

NYMAC 2024 Notebook

- All speaker-shared resources
- Content shared in chat during the session
- Challenges (some will become discussion topics for Session 11)
- Asynchronous participant-shared resources and notes

Notebook Directory

Click on links to jump to a session

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DAY 1 April 18, 2024

Session #1: Looking back: The impact of NYMAC and what you can take away

Presenters: Alissa Terry, ScM, CGC; Melissa Raspa, PhD; Maria Isabel Frangenberg; Enrique Lopez, MS, CGC; Cheyla Clark, MPH, MS, CGC; McKenzie Wood, BS; Mabel Thomas, MS, CGC

Presenter Shared Resources

[Co-Production Theory](#)

[EI family outcomes measures](#)

[NCC data](#)

[NYMAC website](#)

[PhenX toolkit](#)

- [Genomics Outcome Scale](#)
- [Relative Advantage](#)

[360 Engagement Assessment](#)

[7 Regional Genetics Networks](#)

Participant Shared Resources & Notes, Zoom chat

OSEP Spanish language glossary for Part B and C terms. The verbage used in this document has gone through multiple focus groups and the words chosen was agreed upon to be understood across groups of Spanish speakers. <https://www.spanadvocacy.org/glossary/>

Find my Parent Center

Parent Training and Information Centers have resources and information on supporting children and families with Special Health Care Needs.

[Find Your Parent Center | Center for Parent Information and Resources \(parentcenterhub.org\)](#)

Challenges & Requests

Solutions & Resources

Be as specific as you'd like. Feel free to share your contact information in request or response.

[How do I / we ...](#)

How to access new resources in non-English languages - glad the NYMAC existing resources are staying, but what about going forward?

The minority genetics professionals network has done some work in this area, as has SPLAGEN

Need: A new resource that allows parents who work outside genetics to stay connected to conversations and resources.

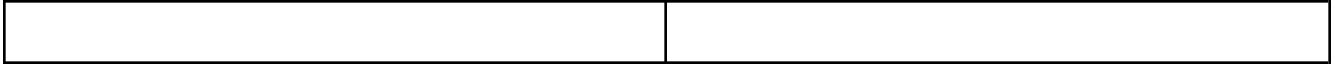
Some of the state Family-to-Family or Parent-to-Parent groups are starting to do more work in genetics (check out Virginia's Genetic Navigator program). Hopefully some of the new HRSA programs will actively engage parents/families as well

I'd like to know where the great resources being developed are being warehoused and for how long?

They are being stored on the NYMAC website, which will remain up for at least a few more years. Most are also in the NCC's resource repository.

What is left behind to provide supports once NYMAC is gone? How are we going to advocate to ensure a source is available to provide these incredible supports and

Dr. Jeff Brosco is going to talk about the new programs that HRSA is developing to support children with special health needs. You'll also hear about what Family Voices has to offer. If there are other gaps you're anticipating with NYMAC gone, we'd love to hear from you about what those are.



Session #2: HRSA's vision for CYSHCN and newborn screening

Presenter: Jeffrey Brosco, MD, PhD

Presenter Shared Resources

[Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs](#)

[Children with Medical Complexity](#)

[HRSA Website](#)

Participant Shared Resources & Notes, Zoom chat

Health disparities responsible largely for SCD lack of equitable treatment

Training and support for families is important:

Training families as advocates is key in that process.

Family engagement and advocacy is essential in that dialog

Family voices is the family engagement leader for HRSA programs for children with special health needs. <https://familyvoices.org/felsc/>

Family voices will be presenting tomorrow about this work

Every state also has a PTI parent training and information center that either is or can connect to the state F2F <https://www.parentcenterhub.org/find-your-center/>

Find Your Parent Center | Center for Parent Information and Resources (parentcenterhub.org)

Community Health Workers can be really helpful in reaching communities

Edhi is a fantastic resource for 🧑🏻‍🧑🏻‍🧑🏻 families

<https://www.cdc.gov/ncbddd/hearingloss/ehdi-programs.html>

Info about HRSA's new Propel and co-Propel grants that support newborn screening:

<https://www.hrsa.gov/grants/find-funding/HRSA-23-065>

Challenges & Requests

Solutions & Resources

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How do I / we ...

Will there be any collaboration between HRSA.gov and the biopharma companies now offering gene therapy for SCD/thalassemias to help make those opportunities available to all eligible patients (especially from a funding \$ POV)?

