

Fostering Self-Advocacy In Kids with Special Needs

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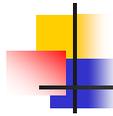
-- The Difficult Art of Letting Go --



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Self-Advocacy

What Qualities Does an Effective Self-Advocate Have?

- Strong self-developed identity
 - knowledge of who they are, and how they fit in (relationships)
- Accurate, synthesized knowledge of their own abilities
 - both strength and challenges
- Broad self-confidence
 - comfortable taking risks
- The habit of appropriately engaging authoritative figures (outside the family)
 - the Outlier Principle



Self-Advocacy

A Note on Special Needs:

- Our children (like all children) will have their own inherent potential and limits
- The degree of self-advocacy they can attain will depend in part on these inherencies
- Fostering means to help develop their potential for self-advocacy within these boundaries

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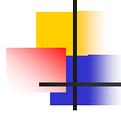
Self-Advocacy

How do we “foster” these characteristics in our children?

Key concepts and tools we'll cover:

- Self-knowledge & independence
- Raising an “I can” child
- Success, failure & resiliency: why failure is important
- Ordinary vs. catastrophic failure
- Product vs. outcome
- Internal vs. external identity
- Affording independence

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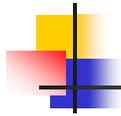


The Basics

True self-advocacy is not situation specific

- It must occur regardless of context
- It must occur regardless of familiarity

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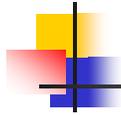


The Basics

There is no single method or style of effective self-advocacy

- Different styles can be effective
- Effective methods vary with context

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The Basics

Fostering self-advocacy is therefore *not* situational training

- It is not training your child what to say or how to say it.

Fostering self-advocacy *is* core character building

- It is helping our children to know who they are, what they need, and giving them practice advocating for themselves.

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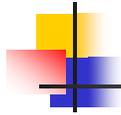


The Basics

Self-advocacy is not “taught” when students begin high school

- Building it should be a philosophy of child-raising
- Be intentional – create a plan for building self-advocacy based on your child’s age

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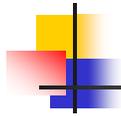
BFO's

- To effectively advocate for self...
you must *know yourself*.

- To advocate for what you need...
You must *know* what you need.

- To know what you need...
You must *know* what you can and cannot do.

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Knowledge of Self

The core foundation of Self-Advocacy is self-knowledge

Effective self-advocacy requires an intuitive, practical, internalized, concrete knowledge of your capabilities, your strengths, and your challenges.

- Like all "true" knowledge, this comes from self-experience
- Doctrine dictated by others will not suffice
 - You cannot "tell" them
 - Think about your own self-knowledge

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A Proposition

You do not know what your child is capable of,
or can or will be



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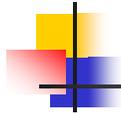
A Corollary

(For those who disagree)

Your knowledge or belief of what your child is capable of is
irrelevant

- Your children ***MUST*** learn this knowledge for themselves to
effectively self-advocate

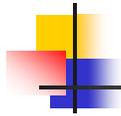
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More BFO's

- For your child to know what he is capable of...
He must be allowed to succeed *independently*
- To succeed on his own...
Your child must be allowed to *fail* independently
There is no success...
...without possibility of failure
- To be insulated from failure...
Is to be insulated from success...
...and from accurate knowledge of self

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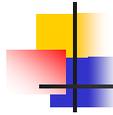
Pause for thought...

There is a direct relationship between effective self-advocacy and independence.

A person who is afforded independence develops the accurate knowledge of his capabilities that is *required* for effective self-advocacy.

(See that theme? Letting go...)

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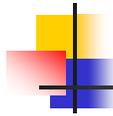
Self Knowledge and Independence

How do we foster self-knowledge and independence?

