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## **Barriers influencing minority clients' access to speech language pathology services. Poster**

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# Barriers influencing minority clients' access to speech language pathology services



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California State University Board of Regents**

# Background – Personal/clinical experience and Research Literature

## Personal and clinical experience

- First author: Multilingual and bicultural personal experiences in three countries.
- Clinical experience as a bilingual SLP in CA – provided considerable anecdotal information about barriers faced by diverse clients and their families, and affirmed that minority clients have varied needs/expectations and awareness of SLP services.

## Research Literature

- Minority clients generally face barriers to accessing health care services and frequently receive lower levels of care (Smedley, Stith, & Nelson, 2003: Institute of Medicine report on Unequal Treatment.
- Compelling study by Drs. Don Barr and Stanley Wanat at Stanford University - **Barr, D., Wanat, S. (2004). Listening to patients: Cultural and linguistic barriers to health care access. *Clinical Research & Methods*, 37(3), 199-204.**

## **Barr & Wanat (2004). *Listening to patients: Cultural and linguistic barriers to health care access***

**Purpose:** To develop an understanding of the perceptions of low-income minority patients regarding cultural and linguistic factors impacting recent health care encounters with physicians and their staff

Conducted ethnically homogenous focus groups with African American, Latino, Pacific Islander, and Native American participants in the SF Bay area.

Participants were generally satisfied with their physicians, however, expressed concerns about:

- Perceived negative stereotyping by health care workers
- Language barriers and inadequate interpreter services
- Perceived lack of respect for elderly
- Fear of privacy violations
- Rushed appointments
- Early intervention/prevention services that target specific ethnic groups (e.g., alcohol abuse prevention programs for Native Americans)

# Background for current study

- Minority clients often face barriers to accessing health care services and frequently receive lower levels of care.

## Yet..

- Scant empirical research examining specific barriers impeding minority clients' access to health care services.
- Hardly any empirical research on cultural and linguistic (CL) barriers impacting access to speech language pathology (SLP) services. Much of this is Phase 1 research (case studies, anecdotal reports).
- Existing research on health care access has largely focused on financial barriers (e.g., inadequate or no health insurance) and not on CL barriers.

# Purpose

- To obtain empirical evidence about CL barriers faced by minority clients when accessing SLP and audiology services.
- Obtaining these data is critical for:
  - Gaining insight into minority clients' perceptions about encounters with SLPs and audiologists, referring health care providers, and third party payers
  - Educating SLPs about best practices to eliminate barriers to access for diverse clients

# Research Questions



- **What *cultural and linguistic (CL) barriers* impede minority clients' access to SLP and audiology services?**
- **What are the perceptions of minority clients and their families as they are referred to SLPs, and access and receive services from SLPs?**

# Study Participants

n = 52

- Residents of 13 cities in Northern California, mainly in the San Francisco Bay area  
*Hayward, Union City, Fremont, Pleasanton, Dublin, Menlo Park, San Leandro, San Lorenzo, Oakland, Castro Valley, Alameda, Campbell, and Roseville*
- Participants
  - Parents of children with speech, language, and hearing disorders
  - Adults with speech/language/hearing disorders
  - Adults with communication differences (e.g. unfamiliar accents)
  - Spouses or adult children of older adults with communicative disorders
  - Had to consent to participate and be able to answer questions and complete written responses to a survey in English



