



TIC

CHILDREN'S VIEWS OF ILLNESS CAUSALITY:

**COGNITIVE-DEVELOPMENTAL RESEARCH MAY HELP US
EXPLAIN TOURETTE'S TO THE DIAGNOSED CHILD, THEIR
SIBLINGS, AND THEIR PEERS**

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**Presented at TIC-CON: The National Conference of the
Tourette Association of America
5/19/2023 - 5/20/2023**

The logo for TIC CON features a stylized human figure in shades of green and blue, with the letters 'TIC' in large blue font and 'CON' in smaller green font below it. A red arrow points from the left towards the text.

A bit about me to provide some context about my interest in this topic...

- **Intrigued by children's concept development (since the 1970's)... concepts of death, illness, life, birth, etc.)**
- **I always taught about Tourette Syndrome (TS) in my own developmental psychology courses.**
- **Then, my nephew and son were diagnosed with TS in the 1980's/1990's, respectively.**

A bit about my interests continued....

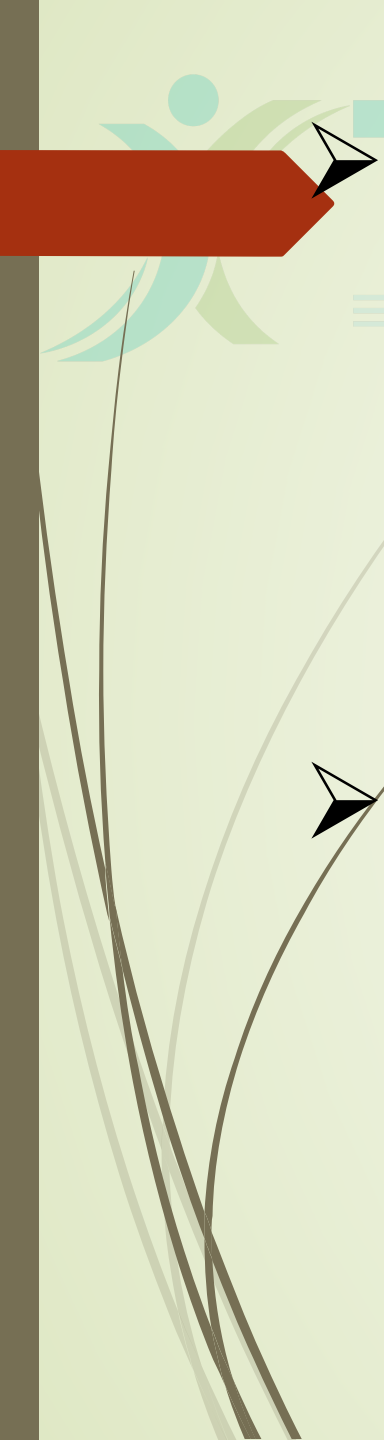
- Volunteer activity with Tourette's organizations in NJ and PA began in the early 1990's.
- TS-related research along with my students, starting back in 2000, on topics such as: siblings of children with TS; interventions to increase understanding of TS in school-aged children, etc.
- *Frequent reading of much of the published literature on children's concepts of illness AND*
- (interrupted) writing of a book about children's illness concepts in 2016 and since.

In an attempt to discover developmentally appropriate explanations!



OVERVIEW:

- ➔ This will be a brief summary of the decades of research I have read on children's changing understanding of what causes various illnesses just to give you a very *general idea* of this field.
- ➔ However, as you will see, we do need *much* more basic research focusing on children's (mis)conceptions about the causes of neurobehavioral disorders, *especially TS!*



And, if time allows, I will say a bit about **SIBLING AND PEER INTERVENTIONS** that have been conducted. There too, I will try and extend the findings to Tourette's.

➤ Hopefully, this general review will help us to formulate “**developmentally-appropriate**” explanations of tic disorders for diagnosed children, their siblings, and their peers.

WHY MIGHT THIS MATTER?