- You already know this...
... At least you did when you had a toddler
- You are now programmed against doing it by two ENORMOUS forces, acting in concert



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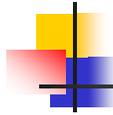


Roadblocks to Fostering Self-Advocacy

To foster a self-advocate, you MUST be alert for the influence (and confluence) of two overwhelming forces:

- The most powerful parental instinct:
PROTECTION
- The most powerful cultural bias:
SUCCESS
- ...which are magnified by parenting a child with special needs

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Parental instinct: PROTECTION

- Hardwired in genes
- Culturally enforced – the “protection racket”
 - Marketing
 - Politics
- Habitually enforced
 - Life decisions: Which job to take? Where to live? Which schools?
 - Daily choices:
 - Organics
 - Medication
 - Helmets
 - Seat belts, air bags
 - Smoke detectors
 - Product safety

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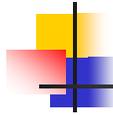
Parental instinct: PROTECTION

We spend a vast amount of our intellectual, emotional, instinctual and economic lives *protecting* our children

- Imagine how hard it is to buck that trend

(Hold that thought...)

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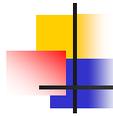


Cultural Bias: SUCCESS

It's EVERYWHERE:

- Cars, homes, celebrities, media, heroes, sports, myths, politics, wealth, marriage, *education...*
 - "My Child is a [fill-in-the-blank] Honor Student"
 - Grades

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Cultural Bias: SUCCESS

Counter-bias:

FAILURE



- How does that word make you feel?

Adults: "He's a failure."

Kids: "Epic Fail!"

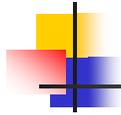
Schools: "F" for Failure



- Are you comfortable yet?

Government: "Failure is NOT an option!!!!"

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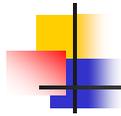
Roadblocks to Fostering Self-Advocacy

Put these two overwhelming forces together:

- The parental instinct to PROTECT
- The cultural bias against FAILURE

Result: We protect our children from failure

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Roadblocks to Fostering Self-Advocacy

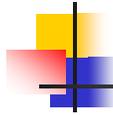
You are under enormous pressure (internal and external) to protect your children from failure

However, to effectively foster self-advocacy...

... you must buck that trend

To self-advocate, your children must know what they can and cannot do

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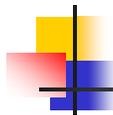
Success & Failure

When is "Success" failure?

When is "Failure" success?

- How do we define these terms?
- Do we define them differently in theory than in practice?

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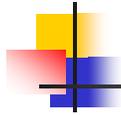
Success & Failure

"Success" is failure when the guarantee of success:

- Robs our children of learning what they are *not* capable of
- Gives them an inaccurately elevated sense of what they can do
- Prevents them from learning how to do something (or doing it better)
- Keeps them from developing pride in their achievements
- *Insulates them from learning what they need to succeed*
- *Prevents them from learning to persevere*
- *Inhibits resiliency*

All of these are necessary for self-advocacy

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Success & Failure

When is "Failure" success?

"I've missed more than 9,000 shots in my career."

"I've lost almost 300 games."

"Twenty-six times, I've been trusted to take the game's winning shot and missed."

"I've failed over and over again in my life..."

"...and that is why I succeed."

-- Michael Jordan

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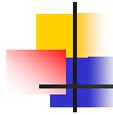


Success & Failure

When is "Failure" success?

- True failure is not falling down, even repeatedly.
- True failure is when we stop getting up and trying.
- Perseverance requires practice at "failure":
 - Resiliency

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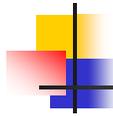
Success & Failure

“Failure” is success when it provides:

- An opportunity for true learning
 - of skills, or about self (self-knowledge)
- a foundation for perseverance, esteem and confidence based on *real* (independent) success
 - The Cub Scout Bird feeder
 - “I Can” child – which one?



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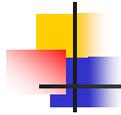


Success & Failure

Won't failure (or repeated failure) hurt esteem?

