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Dipesh Navsaria,
MPH, MSLIS, MD

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Libraries Lift Limits on Life



Libraries, Librarians, and Advocating for Change.



DIPESH NAVSARIA, MPH, MSLIS, MD

DEPARTMENT OF PEDIATRICS
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE & PUBLIC HEALTH

PRESIDENT
WISCONSIN CHAPTER OF
THE AMERICAN ACADEMY OF PEDIATRICS



www.facebook.com/DrLibrarian Twitter: [@navsaria](https://twitter.com/navsaria)
Live-tweeting encouraged!

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DISCLOSURE

I have nothing to disclose that would create a conflict of interest.

One tends to not make money doing health advocacy & messaging.

If anyone knows how to monetize advocacy & messaging in an ethical yet lucrative manner, please see me immediately afterwards.

DISCLOSURE

I will not discuss any unapproved uses of drugs or products in this talk.

(Except for perhaps a foam cow.)

TRUST ME

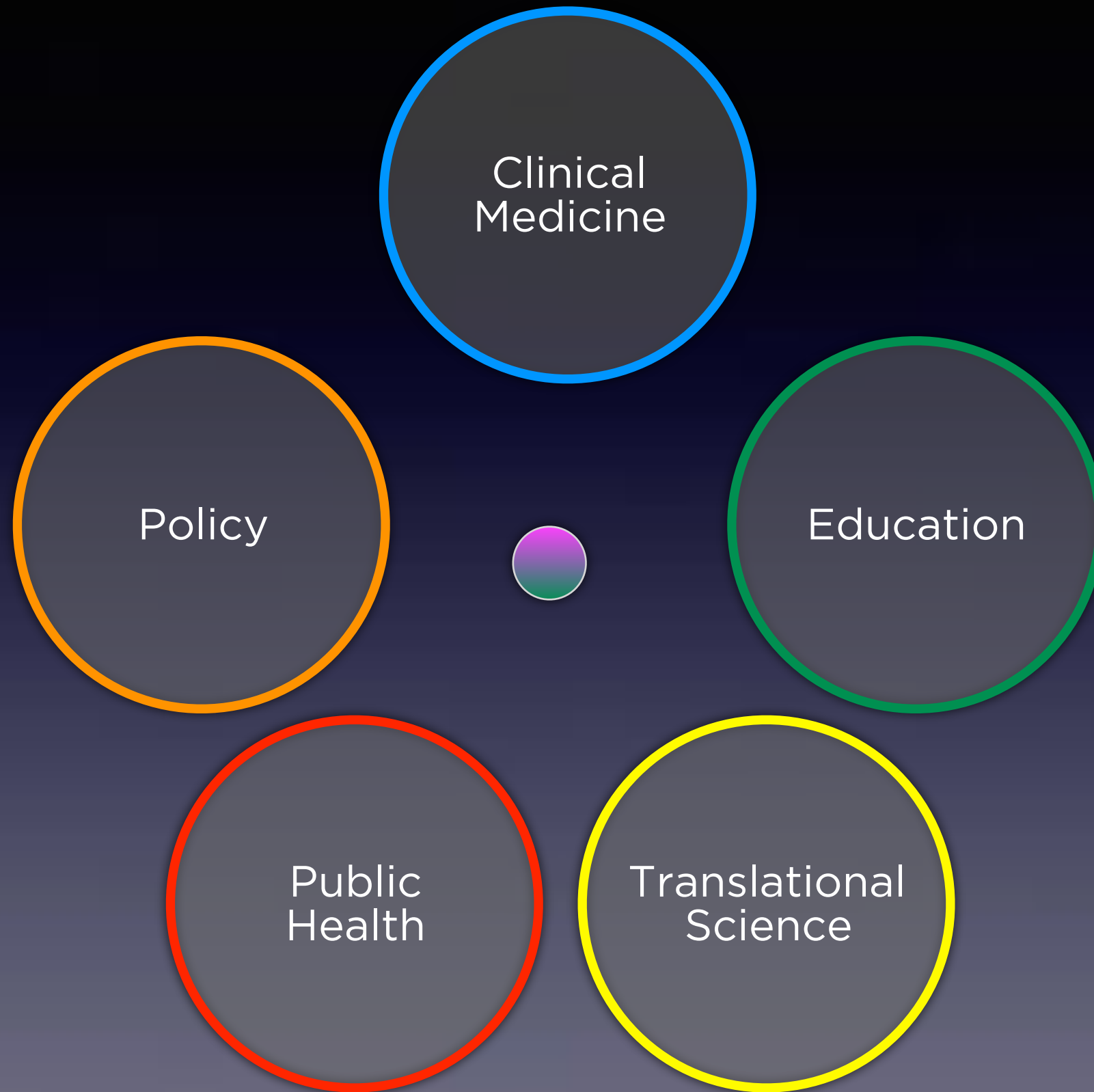
I WEAR A BOWTIE NOW

BOWTIES ARE COOL

DOCTOR

First, a story...











I have always imagined heaven
will be a kind of library.
— Jorge Luis Borges



My two favorite things in life are libraries and bicycles. They both move people **forward** without wasting anything.
— Peter Golkin







Me miserable! Which way shall I fly
Infinite wrath and infinite despair?
Which way I fly is hell; myself am hell;
And in the lowest deep a lower deep,
Still threat'ning to devour me, opens wide,
To which the hell I suffer seems a heaven.



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**“...the organization and access to
the world’s knowledge...”**

LIS 501: Information Organization and Access



education
“Any sufficiently advanced ~~technology~~ is
indistinguishable from magic.”

— Arthur C Clarke

What I learned in library school

LIS breaks down our silos better
than just about anyone

The LIS public service mission is
consistently better than just about
anyone

Saving other people's time
is a Good Thing™

Back to the story...



My house

My office

**Reach
Out
& Read®**



where great stories begin™



Reach Out and Read gives young children a foundation for success by incorporating books into pediatric care and encouraging families to read aloud together.

