



**DEVELOPMENT OF A  
CHILD'S  
UNDERSTANDING OF  
WHAT CAUSES  
"MENTAL" DISORDERS**



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**PPA Annual Conference**  
**June 16<sup>th</sup>, 2026**



ACURA 2014

## Children's Concepts of Physical and Neurobehavioral Illness Causality: How do all the pieces fit?

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In our attempt to complete the puzzle of how and when the typical child understands what causes them to get sick, we updated our review of the research. [See handout with more than 200 references.]

Our journey mimics the child's journey of discovery and possibly even the history of medical science.

We initially assumed that the whole picture would simply and magically reveal itself to us without much (logical) effort. Then we focused on specific articles or puzzle pieces and lost sight of the larger more complicated picture. But now we are trying to integrate the multiple pieces. We even allow for the possibility that pieces which do not appear to fit together (e.g., the religious view of illness causality and the scientific view) may actually coexist without much disruption of the puzzle's solution.

This is a complex puzzle but well worth exploring as there are numerous practical applications:

- Increasing children's health promotion/illness prevention behaviors;
- Increasing self advocacy, self esteem and treatment compliance for the ill child;
- Increasing empathy for and acceptance of persons who are ill;
- Specifying developmentally-appropriate explanations to be provided by pediatricians, nurses, social workers, parents, & teachers.

We hope to bring you along on our journey meaning-making.

We will integrate 10 major "dichotomies" in the research rather than choosing one side or the other as a solution to our puzzle of how children think illness happens.

### 1. COGNITIVE DEVELOPMENTAL VS. INTUITIVE THEORIES

There has been a long standing controversy between the general domain or Piagetian perspective & the specific domain perspective. Does the child of a given age/stage view illness in the way they view the world in general or does the young child have a rudimentary framework of biology and/or psychology and then use specific experiences to fill in the details for that domain? The controversy is sometimes seen as a focus on level of reasoning vs. accuracy of the response. We see value in both perspectives in that the actual effects of experience with illness seem constrained by the child's current level of illness understanding (e.g., Crisp et al., 1996).

### 2. BIOLOGICAL VS. PSYCHOLOGICAL CAUSES OF ILLNESS

The controversy here is often between "internal" causes of illness like *germs getting in the body* and "external" causes like *bad parenting*. While young children often focus on one or the other, children with the illness itself, and/or older children (e.g., McMenamy, 2000) recognize that there are multiple causes, that both cause and effect can be internal events, and they tend to integrate biological and psychological causes.

### 3. PHYSICAL VS. MENTAL (NEUROBEHAVIORAL) ILLNESSES

Early research focused on physical ailments such as colds or AIDS (e.g., Bilbace & Walsh, 1980; 1981), thus themes of contagion and contamination were prominent. As we move into the early part of the 21<sup>st</sup> century, inquiries about causes of disorders such as ADHD and now Autism are prevalent. Mental "invisible" disorders" often receive more negative social attributions as they are likely to be viewed as being under the person's control. We would want to see more research in which the same children are asked about their concepts of both physical and mental/neurobehavioral illnesses.

### 4. CHILD VS. ADULT VIEWS OF ILLNESS

The vast majority of the literature focuses on children's illness concepts and may even include adolescents in the sample. The assumption is that adults have reached the highest (scientific) explanations of illness but we would like to see more research about adult's conceptions as well as studies in which the child and parent(s) are both included to explore connections between illness communications and illness concepts.

### 5. EURO-AMERICAN VS. ETHNIC MINORITY CONCEPTIONS

Recent research has included children (and adults) from various parts of the world living here or abroad with differing cultural and religious beliefs that may influence concepts of illness causality as well as treatment decisions. For example, having a child with autism can be viewed as retribution for past sins that brings shame or as a blessing from Allah and an honor to be chosen (e.g., Jagatheesan et al., 2010).

Euro-American adults may consider these to be magical or immature views but what surprised us was the possible coexistence of supernaturalist nonscientific views and Western scientific views of illness or death being held by the same individuals who were aware of but not bothered by the implied contradiction (e.g., Ravindran & Myers,

### 6. TO TELL THE CHILD VS. NOT TO TELL

There are questions about whether or not to tell and how to tell a child about their own or a family member's illness. The recent "disclosure" research seems to be mostly about autism, parental cancer, and even about genetic disorders that may lead to reproductive risks for the child. We do not see this as an either-or issue but rather that the child/sibling should be told facts about the illness, possibly with the assistance of appropriate children's storybooks, but told slowly in a soft tell scarfrotted approach.

### 7. KNOWLEDGE OF ILLNESS VS. ACCEPTANCE OF ILL PERSON

The assumption in much of the intervention/inclusion research is that if children "know" more about illness causality, they will be more willing to interact with hypothetical or real persons with the illness. Some research supports this carryover effect (Campbell et al., 2004, 2005; Morton & Campbell, 2007; Woods, 2002) but it is not yet clear that the effects are long-lasting (e.g., Pinfold et al., 2003) or translate to actual behavior changes with a real peer vs. a video actor who manifests disorders such as Autism, Tourette's, or OCD. Some intervention research finds no effect (Friedrich et al., 1996; Swaim & Morgan, 2001; Treiber et al., 1986) or finds that such increases in illness knowledge may even make the ill person less attractive (e.g., Potter & Roberts, 1984). We would want to see a more multifaceted approach to intervention (e.g., Lindsay & Edwards, 2013) to determine if, how, and when cognitive and affective pieces fit together.

### 8. CROSS-SECTIONAL VS. LONGITUDINAL RESEARCH

To our surprise, every study that included more than one age group has been cross-sectional in design. No studies have followed the same children over time (i.e., longitudinal). To the extent that there are possible cohort influences on illness concepts (e.g., types of health education in schools) and possible time of measurement influences (consider how the "accepted" causes have changed for autism, or AIDS, depression, or epilepsy), we would hope to see a study that combines approaches (i.e., uses sequential research designs).

### 9. QUANTITATIVE VS. QUALITATIVE RESEARCH

Results have been obtained using in-depth interviews, draw-and-write techniques, structured illness concept assessments, on-line surveys, and even forced-choice answers. Researchers speak about not wanting to underestimate or overestimate children's knowledge. We'd like to see research in which a combination of assessments would be used with the same sample (Raman & Gelman, 2005)) and obtain a fuller picture rather than just one (rote) corner piece of the puzzle.

### 10. EARLY RESEARCH VS. LATER RESEARCH

Now you have a sense of where the research on children's illness concepts has taken us over all these decades with a recent focus on autism, inherited disorders, parental cancer, and non Euro-American views. There are many consistent pieces across the years but the recent inclusion of other ethnicities allows us to consider the coexistence of nonscientific and scientific explanations being held simultaneously.

### LOOKING FORWARD

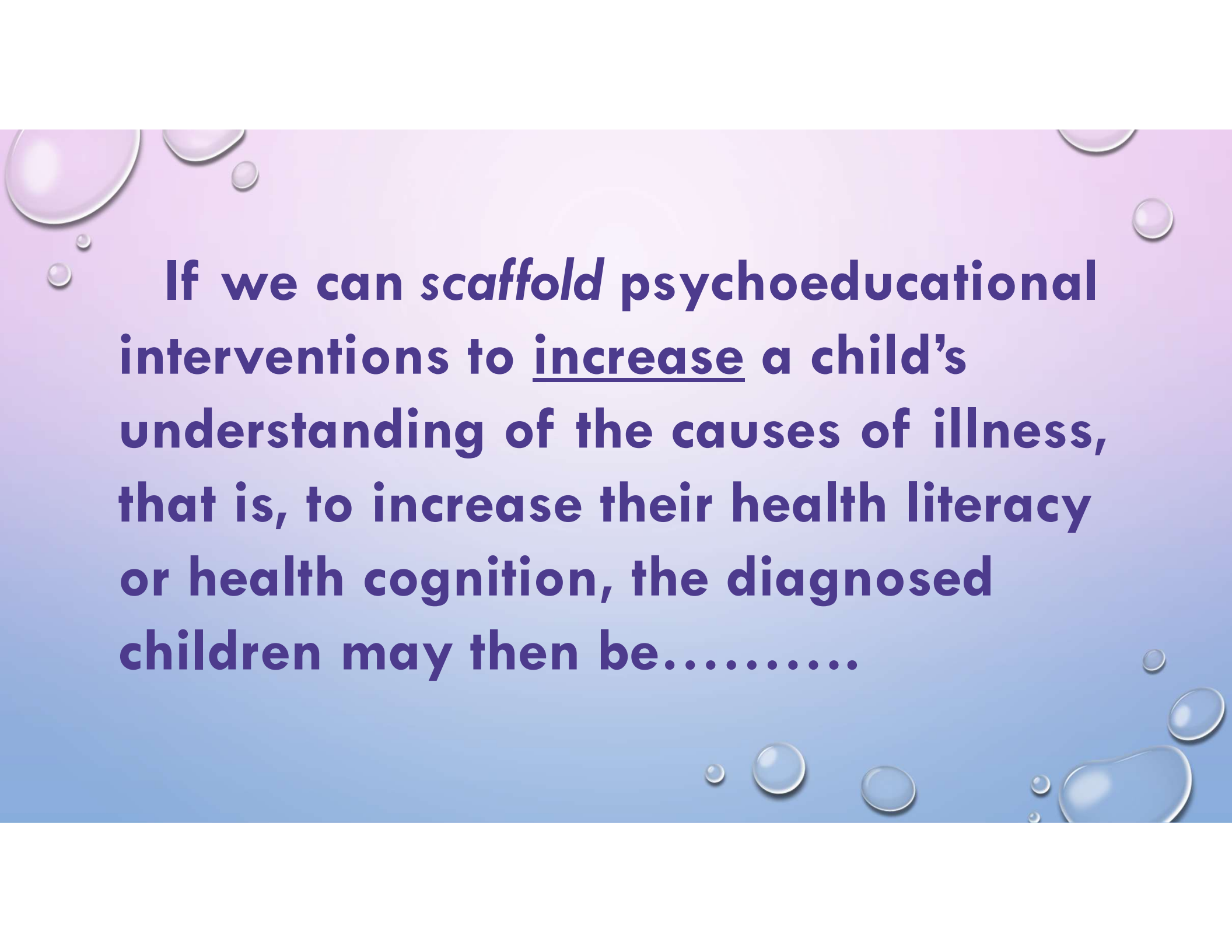
As the "solution" continues to unfold, we look forward to creative research that continues to elucidate the complex puzzle of children's concepts of illness. We now assume that rather than there being 4 sharp-edged (either-or) corners, there may be a softer solution with interchangeable pieces as cognitions may be contextualized and not absolute. The search continues for the best, if not perfect, fit.

# OVERVIEW

- THIS IS A BRIEF REVIEW OF RESEARCH ON CHILDREN'S CONCEPTS OF WHAT CAUSES ILLNESSES, BOTH PHYSICAL AND “PSYCHOLOGICAL” (“mental”; neurodevelopmental).
- THIS GENERAL REVIEW MAY HELP IN THE FORMULATION OF “DEVELOPMENTALLY-APPROPRIATE” EXPLANATIONS FOR DIAGNOSED CHILDREN, THEIR SIBLINGS, AND THEIR PEERS... [OR FOR THE CHILD OF A DIAGNOSED ADULT FAMILY MEMBER].

