



---

# Pathways to Family Leadership: Turning Lived Experience into Collective Impact

Lourdes Quintana-Baez, CHARGE Syndrome Foundation

# Family Engagement Visioning Report

- Published in 2022
- Five-month visioning process
- Partnerships:
  - 130+ families,
  - State deafblind projects, and
  - Partnering organizations
- Shared definition of Family Engagement
- 8 Direct Service Priorities
- 4 State & National Level Priorities for Systems Change

[The Value of Family Engagement: Identifying Unique Needs and Priorities of Families with Children Who Are Deafblind](#)

# Definition of Family Engagement

“Family engagement is helping families find and elevate their voice while feeling a sense of belonging in their community.”

[The Value of Family Engagement: Identifying Unique Needs and Priorities of Families with Children Who Are DeafBlind](#)

# Direct Service Priorities

Meet families  
where they are

Grow family  
connections

Deepen professional  
sensitivity and  
understanding

Empower and honor  
the family as the  
child's primary  
teacher and  
champion.

Strengthen family  
voices, stories, and  
confidence.

Deliver information in  
multiple modalities

Unbiased services  
and supports

Amplify family voices  
and leadership at all  
levels

# State/National Priorities for Systems Change

## Ensure

Ensure continuity and equitable resourcing for family engagement across states and territories.

## Deepen

Deepen the reach and impact of national organizations to the local family level.

## Network

Network nationally to expand each organization's individual capacity to support family engagement. "We are better together!"

## Establish

Establish written collaborative agreements for family engagement across national partner organizations.

# Family Engagement: Equipping families to lead at any level

- Through connection
- Through meaningful resources, information, and referral
- With trust and respect
- Through training with other families on needed individual skills and knowledge
- With direction, consistency and continuity
- In partnership

# Working together

- Invited other organizations in the Deafblind Community
- Shared our efforts in family engagement
- We had a lot in common!
  
- Work smarter by creating a training curriculum that would provide parents with the tools they need to be successful

# Our Partnership

---

National Center for  
Deafblindness

---

National Family Association for  
Deafblind

---

Ava's Voice

---

Global Foundation for  
Peroxisomal Disorders

---

Texas Deafblind Project

---

Hands and Voices

# From lived experiences to action!

- We can provide families the tools they need so they can continue their journeys with the right tools!



Shared our lived experiences and how we found our voice



Sharing stories creates powerful bonds



It is time to learn what you didn't know you didn't know!

# Lourdes Quintana, CHARGE Syndrome Foundation

- On a personal level- Lived experience as a sibling of an individual with complex medical needs and intellectual disability
- How this impacted my professional path
- Bilingual professional



# Our plan- a work in progress!

- Build a curriculum to provide families the tools needed to begin their journey into leadership
- This process will help them solidify their foundation
- Offer curriculum across etiologies, building a stronger community
- Support new parent leaders!

# Moving Forward Together

- **Keep inviting families**—intentionally and meaningfully.
- **Keep communicating**—not just at meetings.
- **Keep mindful** that access and opportunities differ.
- **Keep creating ways** for families to build leadership and confidence.
- **Keep working together!**

**Intentional Engagement is Key!**



---

**Thank You for Joining Us Today!**