HRSA is aware of the issues related to inequities in access to treatments, but does not currently have specific plans to address this gene therapy issue

NBS systems are great for identifying and

Propel aimed to meet each state/territory "where

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Participant Shared Resources & Notes, Zoom chat

PROPEL strengthens that system, how does this new funding structure help the jurisdictions that continue to need investment to set up downstream resources such as the US territories?

Is there a thought to offer supplemental funding for those jurisdictions that need intensive work to set up those fundamental systems of care that just don't quite exist yet?

they are”, newborn screening is fundamentally a state/territory’s responsibility to run and fund, HRSA funding is meant to help support unique issues

How do you plan to engage genetic counselors in the PROPEL grants?

Response: some of the Propel and CoPropel grantees have GCs on the project staff. There are also GCs working with Jeff at HRSA

For the families here: tell us how it helped you (or not) to get your specific genetic diagnosis

We don't have a specific diagnosis. We manage the complex care issues the best we can but other than that we don't have a path forward with getting a diagnosis. With the closing of the RGN that takes away a pathway to feel connected to research and programs

Newborn screen only catches so much though. There are so so many conditions that will never hit the RUSP.

It's hard to find advocates and representation within minorities especially within the hispanic community when they are surviving every day and have so many barriers to overcome

Session #3: Cultivating Connections: Utilizing NYMAC resources and joining forces with local collaborators in your state/district/territory

Presenters: Radhika Sawh, MS, CGC; Enrique Lopez, MS, CGC; Cheyla Clark, MPH, MS, CGC

Presenter Shared Resources

[NYMAC website](#)

- [DC team webpage](#)
- [DE team webpage](#)
 - These flyers are available in Spanish, Haitian Creole, Mandarin and Arabic on the DE team webpage:
 - ["know your sickle cell trait status" flyer](#)
 - [pediatric genetic services flyer](#)
- [MD team webpage](#)
 - All 3 of these flyers can be found in Spanish, Haitian Creole, Mandarin and Korean on the MD team webpage:
 - [family history of cancer flyer](#)
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 - [Genetic Services informational flyer for families](#)
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- [USVI team webpage](#)
- [VA team webpage](#)
 - Informational flier about the Genetic Navigator program
- [WV team webpage](#)

Participant Shared Resources & Notes

Strategies for engaging stakeholders:

- Outreach during a local conference
- Partnerships with early intervention
- Partnerships with MCH Coalitions
- Telling friends, parents, teachers about genetic counseling
- Perhaps utilizing genetic counseling students in programs in each state
- Involvement and collaboration with advocacy organizations

Strategies to expand access to genetics:

- Bringing genetics providers to areas that don't have them
- Expanding telehealth options

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Participant Shared Resources & Notes

- Educate educate
- Partnerships with NBS Advisory Boards
- mOre integration of Primary Care and GCs
- Teach young kids about genetics

Challenges & Requests

Solutions & Resources

Be as specific as you'd like. Feel free to share your contact information in request or response.

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Participant Shared Resources & Notes

How do I / we ...	
Could you please elaborate on the process of identifying the barriers in each of the locations?	Each state/territory had a diverse team of 10-15 people from that location that met each month for a year, and interviews were done with other stakeholders as well, to collectively decide on a key barrier
What's next for USVI?	NBS work in USVI is being funded by the new HRSA Propel grant that Jeff Brosco talked about this morning.

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Participant Shared Resources & Notes

is the Virginia Genetic Navigator Program Flyer available in Spanish?	Not yet, but we can translate it and make it available!
Re: keeping website online, it may be a good idea to note that it is not being routinely updated once the group shuts down	Very good point, will do

Session #4: Resources for Language Access

Presenter: Roseani Sánchez, MEd

Presenter Shared Resources

[Family Voices Resources](#)

[Sign up list](#)

[Survey link](#)

Participant Shared Resources & Notes

Language Access Law—many people are not aware of the law, this was signed in 1964 and gives patients the right to receive care in their own language, even if they don't have citizenship

Family voices did an environmental scan and a survey of families and healthcare professionals, key informant interviews and focus groups

Families reported challenges with translation accuracy/quality, lack of access to interpretation, important medical documents not being translated, not knowing how to access the services they need. Medical records are often not in their native language. Families prefer in person interpretation, many feel lack of understanding and respect from providers. Some providers make assumptions about whether or not a family needs an interpreter without asking them. Families should know they can file a complaint if they don't get the language services they need.