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**WHY IS THIS IMPORTANT?**



**If we can *scaffold* psychoeducational interventions to increase a child's understanding of the causes of illness, that is, to increase their health literacy or health cognition, the diagnosed children may then be.....**

- 
- **more amenable to treatment,**
  - **able to educate others and/or better able to advocate for themselves.**
  - **Informed siblings and peers may be more positive in their attitudes and interactions with the diagnosed child.**

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**OTHERWISE, CHILDREN (AND EVEN PARENTS) MAY FILL IN THE BLANKS WITH INACCURACIES OR MEDICAL MYTHS AS THEY TRY TO MAKE SENSE OF THEIR WORLD AFTER A DIAGNOSIS.**

# **PRESCHOOLER IN NEW ZEALAND EXPLAINING ASTHMA**

**NATALIA - 4 YEARS OLD**

**“BECAUSE IF YOU EAT TOO MUCH ICE-CREAM OR  
STUFF YOU GET ASTHMA. I GOT ASTHMA BECAUSE I  
COUGH ALL THE TIME AND I’M SICK CUZ THE BUGS  
KEEP ON KICKING MY THROAT.”**

**MCINTOSH, C., STEPHENS, C. & LYONS, A. (2012; 2013)**

## **FIRST, AN APOLOGY... AND AN EXPLANATION**

- **THIS LITERATURE REVIEW IS MOSTLY OF STUDIES THAT WERE CONDUCTED UP TO ABOUT 2016.**
- **LET ME EXPLAIN...SABBATICAL 2016....**
- **I WAS ON SABBATICAL AGAIN IN FALL 2025 TO CATCH UP ON THE LITERATURE. A FEW OF THOSE NEWER STUDIES ARE INCLUDED HERE. SOME DIFFERENCES FROM THE PAST ARE NOTABLE.**

## OUTLINE OF THE PRESENTATION

- **DIFFERENT “THEORIES” GUIDING THE RESEARCH**
- **QUICK REVIEW OF RESULTS OF THE RESEARCH STUDIES**
- **PARALLELS WITH THE WAY MEDICAL SCHOLARS HAVE COME TO UNDERSTAND ILLNESS OVER THE CENTURIES**
- **NEWER RESEARCH FINDINGS** (especially regarding psychological and behavioral disorders. I may end here but if time allows then....)
- **SIBLING INTERVENTIONS**
- **PEER INTERVENTIONS**
- **CHILDREN’S STORYBOOKS ABOUT ILLNESS**

# **CHILDREN'S CONCEPTS OF ILLNESS**

## **PIAGETIAN COGNITIVE-DEVELOPMENTAL PERSPECTIVE**

**BIBACE AND WALSH (1980, 1981) ARE TYPICAL OF STUDIES CONDUCTED IN THE LATE 1970'S AND EARLY 1980'S THAT VIEWED ILLNESS CONCEPTS TO BE A FUNCTION OF THE “*DOMAIN-GENERAL*” COGNITIVE LEVEL FROM WHICH A CHILD VIEWED HIS OR HER WORLD.**

**THEY SUGGESTED 3 LEVELS OR STAGES OF UNDERSTANDING..**

# CONCEPTS OF ILLNESS

## I. Prelogical explanations (PO)

Phenomenism

Contagion

## II. Concrete-logical explanations (CO)

Contamination

Internalization

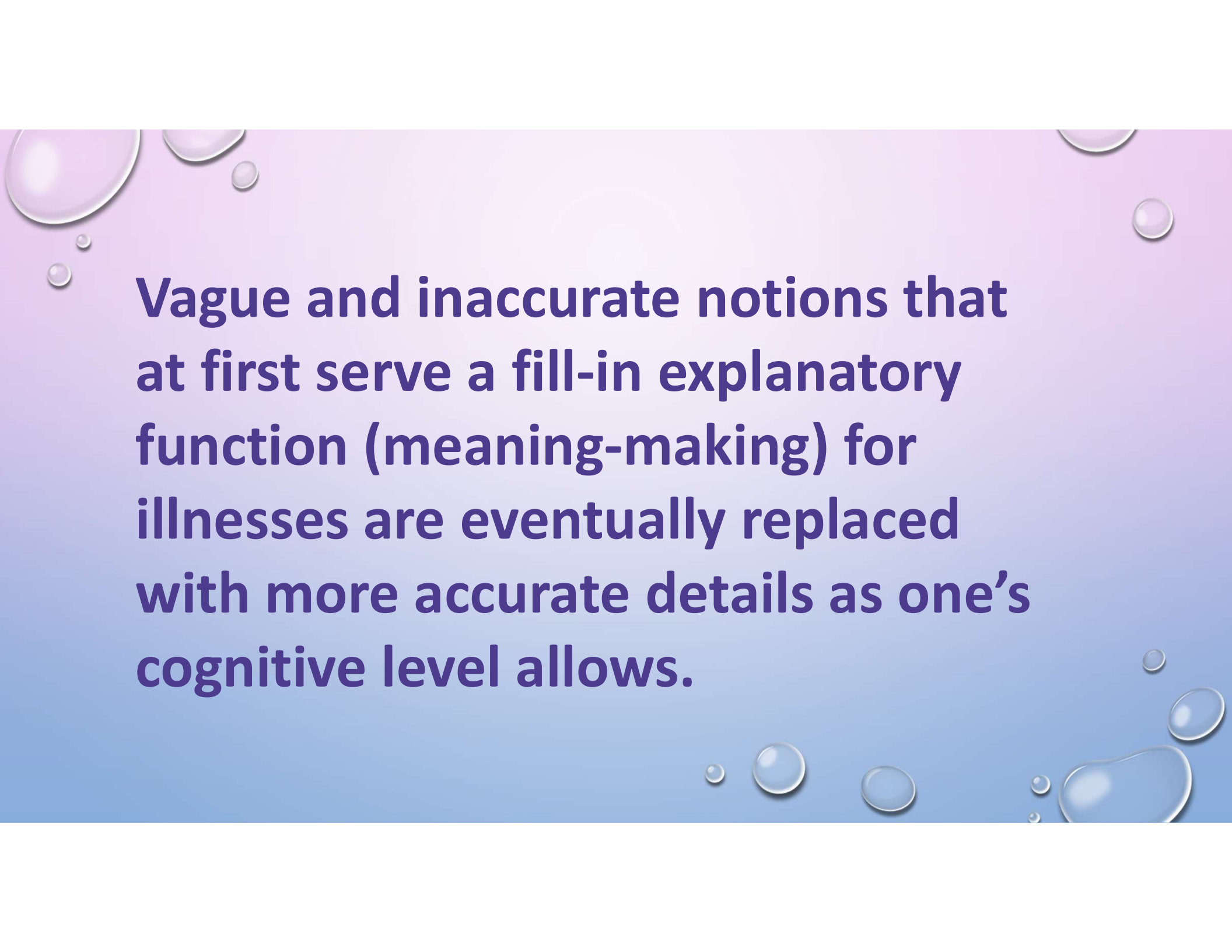
## III. Formal-logical explanations (FO)

Physiological

Psychophysiological



From: Bibace, R. & Walsh, M. E. (1981). Children's conceptions of illness.  
In R. Bibace and M. E. Walsh (eds.), *Children's Conceptions of Health,  
Illness, and Bodily Functions*. New Directions for Child Development  
Series. San Francisco: Jossey-Bass, pp. 31-48.



**Vague and inaccurate notions that at first serve a fill-in explanatory function (meaning-making) for illnesses are eventually replaced with more accurate details as one's cognitive level allows.**

# 1. PRELOGICAL STAGE

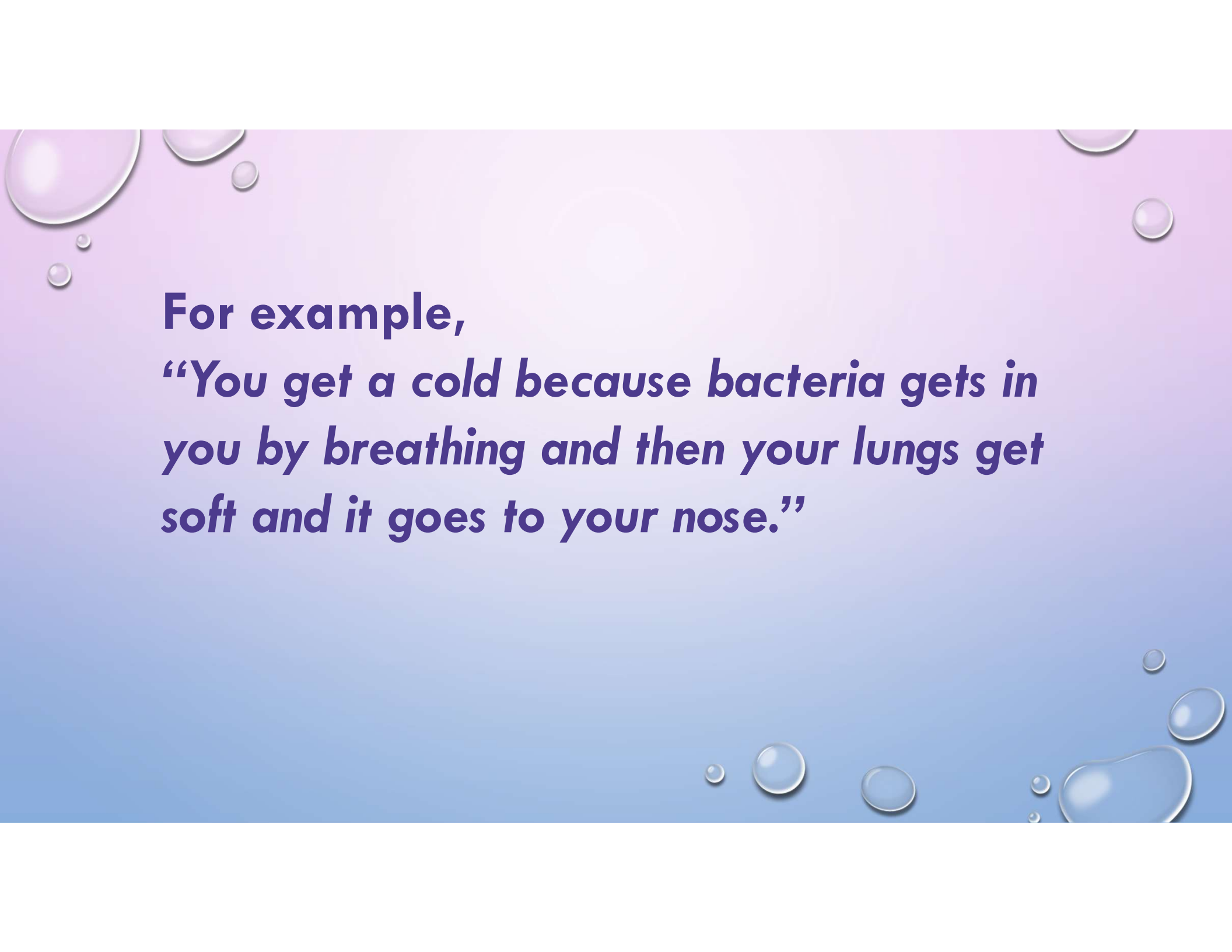
**PRESCHOOLERS VIEW THE CAUSE OF ILLNESS:**

- **AS AN EXTERNAL CONCRETE PHENOMENON WHICH MAY CO-OCCUR WITH THE ILLNESS;**
- **BUT WHICH IS SPATIALLY AND/OR TEMPORALLY REMOTE;**
- **AND THERE IS NO CLEAR DIFFERENTIATION BETWEEN CAUSE AND EFFECT.**
- **FOR EXAMPLE, “IT WAS RAINING AND I GOT A COLD” OR “I CATCHED A COLD ‘CUZ SOMEONE GOT NEAR ME.”**

## 2. CONCRETE LOGICAL

### SCHOOL-AGED CHILDREN

- **DISTINGUISH BETWEEN THE CAUSE OF ILLNESS AND THE MANNER IN WHICH THE CAUSE IS EFFECTIVE;**
- **THEY SPEAK OF A *SEQUENCE* OF EVENTS;**
- **AND MAY INVOKE *GERM* THEORY BUT**
- **SUCH NOTIONS ARE OFTEN OVERGENERALIZED TO ALL DISEASES.**



**For example,**

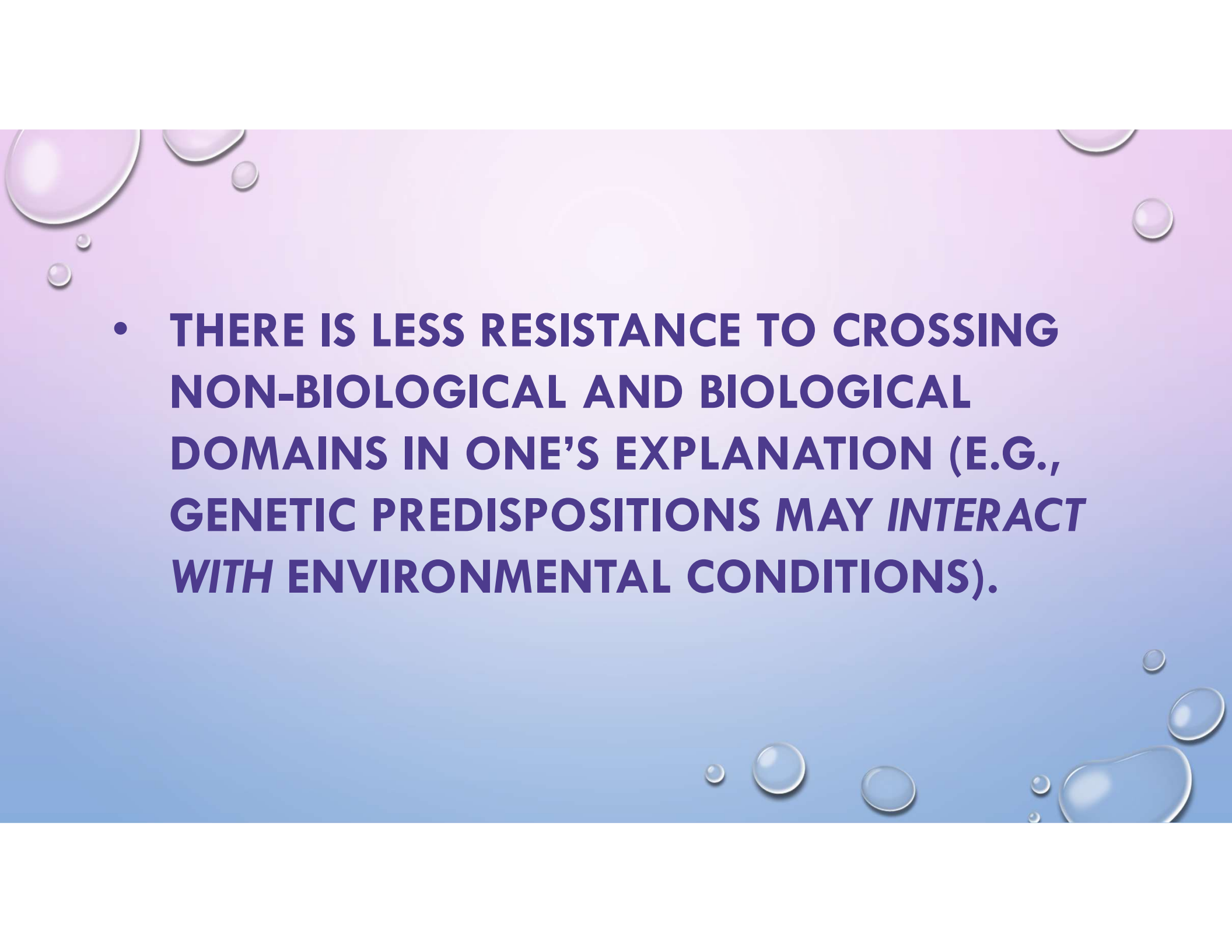
***“You get a cold because bacteria gets in you by breathing and then your lungs get soft and it goes to your nose.”***

