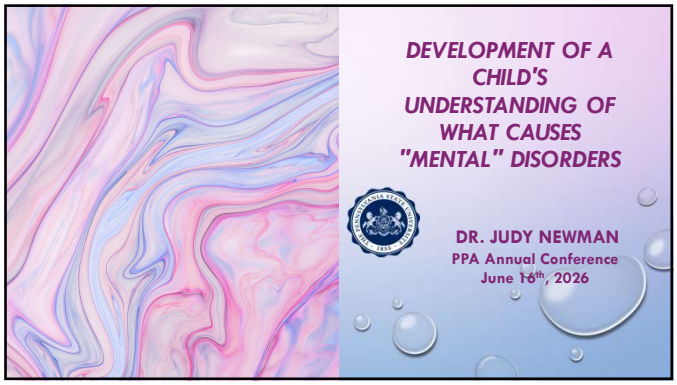

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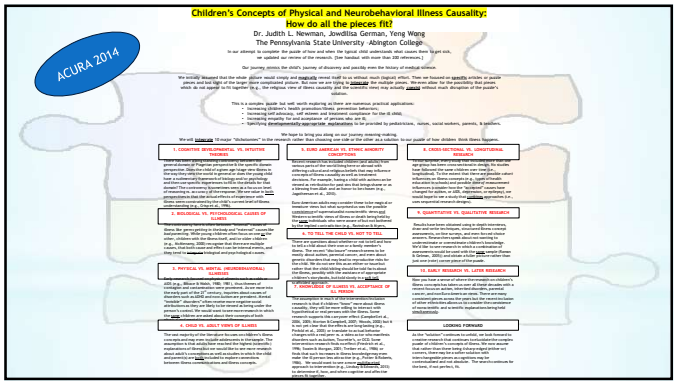


2

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].

3

WHY IS THIS IMPORTANT?

4

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…….

5

- 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.

6

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.

7

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)

8

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.

9

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

10

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…

11

CONCEPTS OF ILLNESS

I. Prelogical explanations (PO)
   - Phenomenism
   - Contagion

II. Concrete-logical explanations (CO)
   - Contamination
   - Internal ization

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

12

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.

13

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.*"

14

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.

15

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."

16

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.

17

- 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*.

18

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

19

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.

20

AND…

CHILDREN'S CONCEPTS OF ILLNESS

THEORY-THEORY PERSPECTIVE

- 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.

21

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.

22

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*.

23

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.

24

MY FASCINATION WITH……

Ernst Haeckel's Biogenetic Law

ONTOGENY RECAPITULATES PHYLOGENY

which implied that

INDIVIDUAL DEVELOPMENT RECAPITULATES OR PARALLELS THE DEVELOPMENT OF THE SPECIES

25

"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)

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

ACURA 2015

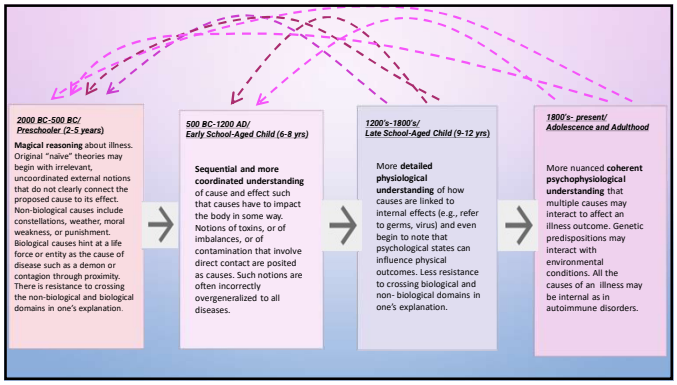
So a premed student and I decided to read some History of Medicine books and see if we could find some *parallels* with what I knew about the developing child's concept of illness causality….and the history of medicine!

26

Parallel discoveries of illness causality in history and in childhood

HERE ARE OUR PARALLELS…
and then a cautionary note

27



28

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.**

29

Cautionary note-

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

30

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.

31

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).

32

- **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 McMenamy (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".**

33

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].

34

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
- 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
- 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

35

- 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).

36

- 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.

37

- 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.

38

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

39

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.

40

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!

41

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.

42

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).

43

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".

44

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)

45

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.

46

- 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.

47

- 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.

48

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.

49

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.

50

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).

51

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.

52

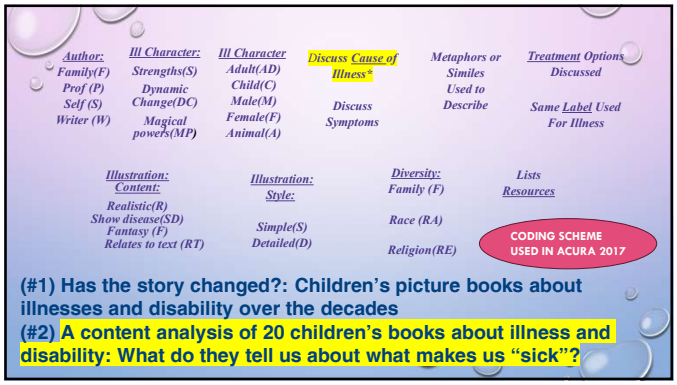
- **We tried to choose a storybook (e.g.,*Taking Tourette Syndrome to School*) that would <u>not underestimate</u> children's ability or increase their misconceptions.**
- **For example, we avoided books that represent TS or OCD as an octopus that wraps itself around the child or as a mean flea or genie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

53

54

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.

55



(#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"?

56

- Turner (2006, pp.183-4):"The majority of the children's picture books contained no content specific to causation."
- In our ACURA 2017study, 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.

57

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.

58

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.

59

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.

60

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

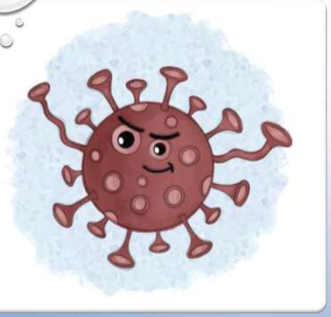
ACURA 2022

PJ's BIG Plan

An Everyday (Pandemic) Adventure Story

Written by Samantha Antell
Illustrated by Alexa Johnson

61



- 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!

62

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.

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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

THANK YOU SO VERY MUCH FOR ATTENDING!

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