

Strong Over Wrong: The Power of Medial Advocacy

Presented by Kayla Schadeegg, BSE
Medical Outreach Representative, Down Syndrome Innovations



STRONG
OVER
WRONG

It's nice to meet you!



I wear a lot of hats...

Kayla Schadegg

Director, My Gym Children's Fitness Center

Medical Outreach Representative, Down

Syndrome Innovations

Mrs. Kansas

- Disability sib, educator, and early childhood development specialist
- Down syndrome mama (birth diagnosis)
- The Strong Over Wrong mission



No Need to be in the Dark...

Diagnosis is step ONE of a lifetime of care for an individual with Down syndrome—BUT we know it's an incredibly important one, often described as a “flashbulb” moment

The unknowns a diagnosis presents (immediate and future) often leave families and medical providers feeling like they're stumbling in the dark...and if there was a light, it seems so obvious to flip it on, right?



...Let's Turn on the Lights!

Medical outreach IS that light!

Let's tap into the critical value that medical advocacy brings to advocates, organizations, and healthcare providers across the lifespan for patients with Down syndrome!

Key questions we'll answer...

WHAT?

What *is* medical advocacy...and why should Down syndrome organizations and healthcare providers establish or participate in such a program?

Key questions we'll answer...

SO WHAT?

How can we establish credibility & trust between our communities (disability & healthcare) to have truly collaborative relationships within medical advocacy?

Key questions we'll answer...

NOW WHAT?

How do we harness the power of those collaborative relationships to modernize views of life with Down syndrome and positively impact healthcare across the lifespan for individuals with Down syndrome?



STOP
COLLABORATE AND
LISTEN

Medical Advocacy: 101

- Our key word of the day is COLLABORATION!
- Experts in medicine & experts in life with Down syndrome paired together
- Diagnosis is ONE step of life with Down syndrome
 - Lifespan support
 - Acting as a team in healthcare settings
 - Presuming competence

Why do we need all of this collaboration?

“Prenatal genetic screening (serum screening with or without nuchal translucency [NT] ultrasound or cell-free DNA screening) and diagnostic testing (chorionic villus testing [CVS] or amniocentesis) options should be discussed and offered to **all pregnant patients regardless of maternal age or risk of chromosomal abnormality.**”

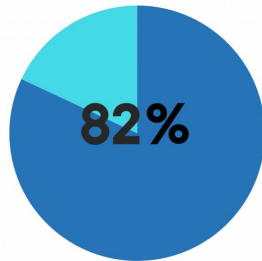
–Current ACOG Guidance

Let's take a guess...

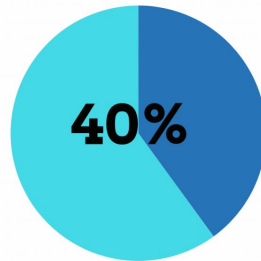
1. **More or less than 50%** of physicians surveyed believed people with significant disabilities have worse quality of life than non-disabled individuals?
2. **More or less than 50%** of physicians surveyed were confident about their ability to provide similar quality of care to disabled and non-disabled patients alike?
3. **More or less than 50%** of physicians surveyed said they welcome patients with a disability into their practice?



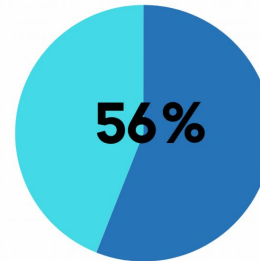
Physicians' Perceptions of People with Disabilities and Their Healthcare



82% of Physicians reported they believed that people with significant disabilities have worse quality of life than non-disabled people



Only 40% of Physicians were very confident about their ability to provide the same quality of care to patients with disabilities



Just 56.5% strongly agreed that they welcomed patients with a disability into their practices

- Cleary-Goldman study:
45% of practicing obstetricians rated their residency training re: prenatal diagnosis as “barely adequate or non-existent”

- 2013 Nelson-Goff study:
35% of patients reported a negative experience when clinicians provided a prenatal diagnosis of Down syndrome > 11% reported a positive experience