### **3. FORMAL LOGICAL**

**BY ADOLESCENCE,**

- **THE SOURCES AS WELL AS THE NATURE OF ILLNESS ARE SEEN TO LIE IN SPECIFIC INTERNAL “PHYSIOLOGICAL” STRUCTURES AND FUNCTIONS,**
- **EVEN IF TRIGGERED BY EXTERNAL EVENTS.**

- *For example, “Colds come from viruses that someone has and it gets into your bloodstream and causes the cold symptoms.”*
- **OLDER CHILDREN AND ADOLESCENTS NOW RECOGNIZE THAT THERE ARE MULTIPLE CAUSES OF ILLNESS THAT INTERACT WITH ONE ANOTHER AND THE CAUSES MAY EVEN BE INTERNAL.**

- 
- **THERE IS LESS RESISTANCE TO CROSSING NON-BIOLOGICAL AND BIOLOGICAL DOMAINS IN ONE'S EXPLANATION (E.G., GENETIC PREDISPOSITIONS *MAY INTERACT WITH* ENVIRONMENTAL CONDITIONS).**

MOVING  
ON...

# CHILDREN'S CONCEPTS OF ILLNESS

## EXPERIENCE-WITH-ILLNESS

### OR THE *FUNCTIONALIST* PERSPECTIVE

- SOME STUDIES INDICATE THAT CHILDREN SHOW A MORE ADVANCED UNDERSTANDING OF THEIR OWN ILLNESS, SUCH AS ASTHMA OR DIABETES.
- SOME, HOWEVER, INDICATE NO SIGNIFICANT EFFECTS OF PERSONAL EXPERIENCE,
- AND SOME EVEN FIND THAT THE AFFECTED CHILD OR SIBLING HAS A LOWER THAN EXPECTED LEVEL OF UNDERSTANDING OF ILLNESS IN GENERAL OR OF *THEIR* ILLNESS IN PARTICULAR.

# CHILDREN'S CONCEPTS OF ILLNESS

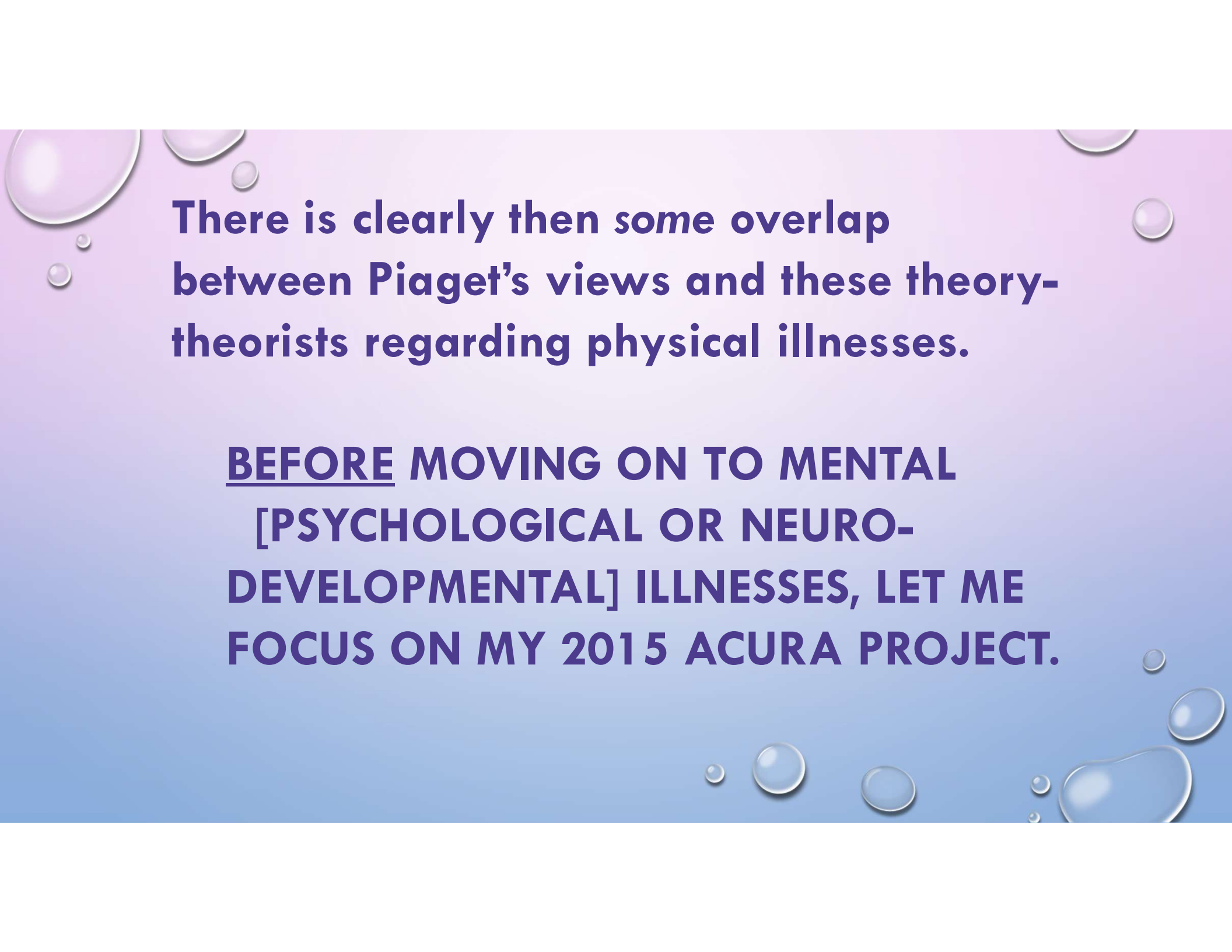
## THEORY-THEORY PERSPECTIVE

AND...

- THESE FOLKS VIEW VERY YOUNG CHILDREN AS HOLDING VARIOUS DOMAIN-SPECIFIC THEORIES ABOUT THEIR WORLD.
- THERE ARE THE MODULARITY THEORISTS (E.G., ATRAN, 1995) WHO ARGUE THAT THERE ARE INNATE NOTIONS OF BIOLOGICAL OR LIVING KINDS THAT THE CHILD FROM BIRTH SIMPLY APPLIES TO THE WORLD AROUND THEM.

Then there are EARLY-EMERGING theorists like Susan Gelman and Frank Keil who suggest that preschoolers construct an intuitive theory of biology by about 4 years of age based on early principles that come face to face with the world of evidence that children are trying to sort out.

And there are the LATE-EMERGING theorists like Susan Carey who argue that preschoolers cannot yet use a true biological causality because their biological reasoning arises *first* from what she calls a naïve *psychology*.



**There is clearly then some overlap  
between Piaget's views and these theory-  
theorists regarding physical illnesses.**

**BEFORE MOVING ON TO MENTAL  
[PSYCHOLOGICAL OR NEURO-  
DEVELOPMENTAL] ILLNESSES, LET ME  
FOCUS ON MY 2015 ACURA PROJECT.**



MY FASCINATION WITH.....

Ernst Haeckel's Biogenetic Law

**ONTOGENY RECAPITULATES PHYLOGENY**

which implied that

**INDIVIDUAL DEVELOPMENT**

**RECAPITULATES OR PARALLELS THE**

**DEVELOPMENT OF THE SPECIES**



**“PIAGET IS ALSO FOND OF DRAWING PARALLELS BETWEEN THE  
CHILD’S ACQUISITION OF LOGICO-MATHEMATICAL KNOWLEDGE  
AND THE HISTORY OF WESTERN SCIENCE.”**

**(GOULD, 1977, P.145)**

**ACURA  
2015**

**GOULD, S. J. (1977). *ONTOGENY AND PHYLOGENY*. CAMBRIDGE, MA: THE  
BELKNAP PRESS OF HARVARD UNIVERSITY PRESS.**

**So a premed student and I decided to read some History of  
Medicine books and see if we could find some *parallels* with  
what I knew about the developing child’s concept of illness  
causality....and the history of medicine!**



# **Parallel discoveries of illness causality in history and in childhood**

**HERE ARE OUR PARALLELS...  
and then a cautionary note**

**2000 BC-500 BC/  
Preschooler (2-5 years)**

**Magical reasoning** about illness. Original “naïve” theories may begin with irrelevant, uncoordinated external notions that do not clearly connect the proposed cause to its effect. Non-biological causes include constellations, weather, moral weakness, or punishment. Biological causes hint at a life force or entity as the cause of disease such as a demon or contagion through proximity. There is resistance to crossing the non-biological and biological domains in one’s explanation.



**500 BC-1200 AD/  
Early School-Aged Child (6-8 yrs)**

**Sequential and more coordinated understanding** of cause and effect such that causes have to impact the body in some way. Notions of toxins, or of imbalances, or of contamination that involve direct contact are posited as causes. Such notions are often incorrectly overgeneralized to all diseases.



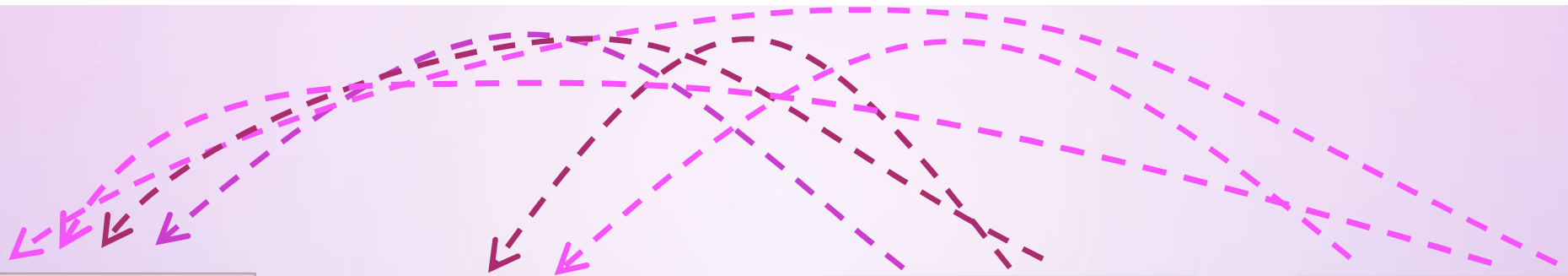
**1200's-1800's/  
Late School-Aged Child (9-12 yrs)**

More **detailed physiological understanding** of how causes are linked to internal effects (e.g., refer to germs, virus) and even begin to note that psychological states can influence physical outcomes. Less resistance to crossing biological and non- biological domains in one’s explanation.