- ➔ If we can scaffold interventions to increase children's understanding of the brain-based causes of TS, the diagnosed child may be more amenable to treatment, able to educate others, and better able to advocate for themselves.
- ➔ And highly informed siblings and peers *may* be more positive in their attitudes and interactions with a child diagnosed with TS.
- ➔ We will see what the research results suggest....

THEORY/RESEARCH FINDINGS

Since the 1970's, many studies that assess *children's understanding of the causes of (physical) illness* have been conducted but mostly within 3 different perspectives:

- 1) Piaget's cognitive-developmental theory
- 2) the "Theory-theory" perspective
- 3) as well as several atheoretical studies.

I will summarize each perspective for you.

1. The Cognitive- Developmental Perspective:

Using Piaget's theory

Bibace, R. & Walsh, M. E. (1981). Children's conceptions of illness. In R. Bibace & M. E. Walsh (Eds.), *Children's conceptions of health, illness, and bodily functions*. New directions for Child Development Series (31-48). San Francisco: Jossey-Bass.



In response to a question like “How do people get colds?.....”

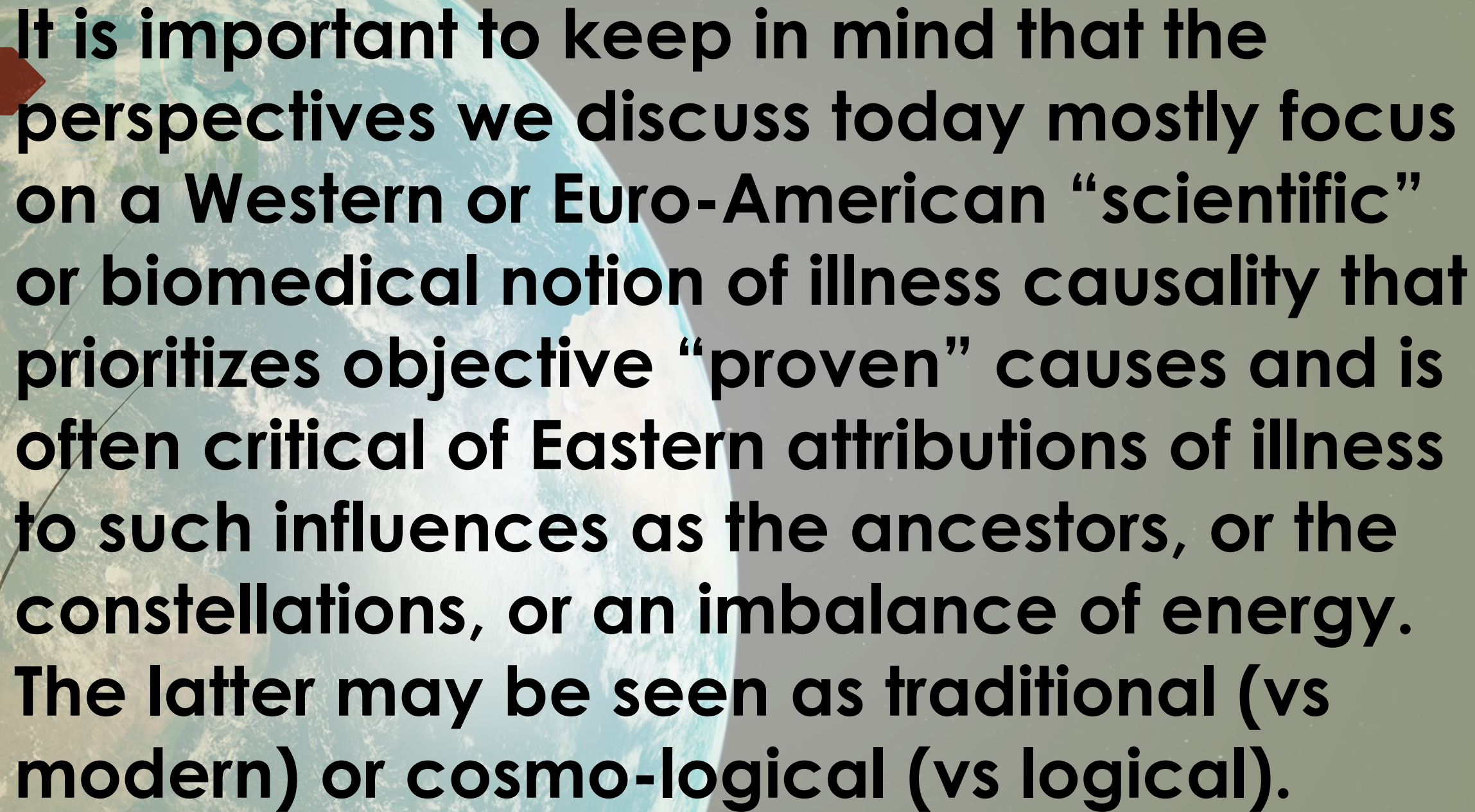
➔ **Preschoolers:** During a given child’s development, as well as from ancient to modern times, illness is at first viewed as due **mostly to external “irrelevant” causes**. (e.g., people get colds *from the sun* or *from trees*) and preschoolers may even suggest that illness is a **punishment for misdeeds**. They may see *all illnesses* as **contagious** (e.g., they catch a cold because *someone with a cold gets near them*).

