


Latino Families of Children with an Autism Spectrum Disorder

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Presentation Outline


- Prevalence of ASD across race/ethnicity
 - Wisconsin Latino Autism Study
 - Demographics
 - Service use and barriers
 - Maternal well-being
 - Autism symptoms
 - Study of adolescents and adults with autism
 - Conclusion
- 



Prevalence across race/ethnicity

(rates per 1000 children age 8; CDC, 2007)

	White	Latino	Black
Wisconsin	6.9	0.3 *	3.7 *
Arizona	7.7	3.4 *	6.3
Colorado	6.4	2.0 *	6.4
New Jersey	12.5	9.7	7.7 *
Penn	7.6	4.7 *	4.2 *





Interpreting prevalence variation by race/ethnicity

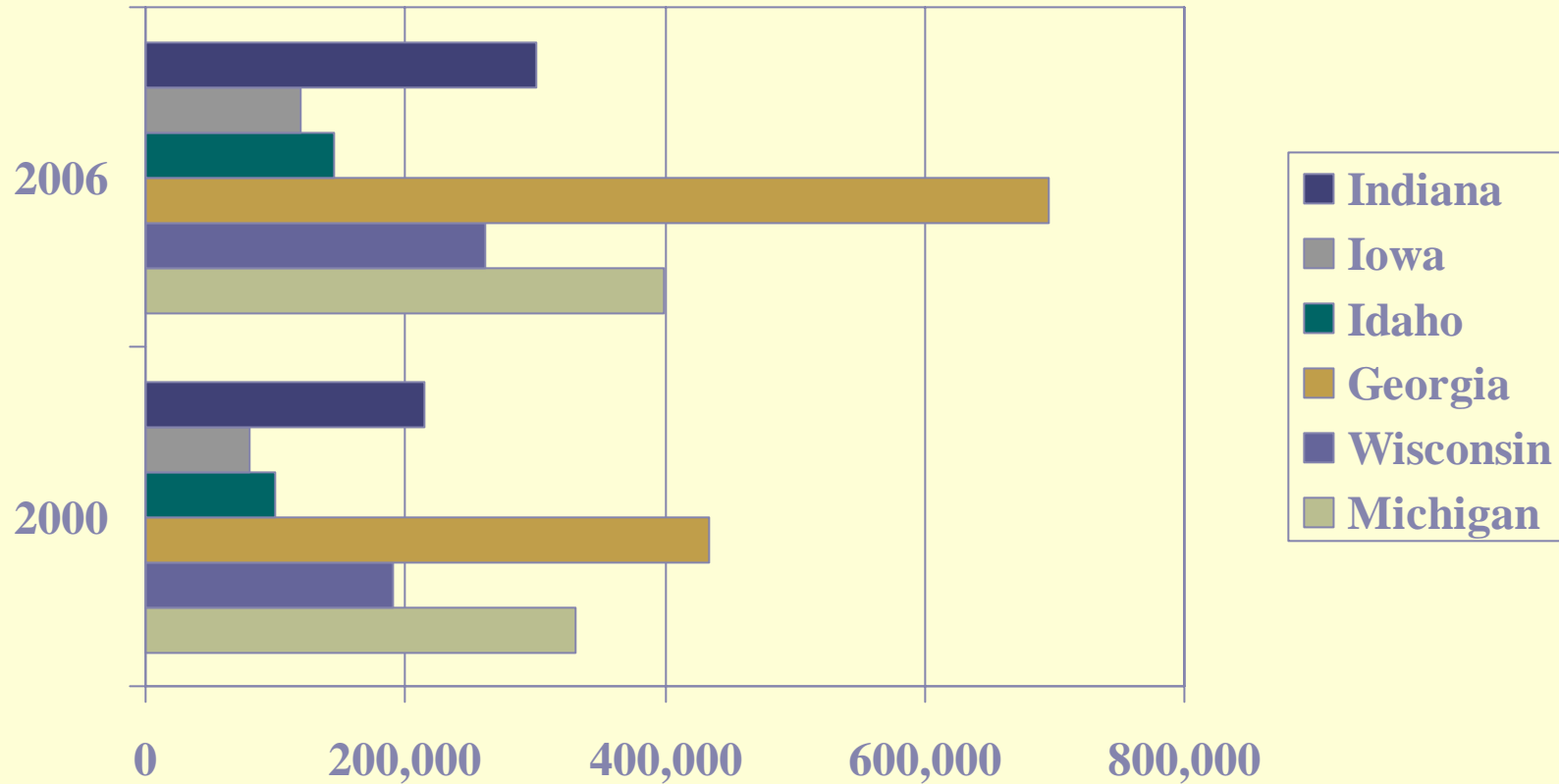
- Researchers agree that prevalence estimates for autism among different racial and ethnic groups are unreliable and should be interpreted with caution
 - clinicians rely on identification of behavioral symptoms to diagnose autism
 - Socio-economic status might influence who gets evaluated for developmental concerns
 - And how these concerns and behaviors are documented
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Low service utilization among Latinos well documented

- Factors that contribute to low levels of service use
 - language barriers
 - reduced access to information about disorders and services
 - fear of deportation among undocumented Latinos
 - reliance on family for support, and cultural differences in problem identification
 - As a result, prevalence rates of Latino children with autism are likely to be underestimated.
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Growing Latino Population in Midwest







Demographics of Current Study

- 49 children, 47 families in study
 - 76% children with ASD male
 - Ages between 2 and 21, average 9.4
 - 2 PDD-NOS and autistic disorder, 15 PDD-NOS
 - 5 Asbergers and autistic disorder
 - The remaining were autistic disorder
 - 57.2 % non-verbal
 - Mothers ages between 27 and 61 years, average 39.9 years
 - Median income \$20,000-25,000 (WI \$46,142)
 - Mothers 80.6 high school or higher (WI 85.1 high school grads)
 - 92% born outside US
 - 91.2% speak Spanish well
 - 50 % do not speak English well
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Demographics continued

- 58% of Mexican descent
 - 20% from Puerto Rico.
 - Others from, Costa Rica, Columbia, & Peru
 - Lived an average of 13 years in Wisconsin
 - 42% live in Milwaukee
 - 27% in Madison
 - Others live in different counties inside Wisconsin.
- 



How did you react when you learned of your child's diagnosis?