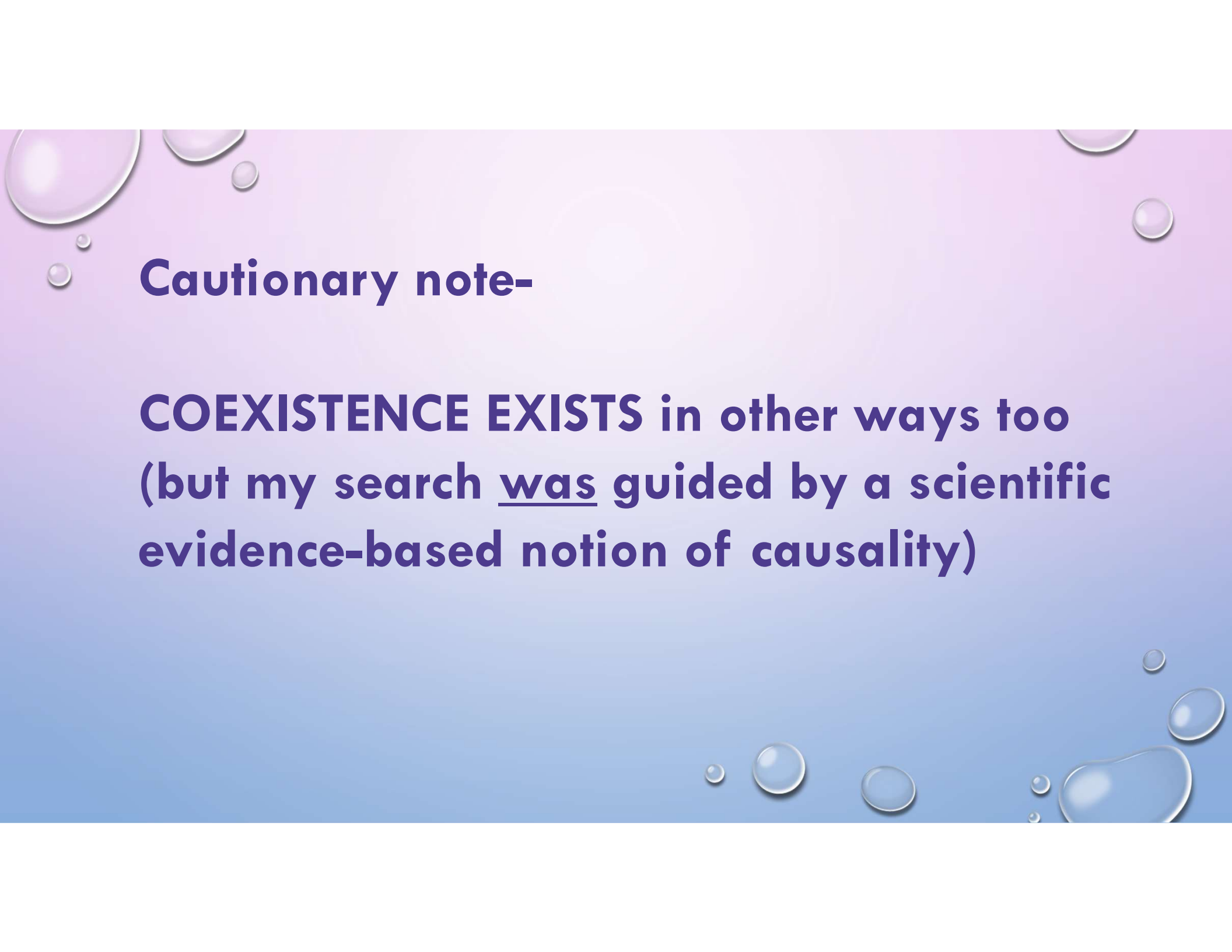
**1800's- present/  
Adolescence and Adulthood**

More nuanced **coherent psychophysiological understanding** that multiple causes may interact to affect an illness outcome. Genetic predispositions may interact with environmental conditions. All the causes of an illness may be internal as in autoimmune disorders.



**SO...MY FIRST REVIEW OF THE LITERATURE SHOWED THAT DURING A GIVEN CHILD'S DEVELOPMENT, AS WELL AS FROM ANCIENT TO MODERN TIMES, ILLNESS (i.e. physical illness) IS....**

- **FIRST VIEWED AS MOSTLY DUE TO *EXTERNAL* CAUSES (PSYCHOLOGICAL, ENVIRONMENTAL, RELIGIOUS)**
- **THEN, *INTERNAL* BIOLOGICAL CAUSES BECOME THE FOCUS OF EXPLANATIONS.**
- **WE ALSO SEE THAT *BOTH* SETS OF CAUSES, INTERNAL AND EXTERNAL, CAN THEN CO-EXIST OR BE ACCEPTED SIMULTANEOUSLY FOR OLDER CHILDREN, ADOLESCENTS, AND ADULTS.**

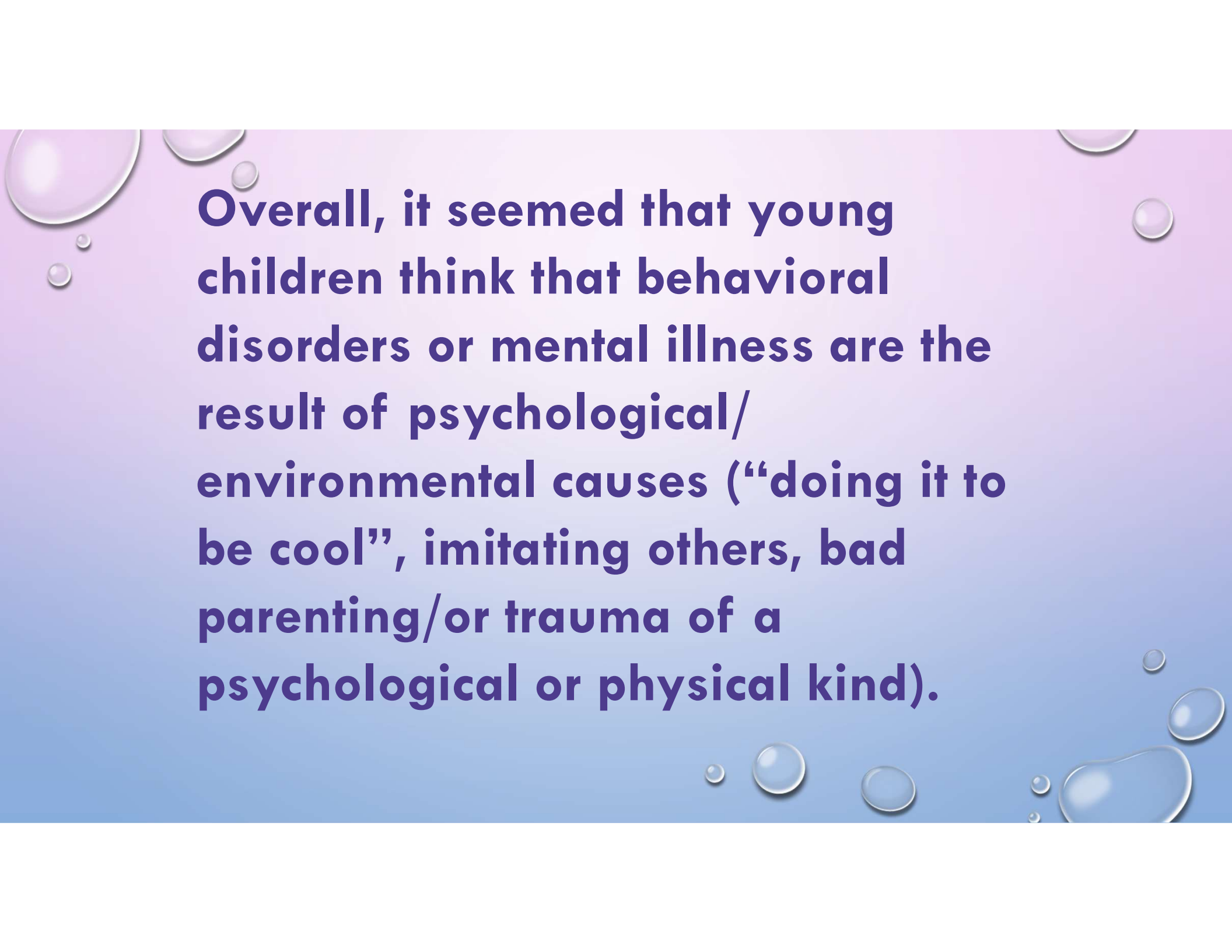


**Cautionary note-**

**COEXISTENCE EXISTS in other ways too  
(but my search was guided by a scientific  
evidence-based notion of causality)**

## PSYCHOLOGICAL/NEUROBEHAVIORAL ILLNESSES

**-IN MY *FIRST* REVIEW OF THE RESEARCH (UP TO 2016), THERE WERE SOME *ATHEORETICAL* STUDIES THAT ASSESSED CHILDREN'S UNDERSTANDING OF AND ACCEPTANCE OF (IN OTHERS) VARIOUS TYPES OF "MENTAL" ILLNESS OR BEHAVIORAL DISORDERS, SUCH AS DEPRESSION, CONDUCT DISORDER, OR ADHD.**



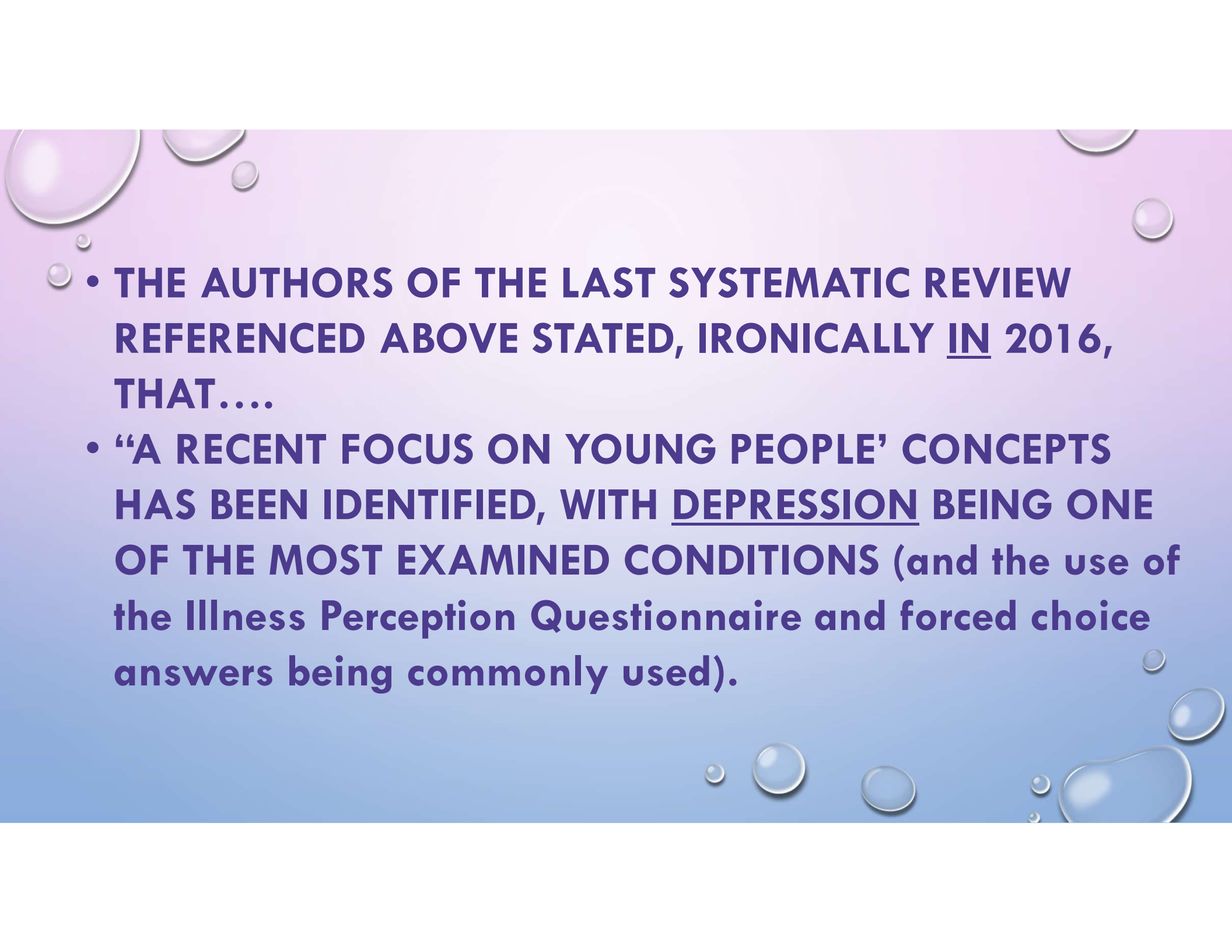
**Overall, it seemed that young children think that behavioral disorders or mental illness are the result of psychological/ environmental causes (“doing it to be cool”, imitating others, bad parenting/or trauma of a psychological or physical kind).**

- But older children, and children with the behavioral disorder itself, can also point to biological causes such as birth complications, genetics, or contagion.
- Similar results were also found by McMenemy (2000), who *combined* the Piagetian and theory-theory perspectives. She presented vignettes to children with and without ADHD. The vignettes described a child with a cold, with ADHD, or with bully-type aggressive behaviors and asked the children about “causes”.