Cognitive-developmental results continued....


- ➔ And then, starting at about **5 or 6 years of age**, children may still view illness as due to **external causes, but now, more “relevant” causes** (e.g., germs, contamination) with a rather **loose connection to internal effects** (e.g., “*You get a cold because bacteria gets in you by breathing and then your lungs get soft and it goes to your nose*”).

Cognitive-developmental results continued....

- ➔ **By late childhood or adolescence,** there is a deeper understanding of biological processes, and **internal biological/psychological causes** (e.g., genetics, brain differences, tension). **Multiple causes** of illness are now seen as possibly interacting *with one another.*



It is important to keep in mind that the perspectives we discuss today mostly focus on a Western or Euro-American “scientific” or biomedical notion of illness causality that prioritizes objective “proven” causes and is often critical of Eastern attributions of illness to such influences as the ancestors, or the constellations, or an imbalance of energy. The latter may be seen as traditional (vs modern) or cosmo-logical (vs logical).




But is also rather interesting to note that across **adulthood**, and even across **cultures**, both non-scientific **and** scientifically-proven sets of causes can co-exist or be accepted simultaneously with little sense of contradiction!

1.5 Cognitive level PLUS experience:


- **Studies have been conducted with children who themselves are physically ill, or whose siblings are ill, to determine whether or not they have a more advanced notion of *that* particular disorder than of other illnesses or of *that* disorder as compared to the ideas of healthy children.**
- **This literature is filled with contradictions.**



Some studies indicate that children show a **more advanced understanding of *their own illness*- such as **asthma or diabetes** (e.g., McQuaid et al., 2002).**