- 2008 Stanford Survey:
 - 85% of pediatric transplant centers consider intellectual/developmental disability as a factor in their transplant eligibility determinants
 - 71% of heart programs surveyed “always” or “usually” considered intellectual/developmental disability when deciding transplant eligibility
- 2019 National Council on Disability study– Primary forms of disability discrimination practiced by organ transplant centers:
 - Refusal to evaluate as a candidate for transplant
 - Refusal to place on national organ transplant waiting list

The GAP

rapid expansion of prenatal screening & testing

+

increasing life expectancy for people with Down syndrome

+

stats that show physicians do not feel well prepared to care for disabled individuals

Medical outreach closes that gap.

Families having access to support and resources from the moment of diagnosis improves long-term health outcomes, but...

- Coordinated care clinics
 - # of states with Down syndrome clinics: 36
 - Provide care for less than 5% of individuals with Down syndrome in the US
- Requirements for medical providers when delivering a diagnosis
 - # of states with Down syndrome information acts: 21

Our organizations can and should be a resource for health care professionals.

The #1 question when I chat with anyone about
medical outreach...

“How do we even get
started on something like
that?”

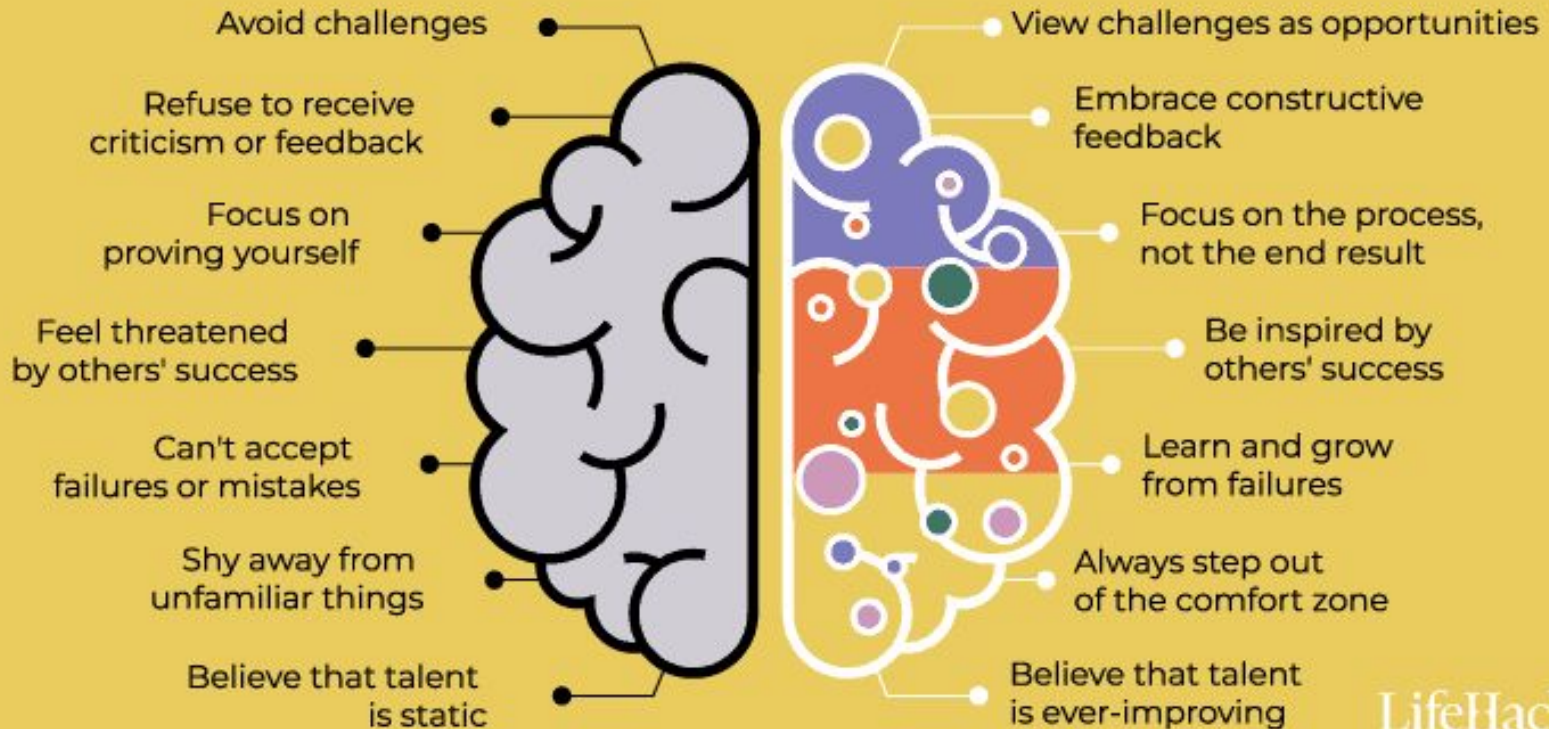
The answer is pretty easy...

