

# Conversations with Panamanian Parents Regarding their Children with Disabilities and AAC

Naima Bhana

AAC Think Tank

Summer 2019

## Panama

The Good



Considered a high income country by the world bank



## Panama

The bad



Ranked 8<sup>th</sup> on wealth inequality



## Panama

### High Income Country

- World Bank
- Out of 149 countries Panama is ranked 8<sup>th</sup> on wealth inequality
- 66<sup>th</sup> in the world in terms of the human development index (out of 189)
  - "High Human Development"

Population=4 million

### Official language Spanish

- English is widely spoken

### Education system

- Public and private schools

## Research Questions

What do Panamanian parents know about AAC?

How do they feel about their child using AAC to communicate?

What are some barriers to successful AAC implementation in Panama?

## Methods

- Qualitative Research Methodology
- Data collected through interviews
- Online messaging, E-mail, Video calls
- Based on parent preference
- Interviews conducted in parent's first language

## Recruitment

- Social Media
- Family and friends
- Professionals in the field



**PennState**

Te gustaría participar en un estudio acerca de la comunicación de personas con discapacidad?

**Cual es el propósito del estudio?** Queremos aprender mas acerca de las necesidades de los padres y profesionales que trabajan con personas con discapacidad en Panamá.

**Cuales son los requerimientos**

- Ser padre o madre de niños o jóvenes con discapacidad (autismo, parálisis cerebral, síndrome de Down, etc.) y dificultades de comunicación
- Profesionales de educación especial, fonoaudiológicos, y terapeutas que trabajen con niños o jóvenes con discapacidad (autismo, parálisis cerebral, síndrome de Down, etc.) y dificultades de comunicación

**Que tendré que hacer?**

- Completar una entrevista vía email, teléfono, o WhatsApp.

**Si estas interesado, escríbeme!**

Naima Bhana  
email: nub168@psu.edu  
+1850-345-5947 (cel)

• Este estudio a sido aprobado por Penn State University. Naima Bhana es una maestra de educación especial certificada y candidata a doctorado en educación especial.

## Participants

- 8 parents
  - Parent Age range 35 to 69
    - 1 father, 7 mothers
- 8 children
  - Child Age range 31 to 6
    - 6 with ASD
    - 1 DS
    - 1 Hydrocephaly
- 3 professionals
  - Psychologist
  - Teacher
  - Special Olympics coordinator

## Probe Questions

Based on literature review  
Huer, Parette, & Saenz (2003)  
Parette, Chuang, & Huer (2004)  
Huer & Saenz (2003)  
Merriam & Tisdell (2016)

1. Tell me about your child
2. Tell about a typical day in your home?
3. What are some strengths/weaknesses of your child?
4. How does your child typically communicate?
5. How do you feel about your child's communication abilities?
6. What do you know about AAC?
7. How do you feel about AAC as a way to help children communicate?
8. What do you think about the Panamanian educational system for children with disabilities
9. When you want to learn something new to support your child, what sources do you consult?
10. What new topics would you be interesting in learning about people with disabilities?



SCHOOL SYSTEM



SUPPORT SYSTEM



COMMUNICATION



LEARNING



BARRIERS



INDEPENDENCE

## Emergent Themes

## Themes

- **School system**
  - Public Vs. Private system
  - Tutors
  - Peers and Rejection
  - National Center School (IPHE)
- **Support System**
  - Grandparents, Nannies, Tutor, Spouse
- **Leisure**
  - Variety of leisure activities
  - "Too much unstructured time"

## Themes

- **Learning**
  - Internet, Social media parent groups, Professionals
- **Communication**
  - Pictures, PECS, Signs, Body Language
- **Barriers**
  - National school and health system
  - Lack of training and professional experience
  - Lack of inclusion
  - Attitude of professionals
  - Financial Resources

### What do Panamanian parents know about AAC?

- Parents who report knowing about AAC are parents of children with ASD
- Most knowledge is limited to the use of pictures
  - One mother reports trying an AAC application
- Terminology is an issue
- Misconceptions about the use of AAC

- Gormley 2017: Haiti Perspective
  - "Many of the children had never participated in a classroom setting or received AAC services. Many of the children had limited peer interaction due to stigmatization related to their disability"

## Preliminary Results

### How do parents feel about their child using AAC to communicate?

- 6 of the 8 parents know "something" about AAC
  - Parents who report knowing about AAC have overall positive feelings about using AAC to help children communicate
- "It's a tool to start language but we should be careful about using them as they may replace language"

- Huer, Parette, & Saenz (2001) Conversations with Mexican Americans Regarding Children with Disabilities and Augmentative and Alternative Communication
- "She doesn't use the machine particularly because she depends on the speech and (speech therapist) brought the device to our house twice to show her about it, but I prefer to say (to daughter), "Talk to me. Talk to me"

## Preliminary Results

### What are some barriers to successful AAC implementation in Panama?

- Lack of training and support for professionals
  - Attitudes
- National school and health system
  - National systems lack structure
    - Therapists may see student 1-3 times a year
    - Lack of parental involvement in therapies
    - Only half-days at school
- Schools require a tutor or family member to be present

## Preliminary Results

### What are some barriers to successful AAC implementation in Panama?

- Financial Limitations
- Lack of support for families of children with disabilities
  - Reliance on other family members, tutors, nannies

- Donohue & Bornman (2014)
  - Cultural Barriers to Inclusion and Ambiguity in Education Policies

## Preliminary Results

## Next Steps

- Complete data analysis for parent perspective paper
  - Reliability coding
- Complete Panama practitioner perspective project
  - Recruit teachers from public and private institutions
  - What populations are teachers serving?
  - What do teachers see as their barriers?
- Extend to Ibero-America
  - Survey
- Create resources and materials in Spanish

## Discussion Questions

- Recruitment of English Language Learners (ELL) parents and caregivers
  - Best practices and ideas for targeting this population in the USA

## Discussion Questions

- We know that access to the home language increases an individual's participation within the family, nevertheless parents and caregivers may sometimes push for the AAC to be in English rather than in the home language.
  - How can we be respectful of parent's wishes while also providing access to the home language?

## Discussion Questions

- Working with families in other countries
  - *Systems change* can be defined as addressing the root causes of social challenges. In the case of AAC, this would mean researching and addressing the barriers to education and implementation of AAC. How do we support "system change" regarding uptake and effective use of AAC? What AAC areas should we address first?