COVID ADVOCACY EXCHANGE

May 13, 2021

Health Equity: Access to Care

Working Group Leader	BMS Champion	GRYT Health Leader
Brad Love Co-Founder and Chief Culture Officer, GRYT Health	**Alison Handler** **Nilam Perpich**	**Eileen Shannon**

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Framing the moment

When a person first joins Advocacy, they do not know the important history that led to this moment nor the systems in place that prevent progress.

- Sheila Thorne

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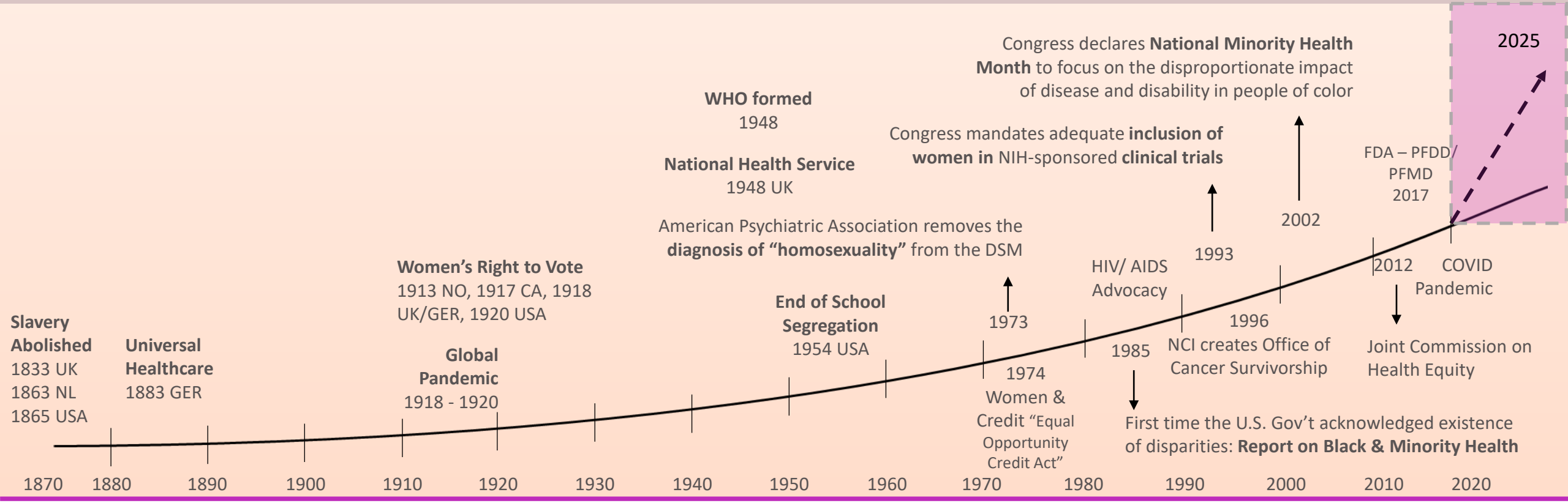
Framing the moment

Our Working Groups can design a framework, from Advocacy perspectives, so that each person can:

- ✓ learn from the past
- ✓ see a direction for progress
- ✓ feel how important their voice is to creating the future (belonging)

It is this history, with the current global pandemic, that has created the opportunity for us to positively bend the arc of advocacy in our four health and healthcare areas.

160 Years of Advocacy



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Framing the moment

Whether you are three days or three decades into advocacy, your experience is critical to creating progress.

"The Advocacy Exchange is an honest broker of what's been tried, what's working and what's not working, so we can co-create solutions together."

- Neil Bertelsen

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Working Groups

Across all feedback = SYNERGY

Where do all our organizations have resources, capacity, and expertise that we can bring together to elevate the collective capacity?

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The Arc, specific to Access to Care

The focus of our Working Group's discussion:

- What has been tried?
- What's not working? What are the pain points? Where can things use improvement?
- What is working well that we can learn from and use?