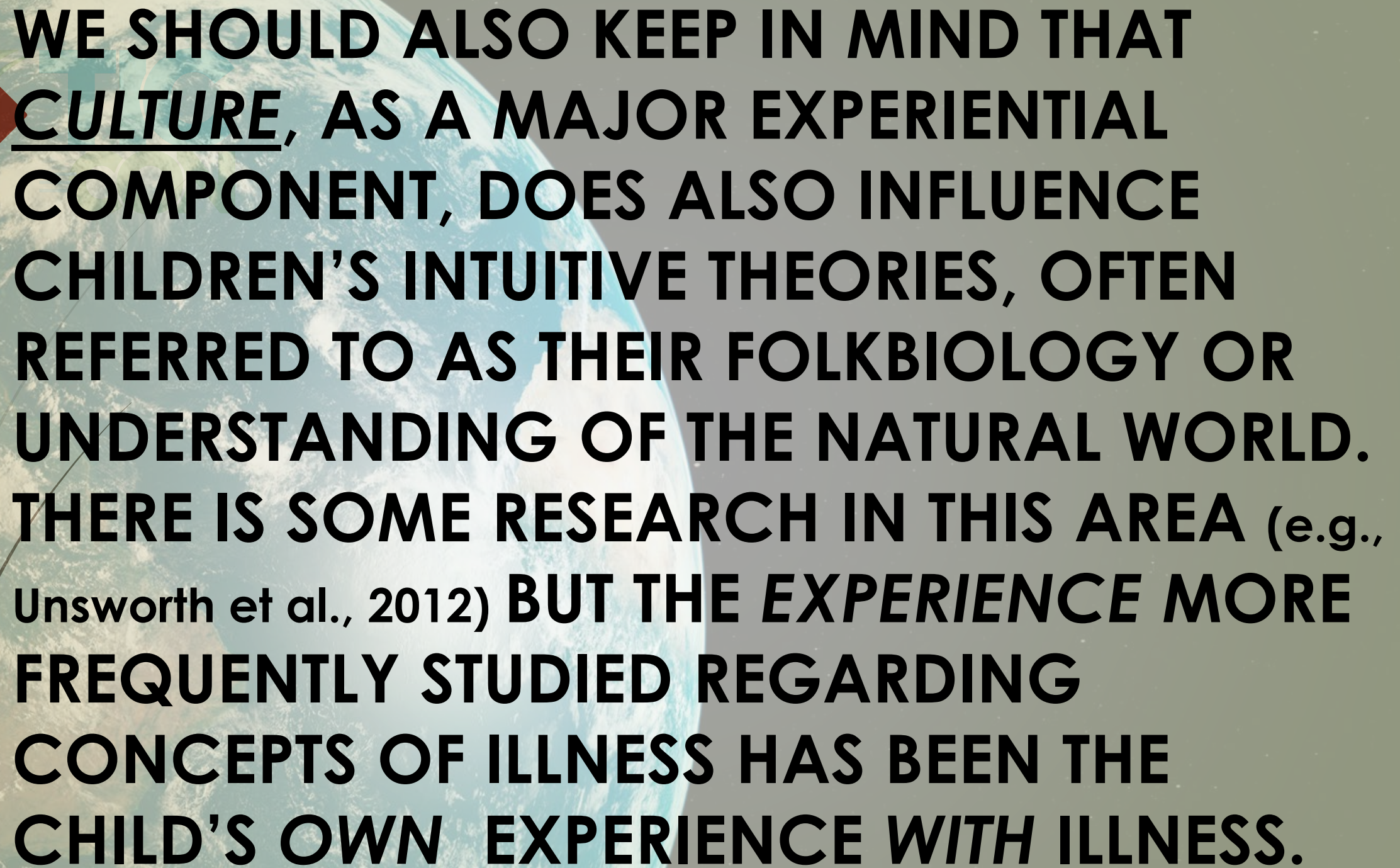
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- **Other studies indicate **NO** significant effects of personal experience,**
- **and still others find that the affected child (or sibling) has a *lower* than expected level of illness understanding in general, or of their illness in particular (Kao et al., 2011).**

We can talk about this more later if time allows.



Some researchers even consider the child's **experiences as the *only* basis** for conceptions of illness. They argue that there is **NO NEED** to even call upon **cognitive development or maturation** (e.g., McIntosh et al., 2012).


EXPERIENCE ONLY



WE SHOULD ALSO KEEP IN MIND THAT CULTURE, AS A MAJOR EXPERIENTIAL COMPONENT, DOES ALSO INFLUENCE CHILDREN'S INTUITIVE THEORIES, OFTEN REFERRED TO AS THEIR FOLKBIOLOGY OR UNDERSTANDING OF THE NATURAL WORLD. THERE IS SOME RESEARCH IN THIS AREA (e.g., Unsworth et al., 2012) BUT THE *EXPERIENCE* MORE FREQUENTLY STUDIED REGARDING CONCEPTS OF ILLNESS HAS BEEN THE CHILD'S OWN *EXPERIENCE WITH* ILLNESS.


2. THE THEORY-THEORY PERSPECTIVE

- *Some* theory-theorists think children are **born with an *innate* theory of all things biological**. Innate notions of illness, germs, contamination, and distinctions between mind and body are part and parcel of this research (e.g., Atran, 1995).
- But *others* think that the **biological domain emerges a little later- at around 4 years of age** (e.g., Keil et al., 1999).
- *And still others* think **biological explanations emerge even later** and that a **psychological domain** or way of explaining things (e.g., mean/angry germs, illness as punishment) **emerges first** (e.g., Carey, 1995).


