

Sociodemographic Disparities in Receipt of an IFSP and IEP



**Early Intervention/Early Childhood Special Interest Group
(EIEC SIG)
Webinar Series
February 28th, 2012**

Webinar Overview

- Introductions
- Presentations
 - Sally Stuart, PhD, MSW, University of Washington
 - Stephan Blumberg, PhD, Centers for Disease Control and Prevention
- Q & A
- Survey
 - Please complete our short survey to give us feedback for the next webinar!

Sociodemographic Disparities in Receipt of an IFSP and IEP

Sally N. Stuart, PhD, MSW
AUCD Early Intervention Early Childhood
Special Interest Group
February 28, 2012

IDEA: Part C and Part B, 619

- ❑ Children with a developmental delay are entitled to intervention services under Part C or Part B, Section 16 of IDEA
 - ❑ Children aged 0 through 2 years are served under Part C and have an IFSP
 - ❑ Children aged 3 through 5 years are served under Part B, Section 619 and have an IEP
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The Issue:

- ❑ Identification of young children who may be eligible for intervention services has been an issue for years
 - ❑ Half of the children who may be eligible are not receiving services
 - ❑ Disparities exist in receipt of services based on sociodemographic factors
 - ❑ Few studies have examined the role of primary language spoken at home
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Why focus on primary language as a source of a disparity?

- ❑ 23% of US population report they speak English not at all or less than very well
 - ❑ Determining a delay is the outcome of a process between parent and provider
 - ❑ Parents can provide accurate information about their child's developmental status (Glascoe, Tervo, etc.)
 - ❑ Language barriers can influence access to services for CSHCN (Flores and others)
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Research Questions

- ❑ What sociodemographic factors predict receipt of an IFSP/IEP?
 - ❑ Is there an association between primary language spoken at home and receipt of an IFSP/IEP?
 - ❑ Is there an association between primary language spoken at home and family-centered care?
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Methodology

- ❑ Data from the 2007 National Survey of Children's Health (2007 NSCH)
 - ❑ Designed and sponsored by MCHB and administered by the CDC's NCHS
 - ❑ Stratified random-digit-dial sampling design achieved a representative sample of 91,642 children aged 0-17
 - ❑ Module of the State and Local Area Integrated Telephone Survey (SLAITS)
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Study Sample

- ❑ Subset of 27,566 children aged 0 through 5 years
 - ❑ Sampling weights produced estimates to represent children nationally
 - ❑ Predictive Analytics Software, Version 18, Complex Samples used for analysis
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Dependent Variable

- ❑ Survey question “Does CHILD have any developmental problems for which he/she has an IFSP or IEP
 - ❑ First time question was included in the NSCH or NS-CSHCN
 - ❑ Dichotomized “yes” or “no”
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Independent Variable

- Primary Language Spoken at Home:
 - English
 - Spanish
 - 4 Asian Languages
 - Mandarin
 - Cantonese
 - Vietnamese
 - Korean
 - Dichotomized English and non-English
-

Covariates

- Child's age
 - Child's gender
 - Child's Race and Ethnicity
 - Mother's education level
 - Family poverty status
-

Access to Care Variables

- Personal Doctor or Nurse
 - Provider Elicited Concerns
 - Family-Centered Care
 - Type of Health Insurance
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Risk for Developmental Delay

- ❑ Survey version of the PEDS
 - ❑ Parents can raise concerns predictive of developmental problems (Glascoe, Glascoe & Camp, Tervo, Tervo & Asis)
 - ❑ Four levels of risk for developmental delay (no, low, moderate, high)
 - ❑ Coded no/low risk and moderate/high risk for developmental delay
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Summary of Variables: Child

- 51% Male; 49% Female
 - 50% ages 0 – 2; 50% ages 3-5
 - Child's Race and Ethnicity
 - 12.5% Black
 - 23% Hispanic
 - 11% Multiracial/Other
 - 54% White
-

