



**Tears in the Key of E:
Including Siblings of
Autism in Special
Music Education**

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Friday February 24th, 12pm

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Agenda

- Perspectives, Definitions, and Intro
- Research!
- Recommended Program
- Poem

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Autism and Disability Language

- Autism is NOT:
 - A disease
 - A curse
 - Contagious
 - Something to fear
 - Etc.
- The goal is NOT to “cure” people. It is ableist to approach education with the intention of eliminating a disability. Doing so implies that there is something inherently bad about being disabled or that a life with a disability isn’t worth living. This bias devalues the experience and lives of people with disabilities.

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Disability language

- Autism is
 - A neurotype (a type of brain, especially related to interpretation and response to the environment)
 - A neurodevelopmental condition characterized by difficulties with social and communicative behavior. Typically accompanied with restrictive or repetitive patterns.
- We will use the term disability and disabled in this discussion.
 - Particularly because we are dealing with autistic individuals *and* their siblings. We need a way to communicate which sibling we are talking about. Disability and disabled are not bad words.

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Vocabulary

- Person First Vs Identity First.
 - This is a person-to-person preference. **However**, it is the consensus of the autistic community that identity first is preferred due to the nature of autism. Autism is closely linked with personality, relationships, and identity, therefore separating the person from the diagnosis is futile.
- Allistic: the term for individuals who are **not** autistic.
 - Siblings of autism might have disabilities! There is research to show a connection between autism within a family and increased incidents of other learning disabilities.
 - Families of autism are also more likely to have mental health conditions or traits of the broad autism phenotype!
 - Allistic is preferable since it simply identifies them as *not autistic* without taking away from any other diagnoses and identities.

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Vocabulary

- Neuro...
 - Diverse: displaying or characterized by autistic or other neurologically atypical patterns of thought or behavior.
 - Can refer to a group (or in this instance, a sibling diad or group, with different neurodiverse statuses)
 - Divergent: differing in mental or neurological function from what is considered typical or normal (frequently used with reference to autistic spectrum disorders).
 - Typically referencing an individual or self. "I am neurodivergent".
 - Typical: not displaying or characterized by autistic or other neurologically atypical patterns of thought or behavior.

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Perspectives & Introduction

- Ableism:
 - Is talking about siblings ableist?
 - The family is the primary support structure; this is true for *most everyone*. The people who surround an autistic individual need resources to be the best support system possible!
- The purpose of this presentation is not to devalue the experience of autistic individuals. Nor is intended to assume that relationships with people who are autistic are strained by nature. Rather, it is to provide music as an opportunity to bring together siblings who do have tense neurodiverse relationships.

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This is Eric

... and myself :)

I am an allistic* sibling. My personal perspective has informed the direction of this research. This could be seen as a positive or negative attribute to this research. You get to decide!

*jury is still out on this.

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A little more background

(pictures and info shared with permission)

Left to Right:
Myself- Meghan 24; Laura 21; Eric 19; Cheyenne 16; Ryan 19; Cody 17

Together we have experienced an array of challenges along with the associated accommodations and services.



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What Research Shows: Autism and Music

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- There is evidence to suggest that, to some degree, autistic individuals have an, "innate musical ability" (Clements-Crotes & Yip, 2017, p. 34).
- Other research suggests that 8 to 12 weeks of musical interventions can alter intrinsic brain connectivity which correlated to parent-reported outcomes regarding social communication (Sharda et al. 2018).
- Other studies have concluded that "the quality of vocal communication was seen, in most cases, to develop with the progression of the [music] therapy course" (Saloman-Gimmon & Elefant, 2019, p.184).
- Saloman-Gimmon & Elefant also saw a decrease in vocalizations that had little to no communicative value, such as self-stimulatory vocalizations in the students who received music-based intervention.

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- "as musical vocal behavior gains so does nonmusical speech production" (Edgerton, 1994, p.57).
- Music, in the Edgerton 1999 and Bakan et. al. 2008 studies, served as initial communication. Participation in music also provided self-regulatory skills that allow people with autism to think clearly and communicate effectively.
- The overall results were, "in favor of music therapy over the play condition with toys in improving joint attention behaviors of the participants" (Kim, Wagwam & Gold, 2008, p. 1763).