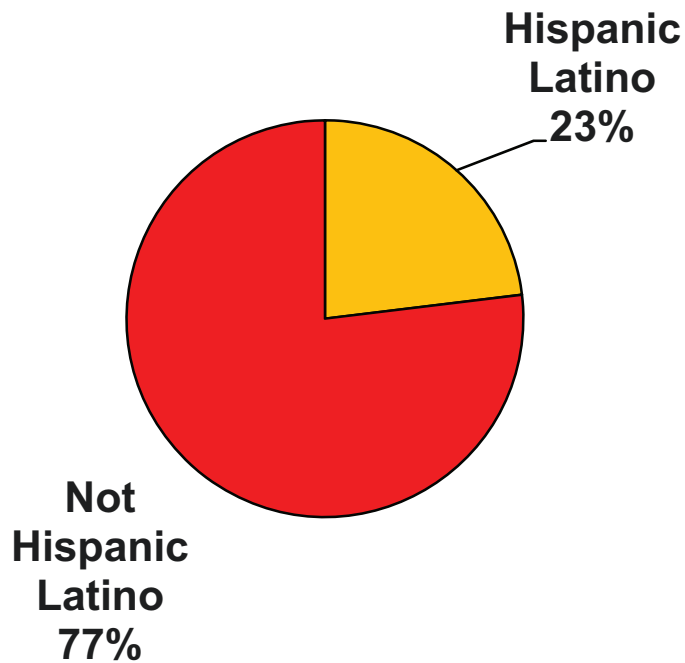
# Study Participants

n = 52

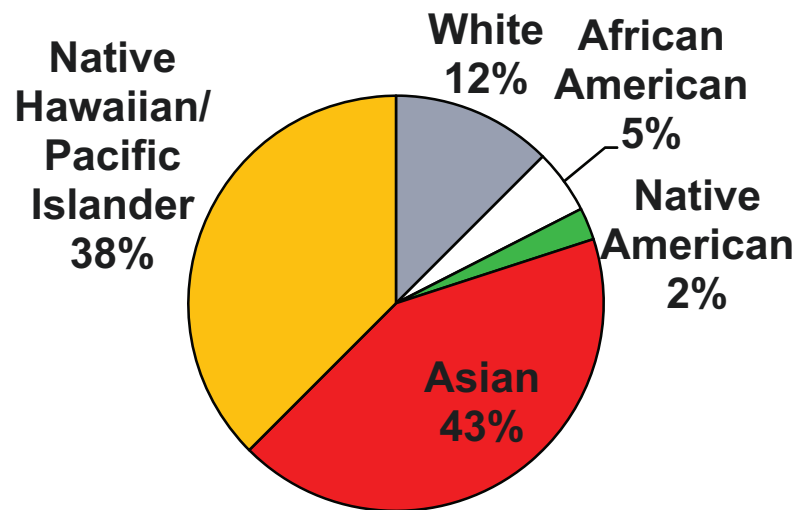
- 6 men and 46 women (ranging in age from 23 to 65 years).
- 2/3<sup>rd</sup>s of the participants were bilingual or multilingual.
- Most participants were first generation immigrants to the U.S.
- 81% of participants were Asian or Native Hawaiian/Pacific Islanders.
- Participants represented 11 female and 41 male patients (ranging in age from 3 to 66 years).
- Nearly half of the participants (46%) represented children diagnosed with autism spectrum disorders.