Summary of Variables: Child

- 26% - Moderate/High Risk for DD
 - 21% aged 0-3 years
 - 31% aged 3-5 years
 - 4% aged 0-5 years had an IFSP/IEP
 - 2.3% aged 0-3 years
 - 5.4% aged 3-5 years
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Summary of Variables: Family

- ❑ Primary Language Spoken at Home
 - ❑ 83% English; 17% non-English
 - ❑ Mothers' Education Level
 - ❑ 13% Less than High School; 23% High School; 64% More than High School
 - ❑ Family Poverty Status
 - ❑ 21% 0-99% FPL; 22% 100-199% FPL; 29% 200-399% FPL; 28% 400% FPL or Greater
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Summary of Variables: Access

- 94% Personal Provider
 - 48% Elicited Concerns
 - 73% Family-Centered Care
 - Type of Health Insurance
 - 35% Public
 - 57% Private
 - 8% Uninsured
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Key Bivariate Findings

- Factors significantly associated with receipt of an IFSP/IEP:
 - Gender, Age, Risk for DD
 - Primary Language, Poverty Status
 - Provider Elicitation, Family-Centered Care, Health Insurance
 - Factors NOT significantly associated with receipt of an IFSP/IEP:
 - Race and Ethnicity, Mothers' Education, Personal Provider
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Key Bivariate Findings

- Factors significantly associated with primary language spoken at home
 - More likely to have moderate/high Risk for DD
 - Less likely to receive an IFSP/IEP
 - More likely to have less than a high school education; 0-99% FPL
 - Less likely to have a personal provider; provider elicit concerns, family-centered care
 - More likely to have public health insurance
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MA: Variables Significant for Receipt of IFSP/IEP: Moderate/High Risk

Variables	Unadjusted OR [95% CI]	Adjusted/Access to Care OR [95% CI]
Primary Language English/Non-English	5.265 [2.384, 11.626]	4.845 [2.158, 10.880]
Gender Male/Female	1.544 [1.087, 2.194]	1.576 [1.093, 2.272]
Age Age 0-2/Age 3-5	0.467 [0.324, 0.671]	0.428 [0.302, 0.608]
Race/Ethnicity Black/White	0.581 [0.352, 0.961]	0.492 [0.273, 0.888]
Provider Elicited Yes/No		2.448 [1.661, 3.608]
Family-Centered Care Yes/No		0.557 [0.366, 0.847]
Type of Insurance Public/Uninsured		2.341 [1.206, 4.546]

Key Multivariate Findings:

- Children were 5 times as likely to receive an IFSP/IEP with English as the primary language spoken at home as non-English
 - Language disparity persisted after adjusting for access to care variables
 - Elicitation of developmental concerns and health insurance increased odds
 - Family-centered care decreased odds of receiving services
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Summary of Findings

- ❑ 94% of children had a personal provider
 - ❑ 48% elicited developmental concerns
 - ❑ Provider elicitation increased odds of an IFSP/IEP
 - ❑ Children more likely to receive an IFSP/IEP with provider elicitation
 - ❑ Non-English primary language less likely to report provider elicitation
 - ❑ 73% reported receiving family-centered care
 - ❑ Family-centered care decreased odds of an IFSP/IEP
 - ❑ Children who were Black, Hispanic, Multi-racial/Other were less likely to receive family-centered care
 - ❑ English increased odds of receiving an IFSP/IEP
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Study Limitations

- ❑ Parent self-reported information
 - ❑ Primary language spoken at home may not be best measurement
 - ❑ PEDS may not establish eligibility
 - ❑ Established or at-risk conditions not included
 - ❑ State variability not accounted for
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Conclusions:

- ❑ Primary language spoken at home other than English may be a barrier to receiving an IFSP/IEP
 - ❑ Factors that may increase receipt of IFSP/IEP and decrease disparities:
 - Provider Elicitation
 - Family-centered care
 - Insurance
-