These findings indicate that basic communication skills and behaviors associated with attentiveness can be influenced by music interactions due to the communicative nature of improvisation.

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Implications for Music Educators

- Music can be used as the initial form of communication and then used concurrently with verbal and nonverbal communication
- Students can practice communication concepts like rhythm, breath support, and phrasing through learning music similar music concepts.
- Concepts that involve sensory information, such as emotion identification, can be challenging for many autistic individuals. This topic, like many others, can be bridged through music.

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The bottom line:

- Autistic individuals who struggle with communication *do communicate*.
- Educators and therapists must decode the child's attempts to communicate in each educational setting.

Music teachers can initiate communication through music learning. Music educators and special educators can use music to encourage communication development.

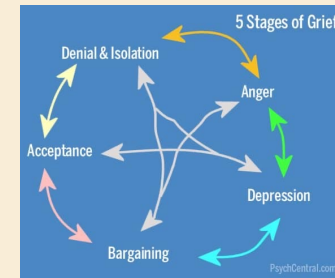
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What Research Shows: The Allistic Sibling

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The Grief Cycle

- The experience is independent from one person to the next.
- Different things will trigger different people.
 - You never know what could end up triggering grief
 - Sometimes you don't know *why*.



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Common Feelings Amongst Allistic Siblings

- Survivors Guilt
- Shame
- Stress
- Anxiety
- Depression
- Broad Autism Spectrum Phenotype
- Undiagnosed neurodiversity (Autism, ADHD, or learning disabilities).

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Common traits of Allistic Siblings:

- Coping styles
 - Parentified Child
 - Withdrawn Child
 - Superachiever
 - (Burak et. al., 2001)
- Mental Health and Allistic Siblings:
 - Negative, "impacts on TD sibling adjustment, including self-reported depression and anxiety" (Jones et. al, 2020)

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The Parentified Child

The child (or children) that take on caretaking roles.

Can be taking care of themselves, other siblings, or their autistic sibling.

Traits of the "parent" child:

Responsible, independent, anxious, emotionally reserved, an "old soul", craves control/leadership opportunities

Might present with behaviors associated with younger children within the classroom; this is the time they are permitted to be a child.



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The Withdrawn Child



- "Withdrawn" can present itself in several ways.
- Socially: lack of interaction with others (peers, parents, educators, siblings, or any combination of withdrawn social behaviors)
- Academically: lack of participation and or falling behind on schoolwork.
- Lack of interest in preferred activities
- Depression Symptoms

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The "Superachiever" (Burak et. al, 2001).

- Intentionally invested in achievement to alleviate stress within the family unit
 - Traits: leaders, near perfect grades. Reactions to things less-than-perfect are disproportionate.
- Might be a way to seek attention from parents
 - Might do the opposite and underachieve to receive attention (conscious or subconscious)



These behaviors can lead to burnout!

If a student has a shift in demeanor or grades start slipping, it might be time to refer to colleagues who specialize in mental health support.

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What Research Shows: The Neurodiverse Sibling Relationship

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- "Often, the TD [typically-developing] – ASD sibling relationship is described as poorer than that for TD siblings of a child with another disability or no disability, and characterized by decreased warmth and affection, less involvement, and more avoidance" (Zucker et. al, 2022).
- Risk factors for a negative relationship can include both siblings' genders and their age difference, as well as the severity of autism symptoms and availability of support and services.

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Neurodiverse Relationships continued.

This is not to disregard the experiences of allistic individuals who have siblings with other disabilities. Rather, it is to highlight that autism is a specific challenge as it affects the entire person and their ability to interact with the world around them

Having an autistic sibling "presents challenges and needs for TD siblings that are distinct from the challenges of having a sibling with a different disability" (Zucker et. al 2022).

With individuals who have more intense symptoms, such as maladaptive behaviors such as self-injury, or limited communication skills, family function may be impaired. This might be attributed to the "increased levels of stress ... in families with children with autism" (Rao and Beidel, 2009).

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Implications

- It should be a concern of schools to help create positive neurodiverse sibling relationships because allistic siblings might become caretakers of their siblings in the future.
- Sibling relationships should be one of the most intimate and longest relationships. We have a unique opportunity to help improve these relationships. By improving the sibling relationship, we can help reduce family stress and improve the mental health of all involved.