The logo for TIC (The Institute for Child Development) is located in the top left corner. It features a stylized human figure in green and blue, with the letters 'TIC' in a large, light blue font. Below 'TIC' is the word 'CON' in a smaller, green font. A red arrow points to the right from the left edge of the slide, partially overlapping the TIC logo.

However, they ALL agree that preschoolers and early school-aged children are MUCH MORE COMPETENT than the Piagetian-based cognitive-developmental research would indicate!





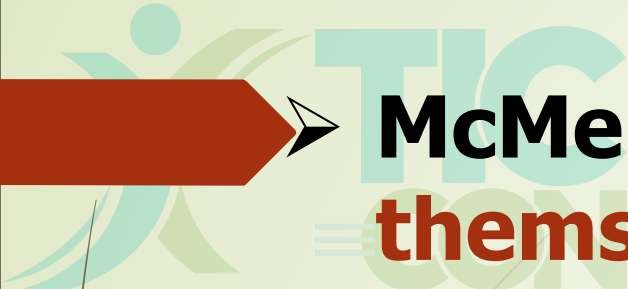
**And now, most theory-theorists suggest:
an early theory of biology may actually
exist next to (rather than deriving *from*)
a theory of psychology and that even
preschoolers DO possess abstract ideas
about biological kinds that can be
separated from psychological kinds.**



So possibly, when it comes to “psychological” or behavioral disorders like Tourette’s, *it may be that children, especially those who have some experience with such disorders, *can* arrive at an earlier biological/brain-based causal understanding than we had thought.*




**Let's consider 2 studies
conducted in 2000 and
2008 by McMenamy
about ADHD that may
prove relevant to us...**

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- **McMenamy (2000) studied children who were themselves diagnosed with ADHD.**
 - **She presented vignettes describing a child with a cold, or with ADHD, or with bully-type aggressive behaviors.**
 - **The respondents (who were 7 to 8 and 11 to 12-year-olds) used biological principles to explain the causes and treatments for colds, and they used psychological principles of an intentional sort as relevant to aggressive bullies. However,**




... THE RESULTS REGARDING “FAMILIAR” ADHD WERE MORE COMPLEX

- Some **7 to 8-year-olds *with ADHD*** saw the cause of ADHD as a **psychological function of childhood events**, while **others mentioned biological causes and treatments.**
- But the **11 to 12-year-olds integrated both the biological and psychological principles into their explanations of ADHD, with a focus on the biological.**



In her 2nd study (2008) of children with *and* without ADHD, the younger children *without* ADHD demonstrated a belief that children with ADHD had control over and chose to exhibit their symptoms.