- We didn't know what autism was
 - I couldn't believe this was happening to me
 - I became very sad, couldn't do anything for a week
 - Many things went through my head, like what could have caused it, I did everything right during pregnancy
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How did your family react?

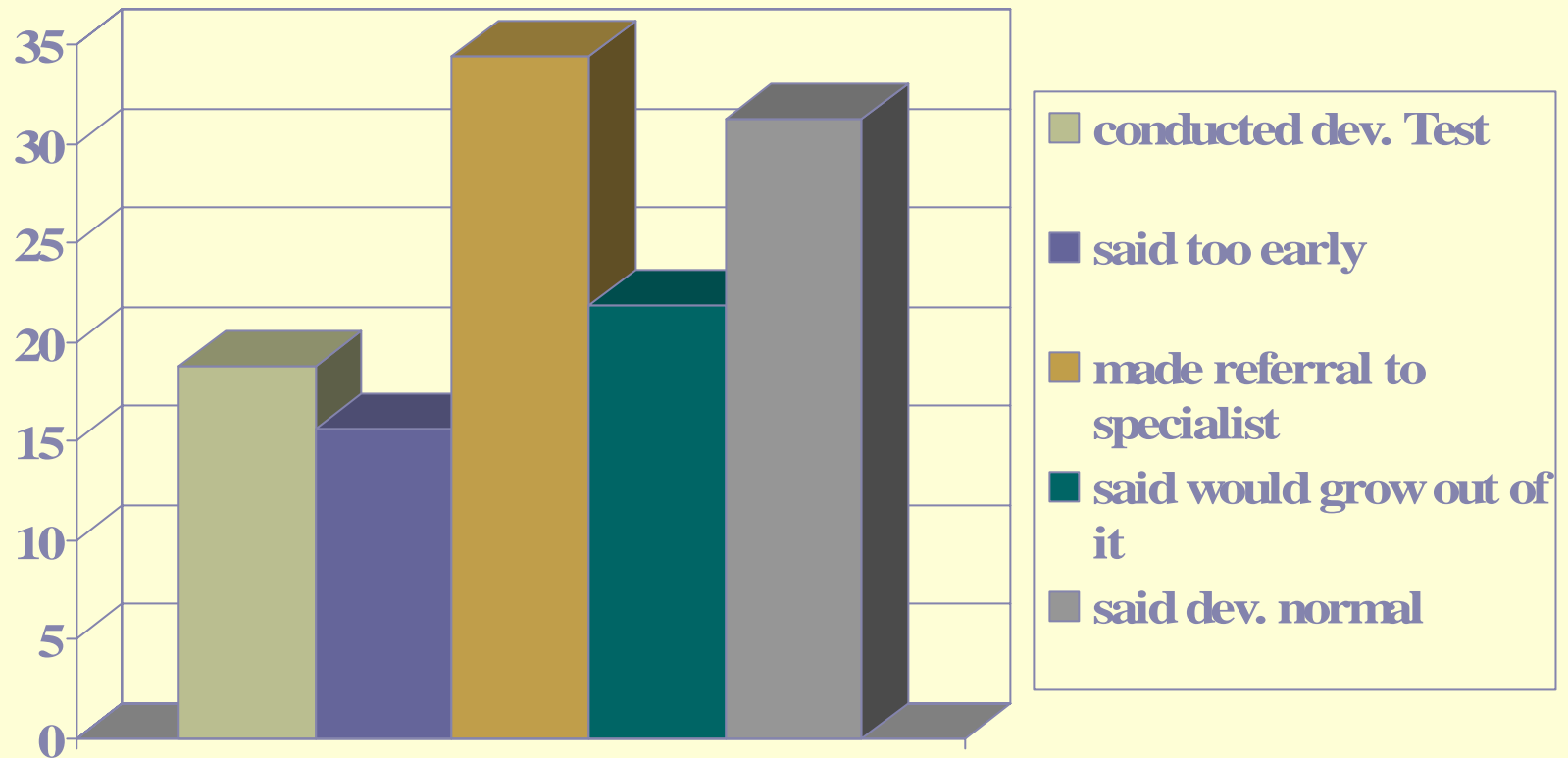
- My husband believes more in spiritual and folk healing (curanderos) and wanted to find a cure, it took me a lot to convince him we need to follow medical treatments
 - They didn't accept the diagnosis, they said it was because of bad parenting
 - They think he's just lazy and will be like his uncles, learning to talk eventually
 - They think it was something to be cured with a medicine.
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Process of Diagnosis

Age when parents first noticed something different	Age when parents expressed concern to doctor	Age of diagnosis of an ASD
Average 1.5	Average 2.1	Average 4
Range 1 mo – 3yrs	Range 1 mo – 9yrs	Range 1.5 – 10yrs