Provider survey showed: lack of access to interpreters they need, time constraints, lack of resources and equipment, technical/connectivity issues, long wait, inconsistent skills of interpreters, written info isn't translated, interpreters may lack medical knowledge, no process in place for providers to be sure translation is accurate, some patient portal and telemedicine platforms aren't translated, but most believe interpreter services are valuable and important for equitable care

Interpreter focus group: interpreters say there is stigma when you don't speak english, families wish to use a bilingual child or family member instead of professional interpreter, and often lack of stable internet, families might not trust that interpreter is really saying what they said, sometimes interpreters and families might know each other, shortage of male interpreters, using face masks makes interpretation harder. They are often dissatisfied with low pay. Most prefer in-person interpretation, and interpreters need education and training

Providers in the conference recommend: hiring providers that speak other languages, make it part of the protocol, better tech, clear signs in the office, more time for sessions that need interpretation

Families in the conference recommend: no cost for interpretation, seek community resources that can help

Other solutions: increase family understanding of interpreters' ethics: that they keep info confidential, building trusting relationships, not share personal opinions with families, not providing transportation to families, offer more provider training to work with interpreters, post signs, give interpreters as much info as possible before appt

Session #4: Resources for Language Access

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Presenter Shared Resources

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Participant Shared Resources & Notes

Family voices is creating a curriculum for families, providers and interpreters to learn about the law, and strategies can be used to improve services, will be in online learning system in 3 languages, sign up list is linked above

Challenges & Requests

Solutions & Resources

Be as specific as you'd like. Feel free to share your contact information in request or response.

How do I / we ...

La ley existe, pero de que manera es enforcada a nivel de los servicios de salud?

The law exists, but how is it enforced at the level of health services?

This is a great site that details the law, along with lots of very useful resources for language access planning. [https://www.lep.gov/about/Executive Order 13166](https://www.lep.gov/about/Executive%20Order%2013166) requires each federal agency to create a federally conducted limited English proficiency (LEP) plan. As part of the one-year anniversary of the Attorney General's November 2022 memorandum on strengthening the federal government's commitment to language access, several Federal agencies are releasing updated federal agency language access plans.

Here is the pertaining section for Department of Health and Human Services (updated Nov. 2023)

Response from Carol Velandia, Community Interpreter:

With regards to the law, it is title VI of the civil rights act. It is not an enforceable law but, if you or your facility receives federal funding your program can get that funding taken away. You can encourage patients to complain to <https://www.lep.gov>

They also can use

Session #4: Resources for Language Access

Presenter: Roseani Sánchez, MEd

Presenter Shared Resources

[Family Voices Resources](#)

[Sign up list](#)

[Survey link](#)

Participant Shared Resources & Notes

	<p>https://web.archive.org/web/20160629044715/http://publicsafety.ohio.gov/links/CJS0007.pdf</p> <p>if they are not receiving the services in their language.</p>
Challenging to find interpreters at the time and in the language you need	contact Equal Access language services! We will be happy to help in over 250 language 24/7 access including ASL 😊
I'm curious to know how you think the rise of AI will potentially help to improve access to and correctness of translation services? How can we ensure services provided with AI Assistance are correct/safe?	Response from Carol Velandia, community interpreter. I participate in an initiative called safe AI that describes all standards suggested by the federal government on using AI for translation.
Issue of families wanting family members to do the interpretation instead of professional interpreters	<p>We experience this at SPAN too, we tell the family that we need both to ensure everyone understands everything</p> <p>Response from Carol Velandia, community interpreter: This is against hospital policies. Family should never interpret for several reasons</p> <ol style="list-style-type: none">1) They don't have to abide by a code of ethics their impartiality might be affected by their relationship with the family. Professional interpreters do have to abide by a code of ethics that demands that they are accurate, AND impartial2) Delivering bad news to a family member is challenging and patients and families should be able to focus on the care, not the language interpretation. It is their right to have language access
Are interpretation services available in all countries? and are they always covered by the facility?	In the US: If the practice receives any money in federal funding they have to pay for interpreters. Policies in other countries vary.