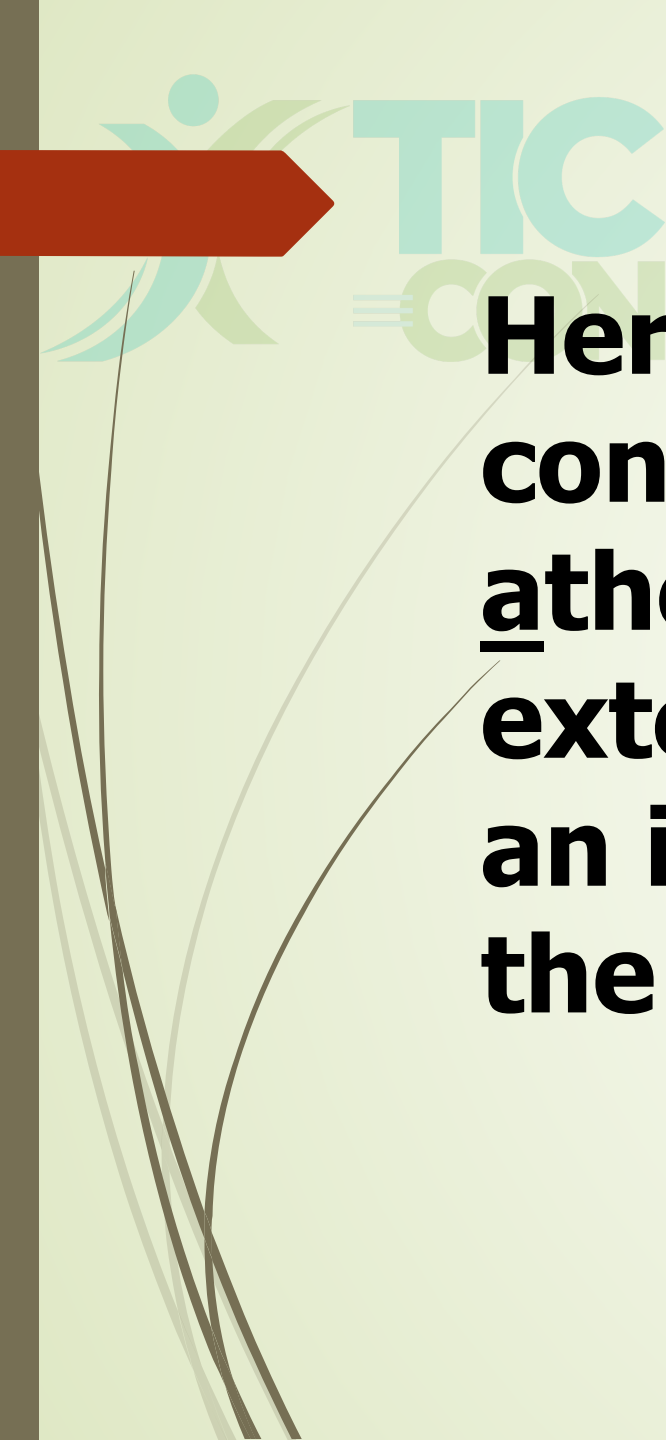
It seems important then that we try to help neuro-typical children know that the neuro-atypical child is not *choosing* to act the way they sometimes do.




This would of course assume that the biological domain IS THERE... *along with* the psychological domain early in a child's life. There likely needs to be more research about this.

3. And now, the **ATHEORETICAL** studies

- **This is group of studies (e.g., Hennessy & Heary, 2008) that have no guiding theory such as Piaget's, or theory-theory that we've discussed.**
- **And they are somewhat *non*-developmental.**
- **But they *did* attempt, as far back as the 1970's, to assess children's understanding and acceptance of various types of "mental" illness (e.g., depression), or behavioral disorders (e.g., conduct disorder or ADHD).**




Here too, there seems to be some contradiction in the results of the atheoretical studies as to **when external causes, internal causes, or an integration of both are used in the children's explanations.**



➤ Let me focus on just the **atheoretical studies about ADHD** and their overlap with the finding of the McMenemy studies that I mentioned earlier as I think this is relevant to our interest in TS.

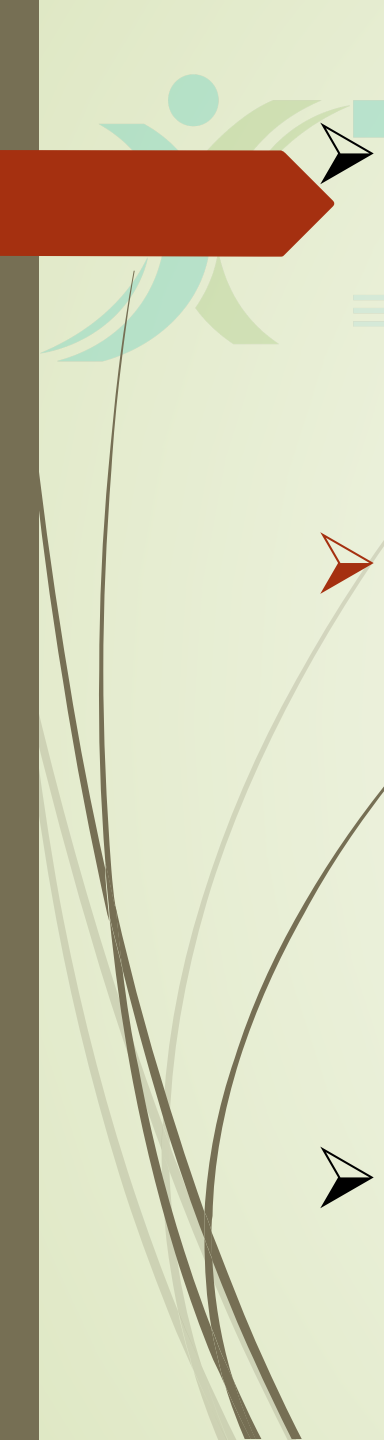
➤ **CHILDREN WITH ADHD, EVEN YOUNG CHILDREN, ATTRIBUTED THEIR ILLNESS TO BIOLOGICAL, PHYSIOLOGICAL, OR CONGENITAL CAUSES AND SAW IT AS PRIMARILY BROUGHT UNDER CONTROL BY MEDICATIONS.**