Prescription for Reading

Name: _____

Date: _____ Age: _____



Rx *Read Books*

- ☐ Every night at bedtime
- ☐ For _____ minutes every day
- ☐ As needed

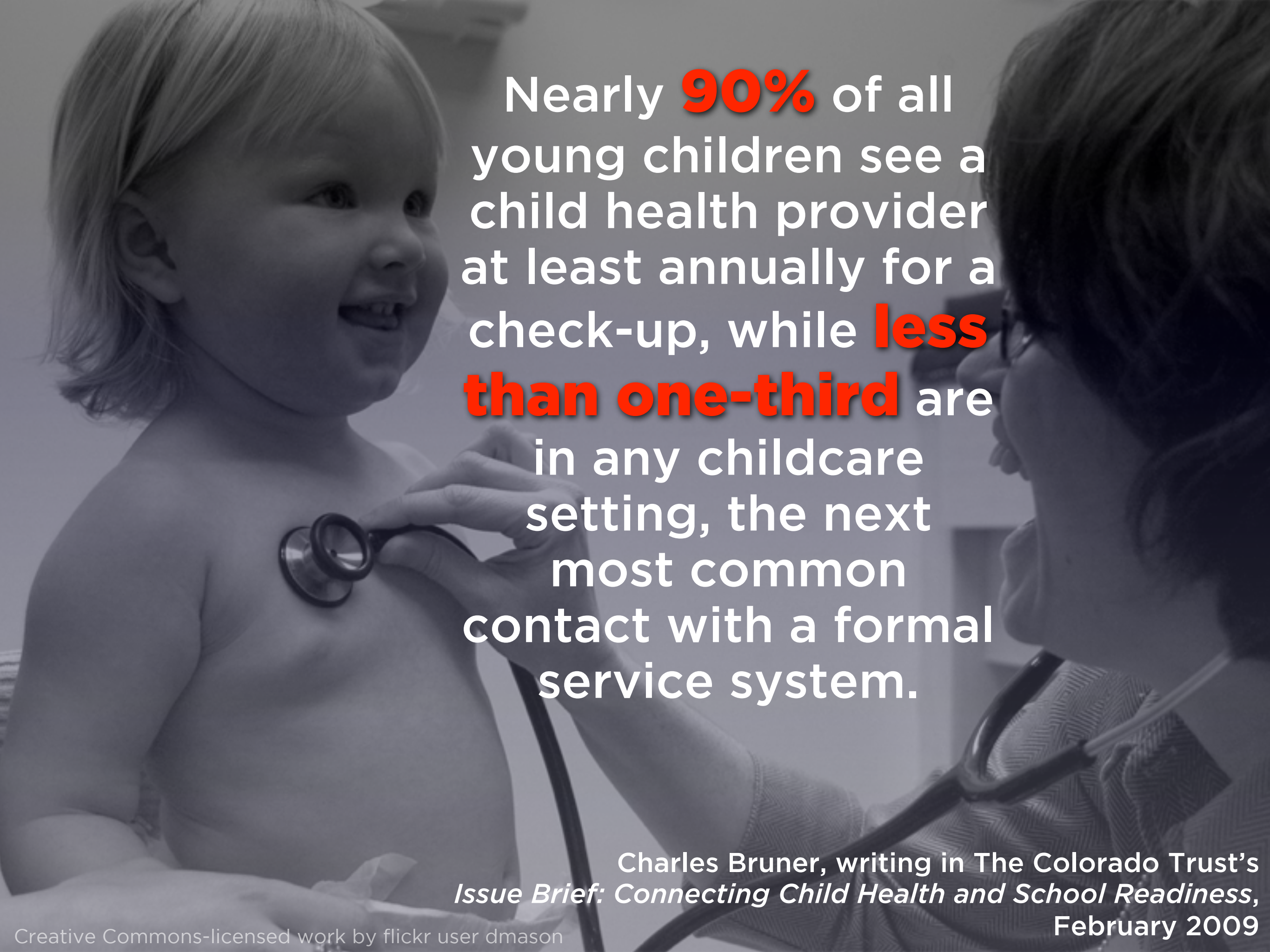
Refills: as requested at local public library

Signature: _____

Dipesh Navsaria, MPH, FELS, MD

Pediatrician & Occasional Children's Librarian

Finalized: Please visit reading.pediatrics.wisc.edu for more information on the joy of sharing books together and how it can make a huge difference in your child's life.



Nearly **90%** of all young children see a child health provider at least annually for a check-up, while **less than one-third** are in any childcare setting, the next most common contact with a formal service system.

Charles Bruner, writing in The Colorado Trust's
Issue Brief: Connecting Child Health and School Readiness,
February 2009

AD



CY



SAVE
BADGER
CARE
+



Don't make me use
my Librarian voice.

Librarians
in
Solidarity



Why?

Sutton's Law:

**Why did you
rob banks?**

**Because that's
where the
money is.**



Medicine is a social science, and **politics is nothing else but medicine on a large scale**. Medicine, as a social science, as the science of human beings, has the **obligation to point out problems** and to attempt their theoretical solution: the politician, the practical anthropologist, must find the means for their actual solution... The **physicians are the natural attorneys of the poor**, and social problems fall to a large extent within their jurisdiction.

— **Rudolph Virchow** (yes, *that* Rudolph Virchow)



ALA

American
Library
Association

It is not enough, however, to work at the individual bedside in the hospital. In the near or dim future, the pediatrician is to sit in and control school boards, health departments, and legislatures. He is the **legitimate advisor** to the judge and the jury, and a seat for the physician in the councils of the republic is what the people have the right to demand.

— Abraham Jacobi, 1904

It should be our aim to discover neglected problems and, so far as in our power, to **correct evils** and to **introduce reforms**.

— Issac Abt (the first AAP president), 1931

Child health advocacy will only be effective when a wide range of professionals, community leaders, and families band together to identify crippling inefficiencies and silly bureaucratic barriers, to attack basic injustices, and to **dream of the best for all children** no matter how young, **how vulnerable**, or how ill they are.

— Judith S Palfrey, MD

Advocacy is the application of information and resources (including finances, efforts, and votes) to effect systemic **changes that shape the way people in a community live.**