# Participant demographics: Ethnicity and race

## Ethnicity

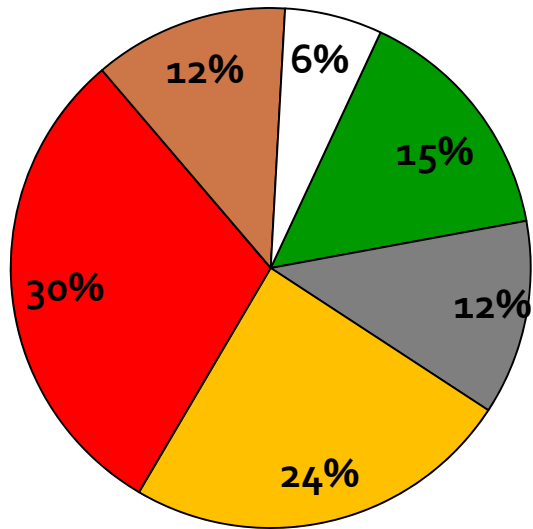


## Race

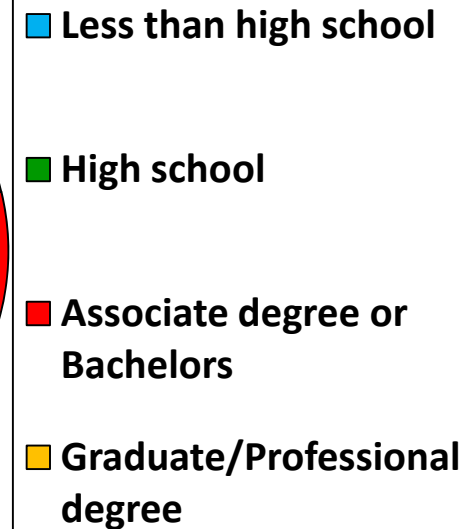
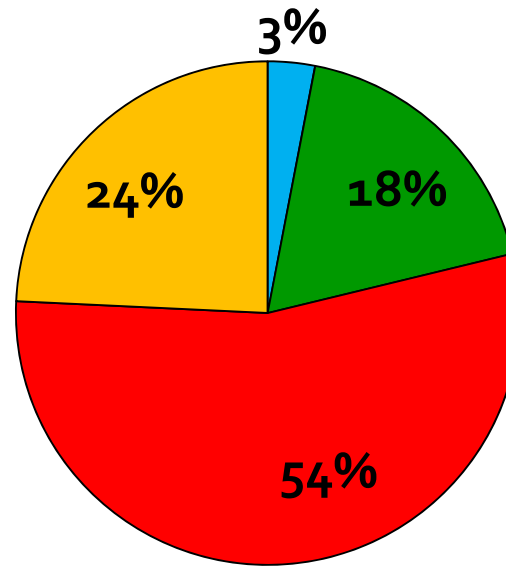