- False esteem defeats effective self-advocacy
 - An accurate perception of independent ability is critical
- Not if we free our children from the cultural bias against failure
 - Normalize failure!
 - Outside examples (e.g., science!)
 - Personal examples (our own!)

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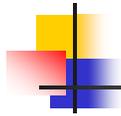
Success & Failure

How many of you are failures?

Think about yesterday's "to do list":

- Did you fail to get everything done?
- Were you bold in setting goals though?
- Was it ok and "normal" not to get everything done?
- Did you brag about your failures to your kids?
 - Cultural bias!

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Success & Failure

Normalizing failure (making it ok):

- Fosters confidence and risk-taking

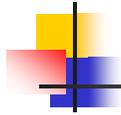
Risk taking (experimenting and creativity)

- Is crucial to learning how you can succeed and what you need to do it

Confidence, and knowing how you can succeed and what you need

- Is crucial to self-advocacy

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Review

Self-Advocacy requires:

- Accurate self-knowledge
- Self-confidence and resiliency

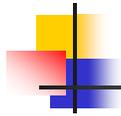
These are fostered by:

- Independence
- Freedom to truly succeed or fail

Two enormous influences working against us are:

- Parental instinct to protect
- Cultural bias against failure

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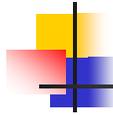


How Do We Do It?

When and how do we allow our children to fail (or succeed) in order to foster independence and self-advocacy?

- (Our children *will* fail – the question is how and when.)

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Ordinary & Catastrophic Failure

Distinguish between ordinary and catastrophic failure

- Allow them to fail when it's safe
- Raise an "I can" child"

- The toddler



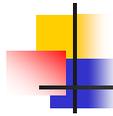
- The Cub Scout birdfeeder



- The bike



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Ordinary & Catastrophic Failure

Madeline Levine

The Price of Privilege

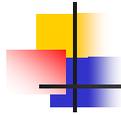
HarperCollins, 2006

- College dropout rates
- Catastrophic outcome rates
- Insulation from ordinary failure leads to catastrophic failure

It impairs development of resiliency

...and inhibits self-knowledge and self-advocacy

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Ordinary & Catastrophic Failure

Failure is safer in high school than college or adulthood

Failure is safer in middle school than high school

...and yet...

A note on Special Needs:

- Parental instinct to protect and support can be even greater
- Advancing independence and accurate self-knowledge is even more crucial

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Ordinary & Catastrophic Failure

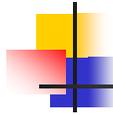
How can we shift our focus to allowing our children independence and ordinary failures?

How do we distinguish between them, and identify safe opportunities for failure?

(F's are scary!!!!)

One powerful tool...

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Product vs. Outcomes

Distinguish between product and outcome

- Most of what you can see is product – and doesn't matter
- Most of what is invisible is outcome – and is important

Fight the natural tendency to focus on the visible

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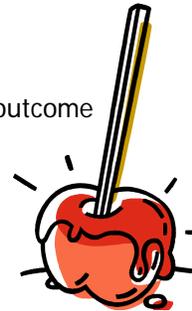
Product vs. Outcomes

The Cub Scout bird feeder

- The apple was the product
 - and it didn't matter
- The learning (and the message!) was the outcome
 - and it *DID* matter!

What did they see & learn?

- The parent
- The “enabled” cub scouts
- The “disabled” cub scout



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Product vs. Outcomes

Doing dishes:



- Clean dishes are a product
 - they don't matter (even if they're broken!)
 - Normalize failure
 - Encourage risk-taking
 - Focus on the outcome
- Learning responsibility, feeling capable and contributing to community was the outcome
 - and it *DID* matter!



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Product vs. Outcomes

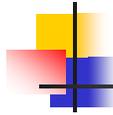
The 4th grade Mission project
(or the 6th grade Egypt Project)
(or the 9th grade Periodic Table):



- The project is a product
 - neither its appearance *nor the grade* matters
- The learning (about how they work and what they can do independently) is the outcome
 - and it *does* matter

(except coloring!)  (accommodations are ok!)