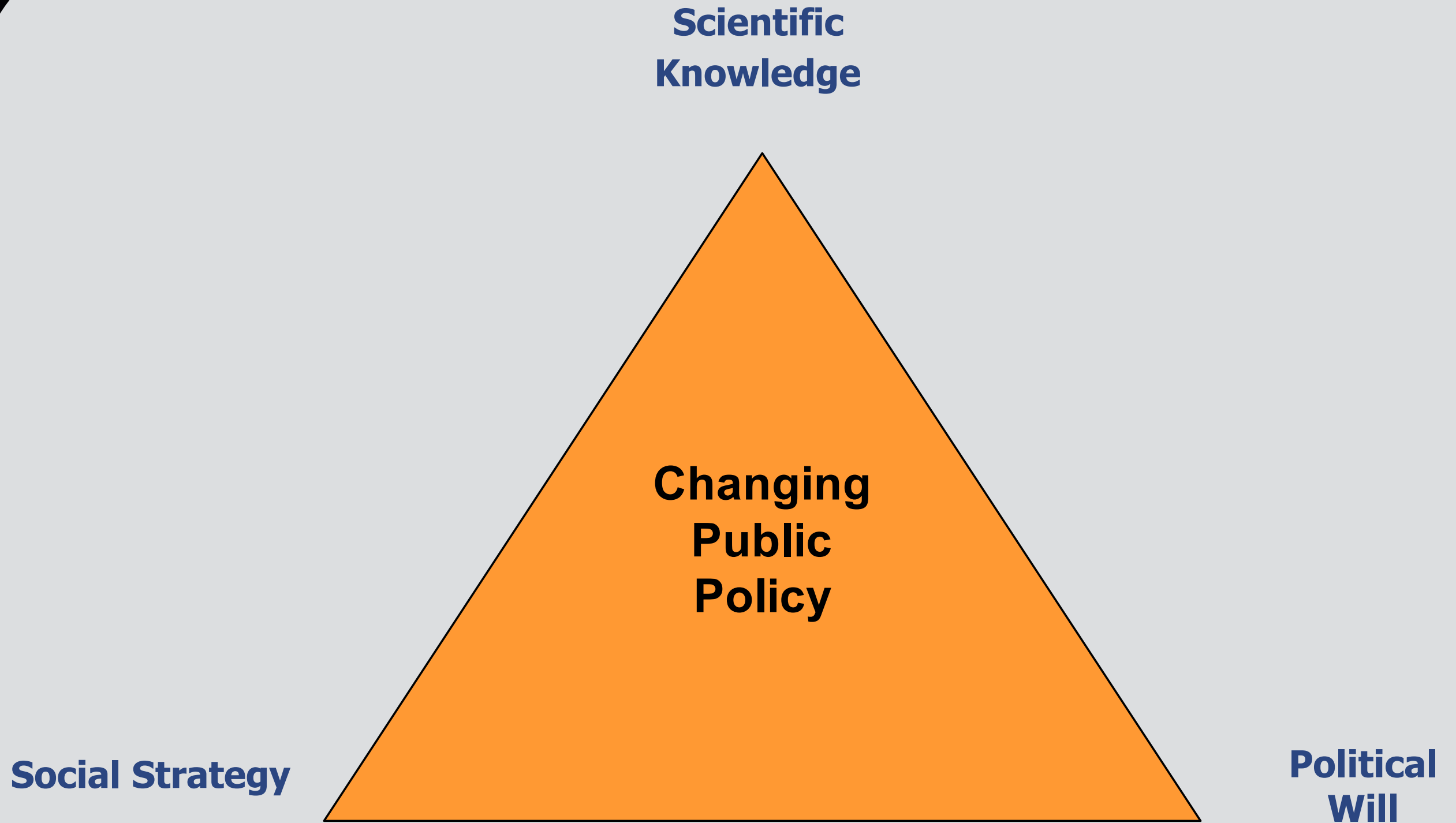
— Christoffel K. “Public Health Advocacy: Process and Product.”

I am no longer accepting the things I can not change. I am changing the things I can no longer accept.

— Source unknown

“Good Policy is Good Preventive Care.”

Julius B Richmond Model











AGENCY *vs* ADVOCACY

“Working the System”

vs

“Changing the System”

Traditional Media

And so
it began...

Dr. Dipesh Navsaria: Vote Nov. 8 with children in mind

DR. DIPESH NAVSARIA | local columnist | Oct 13, 2016



Toddlers and infants enjoy learning time at the Kilbourn Public Library in Wisconsin Dells as part of the library's summer 2016 youth-reading and literacy programs.

Kilbourn Public Library

Dipesh
Navsaria



As a pediatrician with strong interest in child health advocacy and policy, I've watched the debates between our presidential (and vice presidential) candidates with interest. Talking points,

Dear Dr. Navsaria:

This past weekend, hundreds of thousands of people across the country - including many pediatricians - rallied and marched together to **speak out against gun violence**. Leading the way and taking the microphone on every stage were children and teens who have lost friends and family members to gun violence, demanding policy change to keep them safe, transforming their grief and anger into meaningful action.

Pediatricians, pediatric medical subspecialists, pediatric surgical specialists, and pediatric trainees marched with these students and will continue to fight for them in the days and weeks ahead.

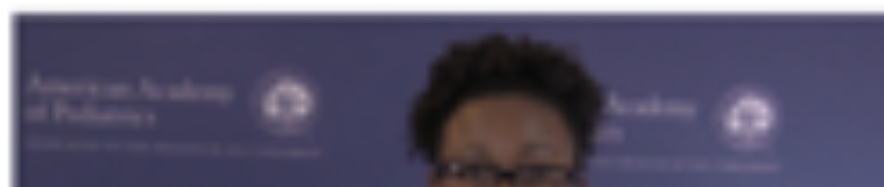
Your advocacy amplified these efforts more than we could have ever imagined. Many of you marched in Washington, DC, and in your home cities alongside your families and colleagues. A few of these moments are captured in this [Facebook photo album](#). Others had letters-to-the-editor published in their local newspapers, such as [The State](#), [The Baltimore Sun](#) and the [Portland Press Herald](#). And many of you participated virtually, sharing messages throughout the day online and encouraging others to join you.

Several of your voices are featured in this [new video](#) that the Academy debuted last Friday. Garnering 430,000 total views on social media and counting, it has become the Academy's most-watched video and most popular post on Twitter by far. An impressive 53 [individual videos](#) from Academy members can also be found on our YouTube channel, echoing perspectives as varied as the toll of gun violence on communities.

We will not stop here. These efforts are part of the robust and sustained advocacy we are undertaking to protect children everywhere from gun violence. The Academy's new [Gun Safety and Injury Prevention Research Initiative](#) will play a critical role as part of this work, and we will continue to keep you updated on this undertaking. To contribute to these efforts, visit our donation page and make a [donation](#) by selecting "Gun Safety & Injury Prevention Research Initiative" from the drop-down menu.

In addition, **there are several ways you can help keep up the momentum for needed action:**

- **Lift up each other's voices.** Consider





COLUMN

Dr. Dipesh Navsaria: Papers, pixels, and pediatrics

By Dr. Dipesh Navsaria | local columnist Nov 6, 2017

Rather than become lost in the electronic versus paper book wars, we would do well to ensure that every child has an adult in their lives who knows how to read well with them and can do so routinely.



COLUMN

Dr. Dipesh Navsaria: Revisiting the value of home visiting

By Dr. Dipesh Navsaria | local columnist Oct 6, 2017

Congress should reauthorize funding for the Maternal, Infant, and Early Childhood Home Visiting Program, which plays an important role in maternal and child health, prevention of child abuse and neglect, coaching and modeling of positive parenting, and promoting child development and school readiness.



COLUMN

Dr. Dipesh Navsaria: The American Health Scare Act

DR. DIPESH NAVSARIA | local columnist Mar 8, 2017

When it comes to children and families, the proposed Obamacare replacement looks fairly grim.

Writing newspaper column provides another outlet for child health work

Dipesh Navsaria, M.D., M.P.H., M.S.L.I.S., FAAP

Mastering the Media

Some pediatricians may have had some success in writing letters to the editor or op-eds for newspapers (See Mastering the Media column "Connect with newspapers to share your child health expertise," <http://bit.ly/2mBunIK>.) What if you'd like to go further and be a regular columnist?

Being a regular columnist does have advantages. You generally are guaranteed that your column will run, so the anxiety of whether it will be accepted usually is not a factor. Also, a newspaper investing in you as a regular columnist sends a message that it believes that what you have to say is worth hearing on a regular basis.