MD's response to concern



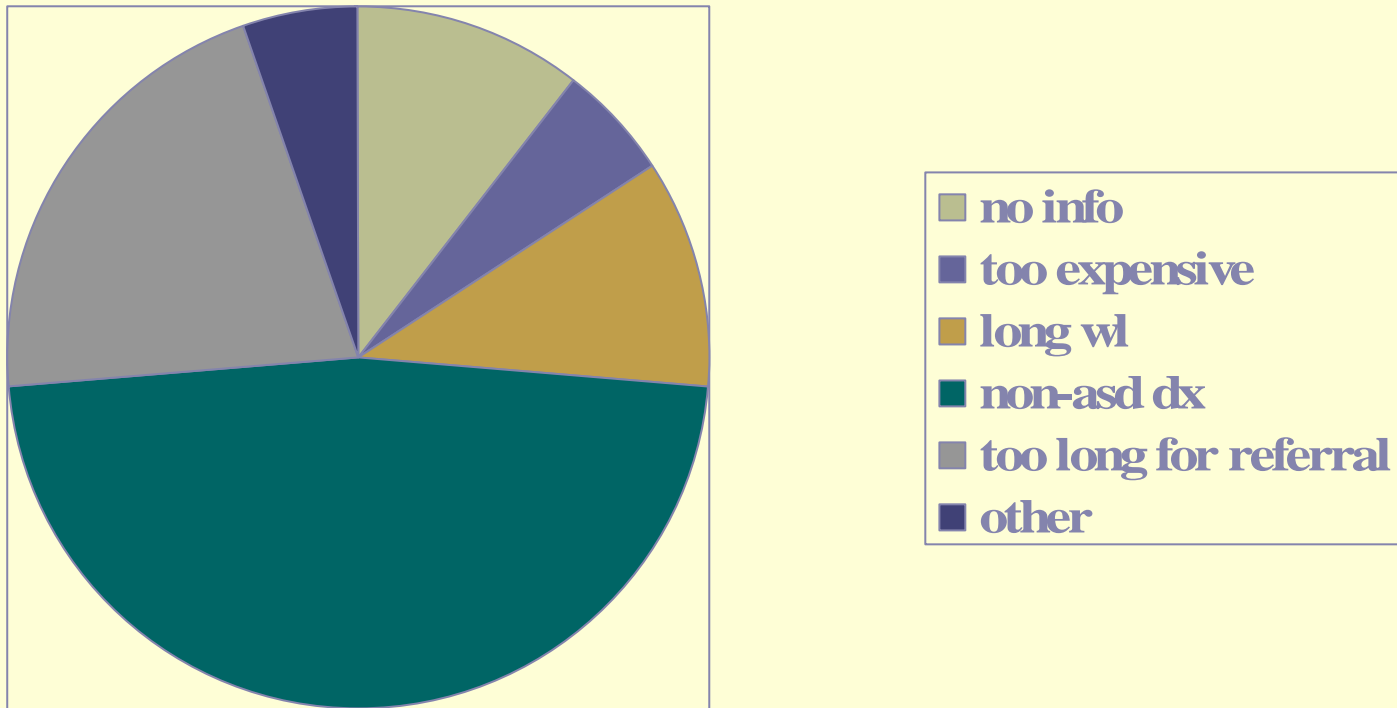


Length of time for diagnosis

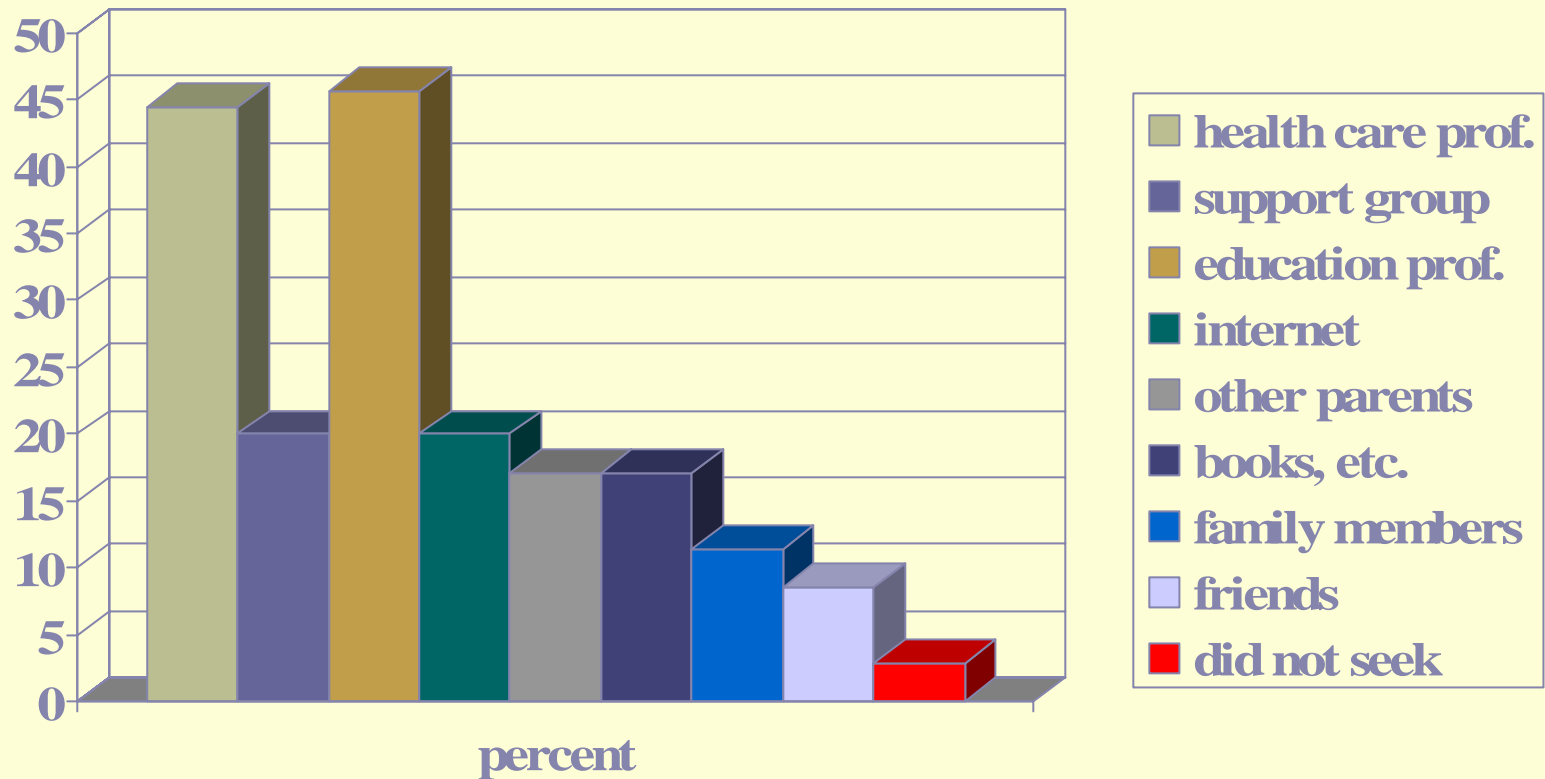
- 52.8% reported that it took 12 months or more to receive a diagnosis