# Participant demographics: Annual household income and level of education

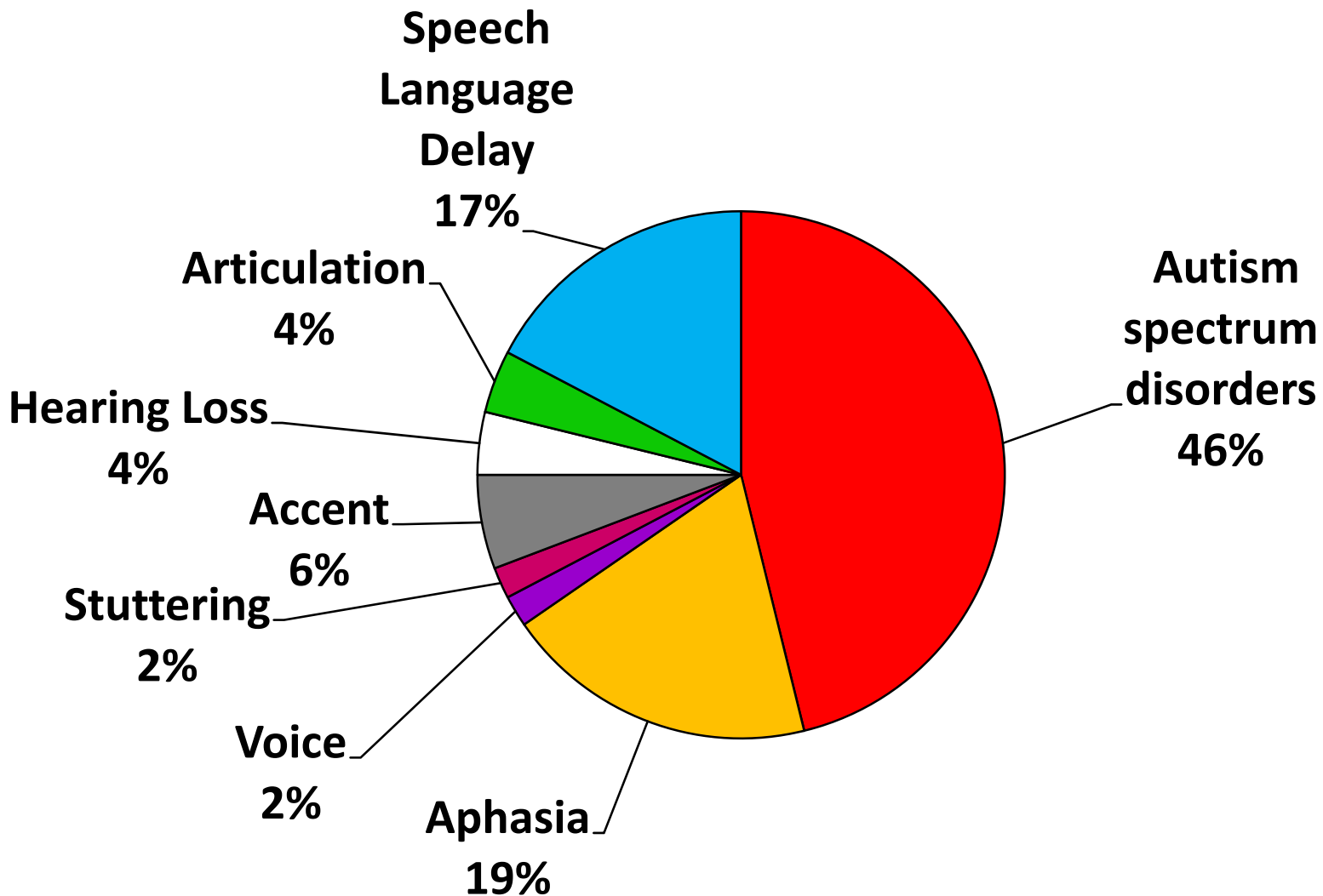
## Annual Income



## Level of Education



# Participant demographics: Communicative disorder represented



# Recruitment Sites

- **CSUEB Speech Language Hearing Clinic**

Department of Communicative Sciences & Disorders

<http://class.csueastbay.edu/commsci/abclinic.htm>

- **Center for Speech Language & Occupational Therapy (CSLOT)**

A private practice with branches in three Bay area cities - Fremont, Los Altos, and San Jose

<http://www.cslot.com/>

# Method

## Based on recommendations by Huer & Saenz (2003)



- Proposal approval from the Institutional Review Board (IRB) at CSUEB. Site approval from administrators at recruitment sites.
- Verbal invitation to potential participants by research team members or assigned SLPs, followed by a written, personalized letter from the PI.
- Verbal consent in person or by phone obtained first followed by signed, informed consent.
- Focus groups, minigroups, triads, dyads .  
(offered snacks/drinks and \$ 10.00 to each person for participation)
- Individual interviews (in person or by phone), if preferred by participants or in c/o logistical challenges.
- Survey to be filled out in person or returned by mail; surveys provided at the conclusion of focus groups or individual interviews.

# Method: Mixed methodology

- Combination of quantitative and qualitative methodology



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- Quantitative analysis
- Considered # of respondents who responded a certain way

Qualitative approach to analysis

Did not count number of respondents who responded a certain way; provided descriptive account of how most participants responded

Used survey data to give context to focus group/interview data

# Data Analysis

- Data gathered
  - Audiotapes/files of focus groups and interviews
  - Session notes by live note-takers (for focus groups; not done for individual interviews)
  - Completed surveys
- Surveys – data entered and quantified – 36 surveys (not all participants returned surveys).
- Transcripts – typed and analyzed manually; also double-coded using a commercially available software - ***The Ethnograph (Version 6.0, Qualis Research)***.
- Analyses based on the tenets of **grounded theory**- combing through the data to identify key themes expressed by participants, and to document what proportion of participants experience or report these themes.