Session #4: Resources for Language Access

Presenter: Roseani Sánchez, MEd

Presenter Shared Resources

[Family Voices Resources](#)

[Sign up list](#)

[Survey link](#)

Participant Shared Resources & Notes

If the family feels more comfortable with a family member do you see a downside to both people (family and interpreter) present

Response from Carol Velandia, a community interpreter: No, it is OK if they are present. It is against Hospital policies to allow family to interpret as they are much less likely to keep impartiality. The interpretation National standard in the US is that no child or family member should interpret in any community situation. This includes hospitals, clinics, courts, schools etc.

Si familia, medico e interpretes estan de acuerdo, se puede grabar todo lo que se diga en la cita medica para que se pueda repasar luego. *If the family, doctor, and interpreters agree, everything said at the medical appointment can be recorded so that it can be reviewed later.*

Recording the session can help sometimes

Additional Language Access Services provided by Equal Access Language Services (provider of simultaneous interpretation).

We are currently running a FREE lunch and learn 45 minute sessions on Language Access to dispel any doubts about laws, regs, and the master class: "Working with interpreters" that is accredited for CEUs. You may check all the resources available in our website:

www.equalaccesslanguageservices.com

<https://www.equalaccesslanguageservices.com/blog/effective-inclusion>

Or contact us [here](#) where you can have a one page resource with information on everything language access.

Also this podcast called: Language Access Matters features experts and organizations using language access successfully

<https://podcastja.podbean.com>

Session #5: NORD, Global Genes, and NHGRI

Presenter: Marybeth McAfee, MA, GC; Shruti Mitkus, PhD; Donna Messersmith, PhD

Presenter Shared Resources

[All in. Rare Website](#)

[Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database](#)

[Genome.gov](#)

- [Direct-to-Consumer Genetic Testing FAQ](#)
- [Healthcare Professionals' Genomics Education Week](#)
- [Inter-Society Coordinating Committee for Practitioner Education in Genomics \(ISCC-PEG\)](#)
- [Nursing Genomics FAQ](#)
- [Pharmacogenomics Learning Series](#)
- [Talking Glossary of Genomic and Genetic Terms](#)
- [2024 DNA Day](#)

[Genome: Unlocking Life's Code Exhibition and Website](#)

[Global Genes Website](#)

- [RARE Concierge Patient Services](#)
- [RARE Disease Community](#)

[Living Rare Living Stronger](#)

[NORD Website](#)

- [NORD Breakthrough Summit](#)
- [NORD En Español](#)
- [NORD IAMRARE Registry Program](#)
- [NORD Rare Disease Centers of Excellence Program](#)
- [NORD Rare Disease Drug Development Series](#)
- [NORD Rare Disease Grant Program](#)
- [NORD Rare Disease Reports](#) (For reports in Spanish, email: galyea@rarediseases.org)
- [NORD Rare Edu](#)
- [NORD RareLaunch](#)
- [NORD Research Ready](#)
- [NORD Resource Library](#)
- [NORD State Report Cards](#)
- [Project RDAC](#)
- [RareCare Patient Assistance Program](#)
- [Rare Disease Day](#)
- [Speak to someone at NORD](#)
- [State Resource Center](#)
- [Ways to Advocate](#)
- NORD Support Helpline: 1-800-999-6673; Español: (844) 259-7178

Participant Shared Resources & Notes

Reasons to contact Global Genes/RareX:

- Disease Info
- Clinical studies/research
- Connecting to a patient advocacy org
- Finding an expert/center of excellence
- Financial info
- Disability info
- Genetic Counseling/testing
- Mental health resources
- Caregiving resources
- Raising awareness

Coming soon:

Providing Access to Free Whole Genome Sequencing

- Pilot phase focused on pediatric onset neurological conditions
- Infants, as well as adults are eligible
- Leverage RARE Concierge and All i. Rare to identify/support eligible patients, particularly from underserved communities
- Pre and post test genetic counseling provided
- Non-physician directed test ordering supported
- Clinical grade testing including insurance covered testing
- Research grade testing available for high-suspicion VUS
- All clinical and genetic data to be collected through RARE-X and made available for research
- All patients and families supported through RARE Concierge regardless of diagnostic outcome