- Choose a topic, theme or format for your pitch. While you don't need to be too specific, it helps editors to know what types of topics you'll be focusing on. My column is on child health policy issues, but I define that broadly. I clearly said this wasn't a medical advice column, because some editors might assume that when first speaking to a clinician.
- Make sure your columns are your own original writing and not borrowed from elsewhere, whether it be a "template" or even your own writing from elsewhere.

Dr. Dipesh Navsaria: Hungry children can't learn

Consider what that same set of sensations may be like for a child. Younger children may not have the words to properly describe the feelings they are experiencing, and likely don't make the connection between hunger

~~and their mood, discomfort and difficulties. It's not~~

Children need adequate food to grow, to learn, to live, and to thrive. We know this. We should not allow poorly construed, experimental government policy to harm them. I call on Congress to reconsider these provisions: Creating additional hungry children shouldn't be considered an acceptable risk.

school test scores due to timing of when in the month nutrition supports were provided — and hence whether there temporarily was adequate food in the home.

As a pediatrician, I am more familiar with hungry children than I ever thought I would be. Many clinics —

Maria Roza: Redesign juvenile facilities to promote rehabilitation

Maria Roza | UW-Madison medical student | **Sep 25, 2018** | 2 min to read

VIEW 1 MONTH FOR \$9.99



The Lincoln Hills School for Boys and Copper Lake School for Girls.

ASSOCIATED PRESS



The decision has been made to close the Lincoln Hills School for Boys and Copper Lake School for Girls campus by 2021 due to numerous incidents of abuse and mistreatment of juveniles by staff at the youth detention center that have surfaced since 2012. While Wisconsin moves forward with re-designing the juvenile justice system, it is important to recognize that simply making sure the abuse seen at Lincoln Hills does not recur is not enough. Wisconsin has an opportunity to design a system that focuses on respect and rehabilitation rather than control and order.



LATEST FROM

E.J. Dionne Jr. Donald
Trump's (in)security

Chris Calvey: Spend
against Brett Kavanaugh

'Shute Kitchen' and
girlfriend

Sen. Joe Brysonback
consistently sided e

'There is no much as
operating budget pe

FEATURED C

'Shute Kitchen' a

"This is a public health disaster, but it can be. There are many
high-performing health systems who reflect the best."
—Richard H. Smith

MONA HANNA ATTISHA

WHAT THE EYES DON'T SEE

*A Story of Crisis,
Resistance, and Hope in
an American City*



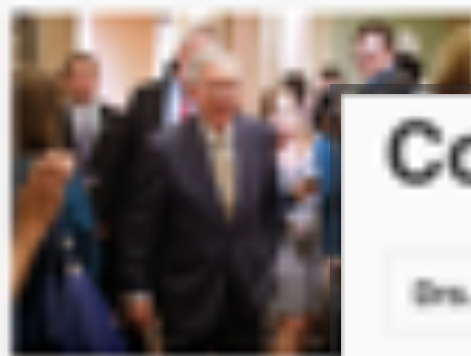
OTHER MESSAGING



Serendipity

Senate health bill would be devastating to children on Medicaid

Drs. Mala Wadhwa, Dipesh Navsaria and Sarah Campbell, for USA TODAY NETWORK-Wisconsin Published 10:30 a.m. CT July 14, 2017



(Photo: Dap Images/Stockphoto)

Currently, the Senate bill that includes unproven coverage for 37 million Wisconsin, 28% of a BadgerCare Plus), these children.



Column: Maintain funding for children's health care

Drs. Mala Wadhwa, Dipesh Navsaria & Sarah Campbell, For USA TODAY NETWORK-Wisconsin Published 3:05 p.m. CT Sept. 18, 2017



(Photo: Dap Images/Stockphoto)



It has been a remarkable journey for children's health care in our country this year. The recently proposed health care bills that were not passed by the Senate this summer have allowed millions of children in our country — [and over 541,000 children in Wisconsin](#) — to continue receiving much-needed health care

coverage. However, we are now faced with another health care crisis for children: the possible loss of funding for the Children's Health Insurance Program, which will run out later this month on September 30th.

[The Children's Health Insurance Program \(CHIP\)](#) was created 20 years ago to help children whose families earn too much to qualify for Medicaid but who earn too little to afford private health insurance. CHIP has been a successful bipartisan solution to a growing issue for low-income working families. It has a proven record of being cost-effective and provides access to high-quality care to this population. These families are an integral part of our communities, our workplaces and our schools.



200th ANNIVERSARY
EVENT

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Framing

ROMANTIC COMEDY...OR HORROR FILM?



You Say...They Think (Immigration)

You Say...	They Think...	What's Triggered in Their Minds?	What Helps?
Immigration is inevitable, and we need to have a well-functioning system to make sure it happens in a way that is fair to everyone.	Look, there are immigration laws in place, and people who don't follow them shouldn't get a free pass. If I break the law, I'd go to jail, so why shouldn't they?	Immigrants Are Them Law-Breakers / Politics As Usual Security and Control	<ul style="list-style-type: none"> • Use the Value Pragmatism to appeal to the public's belief in using commonsense approaches to fix problems. • Use an Explanatory Chain to show how the system itself is outdated, leading to millions of people who are here on expired visas, and why modernizing it will be good for the country.
We need immigrants. They contribute to our economy and diversify our society and culture.	Diversity is great, but there just aren't enough jobs to go around. We need to take care of our own people first before we start giving our jobs and resources to newcomers.	Zero-Sum Game Economic Threat Immigrants Are Them Black Box / Invisible Process	<ul style="list-style-type: none"> • Use a Shared Prosperity Narrative to inoculate against "Them" models of thinking and to trigger the public's ability to recognize comprehensive immigration reform as an important part of building a strong economy. • Apply the Explanatory Metaphor Immigration Sail to illustrate immigrants' contributions to our society and to explain how comprehensive reform will allow them to contribute even more.
The system is broken. The employment visa process doesn't match our country's economic needs, and enforcement policies are costly and ineffective.	Once again, the government proves it can't do anything right. We need to fix our leaky borders.	Government = Ineffective Fatalism Security and Control	<ul style="list-style-type: none"> • Use the Value Pragmatism to counter overly partisan messages. • Finish the story by using a Shared Prosperity Narrative to build support for policy solutions, including pathways to citizenship, that will allow us to address our changing economic needs.
Our current system denies immigrants their basic rights, and that makes them vulnerable to worker exploitation.	Sure, all people deserve respect, but if you're not a citizen, then why should you get the same rights as Americans?	Immigrants Are Them Takers Economic Threat	<ul style="list-style-type: none"> • Use the Value Moral Argument without reference to human rights to cue up productive "Immigrants Are Us" and humanitarian models of thinking that prime the public to consider policy solutions. • Use the Explanatory Metaphor Immigration Sail to discuss how immigration reform will help our entire country to move forward.