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Examples of places we can start

- **Challenge:** Third-party providers try to charge for services that are already included in patients' healthcare
  - Promises of access to specific doctors and services to help manage care needs
  - Many elderly patients are being taken advantage of for services they don't need or that are already covered within their healthcare
    - Awareness and education need to be part of the solution
  - **Potential improvement**: Opportunity to go beyond awareness and start making moves to be preventative in healthcare education
- **Positive example:**
  - Nonprofits that have figured out how to work with payers in a positive way, by putting governance around the use of codes – progress has been made in two months

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Examples of places we can start

- **Challenge:** There is still a stigma attached to certain diseases
  - For example, lung cancer, breast cancer, bladder cancer, HIV/AIDS
    - There are misconceptions about who gets these diseases, though the diseases do not actually discriminate
  - The message is: “We did some action in our lives to cause us to get cancer”
  - **Potential improvement:** Figuring out what access issues are stopping people from getting preventative care, and how to combat stigmas in the process
- **Positive example:** Changing the guidelines for testing so people who are not in the “expected” categories (age, race, health history, for example) have better access to screenings that they were not covered in the past (U.S.)
  - Stage 1 diagnosis can make a world of difference in someone’s prognosis, particularly for certain diseases

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Examples of places we can start

- **Challenge:** Lack of testing in clinical trials
  - For example, Africa has 54 countries and only 4-5% of clinical trials are being done there, usually in only a few of those countries, and with only men in the trials (per recent webinar)
  - There are no studies in oncology in Africa, currently
  - Africa makes up about 20% of the world's cases and they are getting diagnosed later, have less access to treatment
    - One participant knows doctors in Sierra Leone who had less than 10 adequate sets of equipment needed to treat the most severe cases of COVID
  - **Potential improvement:** More pharma investment in testing in these countries to help get a more representative sample – we need to be more internationally-focused in how we can address disparities
- **Positive example:** There are dedicated healthcare providers who are moving heaven and earth to provide care – they are willing and just need resources to do it

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Examples of places we can start

- **Challenge:** Lack of testing in clinical trials (continued)
  - Pediatric cases present a unique challenge, since there are so few clinical trials – "We throw grown-up drugs at little kids in the hopes that they don't die."
  - Pediatric trials also present an access challenge because they often require travel and other restrictions that are prevented by Medicaid or other coverage that can be restricted by the state that they live in – people cannot afford to do this out of pocket
  - **Potential improvement:** Work on the systemic and policy issues that create these barriers
- **Positive example:** Working with the Copay Accumulator Coalition, which has been helpful to work through issues with getting co-pay accumulators taken out, and helps free up pharma dollars to go directly to patients to help with the expense of these life-saving treatments

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What are some examples of successes we can draw from?

- One participant worked in a pediatric office that had written into a study agreement that lodging, meals and transportation costs would be covered for many of the families who would come for the study – this broke down obstacles for patients, especially those who needed to travel out of state for treatments
  - Having the costs covered was a huge success and saved the lives of several children and helped many go inactive on the transplant list
    - It took about 3-4 years to get to that point, and there were systems in place to help with the cost of the drug if the patients couldn't afford the drug after the study, due to insurance
- The pandemic has helped make participation more possible
  - Phone and video options have made it possible for people to participate when they couldn't before
  - Additionally, this alleviated some of the risk that caused people to avoid appointments during the pandemic

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What are some examples of successes we can draw from?

- Transfusion therapy – combined appointments made it possible for people to get care in one appointment with multiple providers, rather than two separate appointments – this helps reduce the burden on the patient
  - **Future state:** Advocate for patients who require different setups, and avoid reverting back to the "old' ways when they didn't work as well for patients
- Technology can be a great tool to create awareness and open discussions
  - Social media can help educate when used correctly – TikTok helped young people learn the difference between MRAs and an attenuated virus vaccine
- Mobile vaccine clinics go where they're needed – communities in need get access

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What do we need to think about?

- Meet people where they are – be as inclusive as possible for treatments and make it easier for patients
- Get the right people involved in the dialogue (e.g., payers)
  - Always go back to: how do we improve the patient outcome?
  - Don't fight each other – be part of the dialogue together
- Universal Health Care plan (Puerto Rico) provided a greater pool of patients with opportunities for better health care
  - This has proven successful outside of the U.S. as well – what can we draw from this that would be helpful in where we're going?

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What do we need to think about?

- Next steps:
  - Bring in other voices from the Advocacy Exchange – we can develop a roadmap but make sure to run it by the larger community
  - Consider where we can borrow from and what case studies we may want to develop that have suggested bits of progress we may want to follow

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Join Us for the Next Working Group Session

Thursday, June 10, 2021

12:00-1:30pm ET

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