Why it took more than 12 months for diagnosis




Where mothers receive information about autism

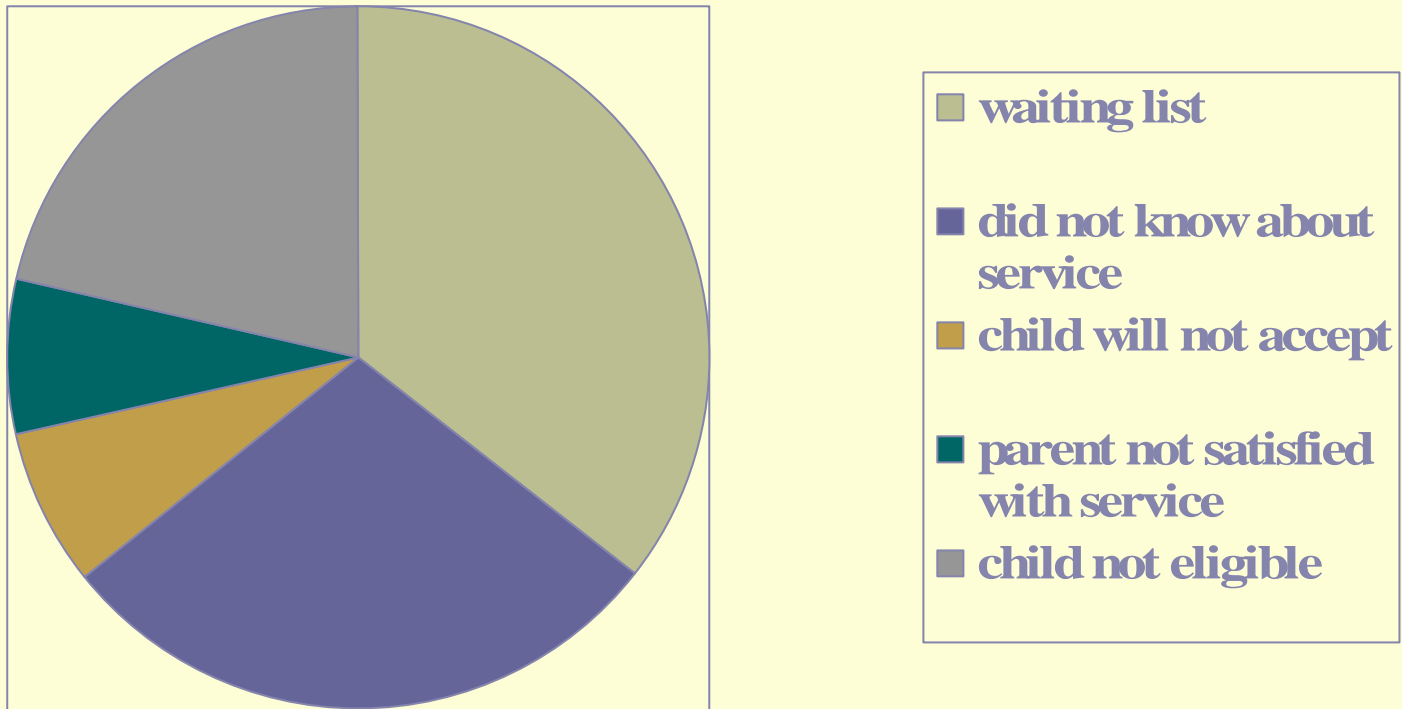




Early intervention services

- 55.6% have or currently receive birth to three
 - 66.7% have or currently receive early childhood services (4-6)
 - 27.8% have or currently receive intensive autism therapy through state waiver program
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Why child did not receive waiver services