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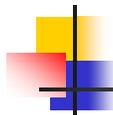
Product vs. Outcomes

A Side Note:

- Avoid “buts”



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Product vs. Outcomes

Can you see a grade?

Grades are products

- they don't matter!!!!

Learning, independence, confidence and resiliency are outcomes

- they matter!

Madeline Levine on grades:

- “What grade did you get on your test today?”
- “What did you learn today?”

Grades are a measure of an external rubric....

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Internal vs. External Identity



A pretty glass ball
or a steel spine?



Build your child from the inside out, not the outside in.

An effective self-advocate has defined who she is, not been told who she is or should be.

- How do we resolve a conflict between our "self" and others' expectations of us?
- How does that impact self-advocacy?



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Internal vs. External Identity

An effective self-advocate has a strong, *self-developed* sense of identity

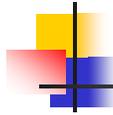
- She knows who she is internally, and knows her relationship to the world around her

This sense of position is her compass



- It allows her to steer her course, to advocate for herself, despite the shifting tides and winds of external force and opinion.

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Internal vs. External Identity

If we define ourselves and our success by external (culturally defined) rubric, our happiness and direction is contingent on others

- We have no internal compass by which to guide our self-advocacy



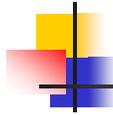
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Internal vs. External Identity

- Madeline Levine's work
product vs. outcome
- Peter Benson's work
40 Developmental Assets
www.Search-Institute.org
Focus on Assets, not curriculum

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Internal vs. External Identity

Pay attention to Adolescence!

- Developmental stages of identity
 - 1st: The mirror of parental reflection (elementary school)
 - 2nd: Shatter the mirror -- peer reflection (middle school)
 - 3rd: Shatter the mirror -- nuanced individuality (late high school)

In adolescence, their developmental job is to reject you, and become what you don't want them to be

(See that theme? Letting go.....)

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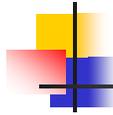


Internal vs. External Identity

This self-development of identity is critical to self-advocacy

- Honor the stage
 - don't force *your* vision of *their* identity upon them
- Doing this requires a "quiet" relationship
 - provide silent spaces, let them fill the silence, and listen!
- Afford increasing independence, to allow their identity to develop...
 - open your hand...
 - (let them go...)

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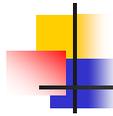


Independence

Find EVERY excuse for giving independence
-- and the self-learning that comes from it



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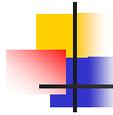
Independence

Boy Scouts of America



- One of the most thoroughly developed, studied, widely-implemented and effective developmental youth programs
- Tracks Peter Benson's work on assets
- Cub scouts (grades 1-5)
 - Family oriented, with increasing independence through ranks
- Boy Scouts (grades 5-12)
 - Boy led (*News Flash!!! Coming Soon.... Girl led!*)
- Engineer for success
 - Stand back and allow failure (and learning)

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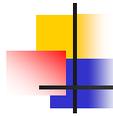
Independence

Have you met an Eagle Scout?

- Definition of an effective self-advocate



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Independence

Scouting's Founder: Lord Baden-Powell--

"Never do anything a boy can do."

- Profound philosophical approach
- Dovetails perfectly with "product vs. outcome" analysis
- Sends a profound message: "I believe in you"

- Baseball glove oil



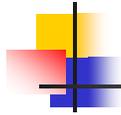
■ Skylight



- Driving



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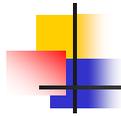
Independence

Never do anything for your child that (s)he can do herself

(Pause for thought)

- Chores
- Schoolwork
- Advocacy
- (and especially...) Thinking!