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Bottom Line:

With support for both individuals and shared experiences, neurodiverse sibling relationships can be healthy and positive. One of those shared experiences can be in the music classroom.

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The Recommended Program

Sibling World Percussion Group

Combining a world percussion group with a sibling support group

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Structure

1 session weekly for 2 hours

- The first hour is the allistic support group
- Second hour is the combined percussion group

2 sessions weekly for 1 hour each

- First weekly session is the allistic support group
- Second weekly session is the combined percussion group

The first hour/session could also be used for other therapies/interventions for the autistic sibling. If this is a school-based program, it is a perfect opportunity for group or individual speech, OT, PT, etc. If not, it is an opportunity for one-on-one time between parent and their autistic child.

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Support Group Structure

- Allistic Siblings can be grouped by several attributes. Common considerations for grouping are their own age and or the severity of the autistic siblings needs and symptoms.
- The intervention needs to happen at a level appropriate for their development and their relationship with their autistic sibling.
- Groups should be large enough to hear diverse experiences but small enough that each allistic sibling feels personally heard and understood.

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Support Group Curriculum

- The allistic sibling support group should be designed to engage allistic siblings in learning about Autism and its typical characteristics.
- Allistic siblings should also be involved in , “discussing feelings, coping strategies, and problem-solving skills” (Jones et. al, 2022)
- Allistic siblings in a support group should develop personal and behavioral related supports that aid in improving their mental health and the relationship they have with their autistic sibling.

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What age range should we serve?

- Littles
 - Help them to understand the diagnosis as it happens
- Elementary
 - Help them to establish and develop a closer sibling relationship
- Middle/high school
 - Help them to cope with changes in their lives and how it affects their sibling.
- Comes down to what you teach, where you teach, and what kind of resources are available to you. This program could be beneficial at any age.



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The World Percussion Group

Allistic siblings can take the information they learn in the support group and apply it practically to the shared experience in the world percussion group.

The benefit of this is that the adults who lead the support group can help to facilitate the first implementation of new skills and behaviors which, hopefully, will lead them to be a positive interaction.

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Before instruments

- Ice-Breakers
- Familiar songs
 - Y.M.C.A
 - Cha-Cha Slide
 - Disney Songs
 - Head, Shoulders, Knees, and Toes
 - The Macarena
- Movement/dance
 - Partner dances
 - Line dances
 - Circle Games and Dances
- Meet all the students where they are socially, emotionally, and musically.
- Bring them from the familiar to the unfamiliar.
- Starting with instruments might be too overwhelming for everyone involved.

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How to “do” world percussion with a combined sibling group.

- Expect the siblings to work together in this setting.
- Assume everyone knows nothing; even your all state choir/band students!
- Follow a world percussion curriculum.
- Start simple and build from there.
 - Movement
 - Beat
 - Repeat after me
 - Question and Answer
 - Call and Response
- Keep the group together!
 - When in doubt, repeat! There is no harm in doing something again to confirm understanding of a concept.

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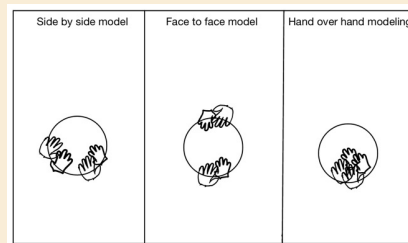
Work together!

Pair siblings up on the same instrument. Tubanos are a great instrument for everyone to start on for this reason.

Some autistic siblings, especially those with greater support needs, might need their sibling (or peer) to model for them.

Expect siblings to work like this or next to each other.

In time you may “switch” siblings to have the allistic siblings gain a better understanding of how to support any autistic person. It is important that they get a practical understanding of common behaviors and how to be helpful.




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Make Music

Above all else, this group should have fun creating music together.

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Where did this idea come from?

A sibling who wants nothing more than to share her love of music with her brother.

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Tears in the Key of E



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Questions?

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Thanks For Listening!


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More information


References



Autism on Tik Tok



Meghan's Linktree



The image shows a slide titled "More information" with a light beige background. Below the title are three black rectangular boxes, each containing a QR code. The first box is labeled "References", the second "Autism on Tik Tok", and the third "Meghan's Linktree". Each box has a thin white horizontal line above its QR code. The bottom of the slide features a decorative wavy line.

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