What parents liked about waiver services

- Therapists taught my son to color and use fine motor skills and how to socialize a little with others
 - As a family we are convinced that if he hadn't received therapy, he would not be talking
 - Made gains in things that my family didn't think he would ever do like read and mathematics
 - Incredible gains—language, social, behaviors, family coping
 - She is what she is thanks to the therapies. She was at such a low level and she has been able to reach a maximum level.
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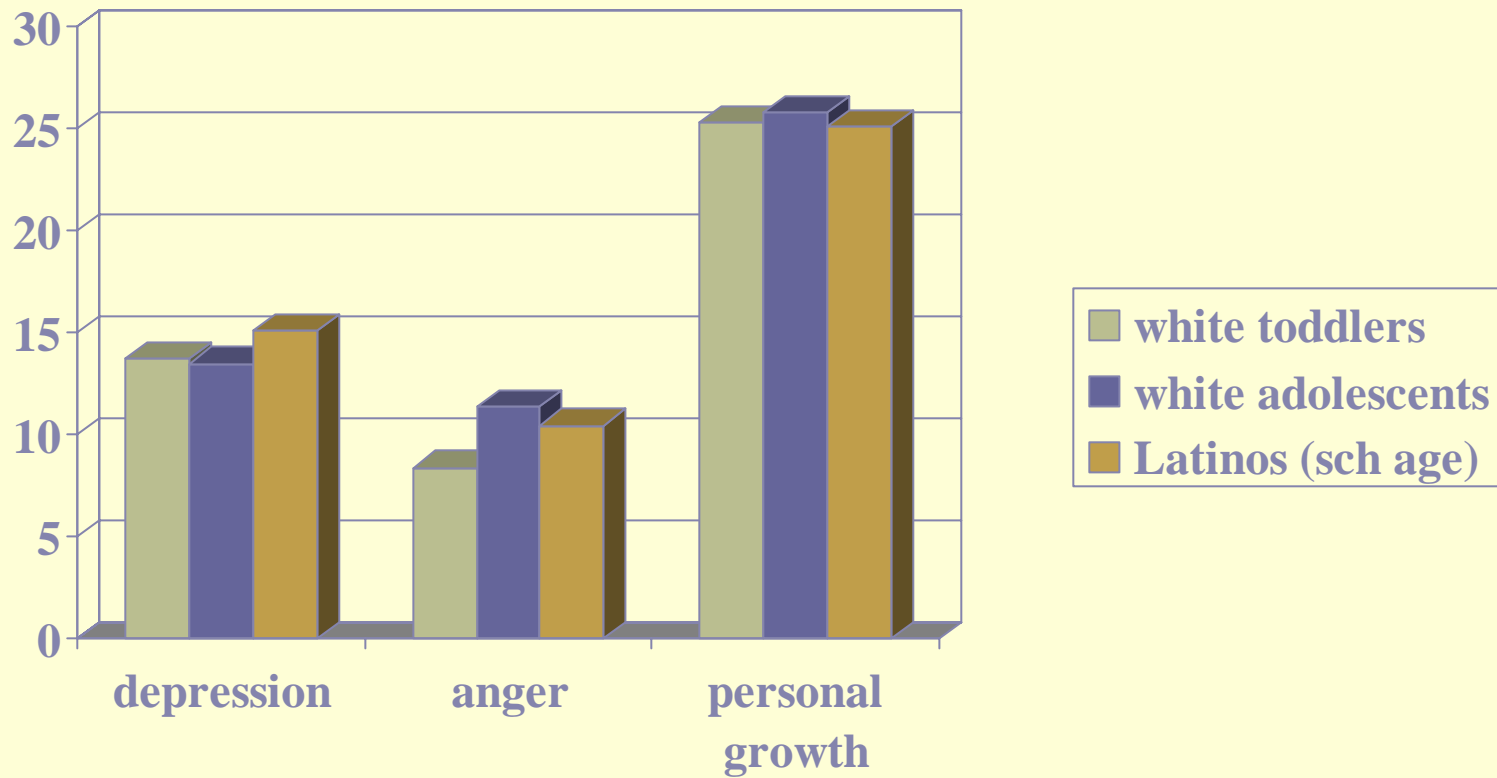


What parents did not like about waiver services

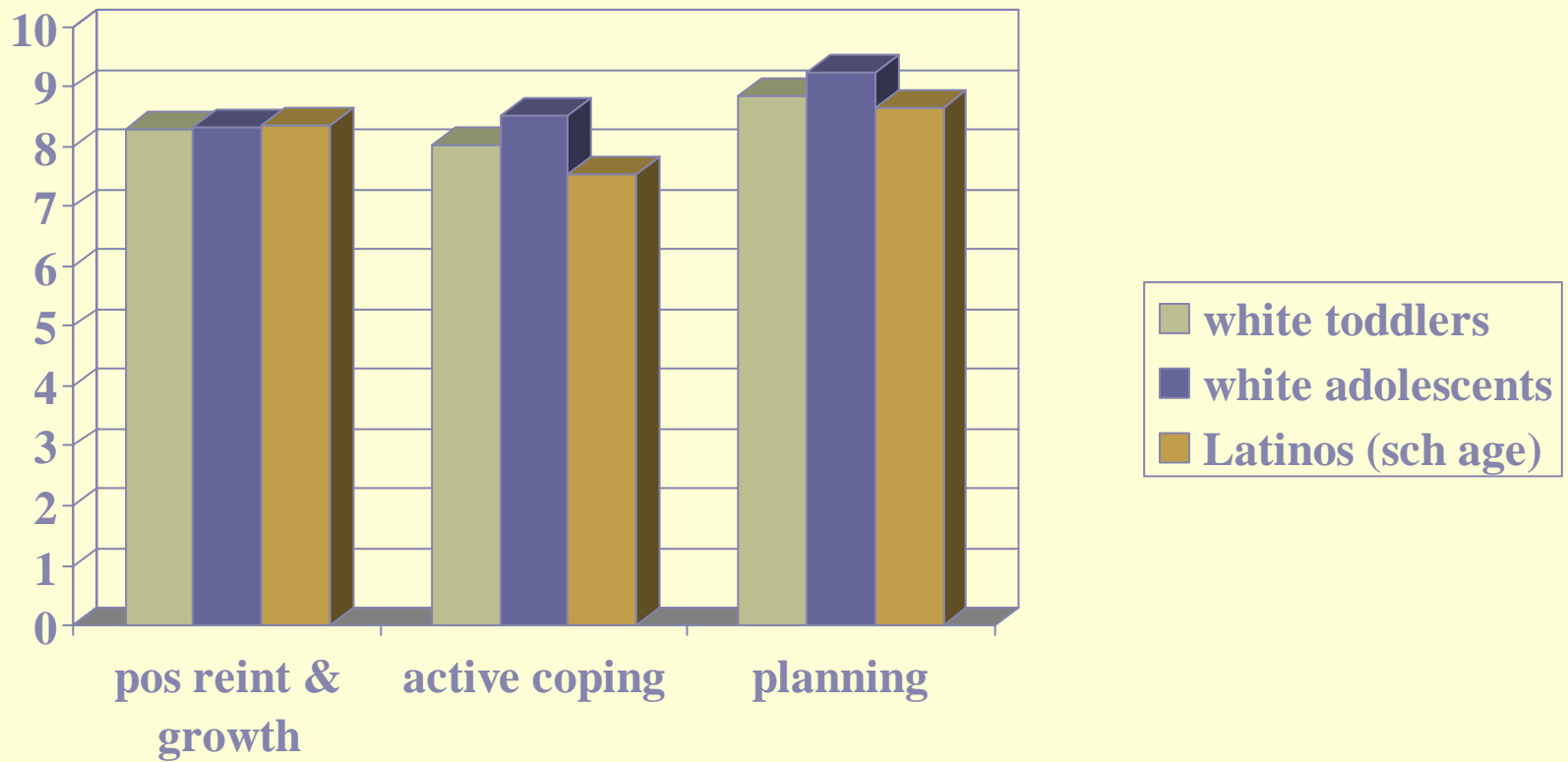
- Some therapists really didn't do anything, instead of helping, child became more frustrated
 - Sometimes therapists not adequately trained
 - Have to be available for long periods, someone always has to be at home
 - High turnover of workers
 - Made child dependent on rewards
 - Only for three years
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Maternal psychological well-being