- But when **healthy children** were asked about the causes of psychological or behavioral disorders, they pointed to **social/environmental factors** such as imitating one's peers or inappropriate parenting. The **healthy children *only*** pointed to **congenital factors** when explaining *physical* ailments.




➤ **SO OVERALL, WE MAY BE SEEING THAT HEALTHY YOUNG CHILDREN THINK THAT BEHAVIORAL DISORDERS OR MENTAL ILLNESS ARE THE RESULT OF PSYCHOLOGICAL/ ENVIRONMENTAL CAUSES LIKE “DOING IT TO BE COOL”, OR IMITATING OTHERS, OR BAD PARENTING/OR TRAUMA OF A PSYCHOLOGICAL OR PHYSICAL KIND.**

➤ **BUT CHILDREN *WITH* THE BEHAVIORAL DISORDER OR OLDER HEALTHY CHILDREN CAN POINT TO BIOLOGICAL CAUSES AS WELL (BIRTH COMPLICATIONS, GENETICS, ETC.).**

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- **This might be a good time to mention a lovely little study I did with a student (Paulina Janovsky) that we did not publish but which corroborates this last slide.**
 - **3rd graders with TS** were more similar to healthy college students in their explanations of disorders such as TS, OCD and ADHD than to 3rd graders without TS. That is, their explanations were often **biologically-based and allowed for multiple causes.**
 - **And none** of the children with TS **used contagion** as an explanation for the behavioral disorders.

What do we know based on SIBLING STUDIES, (mostly regarding Autism understanding)?

- ➔ **Maybe the findings can be generalized to Tourette's families as well.**
- ➔ **Only a small amount of this literature is about siblings' knowledge about Autism. More of it is about children's attitudes towards their diagnosed sibling.**
- ➔ **Glasberg (2000) concluded that concepts regarding "illnesses" such as Autism may be acquired by healthy siblings at a slower rate than other illnesses because they are "more abstract" and "more difficult to grasp".**




➤ **BUT** siblings between 8 and 15 years of age **DID benefit** from interventions about the causes of Autism. According to Roeyers & Mycke (1995), the knowledge “that autism is an organic and not a psychogenic disorder, in particular, was **related to a positive sibling relationship**”.

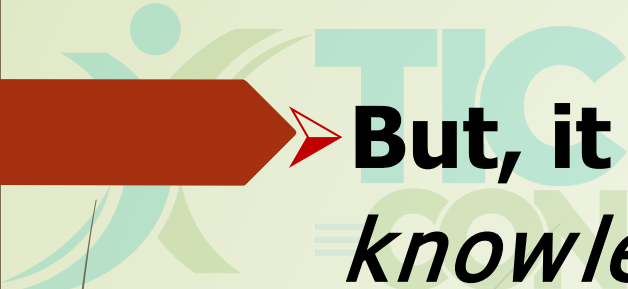
➤ **The accuracy of siblings’ understanding of Autism has also increased following their participation in **Autism sibling support groups** (e.g., Evans et al., 2001).**