**In my *recent* review (2016-NOW), I'm seeing research about the experience of living with parents with mental illness (e.g., depression, bipolar, schizophrenia), or coping with one's own mental illness as an adult [using Leventhal's common sense model of coping, also referred to as the self regulation framework].**

# NEWER RESEARCH (SINCE 2016) DOES SEEM TO FOCUS ON MOOD DISORDERS, e.g.....

- AHUVIA, I. L., SOTOMAYOR, I., KWONG, K., LAM, F. W., MIRZA, A., & SCHLEIDER, J. L. (2024). **CAUSAL BELIEFS ABOUT MENTAL ILLNESS: A SCOPING REVIEW.** *SOCIAL SCIENCE & MEDICINE* 345, 116670. [HTTPS://DOI.ORG/10.1016/J.SOCSCIMED.2024.116670](https://doi.org/10.1016/j.socscimed.2024.116670)
- BACKER, C., MURPHY, R., FOX, J. R. E., ULPH, F., & CALAM, R. (2017). **YOUNG CHILDREN'S EXPERIENCE OF A PARENT WITH BIPOLAR DISORDER:** UNDERSTANDING THE CHILD'S PERSPECTIVE. *PSYCHOLOGY AND PSYCHOTHERAPY: THEORY, RESEARCH AND PRACTICE*, 90(2), 212-228. [HTTPS://DOI.ORG/10.1111/PAPT.12099](https://doi.org/10.1111/papt.12099)
- GEORGAKAKOU-KOUTSONIKOU, N., TAYLOR, E. P., & WILLIAMS, J. M. (2019). **CHILDREN'S CONCEPTS OF CHILDHOOD AND ADOLESCENT DEPRESSION.** *CHILD AND ADOLESCENT MENTAL HEALTH*, 24(1), 19–28. [HTTPS://DOI.ORG/10.1111/CAMH.12266](https://doi.org/10.1111/camh.12266)

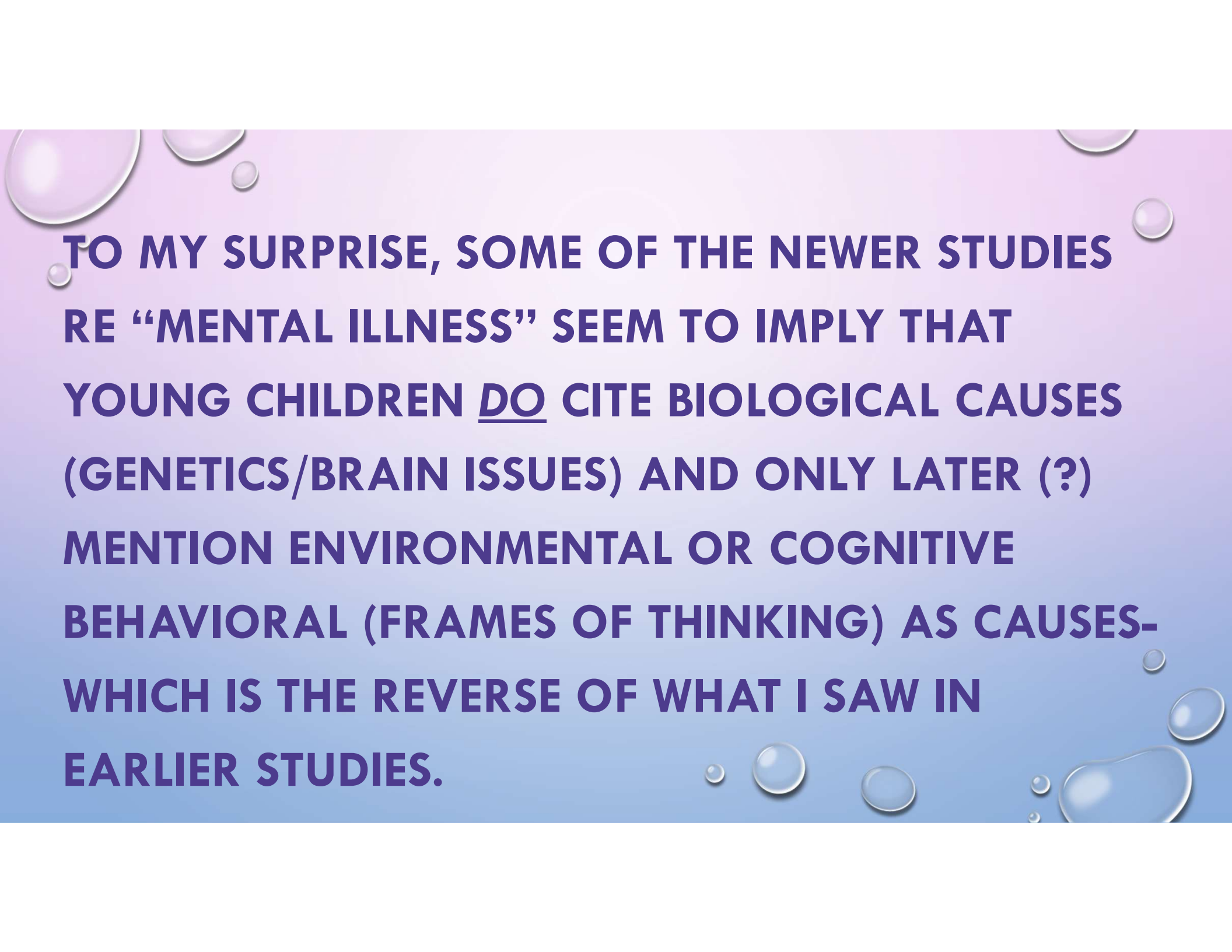
- 
- **THE AUTHORS OF THE LAST SYSTEMATIC REVIEW REFERENCED ABOVE STATED, IRONICALLY IN 2016, THAT....**
  - **“A RECENT FOCUS ON YOUNG PEOPLE’ CONCEPTS HAS BEEN IDENTIFIED, WITH DEPRESSION BEING ONE OF THE MOST EXAMINED CONDITIONS (and the use of the Illness Perception Questionnaire and forced choice answers being commonly used).**

- **Typical forced choice “causes” administered to adult participants include *day to day problems, recent trauma, childhood problems, etc.***
- **I am left wondering why no *genetics*, and no *brain issues* are listed here.**

- Is there concern that this would be reductionistic, or negative, or suggest “no control”, or concern that we should focus on meds rather than therapy??
- In non-forced choice studies, clinical populations of *adults* do seem to provide more biological causes than the general population that tends to focus on environmental and social causes.



**Let me get back to the newer studies  
with child participants.....**

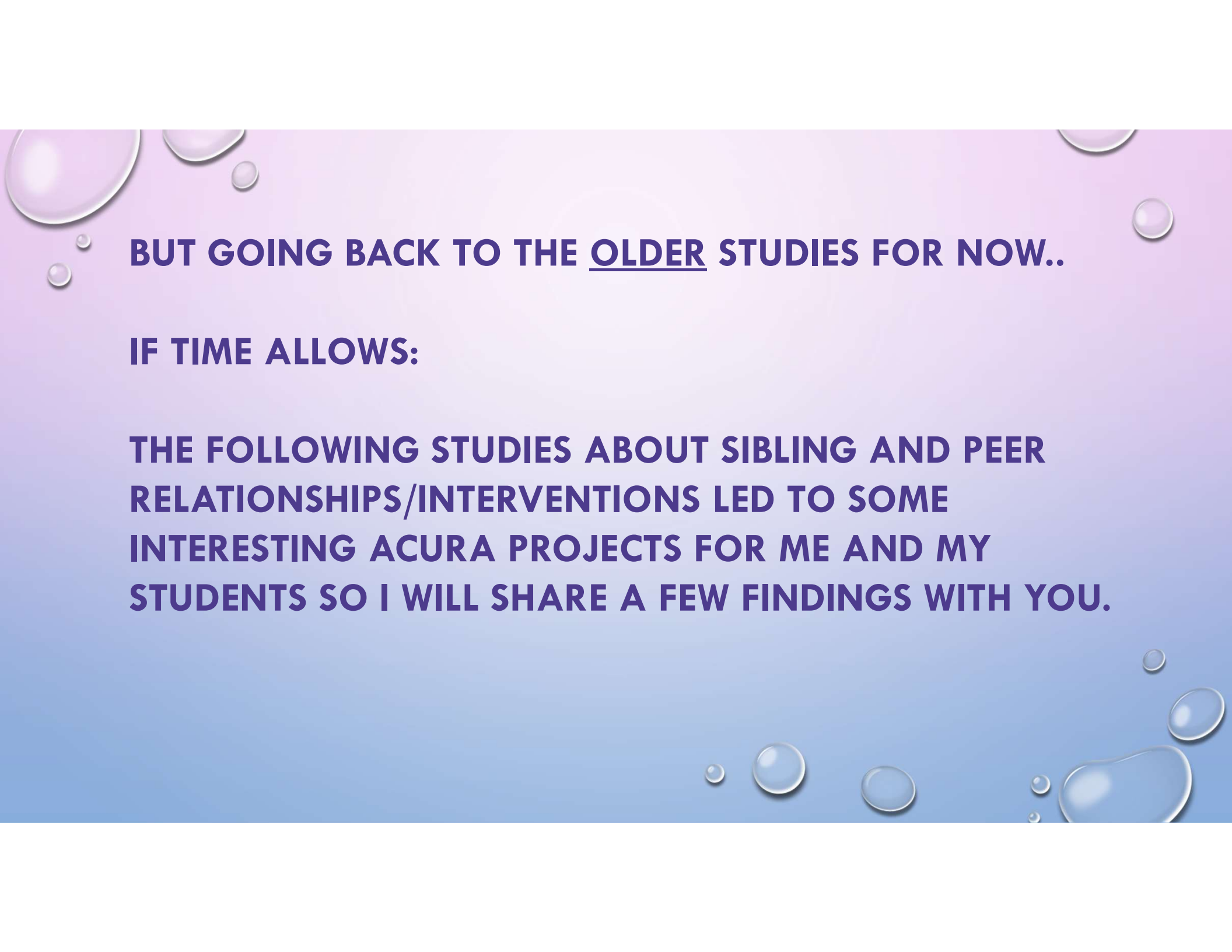


**TO MY SURPRISE, SOME OF THE NEWER STUDIES  
RE “MENTAL ILLNESS” SEEM TO IMPLY THAT  
YOUNG CHILDREN DO CITE BIOLOGICAL CAUSES  
(GENETICS/BRAIN ISSUES) AND ONLY LATER (?)  
MENTION ENVIRONMENTAL OR COGNITIVE  
BEHAVIORAL (FRAMES OF THINKING) AS CAUSES-  
WHICH IS THE REVERSE OF WHAT I SAW IN  
EARLIER STUDIES.**

**So is this “contradiction” due to...**

- **Mental (vs Physical) Illness focus**
  - **[Which mental illness?]**
- **Cohort differences (and more recent education about such issues, less stigma)?**
- **Methodology differences?**
- **Cultural differences? Studies from United Kingdom, Australia, Iran, China, etc.**

**I WILL NEED TO SORT THROUGH THIS!**



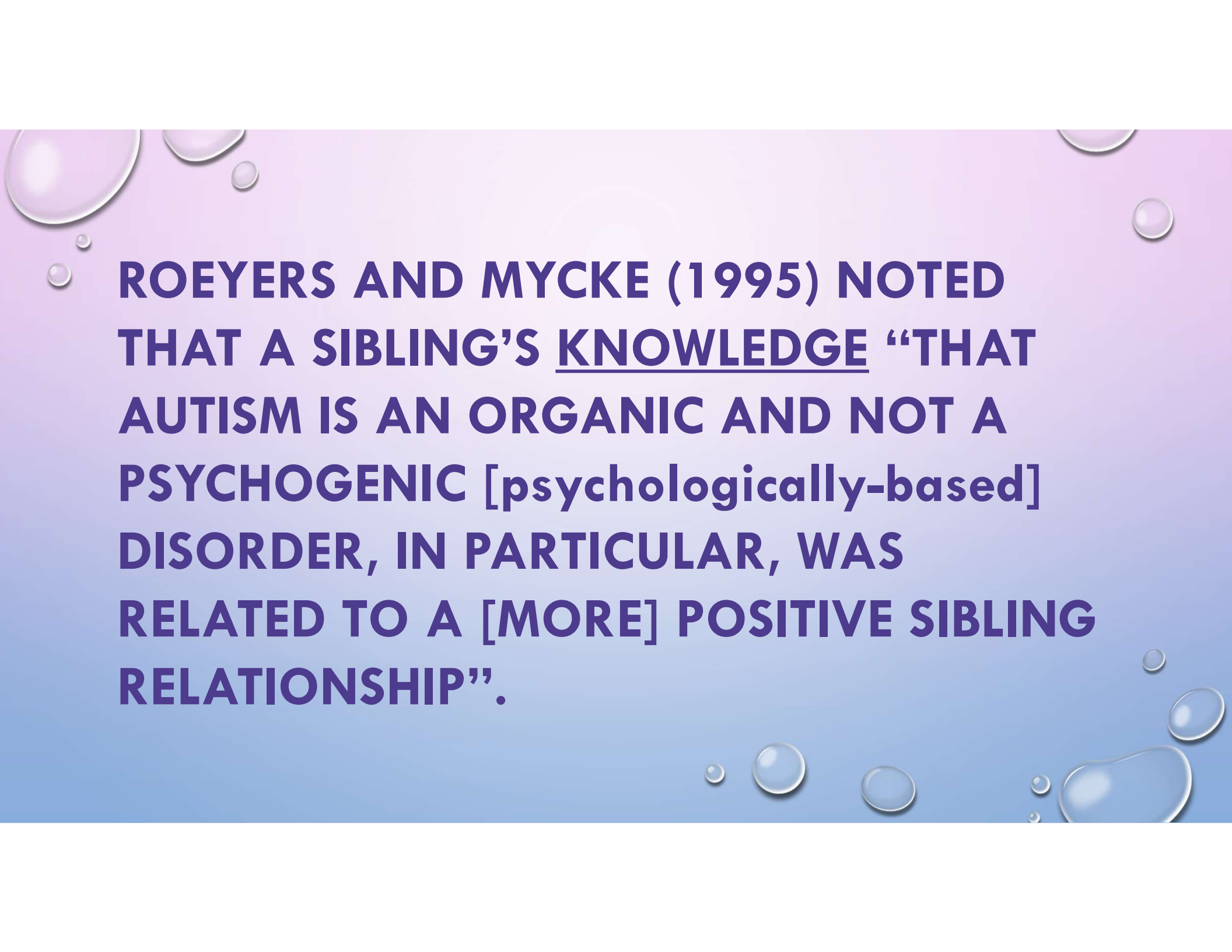
**BUT GOING BACK TO THE OLDER STUDIES FOR NOW..**