Challenges & Requests	Solutions & Resources
<i>Be as specific as you'd like. Feel free to share your contact information in request or response.</i>	
How do I / we ...	_____
Will the Access to Answers program be available to patients around the world or just the USA? I would love to be involved in this!	The pilot is focused on the USA but for future phases (and increased funding!) we hope to expand globally. There certainly is a great need.
Does global genes connect families that would like to meet others with same dx?	Yes, contact Rare Concierge for help with this. Also have a Facebook group where families and advocates can connect
Question to GLocal Genes: Any particular outreach to federally qualified health centers?	Current focus on pilot will be creation of curriculum, next phase is how to dispense information
Info about Global Genes work with CHWs? Can an NJ CHW participate? Asking for me	Global genes is making a community health worker training series by fall 2024 Global Genes: Currently the pilot is for Kansas City and Birmingham but I am really hoping that

	we can get this curriculum accredited and available for the entire country
How does NORD help doctors?	NORD creating guides to help primary care providers know when to connect families to genetics NORD has CME program on the website
..... We had whole genome testing done through Johns Hopkins/Baylor study (Mendelian Project) but never got any answers after running the data twice. Could I work with someone to get our data reevaluated?	NORD can reconnect you to discuss reanalysis

DAY 2 April 19, 2024

Session #6: Developing a Productive and Collaborative Relationship to Change

Presenters: Erica Marx, MS; Fred Brown, MFA

Presenter Shared Resources

Change is **SITUATIONAL**

External to the individual: something that happens to people, over which they have little or no control

Transition is **PSYCHOLOGICAL**

Internal to the individual: something people have control over and can work to manage

Bridges Model of Transition

Focuses on behavioral aspect of change

Axes of importance and time with new beginning, messy middle and letting go

“Yes, and” is common in improv

“Yes, but” to be used here for exercise—makes for a challenging, negative conversation

Yes, but

Slow down & listen:

- What is below the surface?
- What are you protecting?
- What is important to the other person?
- What need is present?

"Yes, what I like about that is ____ AND ____"

This skill, of full acceptance and building from what's in front of you, can help when you are processing change. It can help get you through a messy middle productively and collaboratively. YES,

- what I like about that is...
- what is insightful about that...
- what is important about that is...
- what I appreciate about that is...

AND ...

Stage 1 – full yes

Stage 2 – productive and

opportunity zone, where you can get control & expand productivity

Stage 3 – full and, acceptance, new reality

YES: What would it be helpful to acknowledge or say yes to?

AND: What offer can you make (build on the YES)?

- Validation and acknowledgement foster collaboration!
- Saying yes when it's something you can accommodate even if it's not your preferred option.
- Importance of pausing to find value in the alternate opinion and then build from there

- don't have to completely agree with them but it doesn't mean they're wrong
- Acknowledge all ideas. It is important to do so since sometimes speaking up can be scary

Participant Shared Resources & Notes

AMEN in challenging conversations: bridging the gaps between faith, hope, and medicine

Rhonda S Cooper 1, Anna Ferguson 1, Joann N Bodurtha 1, Thomas J Smith 2

PMID: 24803663

Abstract

All health care practitioners face patients and families in desperate situations who say, "We are hoping for a miracle." Few providers have any formal training in responding to this common, difficult, and challenging situation. We want to do our best to preserve hope, dignity, and faith while presenting the medical issues in a nonconfrontational and helpful way. We present the acronym AMEN (affirm, meet, educate, no matter what) as one useful tool to negotiate these ongoing conversations. We developed a conversational protocol for providers called AMEN (affirm, meet, educate, no matter what), a simple mnemonic similar in spirit to the VALUE (value, acknowledge, listen, understand, elicit) communication system.²⁷ The aim of AMEN is to help providers remain engaged with patients and families during challenging conversations that involve patients' religious beliefs, particularly in response to a poor prognosis.

Our conversational tool can help normalize what is often viewed as religious by framing it in the concept of hope. The belief in the possibility of miraculous medical recoveries is held by adherents of many religious traditions, including Islam,³⁰ Judaism,³¹ Buddhism,³² and Christianity. However, all too often, clinicians unintentionally place themselves in direct competition with the God of the patient's or family's understanding. The provider may be thinking, "Well, you can believe all you want, but that miracle is not going to happen." When the provider verbally responds to the patient's or family's hope for a miracle with the word "but," the patient is dismissed, and simultaneously, the provider places him- or herself in competition with God. **For a religious patient, not even an esteemed or beloved physician will win in a contest with God.**



Challenges & Requests

Solutions & Resources

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How do I / we ...