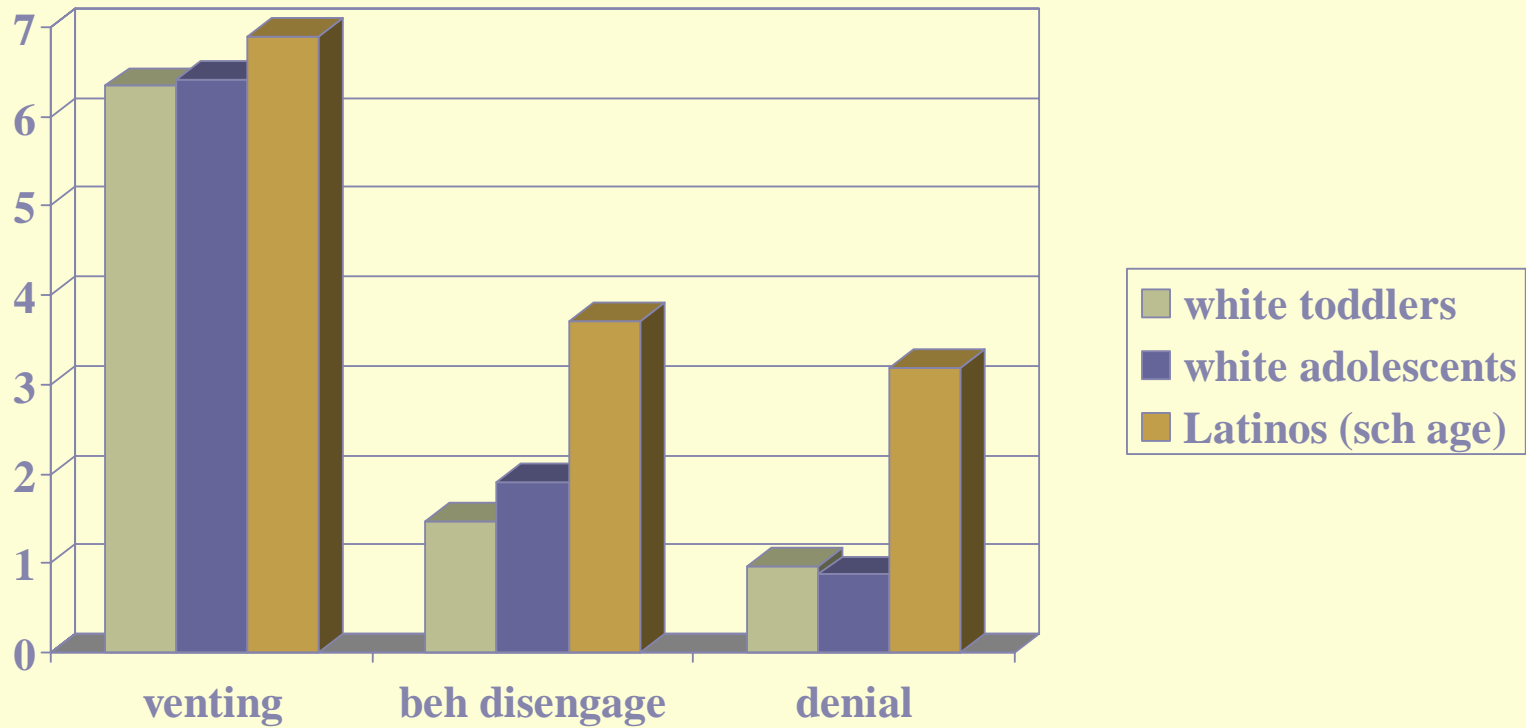
compared to samples in paper by Smith, Seltzer,
Tager-Flusberg, Greenberg, & Carter, 2008



