Heartland Regional Genetics Network (HRGN)

Evaluation: Data Across Time
HRGN 7 Year Journey: Many Paths to Supporting Families and Providers
What were our Strategies and Results?
Build Partnerships to Improve Access to Genetic Services

Family Consultants and Health Care Providers Support Access to Genetics through Facilitated connections

- Families Together (Kansas)
- Munroe-Meyer Institute (Nebraska)
- Marshallese Clinic (Arkansas)
- Family Partnership (Missouri)
- Oklahoma Family Network (Oklahoma)
FACILITATED CONNECTIONS: HEALTH CARE PROVIDER (2A) AND FAMILY NETWORK PROGRAMS (2B) SUPPORT PARENTS' ACCESS TO GENETIC SERVICES

- Year 7 2B: 18 Underserved Patients, 30 All Patients
- Year 7 2A: 25 Patients
- Year 6 2B: 18 Underserved Patients, 66 All Patients (94 total)
- Year 6 2A: 18 Underserved Patients, 25 All Patients
- 1A: 18 Underserved Patients, 25 All Patients (74 total)
There was a 116% increase from Year 1 and Year 6
Facilitate Connections: What did we learn?

• Increased connections between genetic providers and families.
• Parents expanded their knowledge of genetics.
• Project training increased family support staff understanding of the Marshallese community.
• Family organizations may be best-suited to take the lead.
• COVID had a major impact on family organizations’ ability to connect families to providers.
Engage Members of Underserved Communities to Improve Access to Genetics Services
**Distribution of Materials**

- Brochures for parents
- NBS Videos
- Early Hearing & Detection Video
- Tip sheet for providers

**Training**

- 247 Marshallese individuals participated in a genetic training in two events over the past 2 years

**Health Screening and Clinic**

- Genetic Counselor supported a clinic for Marshallese patients as part of her research study

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**Marshallese Community**
Marshallese: Educational Training/Health Screening/Wrap-around Services was the right formula.

• New community connections were made.
• Families were referred to services they needed.
• Families need support to advocate for themselves and to follow-up with recommended services.
• Families were responsive to training.
Response to Training

Thanks for helping us. I know more now than I had before. Now I really understand how important it is for him to be seen for care, but I will need to learn more so I can help my son.

A Marshallese Parent
Spanish Videos were a successful educational strategy: Strategies to maximize their use

• Broaden dissemination to genetic health providers
• Incorporate into education curriculum
• Advocate use in family-to-family organizations
Spanish Videos were a successful educational strategy: Strategies to maximize their use

Disseminate videos as:
• Part of webinars and presentations
• With companion resources
• By expanding marketing
Innovative Telehealth Delivery Model

2 Distant Sites
Arkansas (5)  Oklahoma (2)
Kansas (2)    Colorado (1)  Tennessee (1)

9 Originating Sites
There was an **83%** increase from Year 1 and Year 6.
In first six months of 2023 grant 90% of the patients were from underserved areas.
There was a 71% increase from Year 1 and Year 6
Facilitate Learning through Sharing Resources and Training
TRAINING: # OF INDIVIDUALS PARTICIPATING IN TRAINING

7 HRGN SPONSORED TRAININGS FOR SIX MONTH REPORT.

<table>
<thead>
<tr>
<th>Period</th>
<th>Participants that live in underserved areas</th>
<th>All Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>June-Nov</td>
<td>34</td>
<td>352</td>
</tr>
<tr>
<td>Year 6</td>
<td>133</td>
<td>229</td>
</tr>
<tr>
<td>Year 1</td>
<td>93</td>
<td></td>
</tr>
</tbody>
</table>
There was a 146% increase from Year 1 and Year 6.
In Year 7......

87% of the training participants were individuals/families.

3 events were designed for families.
IHP Training was useful, helping school staff be “more prepared.”

Benefits

• Provided consistency of care
• Helped students increase independence
• Maximized student safety
• Process engaged parents
IHP Training was useful, helping school staff be “more prepared.”

Challenges

• Lack of parent engagement
• Teacher reluctance to participate in process
• Supporting transition to college
Response to IHP Implementation

“I feel better about him being at school. He can be a kid and play like the other kids. I know he is watched and safe, and they all know what to do if something happens.”

... A Parent
Videos

Web-Based Resources

Pamphlets

Distance Modules
27,139 YouTube Views

Reach = 494
Facebook Reach:
Year 1: 207
Year 6: 6779
Year 7: 9487

3174% Increase
Web Sessions:
Year 1: 2714
Year 6: 8821

225% Increase

Primary Web Users:
Year 1: 2324
Year 6: 7002

201% Increase
The HRGN Journey is Complete… Yet the work will continue by building on its success.