**IF TIME ALLOWS:**

**THE FOLLOWING STUDIES ABOUT SIBLING AND PEER  
RELATIONSHIPS/INTERVENTIONS LED TO SOME  
INTERESTING ACURA PROJECTS FOR ME AND MY  
STUDENTS SO I WILL SHARE A FEW FINDINGS WITH YOU.**

# **SIBLING'S NOTIONS**

- GLASBERG (2000) ARGUED THAT CONCEPTS REGARDING NEUROPSYCHOLOGICAL ILLNESSES MAY BE ACQUIRED BY HEALTHY SIBLINGS AT AN ESPECIALLY SLOWER RATE THAN PREDICTED BECAUSE ILLNESSES SUCH AS AUTISM ARE “MORE ABSTRACT AND LESS COMMON THAN MANY PHYSICAL ILLNESSES [AND] MAY SIMPLY BE MORE DIFFICULT TO GRASP” (P. 151).**



**ROEYERS AND MYCKE (1995) NOTED THAT A SIBLING'S KNOWLEDGE "THAT AUTISM IS AN ORGANIC AND NOT A PSYCHOGENIC [psychologically-based] DISORDER, IN PARTICULAR, WAS RELATED TO A [MORE] POSITIVE SIBLING RELATIONSHIP".**

## **PEER INTERVENTIONS (TOURETTE)**

- **SEVERAL STUDIES ASSESSED THE DEGREE TO WHICH CHILDREN WILL SOCIALLY ACCEPT A HYPOTHETICAL PEER WITH TS OR RELATED DISORDERS (OCD, AUTISM).**
- **THE VIDEOTAPED ACTOR WITH TICS OR COMPULSIONS IS GENERALLY RATED LOWER ON SOCIAL ACCEPTANCE TYPE SCALES EVEN WHEN THE ACTOR GAVE A BRIEF INFORMATIONAL STATEMENT ABOUT TS TO 3RD AND 5TH GRADERS**

**(FREIDRICH, MORGAN, & DEVINE, 1996)**

**YET WOODS (2002) FOUND THAT WHEN COLLEGE UNDERGRADUATES WERE EXPOSED TO AN EDUCATIONAL VIDEO ABOUT TS, THEY WERE THEN MORE ACCEPTING OF AN ACTOR WITH TICS AND PUT LESS DISTANCE BETWEEN THEMSELVES AND THE ACTOR THAN THE GROUP THAT WAS NOT SHOWN THE INFORMATIONAL VIDEO.**

- It is not clear whether an increase in understanding was the mediating variable that affected the change in attitude towards “someone” with the disorder.

INSPIRED SEVERAL  
ACURA PROJECTS

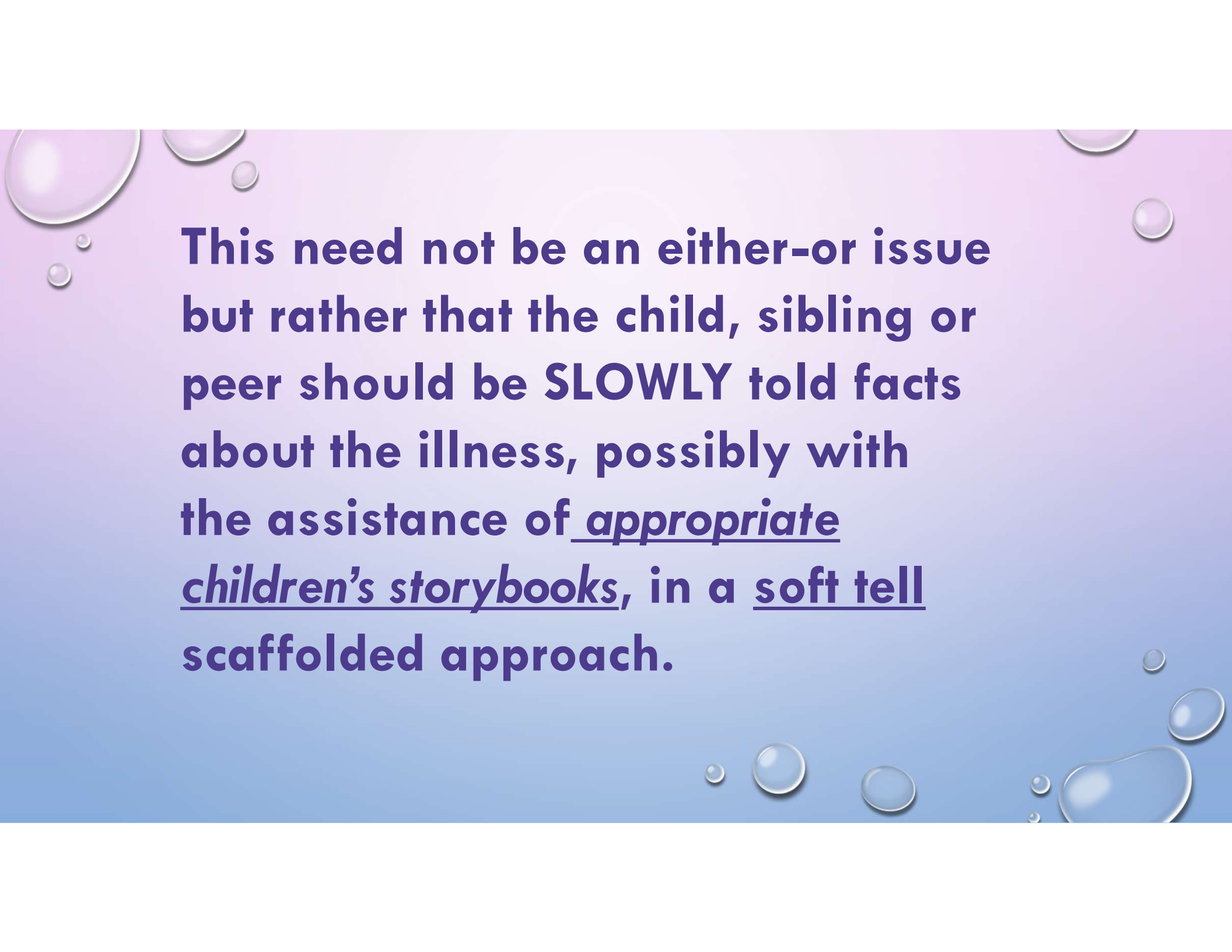
- Nor do we know whether changes in knowledge would affect attitudes or behavior towards a *real* rather than a hypothetical classmate with TS.
- or if the effects would be long lasting.

- Some interventions have ➡+ effects, some - effects, and some ➡no change!
- We surely need a more multifaceted approach to intervention to determine if, how, and when the various cognitive (knowledge) *and* affective (attitudinal) pieces fit together and for whom.

## **TO TELL OR NOT TO TELL**

**THERE ARE QUESTIONS RAISED ABOUT WHETHER OR NOT TO TELL, AND *HOW* TO TELL, A CHILD ABOUT THEIR OWN OR A FAMILY MEMBER'S ILLNESS.**

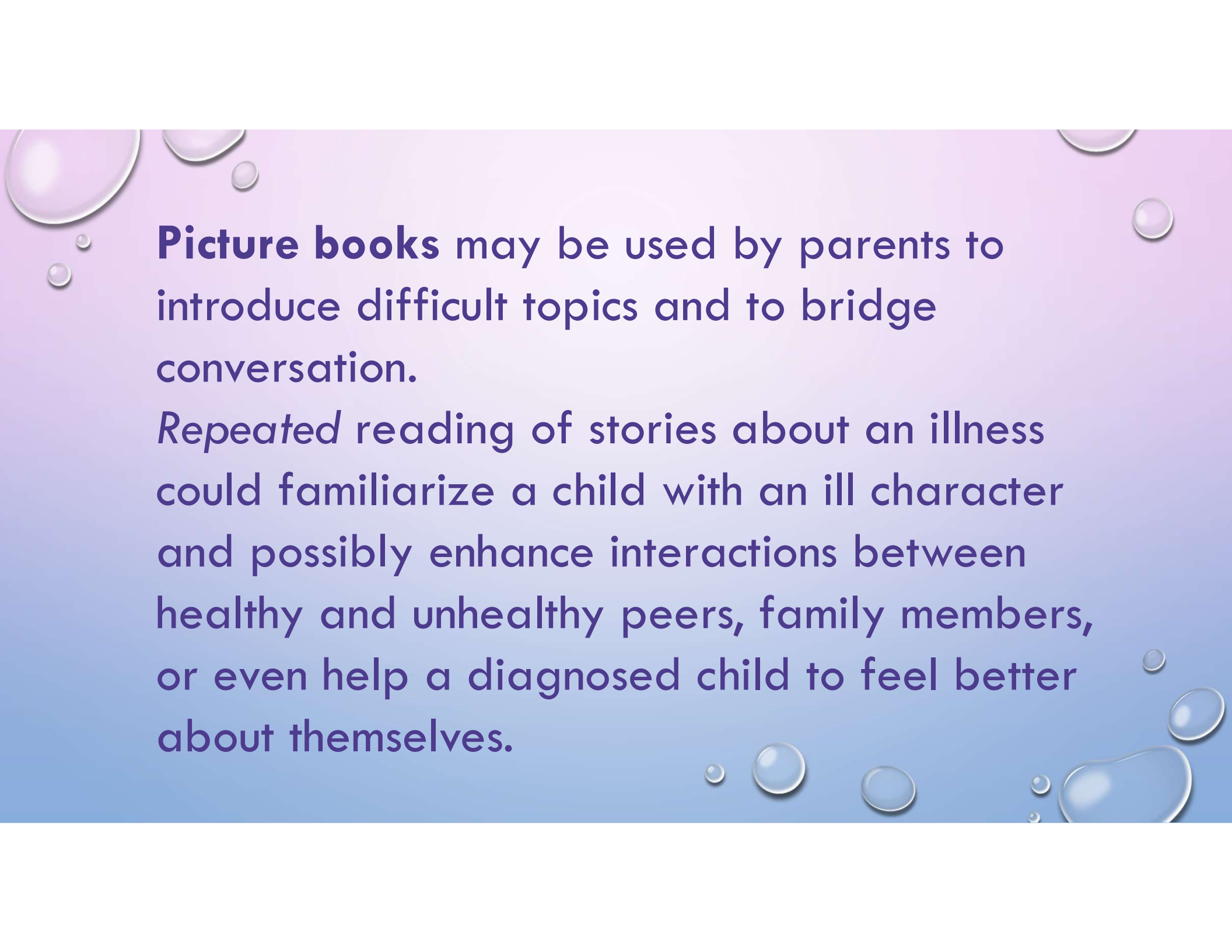
**THE RECENT "DISCLOSURE" RESEARCH SEEMS TO BE MOSTLY ABOUT AUTISM, PARENTAL CANCER, AND EVEN ABOUT GENETIC DISORDERS THAT MAY LEAD TO REPRODUCTIVE RISKS FOR THE CHILD.**



**This need not be an either-or issue but rather that the child, sibling or peer should be SLOWLY told facts about the illness, possibly with the assistance of appropriate children's storybooks, in a soft tell scaffolded approach.**

