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Music Therapy & Rett Syndrome Fact Sheet

Definition: Rett Syndrome is a neurological disorder often misdiagnosed as autism, cerebral palsy or non-specified developmental delay that is caused by a defective regulatory MECP2 gene, found on the X chromosome. It was first described by Dr. Andreas Rett in 1964 but received worldwide recognition after the first English language publication by Dr. Bengt Hagberg in 1983. Development appears normal until 6-18 months of age and then a loss of speech and motor abilities begins.

Incidence: Rett Syndrome, seen almost exclusively in females, is now known to occur in from 1:10,000 to 1:23,000 female births. Unlike females, who have two X chromosomes, males have an X and a Y chromosome. Because males lack a "backup" copy of the X chromosome that can compensate for a defective one, mutations in MECP2 are lethal to the male baby. Rett Syndrome occurs in a variety of racial and ethnic groups worldwide and 99.5 % of cases of RS occur only once in a family.

Characteristics and Need Areas:

Rett Syndrome can be classified into four stages, each characterized by changes in characteristics and need areas:

1. STAGE I (Early Onset; Age: 6 months to 1 ½ years);
2. STAGE II (Rapid Destructive, Age: 1 to 4 years);
3. STAGE III (Plateau, Age: Pre-school to school years);
4. STAGE IV A (Previously ambulant)
STAGE IV B (Never ambulant) Late Motor Deterioration Age: When stage III ceases, 5-15-25-? years

In general, characteristics include:

- **COGNITIVE:** The girl with RS understands far more than what meets the eye. She is capable of taking in much more information than she can give out. Until recently, girls and women with RS have been classified as mentally retarded with little or no room for improvement. Intuition has always told us that she understands a lot. Recent scientific studies have illustrated this point.

- **SPEECH/COMMUNICATION:** Rett syndrome is known to affect expressive language (communicating with others) far more than it affects receptive language (understanding). Apraxia and more basic motor difficulties which involve chewing and swallowing combine with a lack of words or effective body language to make finding ways a girl can communicate functionally quite challenging.
- **MOTOR SKILLS:** Motor development in RS is almost always delayed, but the extent of the delay can vary considerably. Some girls are never able to achieve independent sitting or standing, while others sit, stand and walk at nearly the expected time. Her gait is often wide-based, unsteady and asymmetrical. Specific motor problems which may need to be addressed are hypotonia, ataxia, motor apraxia, loss of transitional movements, spasticity, scoliosis and/or kyphosis, loss of ambulation, loss of hand function, foot deformities and spatial disorientation.
- **SOCIAL:** Disinterest in surroundings and social situations in stages I and II followed by an increasing social awareness and eye contact during latter stages

How can music therapy address the need areas for an individual with Rett Syndrome?

SPEECH: Most girls with RS show an intense desire to communicate through their eyes, gestures and body language. There is often a delay in response to stimuli. There are reports of some girls who use augmentative (non-speech) communication techniques demonstrating good receptive language. Music therapy can be an effective modality for children with Rett Syndrome to develop speech and language skills in the areas of: expressive and receptive communication, choice-making, increased vocalization, communicating information/knowledge and developing an understanding of patterns of language. Eye gaze responses, letter and word boards, touch or switch-operated voice output devices, visual aids, pictures, sign language and augmentative devices are incorporated into music therapy sessions to facilitate communication. Co-treatment with speech therapists also enhances the effectiveness and rate of progress for children and aids in the generalization of skills from the music therapy session to other settings.

COGNITIVE: Music can be used as mnemonic device to teach specific academic information such as colors, numbers, letters and other factual information. In addition, customized, consultation music kits for a specific skill (i.e. brushing your teeth) provide a visual picture schedule with a motivating, fun song to rehearse and check for understanding of the skill.

MOTOR SKILLS: Music therapy can be effective in gait training by providing a steady, rhythmic structure for the children to improve walking abilities. Music and movement activities may include following simple directions in song (clap hands, stomp feet). In addition, using instruments (such as chimes, Q-chord) can be a motivating way for children to purposefully improve hand use, increase grasping/holding, decrease stereotypical movements, cross midline, and reach high/low. Music allows for the stimulation of a variety of musical experiences: texture, pitch, mood, pace, intensity, idiom-style. Co-treatment with an occupational or physical therapist also may enhance the effectiveness of music therapy strategies. Sample goal areas may include: identifying and encouraging use of head, elbows, or other body parts over which she may have better control, maximizing hand use for functional activities, improving ability to assist with dressing, improving ability to perform independent feeding skills, improving ability to assist with grooming activities, improving ability to tolerate sensory input in school setting.

GOAL EXAMPLE for MOTOR SKILLS

By (date), given songs and rhythmic cues, Jane will improve her motor skills by demonstrating purposeful hand movements as evidenced by reaching to play the drum for duration of at least 10 seconds 75% of opportunities with minimal physical prompting.

Baseline: Jane demonstrates hand-wringing during 75% of the day and only reaches out with her hands for food. Due to her increased motivation when music is present, music provides a structured and motivating way for Jane to decrease her hand-wringing and increase her purposeful hand movements.

SOCIAL: With many disorders, repetition of the same activities over and over is reinforcing, and in time, will be learned. However, in RS, no amount of repetition will completely restore hand function. It is not a matter of learning; it is a matter of making the brain connection necessary to carry through the required movement. Providing a variety of activities can lessen boredom and motivate her, therefore music can be a motivating modality to engage with others. She can learn how to take turns using various instruments, partner with other students to play instruments, take leadership roles within a group music therapy session, contribute to a songwriting activity and participate in improvised drum circles. In addition, specific social song stories can target specific skills (making eye contact) which improve and enhance social skills. When music is used, she may participate more in group activities, may sustain eye contact for increased duration and may (where is the rest of this sentence?)

RELATED RESEARCH:

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NATIONAL ORGANIZATIONS

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