Selected References

- ❑ Blumberg et al. (2009). Design and Operation of the National Survey of Children's Health, 2007. National Center for Health Statistics. Vital Health Stat 1. Forthcoming.
 - ❑ CDC, SLAITS Website;
<http://www.cdc.gov/nchs/slait.htm>
 - ❑ Data Resource Center for Child & Adolescent Health
<http://www.childhealthdata.org/>
 - ❑ Rosenberg, Zhang, & Robinson (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*, 121 (6), e1503-e1509.
 - ❑ Zuckerman, et al. (2009). Household language, parent developmental concerns, and child risk for developmental disorder. *Academic Pediatrics*, 9 (2), 97-105.
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Assessing Delay

in the 2007 National Survey of Children's Health

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Centers for Disease Control and Prevention
National Center for Health Statistics

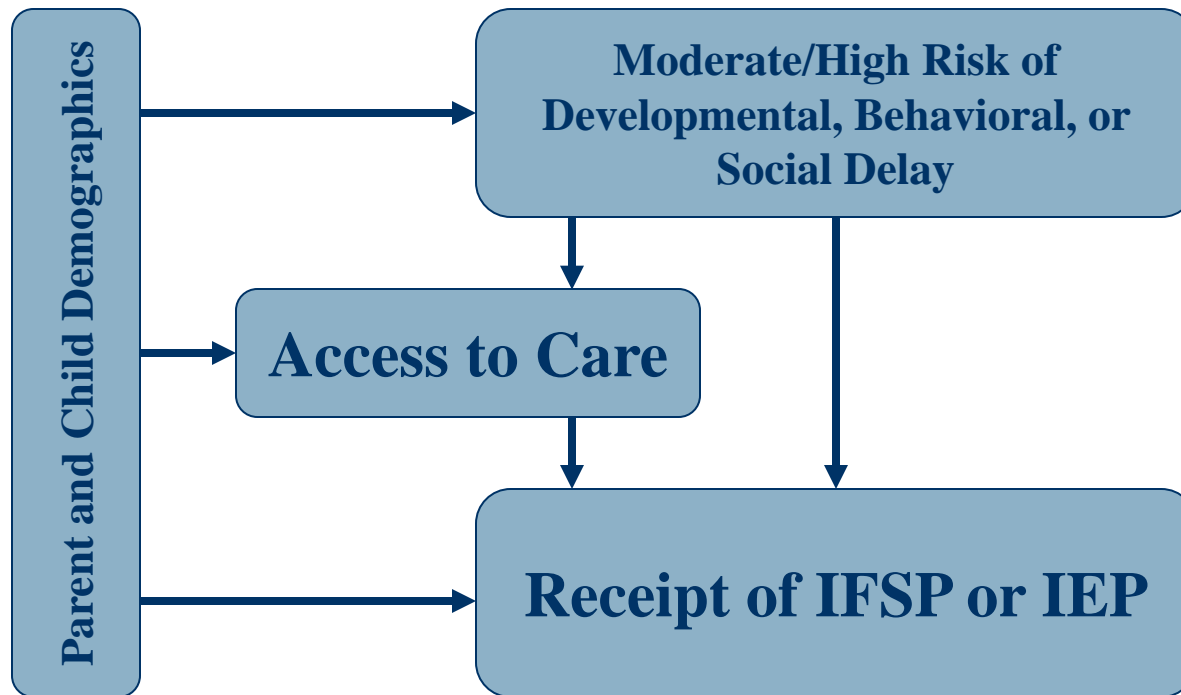
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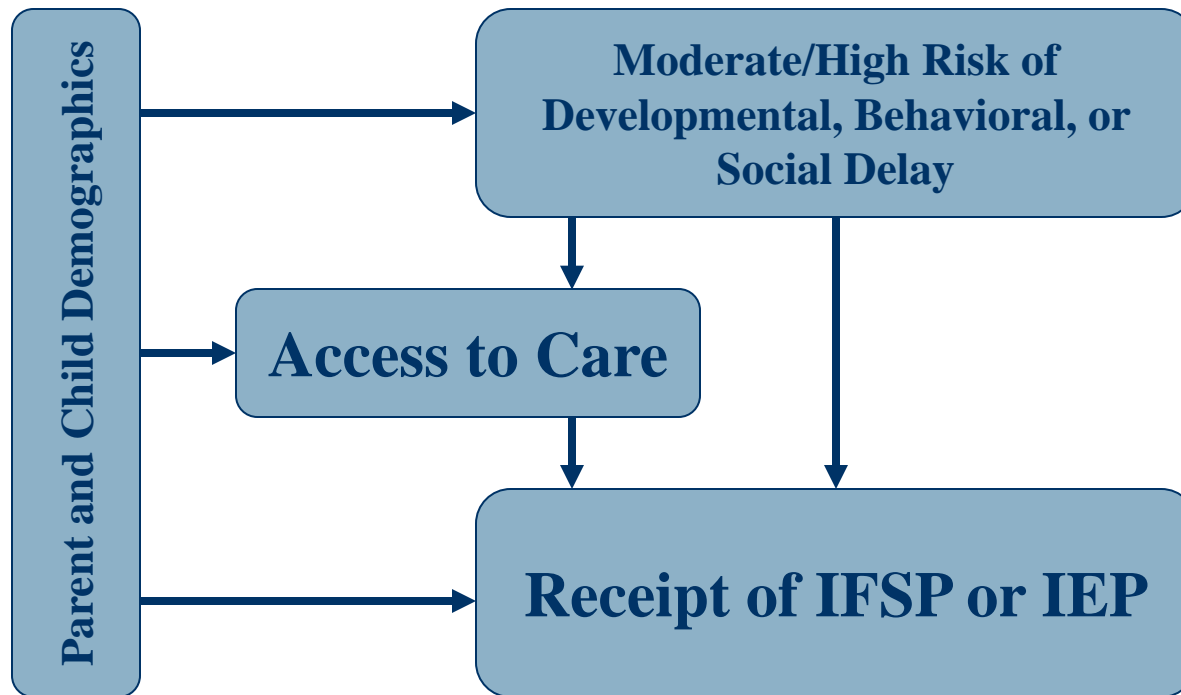
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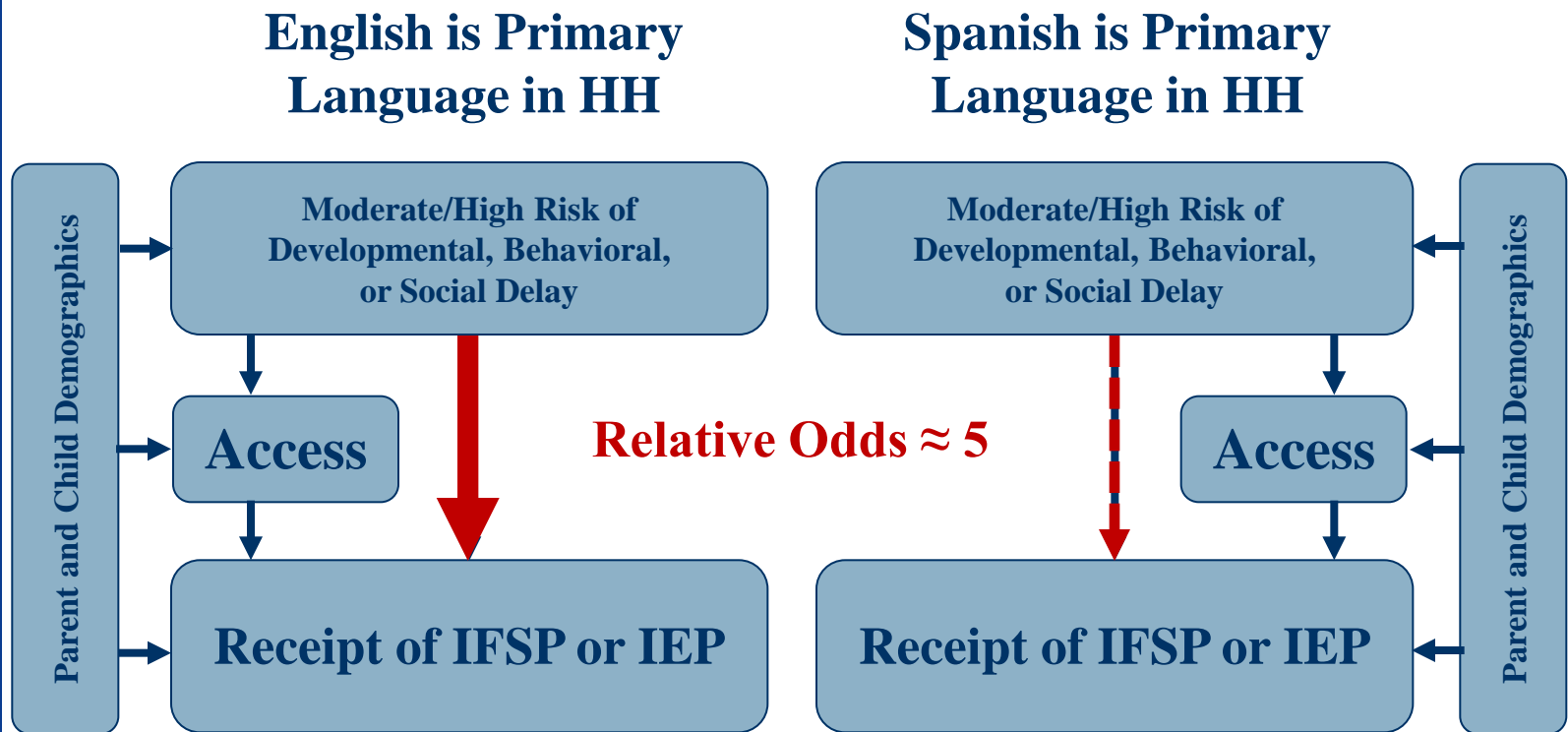
Conceptual Framework