Session #7: Resources for Families with special healthcare needs at the national and local level

Presenter: Pattie Archuleta

Presenter Shared Resources

[Family Voices website](#)

- [Family-Centered Care Assessment](#) (FCCA)
- [Family Engagement and Leadership in Systems of Care](#)
- [Family Engagement in Systems Assessment Tool](#) (FESAT)

FELSC:

TA and support to network of Family-to-Family Health Information Centers (F2Fs) and other MCHB funded entities

TA to 59 F2F health info centers - 50 states, 6 US territories, and 3 tribal nations

F2Fs help families navigate the system, increase awareness about disability, build leadership

Participant Shared Resources & Notes

- State F2Fs have peer mentor training for families to help others
- Challenges finding or providing resources to families?
 - Finding resources in languages of my patients
 - Limited resources for rare conditions
 - support groups for specific conditions
 - financial and transportation
 - education system
 - insurance barriers
 - resources aren't easily accessible
 - Financial barriers to patients accessing conferences related to their dx.
 - Living in rural areas
- Scavenger Hunt and Presentation takeaways
 - Entire site, all new to me
 - easy to access F2F resources
 - easy to navigate
 - My states info needs to be updated
 - plain language resources will be helpful for myself and students
 - learning about national FV resources
 - GCs happy to have links to give to families
 - nice to see specific state resources
 - Resources available in multiple languages
- Operationalize the resources (eg: linking every family you see in genetics clinic to Family voices in your clinic note (Alissa))
- If you are looking for a resource not on your state's F2F website, be sure to reach out to their helpline to ask. It may be that they refer families to other resources/organizations for the information.

Challenges & Requests

Solutions & Resources

Session #7: Resources for Families with special healthcare needs at the national and local level

Presenter: Pattie Archuleta

Presenter Shared Resources

[Family Voices website](#)

- [Family-Centered Care Assessment](#) (FCCA)
- [Family Engagement and Leadership in Systems of Care](#)
- [Family Engagement in Systems Assessment Tool](#) (FESAT)

FELSC:

TA and support to network of Family-to-Family Health Information Centers (F2Fs) and other MCHB funded entities

TA to 59 F2F health info centers - 50 states, 6 US territories, and 3 tribal nations

F2Fs help families navigate the system, increase awareness about disability, build leadership

Participant Shared Resources & Notes

Be as specific as you'd like. Feel free to share your contact information in request or response.

How do I / we ...

Resources for education and genetics

<https://www.negenetics.org/genetic-education-materials-school-success-gemss>

Session #8: Resources and Genetics Practice Models for Rural Health

Presenters: Marc S. Williams, MD; Rhonda Jackson; Doson Nguyen

Presenter Shared Resources

[HRSA Website](#)

- [Find a Health Center](#)
- [HRSA Data Warehouse](#)
- [HRSA Funding Opportunities](#)
- [HRSA Grants](#)
- [HRSA Grant Technical Assistance Resources](#)
- [HRSA Office of Intergovernmental and External Affairs](#)
- [Sign up for HRSA subscriptions](#)

[Mid-Atlantic Telehealth Resource Center](#)

[National Maternal Mental Health Hotline](#): Call or Text 1-833-852-6262

[Rural Health Information Hub](#)

- [State Offices of Rural Health](#)

[Rural Research Gateway](#)

<https://www.ruralhealth.us/programs/state-rural-health-associations>

<https://www.ruralhealth.us/advocate>

Participant Shared Resources & Notes

Challenges & Requests

Solutions & Resources

Be as specific as you'd like. Feel free to share your contact information in request or response.

How do I / we ...

Session #9: Advocating for Resources and Change: Harnessing The Power of A Story

Presenters: Radhika Sawh, MS, CGC; Ashley Bricker, CPACC, ADS; Coralaidee Jiménez; Germaine Powell, MA

Presenter Shared Resources

Participant Shared Resources & Notes

- Stories are powerful!
- Parents have to and can be extremely bold when it comes to their child!
- As a genetic counselor, remember you joined this field as a choice, but that is not the case for parents, caregivers and families.
- Don't hesitate to share your story - it could help others.
- Opportunities are limitless. Don't be afraid to speak up or ask for help.
- Each story that someone tells is so impactful, and you never know who you are helping when you share. It takes courage and bravery!
- Never underestimate a mother advocating for her child!