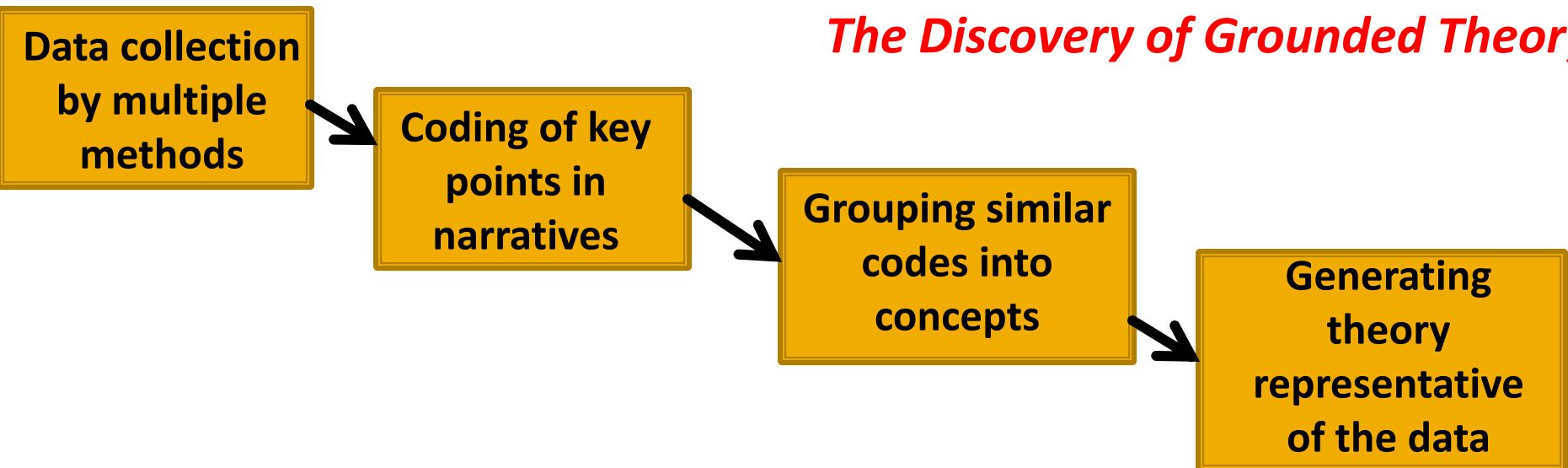
# Nuts and bolts of grounded theory



- Systematic qualitative research methodology in social sciences that emphasizes generating theory from collected data.
- Theory that is developed inductively from a corpus of data, to account for patterns seen in the data gathered.

**Glaser & Strauss (1967).**

***The Discovery of Grounded Theory***



# 25 survey items

## Objective, multiple-choice items grouped into clusters:

- **Demographic data cluster** – Items about age, gender, ethnicity, race, level of education, language history, generational status of respondents.
- **Speech therapy data cluster** – Items about type of communicative disorder, frequency and intensity of ST received, referral source for SLP services, setting, whether therapy was reimbursed by health insurance, and degree of satisfaction with ST services.
- **Narrative response items (3)** - Reasons for degree of satisfaction rating, report of factors that made it easy to access SLP services, and factors that made access difficult.

# 14 focus group questions

(developed with input from Dr. Jan Avent-CSUEB and Dr. Stan Wanat-Stanford)

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## *Opening question (1)*

- Tell us your name, where you live in the Bay area, and how long you have been coming to this clinic

## *Introductory questions (3)*

- What makes your or your family member's communication different from others?

## *Transition questions (2)*

- When you or a family member were first referred for speech therapy or audiology services, what did you know about speech pathology or audiology?

## *Key Questions (5)*

- What are some things speech pathologists/audiologists that you did not like do or say that made you less comfortable?

## *Ending Questions (3)*

- If you could give some advice to SLPs and audiologists about working with diverse clients like yourself, what would you like to share?

# Sample excerpt from transcript

**If you could give some advice to SLPs and audiologists about working with diverse people like you, what would you like to share?**

## **Response from AT (mother of child with stuttering)**

*Please tell me what is my right ...and my child's rights. What can I ask for? When I had his IEP meetings, I did not know what that is, how the process works. I did not how to read the information and what it means for my son....or that I can ask questions about it. I did not know I can take it home, think about it, discuss with my husband and bring it back the next day before I sign it. Ask me what I know or if I know. Maybe I have no clue and then everyone's saying to me "...But you signed this Mrs. Tavares". Also, tell me clearly how serious this speech problem is....you know but I don't.*