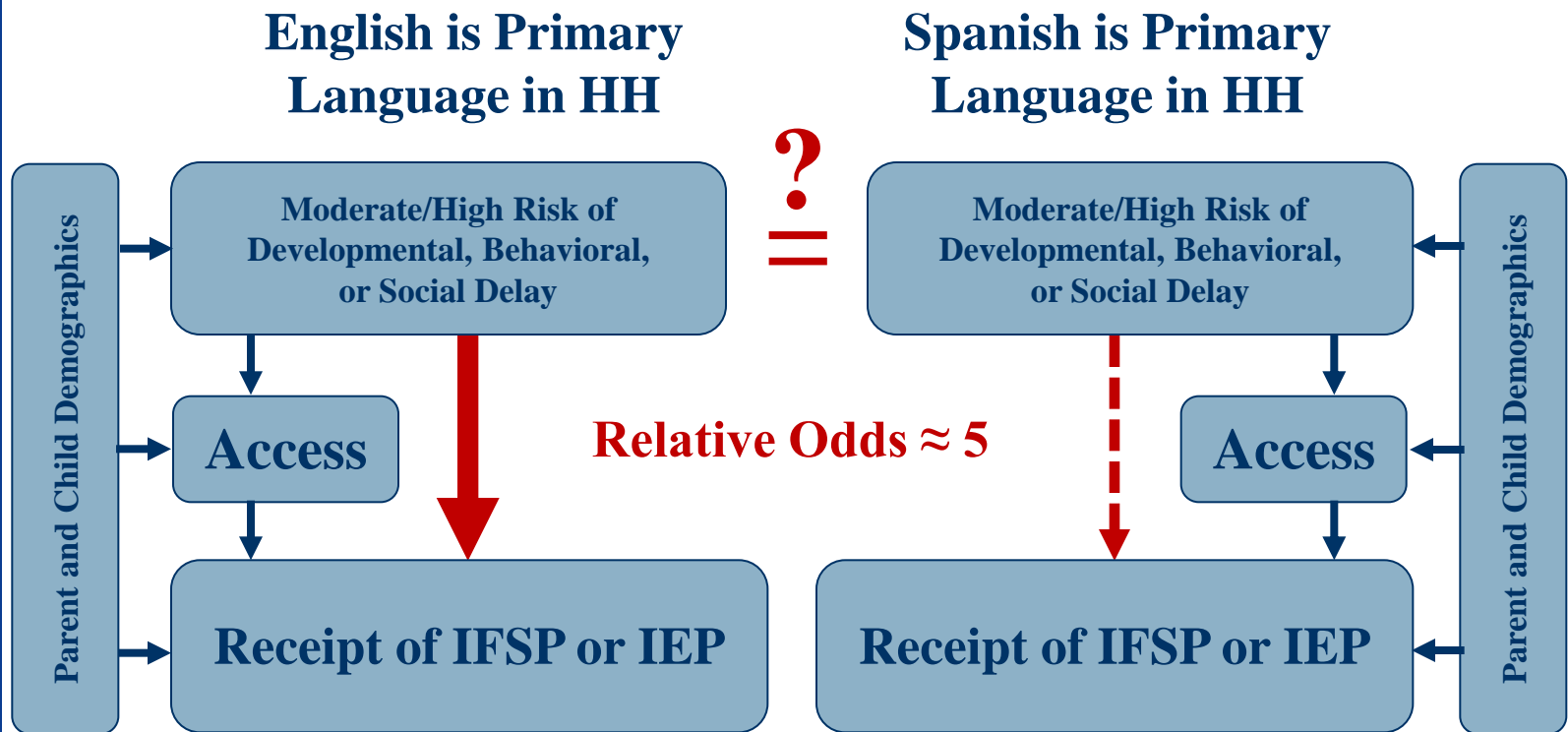
Conceptual Framework



Conceptual Framework



Conceptual Framework



Assessing Risk of Developmental, Behavioral, or Social Delay

- Parents' Evaluation of Developmental Status (PEDS)
 - Developed by Frances Glascoe
 - Well-validated in clinical settings
- Yields 4 categories of risk
 - High risk (probable delay)
 - Moderate risk (possible delay)
 - Low risk
 - No risk



PEDS[®] Response Form

Please list any concerns about your child's learning, development, and behavior.

RESPONSES:	NO	YES	A LITTLE	COMMENTS?
Expressive Language	Are you concerned about how he/she talks and makes speech sounds?			
Receptive Language	Are you concerned about how he/she understands what you say?			
Gross Motor	Are you concerned about how he/she uses his/her arms and legs?			
Fine Motor	Are you concerned about how he/she uses his/her hands and fingers to do things?			
Preschool/school skills	Are you concerned about how he/she is learning pre-school or school skills?			
Behavior	Are you concerned about how he/she behaves?			
Social-emotional	Are you concerned about how he/she gets along with others?			
Self-help	Are you concerned about how he/she is learning to do things for himself?			

Please list any other concerns.



PEDS® Scoring

Domain	Non-Predictive	18 mo - 2 yrs	3-4 years	5 years
Expressive Language		X	X	X
Receptive Language		X	X	X
Gross Motor			X	X
Fine Motor				X
Preschool/school skills				X
Behavior	X			
Social-emotional	X			
Self-help	X			



PEDS[®] Survey Form (as on NSCH)

~~Please list any concerns about your child's learning, development, and behavior.~~

RESPONSES:	NO	YES	A LITTLE	COMMENTS?
Expressive Language	Are you concerned about how he/she talks and makes speech sounds?			
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Self-help	Are you concerned about how he/she is learning to do things for himself?			