IMMIGRATION SAIL

Immigration is wind in our country's sails — it's the labor, skills and ideas that move our country forward. But right now our sails are poorly positioned — and our policies are letting valuable wind power go to waste. We need to fix the policies and laws that make up our sails so that all of our wind power can fill our sails and move our country forward.



QUESTION

Can't we just enforce the laws already in place to fix the immigration system?

ANSWER

THE FALSE START ANSWER

The laws we have in place right now aren't doing the job. For example, our organization recently worked with an undocumented immigrant named Maria, whose removal was being expedited because she had been previously deported by the border patrol without a judicial hearing over a decade ago. Therefore, she was subject to reinstatement of removal. Maria's husband, who is here legally, explained to me that he suffers from numerous ailments and Maria cares for him. If she were sent back to Mexico, he would lose his primary caregiver. Maria, who has been here for years, has a U.S. citizen child and a child with DACA, but she faces deportation and separation from her children.

The system is broken. The U.S. government has failed on immigration. Meanwhile, families have been torn apart as millions have been deported. Each year, businesses have to wait for a random lottery to determine whether they will be granted the privilege to pay an average of more than \$2,000 in filing fees just for the government to decide if they will

THE REFRAMED ANSWER

Right now, our immigration system isn't meeting our country's needs, and it is time for us to take a commonsense approach to fixing the problem. For example, the process for obtaining and renewing visas is so cumbersome that many immigrants who have been here for years lose their legal status even though they have been working in the United States and contributing to our economy for a long time. They are then subject to deportation, which has unintended consequences: sending everyone without documentation back to their country of origin means that businesses lose workers, our economy loses entrepreneurs, communities lose valuable customers, and thousands of families are forcibly separated every year. This is impractical and it is actually working against our goals. We need a system that works for our economy and our communities.

Modernizing the system can help by making it simpler to obtain and renew visas, by increasing the number of



- **GO:** Pair the value of **Moral Responsibility** with explanations of the effects of adolescent substance use.
- **GO:** Use the **Boiling Over** metaphor to correct misperceptions and boost understanding.
- **GO:** Explain primary care providers' role in preventing adolescent substance use.
- **GO:** Feature pediatricians and adolescents as messengers.
- **GO:** Use alternatives to the word "screening" whenever possible.



- **CAUTION:** The order of your message matters, so curb the impulse to open with an appeal to the value of prosperity.
- **CAUTION:** Think twice before hitting the gas on analogies to other health problems, which is a largely ineffective strategy.



- **STOP:** Don't appeal to the value of health and happiness.
- **STOP:** Don't let the term "screening" drive solo.

- The pot won't heat up if the stove isn't turned on. This metaphor can be used to explain how prevention works and to talk about the relationship between social factors and adolescent development.
- Even when things start simmering, adjusting the heat can temper the situation. This metaphor can be used to explain that intervention can make a difference and good outcomes are possible at any point.
- Lowering the heat can be a simple but effective correction. The metaphor can be used to introduce the idea that intervention can be as simple as a conversation between a pediatrician and an adolescent patient about substance use, fostering public optimism that feasible interventions exist.
- Evidence-based programs and policies can prevent adolescent experimentation from boiling over. Use the metaphor to keep the focus, and the responsibility, on contextual factors.

Social Media

Social Media and Medical Professionalism: Rethinking the Debate and the Way Forward

Tara Fenwick, MEd, PhD

Abstract

This Perspective addresses the growing literature about online medical professionalism. Whereas some studies point to the positive potential of social media to enhance and extend medical practice, the dominant emphasis is on the risks and abuses of social media. Overall evidence regarding online medical professionalism is (as with any new area of practice) limited; however, simply accumulating more evidence, without critically checking the assumptions that frame the debate, risks reinforcing negativity toward social media.

In this Perspective, the author argues that the medical community should step

back and reconsider its assumptions regarding both professionalism and the digital world of social media. Toward this aim, she outlines three areas for critical rethinking by educators and students, administrators, professional associations, and researchers. First she raises some cautions regarding the current literature on using social media in medical practice, which sometimes leaps too quickly from description to prescription. Second, she discusses professionalism. Current debates about the changing nature and contexts of professionalism generally might be helpful in reconsidering notions

of online medical professionalism specifically. Third, the author argues that the virtual world itself and its built-in codes deserve more critical scrutiny. She briefly summarizes new research from digital studies both to situate the wider trends more critically and to appreciate the evolving implications for medical practice. Next, the author revisits the potential benefits of social media, including their possibilities to signal new forms of professionalism. Finally, the Perspective ends with specific suggestions for further research that may help move the debate forward.

that the medical community should step
in this Perspective, the author argues
toward a new way of thinking about social media
professionalism that moves the debate forward

re thinking in reconsidering notions
of professionalism generally within
the changing nature and contexts
of professionalism. Current debates about
the changing nature and contexts of professionalism

the debate forward.
Further research that may help move
the debate forward. Finally, the Perspective
ends with specific suggestions for
further research that may help move the debate forward.

“The most important question may not be how to protect professionals online but, rather, how social media can open new debates about medical professionalism for better patient care and healthier societies.”

societies”

patient care and healthier

Climbing Social Media in Medicine's Hierarchy of Needs

Katherine C. Chretien, MD, and Terry Kind, MD, MPH

Abstract

The social media and medicine landscape is evolving rapidly. Early research, social media policies, and educational efforts focused on risk avoidance, while more current efforts have encouraged reflection and explored opportunities. This trajectory has affirmed physicians' professional commitment to maintaining public trust in the face of new challenges in the digital age. In this Commentary, the authors propose viewing physicians' social media use as a hierarchy of needs, similar to Maslow's psychological theory which posits that more basic

levels of needs must be met before higher, aspirational levels can be fully attained. The three levels in the social media in medicine's hierarchy of needs are Security, Reflection, and Discovery. Critical to this model is respecting the essential need for Security in order to move towards Reflection and into Discovery. The social media in medicine hierarchy of needs pyramid rests on a foundation of Public Trust. How physicians as a profession have responded to past—and continue to respond to present and future—social

media challenges to professionalism reveals what matters most: maintaining public trust and honoring the physicians' contract with society. A victory for online professionalism would be providing trainees with the tools and guidance needed to ascend to Discovery, while ensuring that their basic social media needs are first met. To do this, physician educators need to continue increasing trainees' awareness through designing relevant curricula, encouraging reflection, and providing positive role modeling and effective mentorship.

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needs' similar to Maslow's psychological
social media use as a hierarchy of
the authors propose viewing physicians'

responded to present and future—social
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How physicians as a profession have
rests on a foundation of Public Trust.