BUILD RELATIONSHIPS

+

BUILD TRUST

Fixed Mindset vs Growth Mindset



Laying the Foundation...

- “Educational” vs “collaborative” mindsets
 - Address biases
 - Build mutual respect
 - It’s all about RELATIONSHIPS!



Building up the structure...

- Great places to start your research and expand your expertise:
 - Lettercase
 - National Down syndrome organizations
 - Down syndrome Program at Massachusetts General Hospital
 - Published studies
 - Hope Story

Adding the furnishings...

- What resources are we referencing and/or providing? (What are you receiving as a medical professional?)
 - Do they come recommended by major medical organizations?
 - Do they come recommended by major advocacy organizations?
 - Have we read them cover to cover?

Walk the Walk

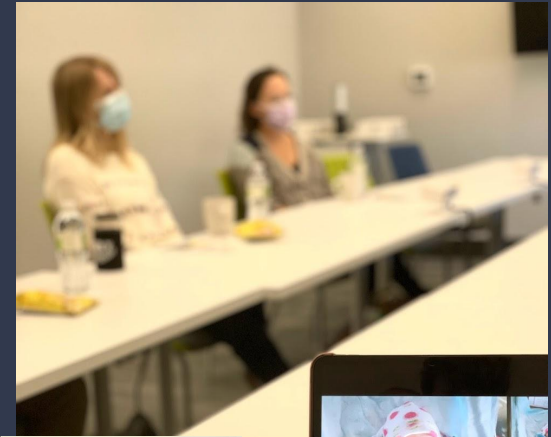
- Professionalism is key!
 - Timely, professional communication & follow-ups
 - Proofread materials (and review!)
 - Attire
 - Attitude
 - Practice what we preach!
 - Encourage questions—if you don't know the answer, help find someone who does!



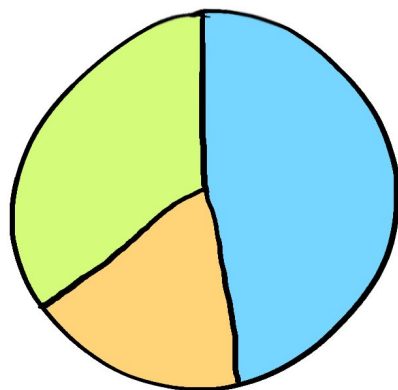
...and Talk the Talk

- Vet your representatives and volunteers
- Prep your representatives and volunteers
 - FREE Lettercase training
 - Opportunities to practice
 - Go over materials with them in advance

Resources can be utilized with your medical outreach reps—but you should also offer resources for the medical professionals you're meeting with!



Tackling Imposter Syndrome



- PEOPLE WHO GET IMPOSTER SYNDROME
- OTHER PEOPLE WHO GET IMPOSTER SYNDROME
- LITERALLY EVERYONE ELSE (THEY ALSO GET IMPOSTER SYNDROME)

EVERYONE FEELS LIKE AN IMPOSTER
SOMETIMES, AND THAT'S OKAY

ERRANTSCIENCE.COM

- Everyone has to start somewhere
- Outreach is a collaborative experience—you will learn just as much as you share
- Prep and TRUST yourself and your teammates!