~~Please list any other concerns.~~



Parents Don't Always Answer the Question Asked!

- Open-ended questions matter (Cox et al, 2010)
 - 27.5% of concerns included a written comment
 - 23.9% of comments did not match question intent
- No mismatch differences by language
 - Equally likely to qualify concerns with comments
 - Rate of mismatch was equal
- More concerns reported on English forms than on Spanish forms
 - Cultural differences in concern thresholds and expectations may exist



Translations May Lead to Observed Cultural Differences

- PEDS:

“Are you concerned a lot...”

- 2003 NSCH:

“¿Esta muy preocupado(a)...”

- 2007 NSCH:

“¿Le inquieta mucho...”

	2003 NSCH	2007 NSCH
Non-Hisp. White	22.2%	24.0%
Hispanic, English	24.1%	28.3%
Hispanic, Spanish	24.3%	38.2%

- *Preocupado* has stronger validity (Glascoe)



Translations May Lead to Observed Cultural Differences

- Stuart (2007 NSCH):
 - After controlling for other sociodemographics, children in Spanish-language HHs **more** likely to have moderate/high risk for delay
- Zuckerman (2003 NSCH):
 - After controlling for other sociodemographics, children in Spanish-language HHs **less** likely to have moderate/high risk for delay

	2003 NSCH	2007 NSCH
Non-Hisp White	22.2%	24.0%
Hispanic, English	24.1%	28.3%
Hispanic, Spanish	24.3%	38.2%



Conceptual Framework

**English is Primary
Language in HH**

Moderate/High Risk of
Developmental, Behavioral,
or Social Delay



Receipt of IFSP or IEP

**Spanish is Primary
Language in HH**

Moderate/High Risk of
Developmental, Behavioral,
or Social Delay



Receipt of IFSP or IEP

?
=

Relative Odds ≈ 5



Recommended Actions Differ

- High risk / probable delay:
 - Refer for diagnostic testing
- Moderate risk / possible delay:
 - Conduct or refer for additional screening



Adjusted Odds Ratios For Having Possible or Probable Delay (2007 NSCH)

	Possible Delay	Probable Delay
Age (ref = 18-35 mos)		
3 years	1.25	1.54
4 years	1.36	1.48
5 years	1.70	2.86
Male	1.35	1.54
Low birth weight	1.54	2.01
Race/Eth/Lang (ref = NH white, English)		
Non-Hispanic Black	1.22	1.43
Hispanic, English	1.21	1.50
Hispanic, Spanish	1.61	2.02

Source: Simon, Pastor, Avila, & Blumberg (MCH Epi, 2011)



Adjusted Odds Ratios For Having Possible or Probable Delay (2007 NSCH)

	Possible Delay	Probable Delay
Poverty Level (ref = 400%+)		
>200-400%	1.16	1.31
>100-200%	1.17	1.59
≤100%	1.07	1.70
Highest level of parent/ guardian education (ref = at least some college)		
High school only	0.86	1.25
Less than high school	1.15	1.70

Source: Simon, Pastor, Avila, & Blumberg (MCH Epi, 2011)



Final Thought

- Difficulties assessing developmental delay in the clinical setting can be magnified in the survey world



Q & A

- There are two ways to ask questions
 - Type a question into the Q&A box next to this slide and we will read it aloud.
 - Ask a question over the phone by pressing *# on your phone to enter the question queue. The system will unmute your line when it is your turn to speak.

THANK YOU

Visit the Websites

- AUCD Website: <http://www.aucd.org>
- EIEC SIG Website: www.aucd.org/eiec

Questions about the SIG?

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- Jennifer Bogin: jbogin@aucd.org
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Please take a few minutes to complete our survey!