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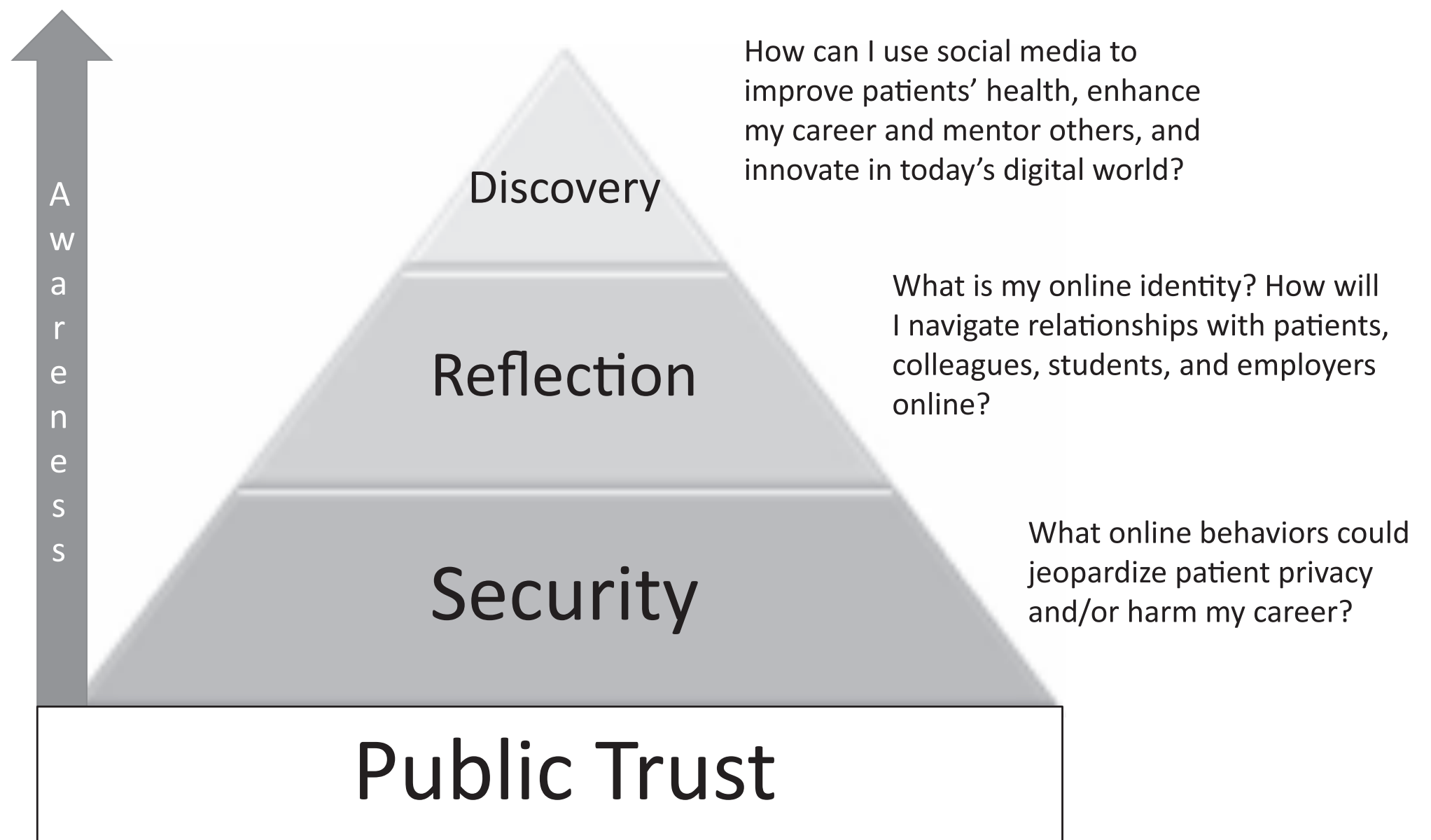


Figure 1 Social media in medicine hierarchy of needs pyramid.

Why not set up your own social networking site?



The Scream, by Edvard Munch. Out of copyright.



 **CDC** @CDCgov · 10h

The VFC program provides vaccines for eligible kids thru VFC-enrolled doctors. See if your child is eligible: 1.usa.gov/1fAGj7A
[#CDCvax](#)



13



5



 **CDC** @CDCgov · 10h

Consider sharing this [#CDCvax](#) video to spread the word about the importance of immunization:
bit.ly/1IOpH4m



Amer Acad Pediatrics @AmerAcadPeds · Apr 29

RT @nacersanobaby RT @nacersano: El alcohol pasa de la madre al bebé a través del cordón umbilical. #pregnancychat

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Retweeted by Amer Acad Pediatrics



Dr. Coleen Boyle @DrBoyleCDC · Apr 29

You may not know early on if your child has effects. Some FASD effects may not show until school age #pregnancychat 1.usa.gov/Q7hytl

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Amer Acad Pediatrics @AmerAcadPeds · Apr 29

Watch the FASD prevention video cautioning women not to drink while pregnant healthychildren.org/fasdrisk #pregnancychat

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Christina Wilson [@mrsjcwilson](#) · 1d

[@JerryMcCarthy](#) asks folks everywhere for ideal mate qualities w/ [@JerryKates](#). Responses awesome! <https://twitter.com/jerrykates/status/1442444444444444444>

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m. bryant [@PardParks](#) · 1d

100% RT [@ThePolymath](#). I look for intelligence and someone who is up to date with their vaccinations. [@JerryKates](#)

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William Reynolds [@wreynolds](#) · 1d

[@JerryKates](#) [@JerryMcCarthy](#) Someone that cares enough about children to vaccinate against severe and preventable diseases would be nice.

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Just What Writing [@justwhatwriting](#) · 1d

Jerry McCarthy asked people what they looked for in an ideal mate w/ [@JerryKates](#). "Someone who won't give my kids measles!" sums up right.

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Andy Elliott [@ahargr12](#) · 1d

[@JerryMcCarthy](#) Intelligence, as in knowing how vaccines work. [@JerryKates](#)

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Kristen Ellis (@kristen_ellis) · 1h

What do I look for in a mate? Maybe someone with a/I measure? Well, with the common sense to recognize that too. [@JerryMcCarthy](#) [@JerryKates](#)

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Luke Lewis (@lukelewis) · 1h

[@JerryKates](#) smart enough to ignore pseudoscience [@VaccinateYourKids](#)

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Mike Campbell (@mikecampbell) · 1h

[@JerryMcCarthy](#) my dad's partner isn't a mass murderer. He yea [@JerryKates](#)

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Chris Espenrich (@cespenrich) · 1h

Opposed to scientific data. RT [@JerryMcCarthy](#) What is the most important personality trait you look for in a mate? Reply using [@JerryKates](#)

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👍 Reply 🗨️ Retweet 📌 Favorite 🔍 More



Katherine Bates (@katherinebates) · 1h

[@JerryKates](#) I'm going to with intelligence. As in, someone who understands some basic facts about medicine and immunology.