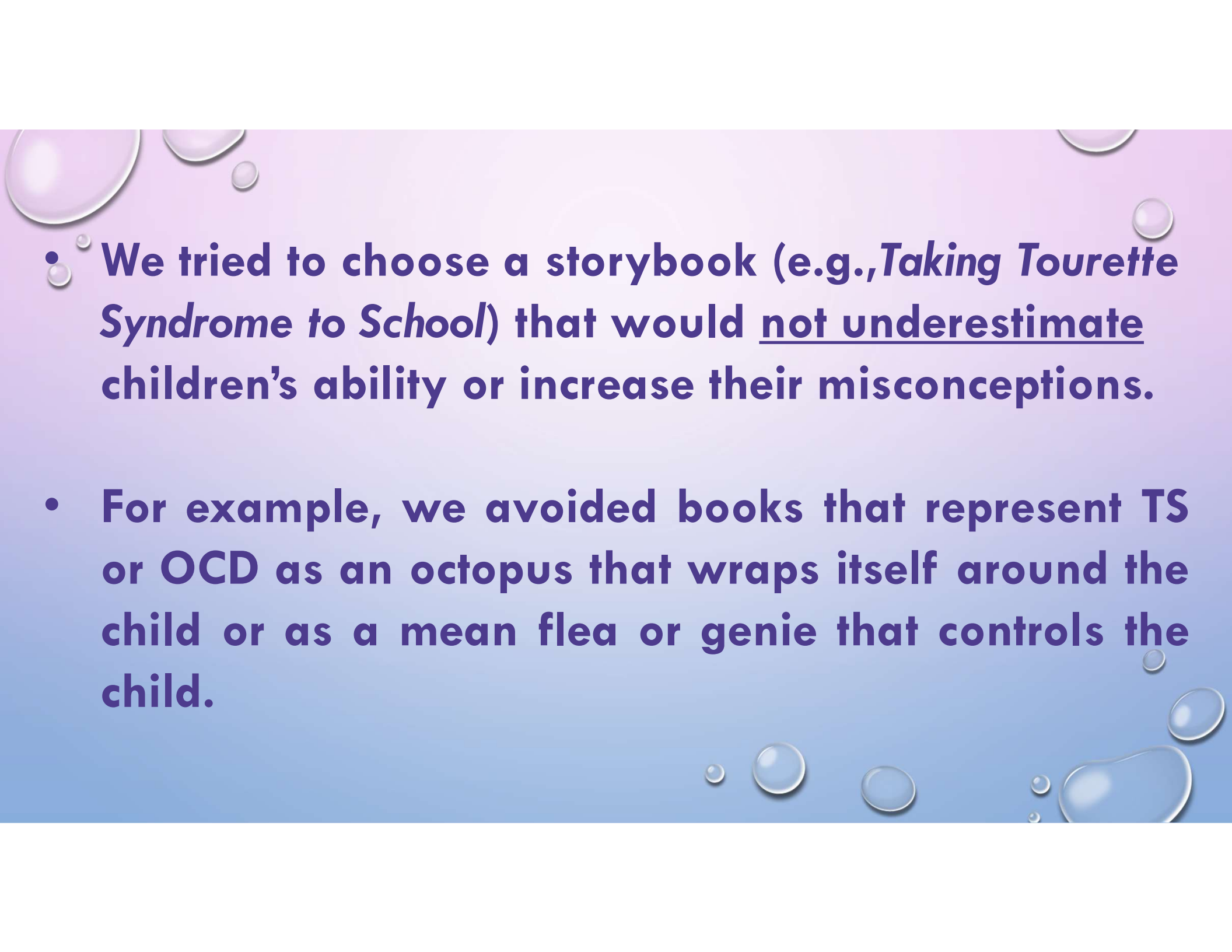
## **CHILDREN'S STORYBOOKS (ABOUT TS)**

**ONE OF THE EFFECTIVE (BUT STILL LIMITED) PEER INTERVENTIONS I HAVE USED IN SOME UNPUBLISHED ACURA RESEARCH WITH 3RD GRADERS TO INCREASE KNOWLEDGE AND CHANGE ATTITUDES ABOUT A HYPOTHETICAL PEER WITH TOURETTE'S OR AUTISM HAS BEEN THE READING OF RELEVANT STORYBOOKS (NEWMAN, JACOBS, & JANOVSKY, 2004; NEWMAN, NAGARAJ, & SCOTT, 2009).**



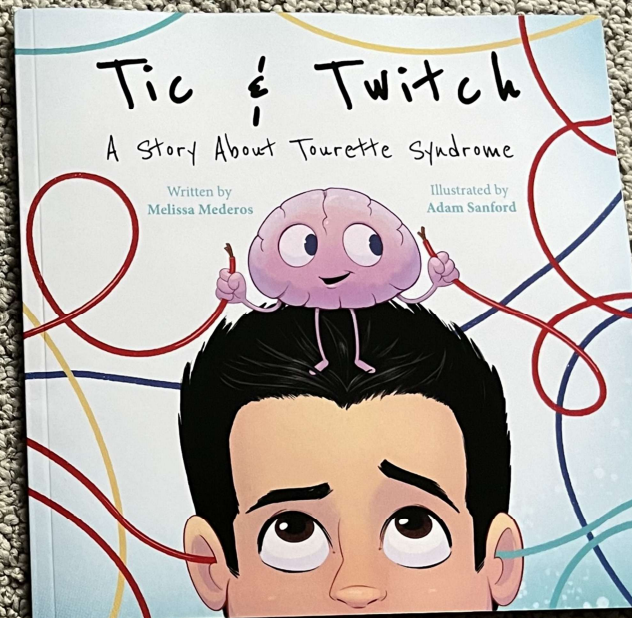
**Picture books** may be used by parents to introduce difficult topics and to bridge conversation.

*Repeated* reading of stories about an illness could familiarize a child with an ill character and possibly enhance interactions between healthy and unhealthy peers, family members, or even help a diagnosed child to feel better about themselves.

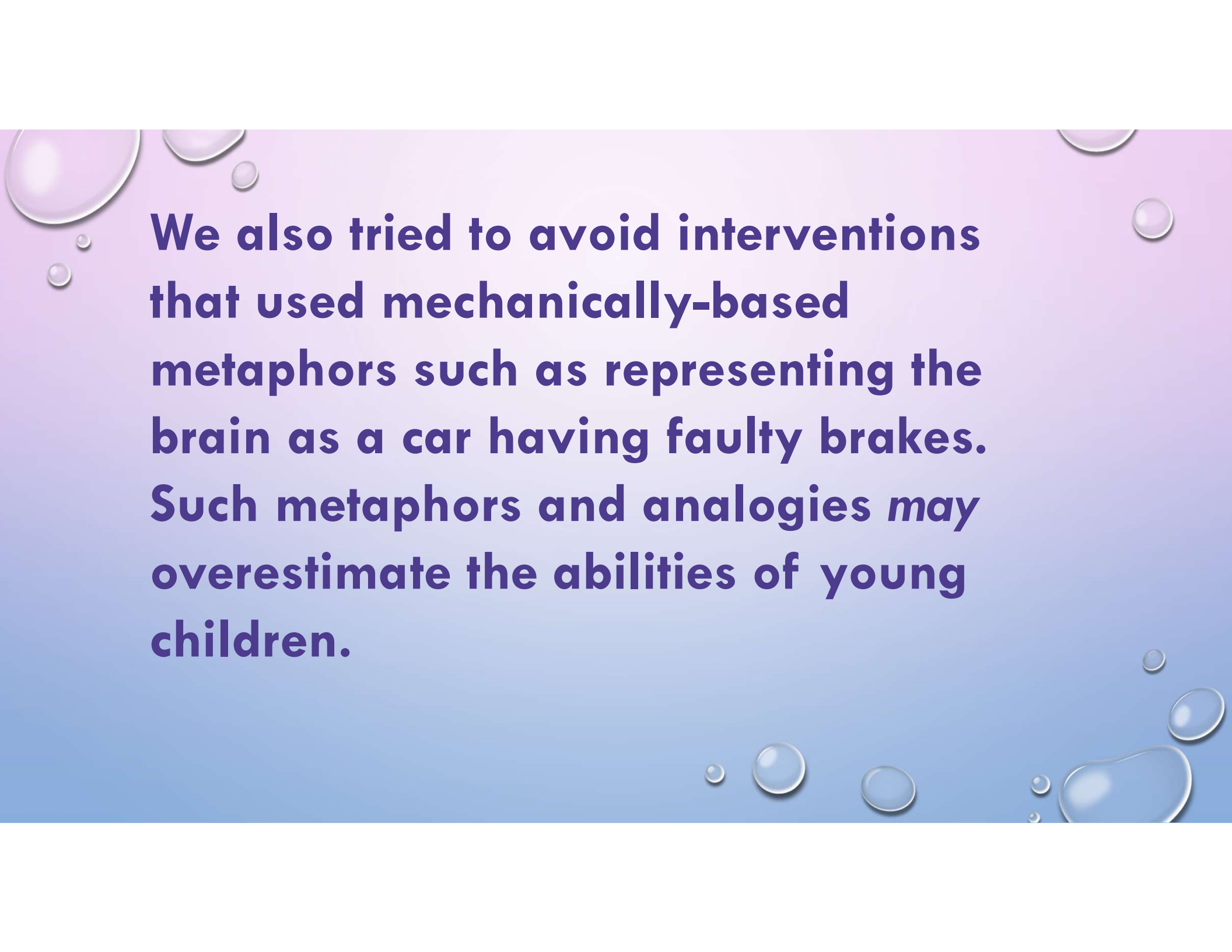
- 
- We tried to choose a storybook (e.g., *Taking Tourette Syndrome to School*) that would not underestimate children's ability or increase their misconceptions.
  - For example, we avoided books that represent TS or OCD as an octopus that wraps itself around the child or as a mean flea or genie that controls the child.



2001



2022



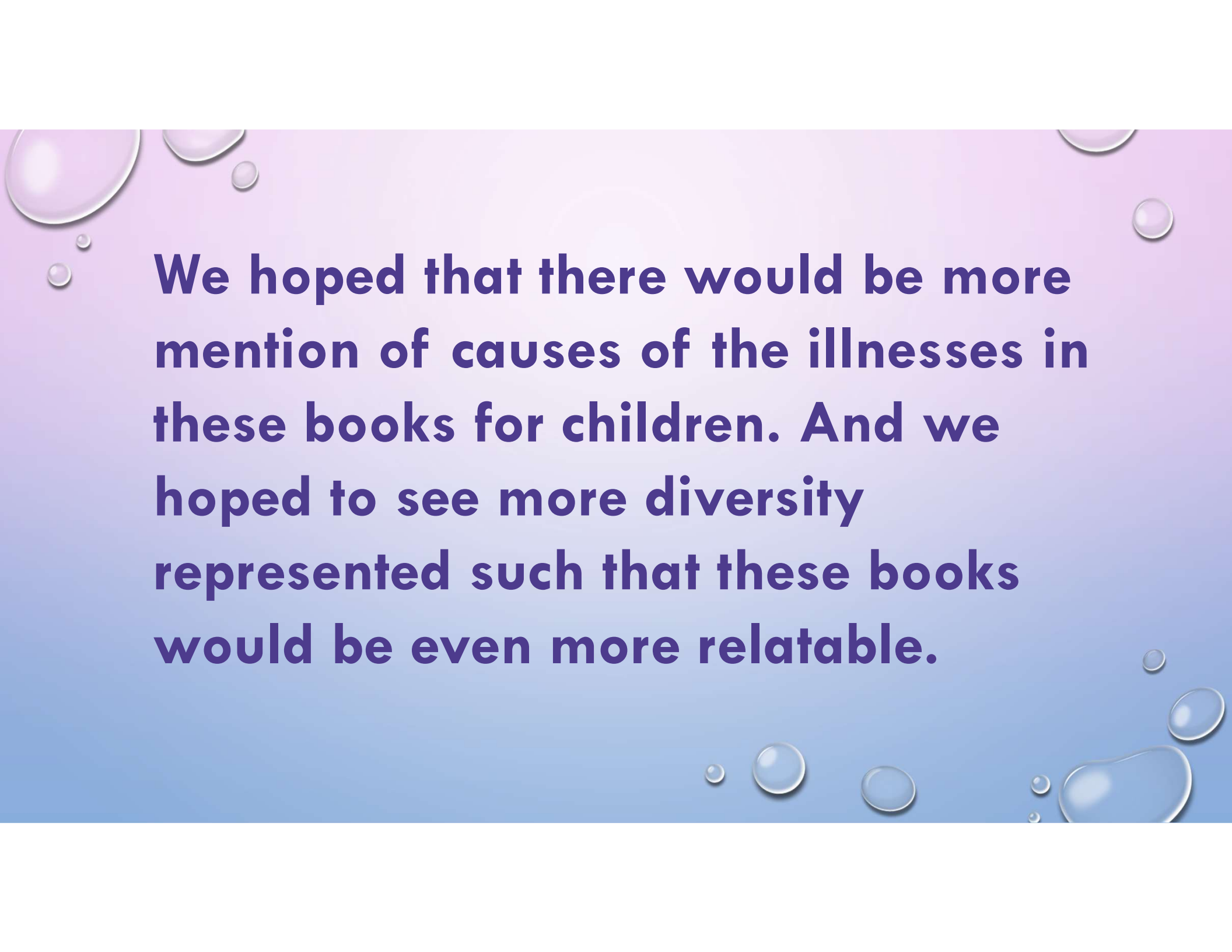
**We also tried to avoid interventions that used mechanically-based metaphors such as representing the brain as a car having faulty brakes. Such metaphors and analogies *may* overestimate the abilities of young children.**

| <u>Author:</u>                | <u>Ill Character:</u>       | <u>Ill Character</u> | <u>Discuss Cause of Illness*</u> | <u>Metaphors or Similes Used to Describe</u>    | <u>Treatment Options Discussed</u> |
|-------------------------------|-----------------------------|----------------------|----------------------------------|-------------------------------------------------|------------------------------------|
| Family(F)                     | Strengths(S)                | Adult(AD)            |                                  |                                                 |                                    |
| Prof (P)                      | Dynamic                     | Child(C)             |                                  |                                                 |                                    |
| Self (S)                      | Change(DC)                  | Male(M)              | Discuss                          |                                                 | Same <u>Label</u> Used             |
| Writer (W)                    | Magical powers(MP)          | Female(F)            | Symptoms                         |                                                 | For Illness                        |
|                               |                             | Animal(A)            |                                  |                                                 |                                    |
| <u>Illustration: Content:</u> | <u>Illustration: Style:</u> | <u>Diversity:</u>    | <u>Lists Resources</u>           | <div>CODING SCHEME<br/>USED IN ACURA 2017</div> |                                    |
| Realistic(R)                  |                             | Family (F)           |                                  |                                                 |                                    |
| Show disease(SD)              |                             | Race (RA)            |                                  |                                                 |                                    |
| Fantasy (F)                   | Simple(S)                   | Religion(RE)         |                                  |                                                 |                                    |
| Relates to text (RT)          | Detailed(D)                 |                      |                                  |                                                 |                                    |

(#1) Has the story changed?: Children's picture books about illnesses and disability over the decades

(#2) A content analysis of 20 children's books about illness and disability: What do they tell us about what makes us "sick"?