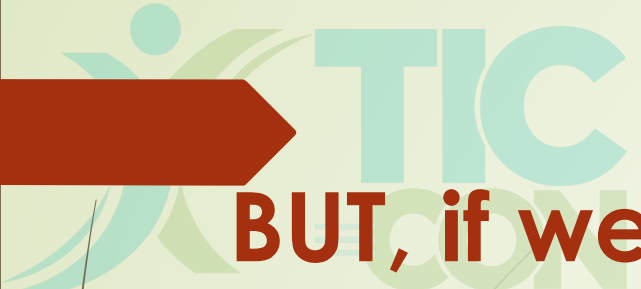
PEER intervention studies about TS (e.g., Woods, 2002)

- **Students from 3rd, 5th, 8th grade and even college undergraduates, have been exposed to same-aged videotaped **actors with motor tics, and/or vocal tics,** from mild to severe, or to a compulsion known as trichotillomania.**
- **Info of different types is then shared with the children.**

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- **The effects of these educational interventions have yielded somewhat mixed results but do suggest that **even very brief presentations of information about TS can bring about some positive changes in the attitudes of children and adolescents.****
 - **One of the effective interventions even I, along with 2 of my students* have used to increase the TS knowledge of 3rd graders and improve their attitudes about a *hypothetical* peer with TS has been the reading of a relevant storybook.**

***Paulina Janovsky and Brooke Jacobs**

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- The logo for TIC (The Institute for Community Inclusion) is located in the top left corner. It features a stylized human figure in green and blue, with the letters 'TIC' in a large, light blue font. Below the figure, the word 'community' is written in a smaller, light green font.
- But, it is **not yet clear whether** an increase in *knowledge or understanding* **IS** the mediating variable that affects changes in attitude towards someone with the disorder.
 - Or whether changes in *actual* behavioral interaction with a **REAL** peer with TS will result from such brief interventions.
 - More research is clearly needed.



BUT, if we can somehow *scaffold* interventions to increase children's understanding of the brain-based causes of TS, my hope (again) is:

- **The diagnosed child may then be more amenable to treatment, able to educate others, and to better advocate for themselves.**
- **And highly informed siblings and peers may be more positive in their attitudes and interactions with a child diagnosed with TS.**

Future plans:

- You may recall that I mentioned stopping work on a book on this topic in 2016 at the time of my son's death.
- I have therefore not kept up as much with research being conducted in this area so it may be that some of the answers to the contradictions and questions I've raised *have* been resolved.
- But I now plan to resume my work in this area and may even take yet another sabbatical before I finally retire which would afford me the time to catch up.
- I am excited though by small snippets I am reading already. For example, here is something that may surprise you as much as it surprised me recently....

Goldie Hawn's Mind-UP curriculum

This seems rather relevant!

- ➔ In her concern about depression and anxiety and even suicide among children (and this was 20+ years ago), Goldie Hawn, along with educators and neuroscientists, developed a K-8th grade curriculum.
- ➔ Based on the notion that providing the child with an **understanding of the structure of the brain and how it functions** can give them a sense of control & empowerment.
- ➔ If it is so effective in this regard, ***could teaching about the brain also be effective for explaining the causes of neuropsychological disorders like TS?***

I plan to pursue!

And *another* hopeful example of scaffolding:

- The work of Gripshover and Markman (2013) may be relevant.
- They were able to increase the healthy eating behaviors of preschoolers by building on the gaps in 4- to 5-year-olds' own intuitive theories of nutrition and allowing the children to comprehend a newer slightly more accurate theory of nutrition that was taught to them in an "intuitive-theory intervention".
- The authors stated, *"We believe it is premature to discount children's ability to learn such concepts **if educational materials are tailored to children's developing theories and address gaps or misconceptions** that may constitute obstacles to understanding the new concepts."* (p. 1541)
- *"...our results suggest that young children **can acquire** a complex and abstract set of concepts when the concepts are **presented in a way that respects, utilizes, and helps children** revise their [own] developing theories."* (p. 1551)

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**For an extensive reference list,
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Thank you for your attention.

Any comments?