Ok, that makes sense.

...but now what?

“Community has the power to transform [...] outcomes.”

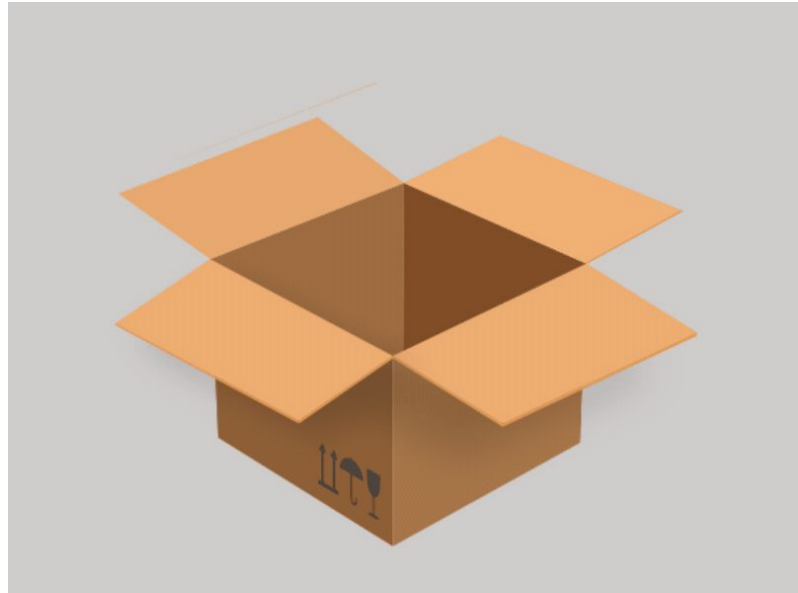
Built to Belong, Natalie Franke

Getting Started

- Making connections (start with YOUR providers and branch out)
- Lunch & learn opportunities
- Don't see "no" as a failure, maintain contact and consistency

Think Outside the Box

- Who can you reach that impacts the healthcare experience for your community?
 - Residency programs
 - Nursing schools
 - OT/PT programs
 - Nursing homes



Ready, set, go!

How do we use these opportunities to modernize views of Down syndrome?

- engage in discussion!
- ask questions
- get feedback

Share Your Story!

One of the most powerful ways to connect with others is by sharing our story. Practicing this presentation so you can do it in a calm and professional manner is important—but will help to “humanize” the issue for anyone you meet

AND share the many sides sides of the coin...

We all know Down syndrome is NOT one standard set of characteristics! If you've met one person with Down syndrome...you've met ONE person with Down syndrome!

- Your story is just that...YOURS
- Charlie & Kerrigan
- Offer a section of time for a self advocate to share their story

Heads...

- How does Down syndrome impact livelihood in ways people might not expect?
 - Eg. \$2,000 asset limit (not adjusted since 1989)
 - Marriage penalty on benefits
 - Transplant discrimination

AND tails...

- Offer stories to help people understand presuming competence
- “Celebrity” stories can be fun to share to help modernize views (Chris Nikic, Chelsea Werner, Madison Tevlin)

“Who can I reach out to?”

- My #1 tenet is that we are ALWAYS available to help locate resources
- Provide links to prominent local and national resources so HCPs can continue to stay connected and up to date
- Provide a way for them to stay connected to your organization via newsletters, mailings, etc. if they'd like
- Down Syndrome Medical Interest Group
 - Down Syndrome Project ECHO

Impacts & Outcomes

- practical tools & best practices for working with patients with Down syndrome
- more in-depth and thorough understanding of life with Ds
- knowledge of and access to specific resources and support (for both HCPs and families)
- better comprehensive & coordinated care (especially in a “newly” aging population),

Added benefits

- Applicable across a range of disabilities AND non-disability diagnoses and care
- Expands your connections to your local community and beyond

QUESTIONS?

Resources

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Resources

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