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Social Media Methods for Studying Rare Diseases

Authors: Kurt R. Schumacher, MD, MS,¹ Kathleen A. Bringer, PharmD,² Janet E. Donohue, MPH,³ Sunkyung Pa, MS,¹ Ashley Shaver, BS,¹ Regine L. Canuthers, PharmD,¹ Brian J. Diamond-Fisher, PhD,¹ Carlen Fifer, MD,¹ Daren Goldberg, MD, MS,² and Mark W. Russell, MD¹

¹Congenital Heart Center, C.E. Mark Children's Hospital, ²College of Pharmacy, and ³University of Michigan School of Public Health, University of Michigan, Ann Arbor, Michigan

KEY WORDS

rare disease, social media, Fontan

abstract

For pediatric rare diseases, the number of patients available to support traditional research methods is often inadequate. However, patients who have similar diseases cluster "virtually" online via social media. This study aimed to (1) determine whether patients who have the rare diseases Fontan-associated protein losing enteropathy (FLE) and plastic bronchitis (PB) would participate in online research, and (2) explore response patterns to examine social media's role in rare

book, internet forums, and traditional websites. Overall, social media outlets referred 84% of all responses, making it the dominant modality for recruiting the largest reported contemporary cohort of Fontan patients and patients who have FLE and PB. The methodology and

data collection instruments aided in data collection, aided in statistical analysis, and reviewed and revised the manuscript. Ms Pa aided in statistical analysis and reviewed and revised the manuscript. Dr Diamond-Fisher aided in design of the data collection instruments and reviewed and revised the manuscript. Ms Shaver aided in data collection and study recruitment and reviewed and revised the manuscript. Dr Canuthers aided in study design and conceptualization and reviewed and revised the manuscript. Dr Fifer aided in study design and conceptualization and reviewed and revised the manuscript. Dr Goldberg aided in study design and conceptualization and reviewed and revised the manuscript, and all authors approved the final manuscript as submitted.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NCI or the National Institutes of Health.

and 46 who had PB. Responses over time demonstrated periodic, marked increases as new online populations of Fontan patients were reached. Of the responses, 574 (80%) were from the United States and 97 (14%) were international. The leading referral sources were Facebook, internet forums, and traditional websites. Overall, social media outlets referred 84% of all responses, making it the dominant modality for recruiting the largest reported contemporary cohort of Fontan patients and patients who have FLE and PB. The methodology and response patterns from this study can be used to design research applications for other rare diseases. *Pediatrics* 2014;133:e1340–e1350



RT @andyneddie: Thanks for tuning in! For a more complete documentation of our experience learning about #weemilk for #UWSMPH&C head to <http://t.co/CY2oFDEw>

13-Oct-11 21:54 | andyneddie



Feel strongly about #weemilk ? Tell your state legislature what you think. Voicing your opinion does the governing body good! #weemphic

13-Oct-11 21:54 | andyneddie



Even Abba urging the Feds to allow more #medicalmarijuana research. <http://t.co/nEwDGGY> #UWSMPH&C

13-Oct-11 21:54 | MZweHC



RT @jcpmed2014: Med students speak their minds with legislators. <http://t.co/yKc5dlay> #UWSMPH&C #medicalmarijuana

13-Oct-11 21:54 | UWSMPHStudentGroup



@brevalentine Agree re local farmers. #weemilk #weemphic

13-Oct-11 21:54 | weemphic



please dont test and drive! #weemphic #wed #wehc2011 #reallboyfriend

13-Oct-11 21:54 | wephette



Thanks for tuning in! For a more complete documentation of our experience learning about #weemilk for #UWSMPH&C head to <http://t.co/CY2oFDEw>

13-Oct-11 21:54 | andyneddie



RT @BrianTully: Is childhood obesity a problem? duh! Here's a way to combat it with NZ/CM at WISC Channel 3 <http://t.co/LZ9Jekb> #UWSMPH&C #childhoodobesity



Mooley: similar brain circuits activate during pain to self or viewing pain to others. #empathy #doctor #patient #gha10yrs

25-Oct-12 18:25 | GoodCareMed



There is a lot of neuroscience in Dr Mooley's talk that I can't put into 140 characters, let alone 140,000 characters. #gha10yrs

25-Oct-12 18:40 | GoodCareMed



@suzanahm: Article in @JAMA on exquisite empathy & clinician-patient interaction #gha10yrs
<http://t.co/Q8P3Lm72>

25-Oct-12 18:49 | suzanahm



@suzanahm: Empathy training for resident physicians - Raise JGenIntMed #gha10yrs #meded
<http://t.co/5dVtpp>

25-Oct-12 18:50 | suzanahm



RT @suzanahm: @suzanahm: Article in @JAMA on exquisite empathy & clinician-patient interaction #gha10yrs
<http://t.co/Q8P3Lm72>

25-Oct-12 18:50 | GoodCareMed



"@suzanahm: @F10medicine epitomizes bold integrity, courage in creating a new curriculum for #meded design #gha10yrs"

05-Oct-12 18:52 | igcommunity

02-Oct-12 18:25 | @community



Dr. Dave Stulus  @AllergyFoodDoc · Sep 18

There is zero indication to ever order a **Food allergy** panel or large assortment of food allergy tests. The history should guide the testing. If a result is obtained, it must be interpreted properly - foods should **NOT** be removed from the diet if not causing symptoms!



[Show this thread](#)



Dr. Dave Stulus  @AllergyFoodDoc · Sep 18

Skin tests and blood tests both reliable when used properly but neither are screening tests due to high false positive results. They also **do NOT** indicate how severe someone's **Food allergy** is, there is no such thing as an allergy test showing a 'deadly' allergy.

Skin Prick and Serum IgE Testing – Similarities

- High negative predictive value
- Low positive predictive value
- Size of test confers likelihood of allergy being present
- **Test result DOES NOT determine severity of reaction**
- High correlation between these tests
 - Especially when negative