*Another thing is...I still don't understand if I should talk to him in English or Spanish, or both?*

*If I talk in English, my accent is not too okay and how does it affect him? My Spanish is excellent...should I be talking more in that? Many therapists can't tell about this language issue or give me any information in Spanish.*

# Raw data with themes identified in participant responses

Response: *Please tell me what is my right ...and my child's rights. What can I ask for?*

***Desire for knowledge about consumer rights***

*When I had his IEP meetings, I did not know what that is, how the process works. I did not know how to read the information and what it means for my son....or that I can ask questions about it. I did not know I can take it home, think about it, discuss with my husband and bring it back the next day before I sign it. Ask me what I know or if I know. Maybe I have no clue and then everyone's saying to me "...But you signed this Mrs. Torres".*

***Need for information about IEP process, its purpose, and components***

*Also, tell me clearly how serious this speech problem is....you know but I don't.*

***Different perceptions of urgency of need for speech therapy***

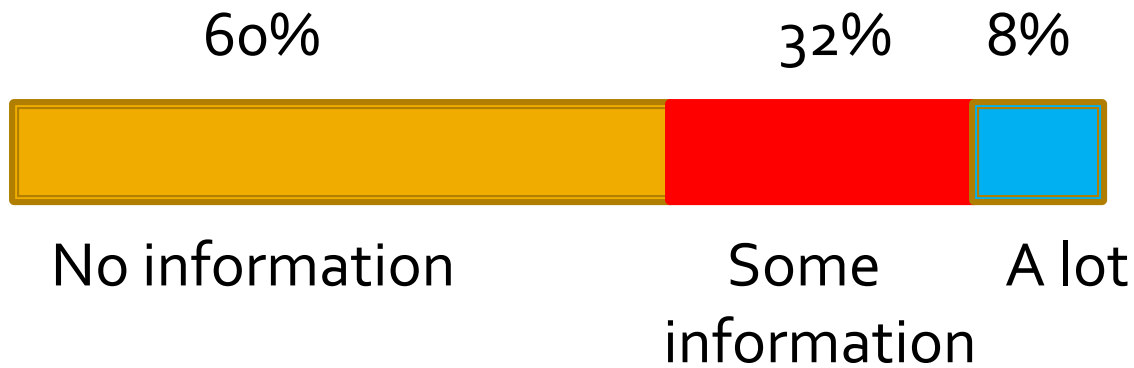
*Another thing is...I still don't understand 'Should I talk to him in English or Spanish, or both? If I talk in English, my accent is not too okay and how does it affect him??? My Spanish is excellent...should I be talking more in that or not? Should we not talk to him in Spanish?*

***Confusion about choice of language and its impact***

*Many therapists can't tell about this language issue or give any information in Spanish.*

***Concern about SLPs limited knowledge about bilingualism and ability to provide resources in non-English languages.***

# When you were first referred for speech therapy or audiology services, what did you know about speech pathology or audiology?



# Facilitators of access to and knowledge about available SLP services

- Input from the regional centers
- Physician referral
- Referrals from school teachers and school-based SLPs
- *Word of mouth* – social networks, other parents, internet parent groups
- University settings: Non-clinical staff and academic advisors
- Classes by Kaiser Permanente about therapy resources
- *Information available on the internet*
- Resources in the local yellow pages

# **Barriers that limited access to and knowledge about available SLP services**

- **Inadequate advertising of SLP services**
- **Lack of timely and/or appropriate advice from primary care physicians and pediatricians (e.g. “wait and watch” advice)**
- **Recent relocation to the Bay area and restricted social networks**
- **Insufficient knowledge of SLPs’ full scope of practice**
- **Limited understanding about laws/entitlement for services for persons with disabilities in the US or school settings**
- **Limited or no knowledge about typical speech and language development and expected milestones**
- **Lack of special education services in private schools**
- **Low health literacy or lack of access to computers/internet**