From Chat:

- Thank you all for such incredible and beautiful stories. Your experiences are so impactful, and it takes courage to share with others!
- Thank you to the panelist for sharing their incredible courageous stories!
- Thank you all so much for sharing your journeys.
- It's scary when he was diagnosed it was all bad info online. The hope and joy we have experienced is nothing like what we read. I just want to give others that hope.
- I feel honor and blessed to be part of this community!

International Story Telling Center in TN: <https://www.storytellingcenter.net/>

Challenges & Requests

Solutions & Resources

Be as specific as you'd like. Feel free to share your contact information in request or response.

How do I / we ...

Session #10: Resources for telehealth

Presenters: Kathy H. Wibberly, PhD; Lloyd Sirmons; Danielle Louder; Alissa Terry, ScM, CGC; Lisa Richard, MS

Presenter Shared Resources

[ADA National Network](#)

- [Accessible Health Care](#)
- [ADANN Webinar Series: Health Care and the ADA - Inclusion of Persons with Disabilities](#)
- [Health Care and the ADA](#)
- 1-800-949-4232

[American Academy of Pediatrics \(AAP\)](#)

[American Medical Association \(AMA\)](#)

[American Telemedicine Association \(ATA\)](#)

[The Family Center](#)

- [Telegenetics Infographic](#)

[Family Voices](#)

[HHS Telehealth Webpage for Patients/Consumers](#)

[Midwest Genetics Telegenetics](#)

[NCC Telegenetics](#)

[Starting a Telegenetics Clinic](#)

[Telehealth Resource Centers](#)

[Western States Telegenetics](#)

[When Ransomware Strikes, Who to Call?](#)

[4 Things to Keep You Cyber Safe](#)

[National Digital Equity Center](#)

[National Digital Inclusion Alliance](#)

HHS Telehealth Webpage for Patients/Consumers: <https://telehealth.hhs.gov/patients/>

TRC and Other Consumer Resources:

Mid-Atlantic TRC – [Digital Inclusion and Broadband page](#)

[How Patients Can Engage Telehealth](#), [Telebehavioral Health](#), [Tips to Keep Your Telehealth Visit Private](#), [Downloadable Tech Guides](#), [Virtual Healthcare for Patients/Consumers](#)

Devices/Connectivity:

FCC [Lifeline Program](#) and FCC [Affordable Connectivity Program \(ACP\)](#)

- ACP Wind-Down [Fact Sheet](#)

- ACP Wind-Down [Frequently Asked Questions \(FAQs\)](#)

- ACP/Lifeline [FAQs](#)

[iCanConnect](#) - National Deaf-Blind Equipment Distribution Program

[Telehealth Access for Seniors](#)

[North Carolina DHHS Telehealth Guidance and Resources: Communication Access for Deaf, Hard of Hearing and DeafBlind Patients and their Providers](#)

[National Consortium of TRCs - Telehealth and Disabilities: Recommendations for Providers](#)

[WHO-ITU Global Standard for Accessibility of Telehealth Services](#)

APA/SAMHSA Tip Sheets - How to Prepare for Video Appointments with Your Mental Health Clinician: [English](#) and [Spanish](#)

[ADA National Network](#) 1-800-949-4232 (voice/TTY/relay)

- Information, guidance and training to “make it possible for everyone with a disability to live a life of freedom and equality.”
- Customized [regional and national trainings](#) on the ADA
- [Accessible Health Care](#) - www.adata.org/factsheet/accessible-health-care
- [Health Care and the ADA](#) - www.adata.org/factsheet/health-care-and-ada
- [ADANN Webinar Series: Health Care and the ADA - Inclusion of Persons with Disabilities](#) - www.adapresentations.org/healthcare/schedule.php

Participant Shared Resources & Notes

- [The International Storytelling Center | Jonesborough, TN](#) (mentioned by Lisa Richard) as a way to be heard <https://www.storytellingcenter.net>
- Rest Stop Telehealth: where families drive across a state line to take a telehealth appt

Challenges & Requests

Solutions & Resources

Be as specific as you'd like. Feel free to share your contact information in request or response.

How do I / we ...

State Licensure info for Telehealth

Any funding coming out?

Federation of State Medical Board Key Issues by State

Additional funding coming out for people to deal with creative ways of resolving licensure issues