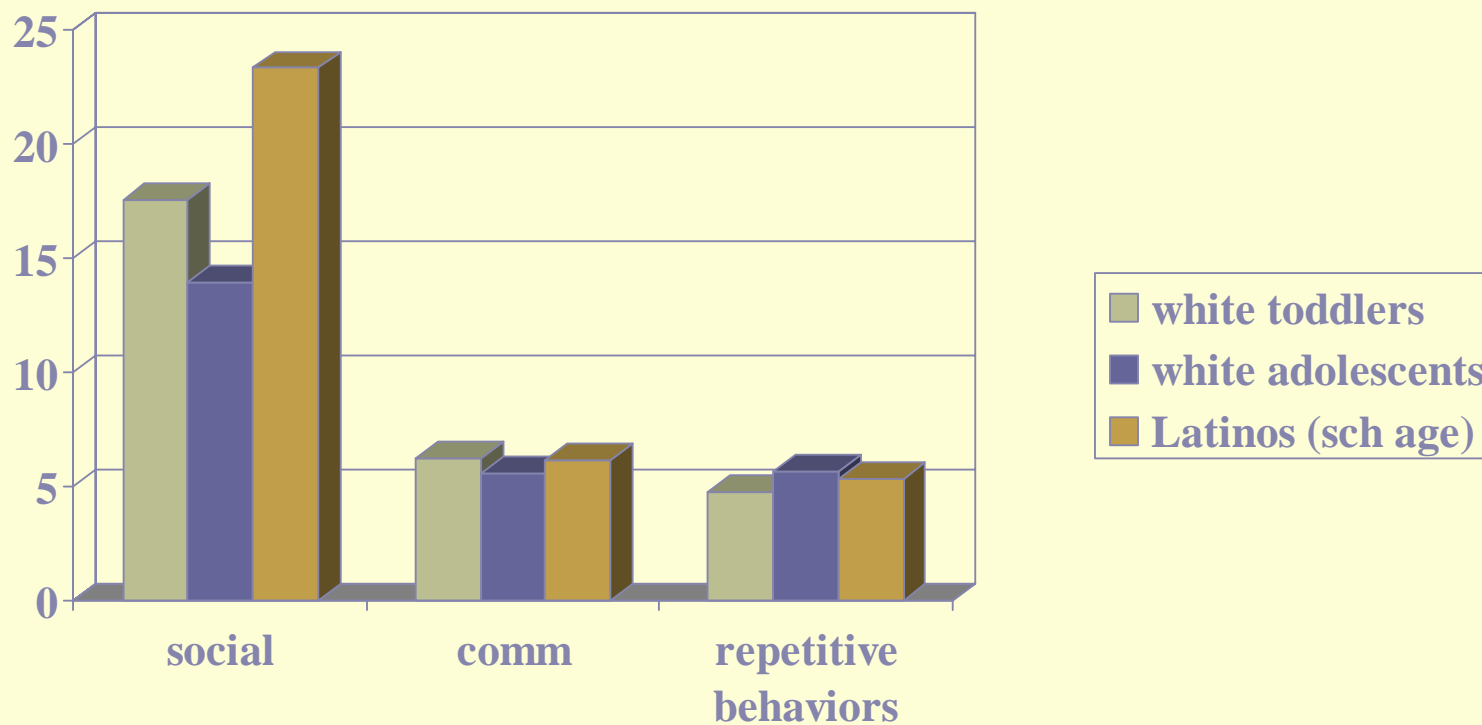
Problem focused coping strategies



Emotion-focused coping




Autism symptoms (ADI)