# What do speech therapists and audiologists that you really like do or say, compared to others?

## **Personality aspects**

- Display warmth to the client and family
- Create a fun atmosphere
- Have an energetic and positive personality

## **Ability to work with and relate to parents**

- Empower parents
- Spend time with parents and families to answer questions
- Teach parents hands-on strategies
- Provide information on helpful resources and are aware of the latest research

## **Cultural aspects**

- Support bilingualism and biculturalism
- Ask about non-English languages spoken and attempt to learn information about them
- Are not dismissive of parents' dialects and accents
- Ask about perceptions of causes of communicative disorders

## **Communication Skills**

- Able to explain complex concepts in simple terms
- Have good, clear articulation
- Animated communication
- Not afraid to say "I don't know enough about that"

# What are some things speech pathologists/audiologists that you did not like do or say that made you less comfortable?

## Therapy session aspects

- Very short or few therapy sessions when more are appropriate
- Unclear explanations for discontinuing therapy
- Unclear explanation for a client's ineligibility for a particular type of therapy

## Linguistic communication aspects

- Dismiss bilingualism as 'problematic' or contributing to language disorders
- Not knowledgeable about language/cognitive development of a bilingual child with or without speech and language problems
- Refer to parent or family members accent/dialect model as "poor model"
- Glossing over client's performance (e.g., "he's doing so well" or "today was a rough day") without being specific

## Interpersonal skill aspects

- Not able to empathize with parent concerns when treating SLPs are not parents themselves
- Being too negative about prognosis after spending a short while during evaluations
- Not asking parents about performance at home or asking parents if performance during an evaluation was representative of child's typical performance

# Types of barriers identified

- **COMMON** barriers – Those that could equally affect any client - minority or majority - in accessing SLP and audiology services.
- **CULTURAL** barriers
- **LINGUISTIC** barriers

# Common or conceptual barriers

- Limited knowledge about speech pathology and audiology
- Difficulty obtaining timely referrals from medical practitioners
- Receiving referrals for ST but no assistance for identifying qualified providers
- Internet access barriers
- Financial barriers

# Cultural barriers

- Different perceptions about the causes of a communication disorder.
- Difficulty verbally asserting concerns to health care service providers.
- Recent immigration to the US and little to no knowledge about the US health care/educational system and rights of persons with disabilities.
- Lack of extended family in the United States or close by and/or limited social support and networks.
- Multiple respondents shared how many members of their cultural groups had limited knowledge about disabilities, specifically communicative disorders and their effects, thus making their own ethnic group less accepting and less sensitive.

# Linguistic barriers

- Partial fluency/literacy in English leading to failure to comprehend recommendations about the urgency of SLP services.
- Assessments not conducted in a first language, or an "actual" disorder dismissed being attributed to limited English proficiency.
- Many participants reported being advised by SLPs that bilingualism or bidialectalism was causing their child's language disorder and that they needed to restrict communication to English to maximize a child's success in school.

# Emerging thoughts

- Common barriers, cultural, and linguistic barriers exist at multiple levels (organizational and clinical) for clients requiring access to SLP services.
- Data on barriers affecting access to SLP services for any group of clients is vital for eliminating health disparities in the long term.
- Many prevalent myths about typical and atypical second language acquisition that must be addressed urgently.
- Inadequate understanding of what SLPs do in assessing and treating communication disorders.

# Challenges in conducting this study

Inability to provide childcare for participating parents and families, for the duration of the focus groups.

Limited resources to develop surveys in Spanish and conduct focus groups in Spanish.

Complex and unexpected themes often emerged in focus groups, sometimes requiring extensive follow-up.

Participants required lots of encouragement and support (reminders, flexibility to reschedule, provide information on weekends).



# Where do we go from here?

- Conduct focus groups with participants that do not speak English
- Move from documenting barriers to designing interventions to eliminate barriers
- Study the efficacy of various interventions
  - Community outreach
  - Consumer education
  - Strategic resource development, targeted for specific groups
  - Student training – coursework and clinical practicum
  - Professional development for certified SLPs, clinic directors, and facility administrators