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Ask Don't Tell

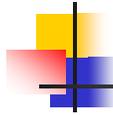
Never provide an answer to a question that they can answer themselves

-- even wrongly



- Respond to questions with questions
- Don't teach them -- ask them to teach you
- You will foster a "thinker" who has the habit of solving their own problems
 - i.e., a self-advocate

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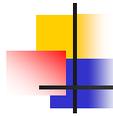


Foster Other Adult Relationships

BFO: The Outlier Principle:

- The more you do something, the better you are at it
- Self-Advocacy requires a comfort level in engaging authority figures
- You must give your children experience doing so
 - Scouting
 - Peter Benson's Assets
 - Get elementary kids an email account
 - Have them email teachers, coaches, etc.
 - Middle and high school – interviews for research projects

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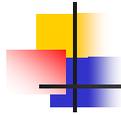


Review

Self-Advocacy requires:

- Accurate, internalized self-knowledge of abilities
- Broad self-confidence, risk-taking and resiliency
- Strong self-formed identity (focusing on internal rubric)
- Comfort in engaging authority

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Review

Key foundations are:

- Independence (“I can”)
- Freedom to succeed or fail (and build resilience)
 - accurate self-knowledge and confidence

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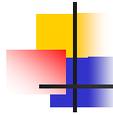


Review

Two enormous influences working against you are:

- Parental instinct to protect
- Cultural bias against failure

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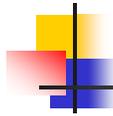


Review

Strategies to foster self-advocacy are:

- Normalizing failure (to encourage risk-taking and build resiliency)
- Distinguishing between ordinary and catastrophic failure (and allowing ordinary failure)
- Distinguishing between Product and Outcome (and focusing on Outcome)
- Promoting a self-developed internal identity (de-emphasizing external rubrics)
- Seeking opportunities for independence
- Asking, not telling (to promote habits of independent thinking and problem-solving)
- Creating a habit of engaging authority figures

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Discussing Disability With Your Child

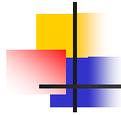
Will we risk limiting them by telling them they are “disabled”?

- Creating an “I can’t” or “I’m broken” child?

Will we risk their frustration or feeling stupid if we don’t tell them?

- They know they struggle; they need an explanation?

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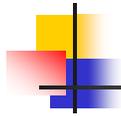
Discussing Disability With Your Child

Entirely dependent upon:

- Age
- Disability
- Cognitive ability
- Style (yours and theirs)

Rob Kessler's Vision

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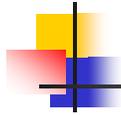


Discussing Disability With Your Child

Consider...

- Start by normalizing strengths and challenges – REALLY normalizing it
 - Highlight your own challenges, and those of other successful people
 - Highlighting and normalize different learning and thinking styles
 - The linear thinker (the engineer)
 - The linguistic thinker (the author)
 - The visual thinker (the artist)
 - The musical thinker (the singer or musician)
 - The emotional thinker (the therapist)
- Use lots of "little" conversational opportunities
- Always focus on strengths
- Not using the term "disabilities," but "different abilities" or "challenges"
- At the right developmental age, discussing "diagnosis"

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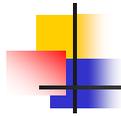


IEP (or 504) Meetings

When and how your child should participate in their own IEP or 504 meetings will be entirely dependent upon:

- Age
- Disability
- Cognitive ability
- Style (yours and theirs)

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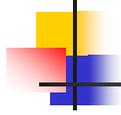


IEP (or 504) Meetings

Consider:

- Beginning in 6th grade
- Acknowledge beforehand the supports they receive for their challenges
- Tell them it's their opportunity to tell their support team what works for them, what they need
- Start with brief participation (not full meeting)
 - Have them relate how they feel their classes are going, what's working and not working for them
- Do NOT tell them what to say!
 - Don't confuse product with outcome!
- Acknowledge and praise their efforts, regardless of efficacy

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Questions & Conversations

Outrage?

Resonance?

Sparks?

But, but, but?