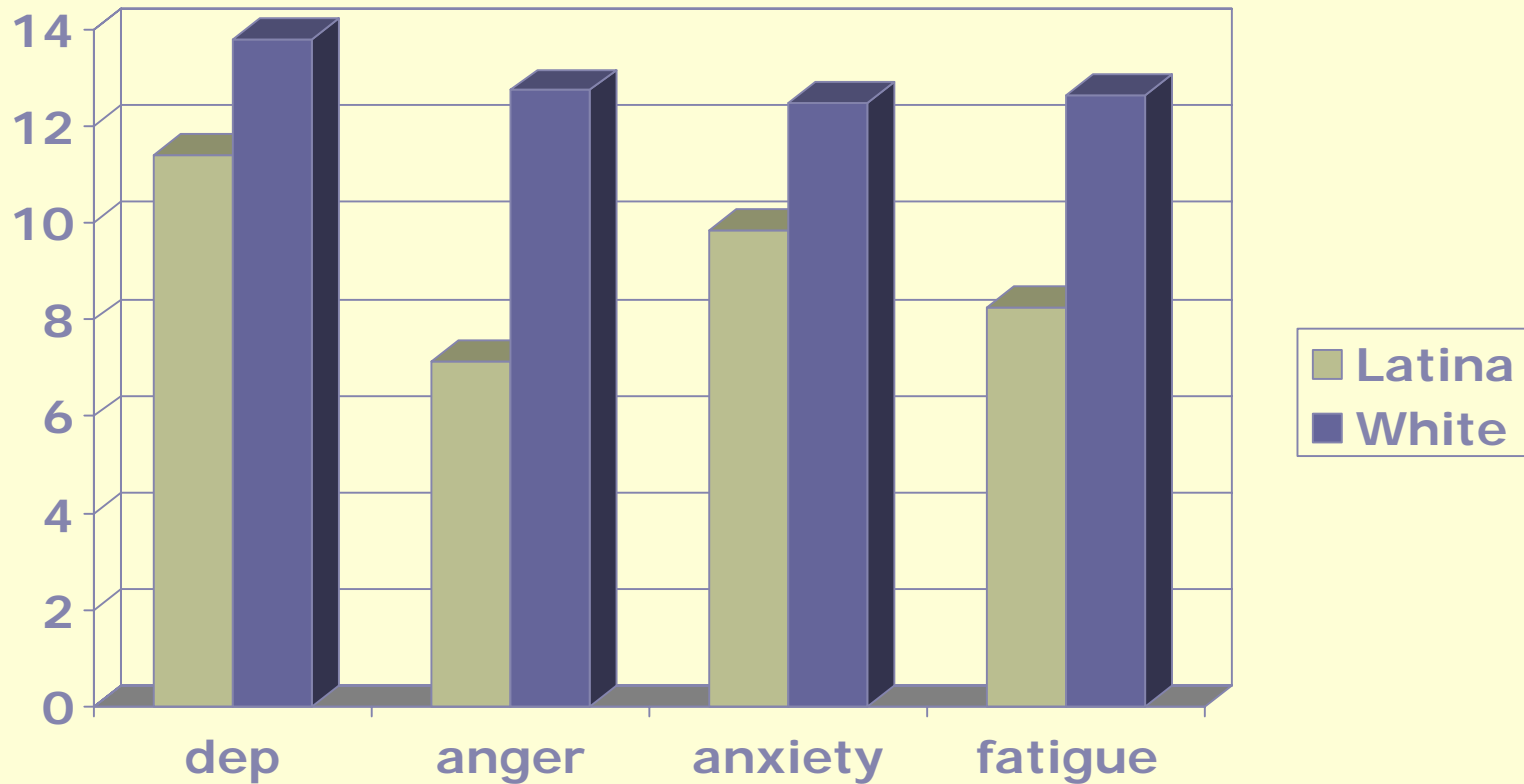




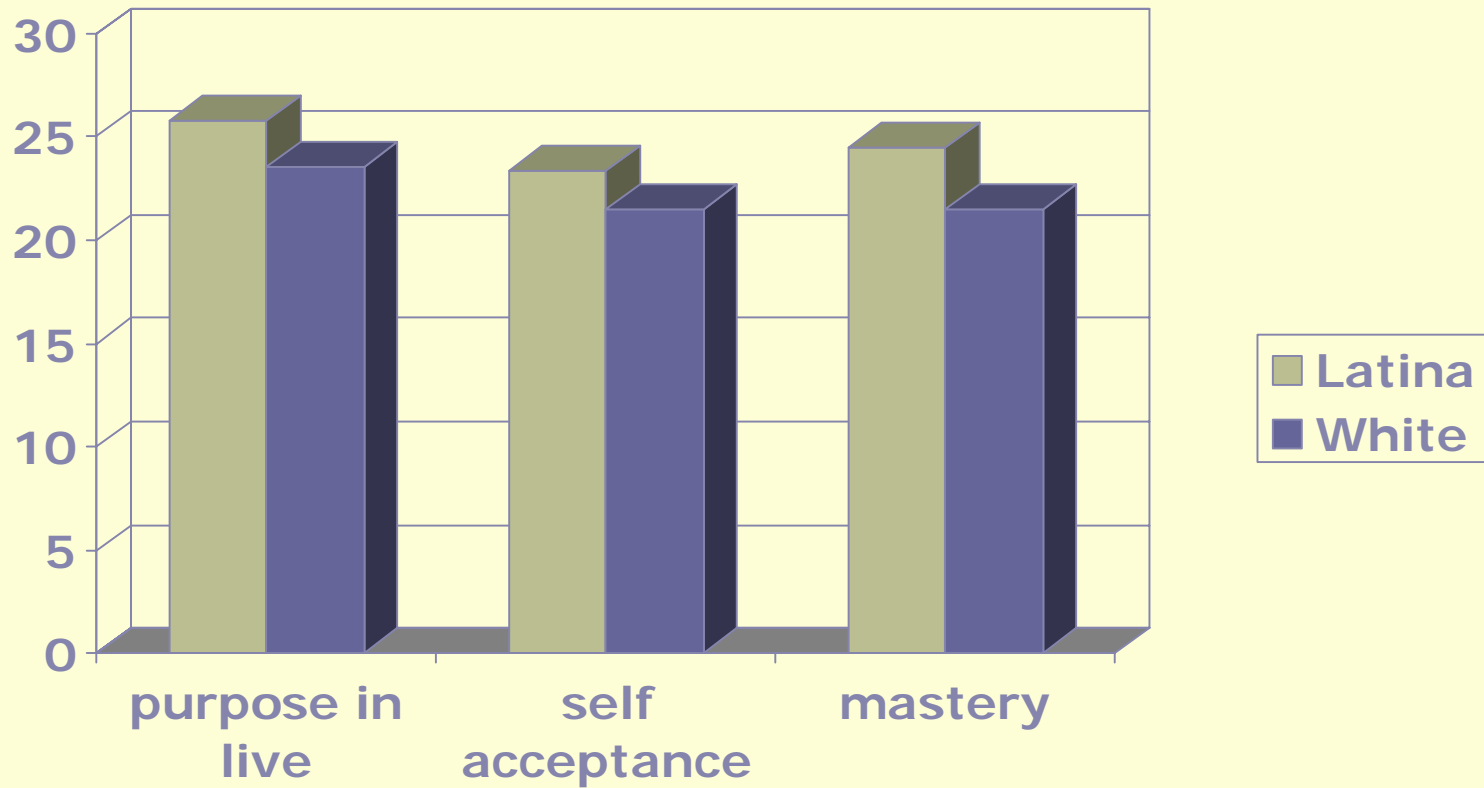
Different study: Adolescents and adults with ASD

- Compared Latino sample to non-Latino whites who were co-residing
 - Study in Massachusetts
 - Latino sample mostly Puerto Rican
 - 20 Latina mothers, 88 non-Latino white mothers
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Psychological distress



Differences in positive psychological well-being




Mediation of ethnic differences





Summary of Findings

Services

- Average of 2 years from time of expressing concern to doctor to time of diagnosis with ASD
 - Reasons for delay- many doctors saying development normal, child will grow out of it or misdiagnosis
 - Substantial number not getting birth to three and intensive autism services
 - Barriers include late diagnosis, lack of information, waiting list
 - Those that do are very satisfied
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Summary of findings

● Maternal well-being

- In WI study, similar to non-Latino whites, all have high levels of depression
- In MA study, when looking only at co-residing families, Latina mothers had lower levels of psychological distress, higher positive outcomes, mediated by satisfaction with living with child

● Coping strategies

- Latinas similar to whites in problem focused coping, but higher in some aspects of emotion focused coping

● Child symptoms

- Differences in how parents rate social impairments (Latinos higher)
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Implications for practice and future research

- Early screening important, in places where Latinos receive pediatric and medical care
 - Increase participation in birth to three and intensive autism therapies
 - Good quality information needed in Spanish
 - Help increase knowledge for parents and extended families
 - Doctors need more education about autism
 - More research needed on maternal well-being and coping strategies, examine cultural ways of coping as well
 - More research needed on diagnostic instruments such as ADI
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