
- Gross motor exercise, rough & tumble play (3 students)
- Calm spaces
- Consider influence of sensory sensitivities (Theme #3)
- Support students to learn & identify their individual strategies:
 - **Gail**: Use of mature behavior sheet, turning down hearing aids when overwhelmed, establishing physical distance from irritations

+ Support students - cope with anxiety (con't.)

- Redirect to new activity if obsessional compulsive disorder (OCD) behavior is difficult for student to control
- Switch communication forms: Use sign instead of speech with **Gail** and fingerspelling or tactile sign instead of visual sign with **Joe**
- Relaxation techniques: For example, deep breathing, sighted guide and deep pressure for **Gail**
- Use counting-1st, 2nd, 3rd for what will happen (**Joe & John**) and count to 5 to relax (**Gail**)
- Suggest he not worry about that now (**Nathan**)

+ Support students - cope with anxiety (con't.)

- Unexpected touch as source of anxiety for most students (deafblindness impact)-avoid situations where unexpected touch is likely to occur-or restructure
- Introduce something new to break up OCD (**Renee**)
- For repetitive talk: Know their topics; acknowledge communication and redirect topic to appropriate time and place, may need to reassure
 - Example: **Gail's** talk about Wizard of Oz
 - Example: Repetitive talk about future event-such as holiday (3 students)

+ Example of Repetitive Talk: Excerpt from PBIS Profile Draft re: **Gail**

- Behavior = Repetitive talk about Wizard of Oz
- Staff must be aware of manipulations to get into such conversations
 - She might say "Call me Dorothy"
 - She might say "Do you like shoes?" Who wears red shoes?" This leads to Dorothy conversation.
 - She might say, "I like yellow." This leads to talking about the yellow brick road.
- Adult use of language: Staff talk about real/not real

+ Theme #3: Address Students' Sensory Needs

- Examples of sensory needs/sensitivities:
 - **Joe:** Comfy chair with body parts touching specific parts of chair, deep pressure, weighted backpack
 - **Jon:** Prefers chairs without arms, weighted beanbag & cart, sensory diet, spinning
 - **Gail:** Sensitive to sounds and accidental touching- avoid crowded elevators. She knows her strategies for sound.

+ Address Students' Sensory Needs (con't.)

- **Nathan:** Hot and cold temperatures, must have goggles for swimming, likes rough and tumble play, needs exercise and stretching to stay positive (treadmill), beanbag and computer access for calming after meltdown
- **Renee:** Needs lots of sensory input-body sock, weighted blanket, beanbag, clapping, squeezes, deep pressure, she often leans on surfaces to satisfy a sensory need

+ Theme #4: Support On Task Behavior



- Provide sufficient wait time for response
- Reinforcement-higher for non-preferred tasks
 - Remind of upcoming reinforcer
- Counting down to give foreseeable end (how many more)
- First/then language
- Reduce distractions (including watching what you do)
- Redirection
- Consider preferred activity-end each session w/ preference(**Joe**)
- Token economy (**Nathan**)

+ Theme #5: Support Transitions Between Activities & Environments



- Consistent use of finished sign
- Consistent use of daily schedule
- Preview what will happen in next environment
- Sufficient wait time
- First/then language (**Renee**)
- Simple language (**Renee**)
- Adult use of language (Theme #8 applies here)

+ Theme #6: Support Mature Behavior (cooperation & "adult-like" behavior)



- Wait time to process (**Joe, Jon**)
- Verbal compromise (**Gail**)
- Use of mature/adult behavior sheet
- Talk about "mature" and "not mature" (**Nathan, Gail**)
- Use of self-evaluation sheet (**Gail**)
- Know student's types of refusals & be prepared
- Set limits
- Give physical space as needed

+ Journal Excerpt re: **Joe's** Behavior

"When he starts having negative behavior (pushing things, ignoring staff, not aggressive-but maybe on edge), give him a reminder—"If you want to _____ (name preferred activity), you need good behavior"... Seems to be more effective since it gives him an incentive instead of just reminding him about the rules."

+ Theme #7: Establish & Maintain Positive Climate

- Keep staff attitude/behavior positive-wording, signs, voice, facial expression
- Use reassuring language and tone
- Physical distance from upsetting events-some students can initiate this, others need adult support
- Adjust expectations on difficult days
- Appropriate types/levels of reinforcers
- Preferences: Favorite topics (**Gail**), computer (**Renee**)
- Consistency in environments

+ Establish & Maintain Positive Climate
(con't.)

- Provide choices, but consider each student's requirements (open ended or choice of two)
 - **Nathan** likes choices of reinforcers
- Watch your position-stay in close proximity-but where depends on student
- Restructure environment to keep it positive (sensory inputs)
- Provide socialization opportunities
 - **Joe** needs silly time with others
 - **Gail** needs contexts for relationship building

+ Theme #8: Adult Language Supports Positive Behavior

- Use very few directives (decide what you will save this for)
 - Example-Use of "no" for touching others
- Keep your language positive
- Be aware of trigger topics
 - Topics you don't have info about/vague topics (**Joe**); home, people who have disappeared from his life, deaf, death, skinny vs. fat (**Nathan**)
- Be aware of students' trigger words and possibly substitute other words
 - **Joe**: Use "celebration" not "party"
 - **Nathan**: "death" and "deaf"
 - **Renee**: "no" and "you need to ..."

+ Adult Language Supports Positive Behavior (con't.)

- Provide specific information
 - **Joe, Jon, & Gail** need info about environments-who is there, what they will do, noise levels...**Nathan** seeks much information, but be careful it doesn't become task avoidance
- Refer to past events that are similar-point out student success in past event
- Talk about mature/not mature behavior (**Gail, Nathan**)
- Provide language for their concerns-words/signs
 - **Nathan**: Model correct American Sign Language structure
Encourage students to use their strategies

+ Adult Language Supports Positive Behavior (con't.)

- Modify forms (from visual to tactile sign..)
- Suggest thinking before action (**Nathan** only)
 - Adult Messages:
 - "I want you to think"
 - "Think before, what's next?" (for schedule reinforcement)
 - "Try and think before doing"
 - "Stop and wait. I want you to think. Slow. Patient. One minute."

+ Journal Excerpts on Adult Use of Language with **Gail**

- For disorganized thinking, thinking in the past or too far in the future-help to refocus **Gail** on the NOW. "Let's save that until June. You can ask me in June. When can we talk about that? Why don't we save that for _____(name month)."
- In response to her talking in detail about past events- because she wants things to happen exactly the same way-----"Use language that points this out to her- acknowledge that via language. Are you asking if same people are going/we're doing same thing because you like things to be the same?"

+ Video: **Gail** reviewing her self-evaluation sheet & strategies

+ Video: Identifying Positive Behavioral Interventions & Supports fro **Joe**

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Discussion



- Common needs (such as defined and organized spaces, sensory sensitivities)
- Unique needs-to each student
- Must know each student well-their likes/dislikes-level of detailed knowledge held by teachers-amazing
- Adults could act in specific ways to prevent negative behaviors

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Discussion



- Collaboration important-in our study students were known by all three teachers
- Consistency important-yet must be willing to adjust in the moment
- Profiles can be used to shape PBIS plans
- Profiles are helpful to share across environments and for transitions to adult environments

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Study Limitations



- Difficult to identify clear action research cycles (and connections between specific strategies: behaviors as instructional adjustments occurred frequently)
- Study of just 7 students, 5 with CHARGE syndrome (including one who was not deafblind)

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References



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