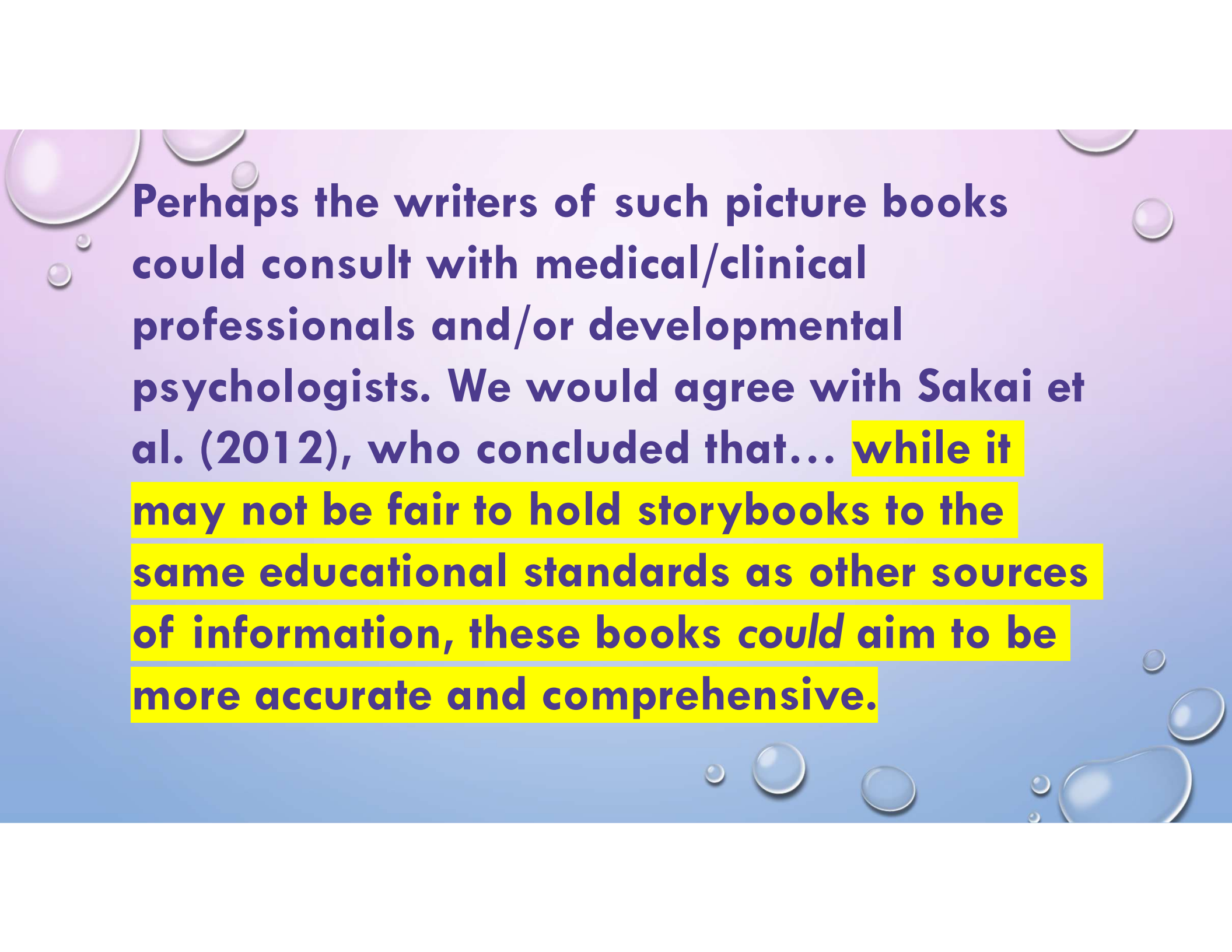
- **Turner (2006, pp.183-4):“The majority of the children’s picture books contained no content specific to causation.”**
- **In our ACURA 2017 study, only 50% mentioned the cause of the disorder (e.g., Down Syndrome is having an extra chromosome) and more of these were actually published *before* 2000 than after.**



**We hoped that there would be more mention of causes of the illnesses in these books for children. And we hoped to see more diversity represented such that these books would be even more relatable.**

## **Need more research to know:**

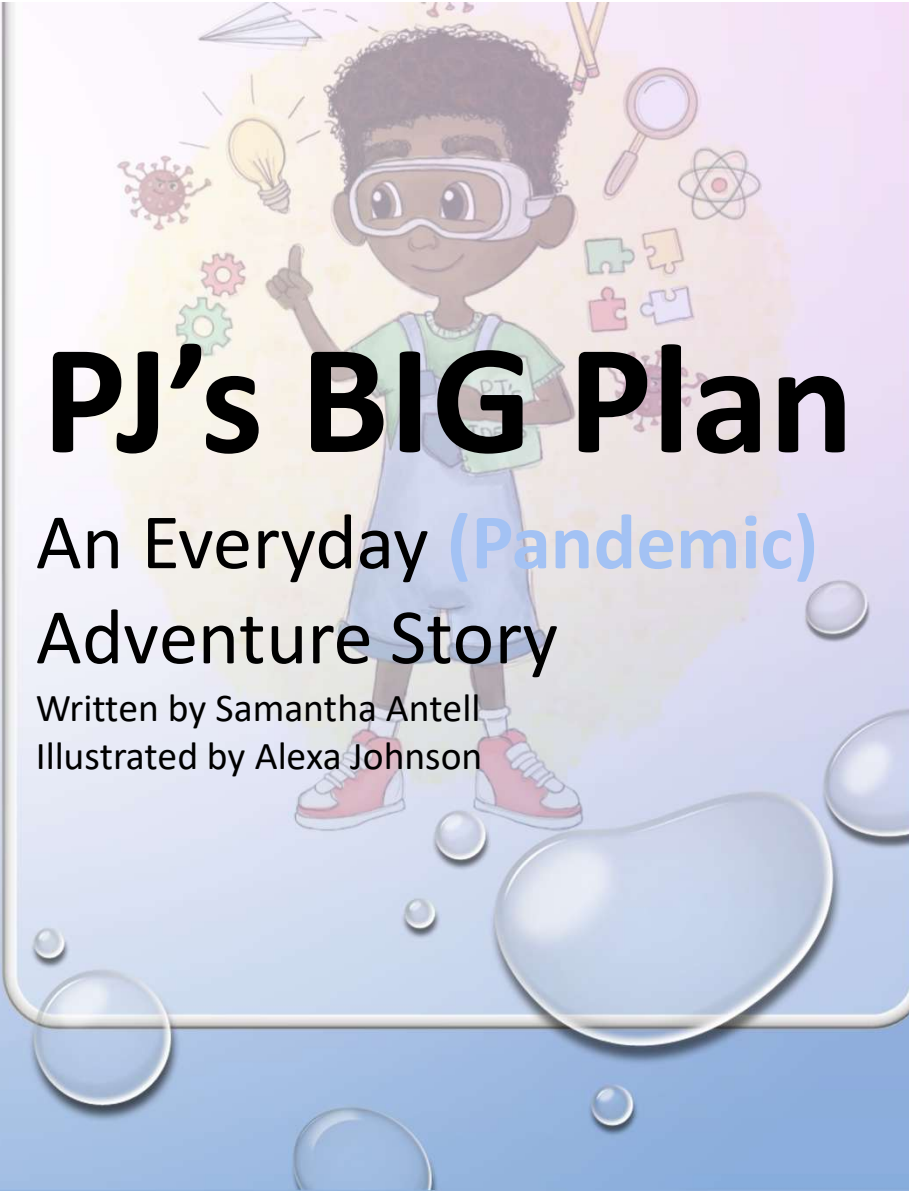
- **whether mere *exposure* to strong story characters with an illness can change a child's attitudes and behavioral intentions towards persons with the illness.**
- **Or, whether the story would have to actually increase the child's knowledge about the *cause* to have such effects.**



Perhaps the writers of such picture books could consult with medical/clinical professionals and/or developmental psychologists. We would agree with Sakai et al. (2012), who concluded that... while it may not be fair to hold storybooks to the same educational standards as other sources of information, these books *could* aim to be more accurate and comprehensive.

**EXPLAINING THE COVID-19  
PANDEMIC:  
THE VERY INTENTIONAL  
CREATION OF A  
CHILDREN'S PICTURE BOOK**

ACURA 2022

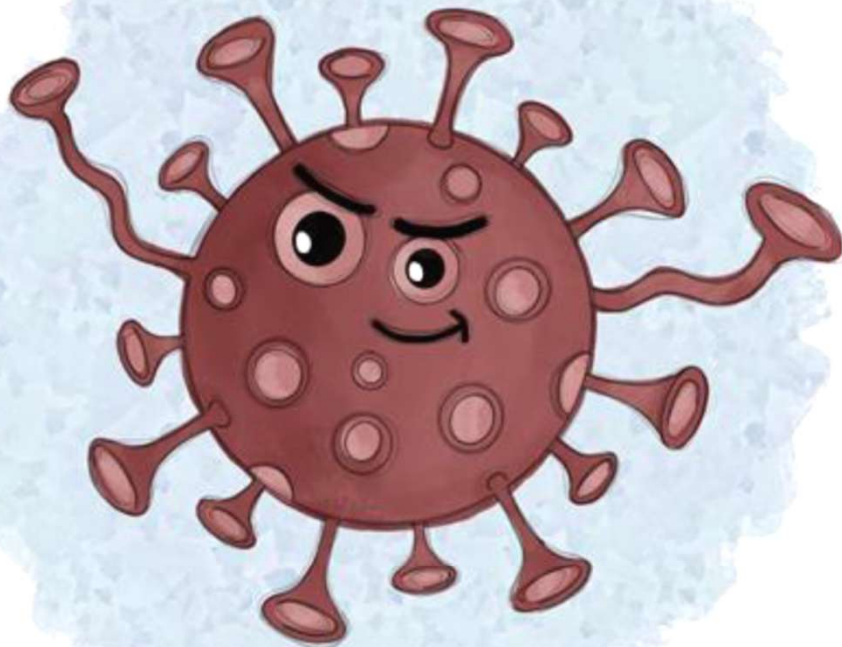


# **PJ's BIG Plan**

An Everyday **(Pandemic)**  
Adventure Story

Written by Samantha Antell

Illustrated by Alexa Johnson



- **IT WAS STRANGE LOOKING, WITH A BUNCH OF ARMS LIKE PUZZLE PIECES. BUT PJ THE SCIENTIST RECOGNIZED THOSE ARMS...**
- **... THEY GRAB ONTO THE CELLS OUR BODIES ARE MADE OF. THAT'S HOW THE VIRUS ATTACKS OUR BODIES, AND MAKES US FEEL SICK!**

# SUMMARY

- WE NEED MORE BASIC RESEARCH THAT SPECIFICALLY FOCUSES ON CHILDREN'S CONCEPTIONS, OR MISCONCEPTIONS, OF THE CAUSES OF DISEASES/DISORDERS TO MORE EFFECTIVELY CONSTRUCT APPROPRIATE EXPLANATIONS AND STORYBOOKS FOR THE CHILD, THEIR SIBLINGS, AND THEIR PEERS.
- AND FURTHER EXPERIMENTAL RESEARCH IS REQUIRED TO DETERMINE WHETHER INTERVENTIONS CAN EFFECT A CHANGE IN THE CHILD'S LEVEL OF UNDERSTANDING AND WHETHER SUCH CHANGES HAVE ANY IMPACT ON ATTITUDES AND INTERACTIONS OR VICE VERSA.

# QUESTIONS/COMMENTS

If you have any questions or comments, I hope we have some time left over but you can always contact me at [jln1@psu.edu](mailto:jln1@psu.edu)

**THANK YOU SO VERY MUCH FOR ATTENDING!**