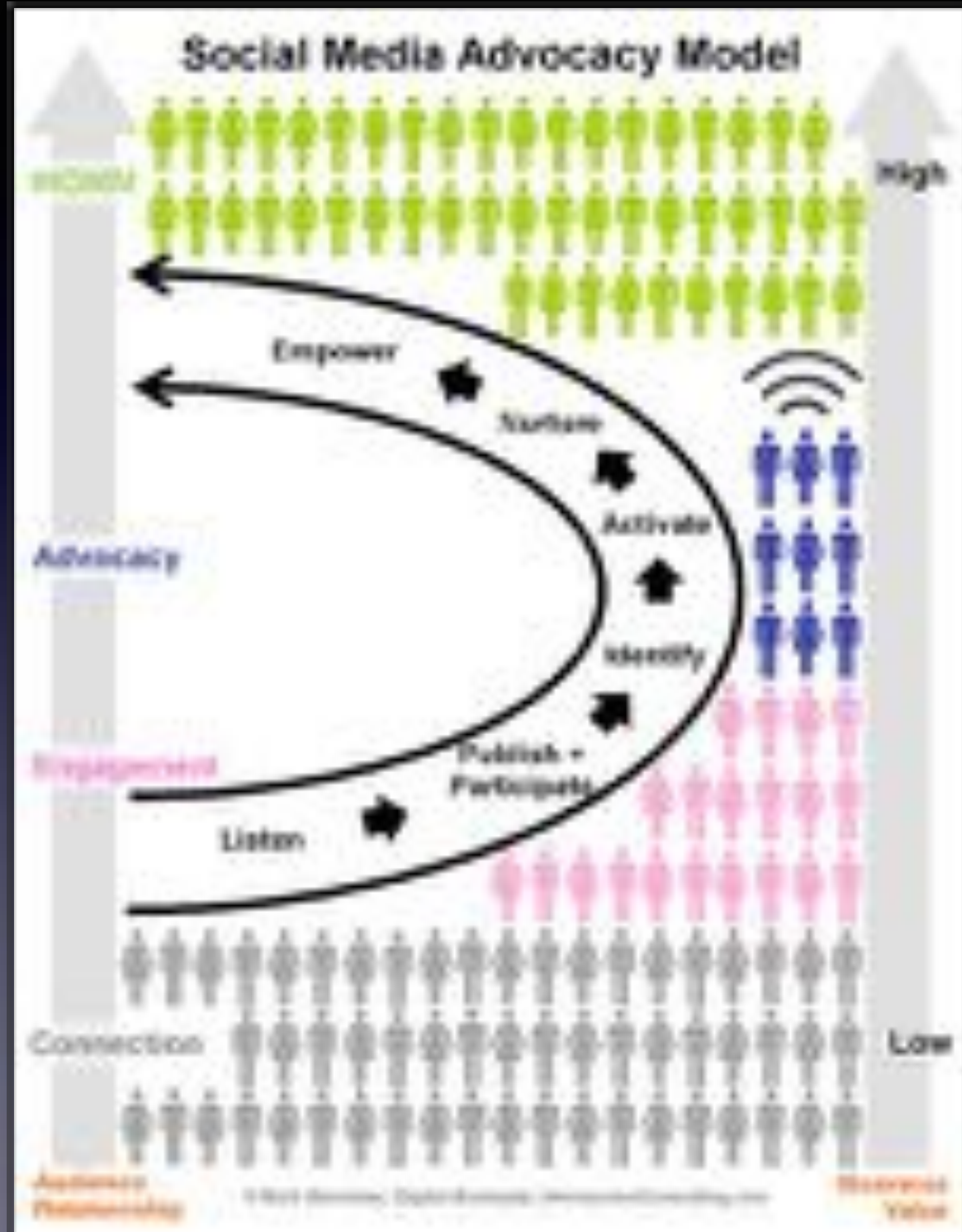


ONE DOES NOT SIMPLY

SET UP SOCIAL MEDIA WITHOUT A PLAN

imgflip.com

One model:



ANOTHER VIEW



SOCIAL MEDIA ADVOCACY



**YOU MEAN TO SAY MY DOCTOR
DOESN'T USE SOCIAL MEDIA**

TO HELP KIDS???

memegenerator.net

**I DON'T POST MUCH
ON SOCIAL MEDIA**



**BUT WHEN I DO, I MAKE
SURE IT'S WORTH READING.**

AN UNFORTUNATE EXAMPLE



But...what are we allowed to say?

Creativity

DR MOO
HERE AGAIN.

BUT
THEY'RE ONLY
19% OF
COSTS!

I DON'T
UNDERSTAND WHY
CUTTING CHILDREN
FROM MEDICAID
MAKES ANY
SENSE.

THIS MAKES
NO ECONOMIC
SENSE.

I HOPE CONGRESS
IS LISTENING!

NATIONALLY, 43%
OF MEDICAID
ENROLLED ARE
CHILDREN.

#KEEPKIDSCOVERED

RESTORE FUNDING FOR CHIP!

CONGRESS,
YOU LET FUNDING FOR
A SUCCESSFUL, BIPARTISAN
PROGRAM THAT COVERS
HEALTH INSURANCE FOR 9
MILLION CHILDREN EXPIRE
LAST WEEKEND.

PLEASE GIVE STATES
CERTAINTY BACK BY
PASSING A FULL, FIVE-YEAR
FUNDING EXTENSION TO
CHIP...AND THE MIECHV
HOME-VISITING PROGRAM
AS WELL!

PLEASE
DON'T ADD
UNRELATED
PROGRAMS TO THE
FUNDING BILL,
EITHER.

WE COWS
DON'T LIKE
ADDITIVES.

#EXTENDCHIP



Doctor Moo #17 • Twitter @DrMoo4kids • Facebook @WIAAP









Dr Moo

@DrMooOfficial

Dr Moo, the Spokescow for [@NNAAP](#),
Handling services provided by [@manuvia](#).

📍 Madison, WI

🌐 [nnaap.org](#)

📅 Joined July 2017

Tweet to Dr Moo

👤 34 Followers you know



Tweets
104

Following
6

Followers
66

Likes
120

Tweets

Tweets & replies

Media



Dr Moo @DrMooOfficial · 40m

So excited to be here at the [@NNAAP](#) conference at my first [NNAAP PlayCorf](#)!



FAME!



I'VE GOT TO CUT STAFF IN
ENGINEERING. I'M TRY-
ING TO DETERMINE WHICH
ONE OF YOU IS MORE
VALUABLE TO KEEP.



S. Adams E-Mail: SCOTTADAMS@aol.com

I'VE BEEN HEARING
GOOD THINGS ABOUT
ZIMBU THE MONKEY.
WHICH ONE OF YOU IS
ZIMBU THE MONKEY?



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THIS IS NOT THE
PROUDEST MOMENT
OF MY PROFESSION-
AL CAREER.



TRY THIS.

Commit to scheduled tweets or posts.

Write op-eds...start low and go slow.

Talk to a friend
and ask them to “do something”.

From
The Sandman
by Neil Gaiman

(a resident of Wisconsin,
you know...)



“Internet users trust **library staff** more than most other providers of online support and information, and public library staff are second only to doctors in terms of the **trust** placed in them by seekers of information...”

Be more **visible**.

Get in people's faces...and get in curriculae.

Be part of the wider world.
You **should** be there.

Find champions to help you
from "the inside".

Be **confident** about your status and
your ability to contribute.

You should fill this hunger,
not the information amateurs.

Be the trusted guides through the many
worlds patrons must navigate.

I cannot praise a fugitive and
cloistered virtue, unexercised and
unbreathed, that never sallies out
and sees her adversary, but slinks
out of the race where that
immortal garland is to be run for,
not without dust and heat.

— John Milton's *Areopagitica*, 17th c.

A photograph of a modern library building with a curved glass facade and a green lawn in front of it. The building has multiple levels and a prominent curved section. A car is parked on the left, and a person is visible near the entrance. The sky is clear and blue.

*Our libraries create dreams. If you take away
the libraries, you take America's dreams away.*

— Ilker Turgun

**I'll be a story in
your head. But
that's OK: we're all
stories, in the end.**

**Just make it a good
one, okay?**
— The 11th Doctor



**THE
END**

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