

Serving Diverse Families A Wisconsin FACETS Webinar

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Our Agenda

1. Understand Culture, Cultural Sensitivity & Cultural Competence
2. Principles of Equity and Diversity
3. Considerations in working with diverse families
4. Example: Latino families of children on the autism spectrum
5. Tools and ideas for serving diverse families



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What is Culture?

- The characteristics of a particular group of people, defined by everything from language, religion, cuisine, social habits, music and arts

<http://www.livescience.com/21478-what-is-culture-definition-of-culture.html>

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What is Culture?

- The customary beliefs, social forms, and material traits of a racial, religious, or social group
- The characteristic features of everyday existence; a way of life shared by people in a place or time

<http://www.merriam-webster.com/dictionary/culture>

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What is Cultural Sensitivity?

- *Cultural sensitivity* = taking into account the unique beliefs, values, actions, and customs of a group of people
- Recognizing and respecting diversity in individuals and within groups

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Cultural Sensitivity Can...

- Enhance interpersonal **communication** and strengthen the **relationship** between a family and staff or providers.
- Maximize successful **outcomes** and improve **satisfaction**

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Cultural Competence

- **Cultural competence** refers to an ability to interact effectively with people of different cultures and socio-economic backgrounds
 - particularly in the context of non-profit organizations and government agencies whose employees work with persons from different cultural/ethnic backgrounds.

http://en.wikipedia.org/wiki/Cultural_competence

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Four Components of Cultural Competence



1. Awareness of one's own cultural worldview
2. Attitude towards cultural differences
3. Knowledge of different cultural practices and worldviews
4. Cross-cultural skills

Developing cultural competence results in an ability to understand, communicate with, and effectively interact with people across cultures.

Martin, M. & Vaughn, B. (2007). "Strategic Diversity & Inclusion Management" magazine, pp. 31-36. DTUI Publications Division: San Francisco, CA

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Principles of Equity & Diversity

Goal and vision of agencies and staff:

- All families/individuals receive services in a timely, fair, appropriate and efficient manner regardless of their cultural, racial, ethnic, or socio-economic factors
- Improve individual outcomes

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Principles vs. Reality

- Identification and services vary by race & ethnicity
- Average spending per child w ASD across the CA developmental services system = racial disparities
 - White \$11,723
 - Asian \$11,063
 - Latino \$ 7,634
 - Black \$ 6,593

Source: California Dept. of Developmental Services. Graphics reporting by Alan Zarembo, Data analysis by Sandra Poindexter
<http://www.latimes.com/news/local/autism/la-me-autism-day-two-html,0,3900437.htmlstory>

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A Shared Goal

- Children should be treated equally, without bias or discrimination.
- Families need culturally competent assistance to access the services and supports to which the children are entitled.

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Organizational Culture

- The set of shared attitudes, values, goals, and practices that characterizes an institution or organization
 - For example, an agency *culture* focused on serving diverse communities and promoting equity

<http://www.merriam-webster.com/dictionary/culture>

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Organizational Culture = Skills and Actions

- Ensure that staff are aware of cultural differences and prepared to **respond** to them to **serve** families effectively
- Work to **create equal access** and **correct inequities** in identification, diagnosis, provision of services, and access to resources

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Demands on Families

All families of children with special needs face challenges to

- obtain a diagnosis
- become informed about the child's condition and needs
- access supports, therapies and other services

Bailey, D.B. Jr., Skinner, D., Correa, V.I., Arcia, E., Reyes-Blanes, M.E., Rodriguez, P., Vazquez-Montilla, E. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation*, (104)5, 437-451.

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Understanding Diverse Families



1. View of Disability
2. Family Roles & Responsibility
3. Decision Making
4. Religious beliefs
5. Language
6. Access to information, resources & services
7. Additional stressors

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Example: Understanding the Needs of Latino Families of children with autism

- Impossible to generalize to every case, consider ideas as guidelines
- Use this example to understand “parallel” considerations in other ethnic or cultural groups (African American, Asian, Deaf, etc).

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Growth in the Latino Population

Agency staff will be interacting with more Latino families than in the past.

- Hispanics are the largest minority group in the nation, numbering 37.4 million, or 13.3% of the total population.
- Hispanics/Latinos are expected to represent 24% of the national population by the year 2050
- Children in immigrant families are the fastest growing segment of the child population in the United States.

(Source: U.S. Bureau of the Census, 2004).

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Diversity within the Latino Community

- Country of origin
- Length of time in the US
- Area of residence
- Language
- Education and Literacy
- Socio-economic status
- Political Climate
- Legal Status
- Acculturation- level of interactions with people and institutions in the mainstream culture

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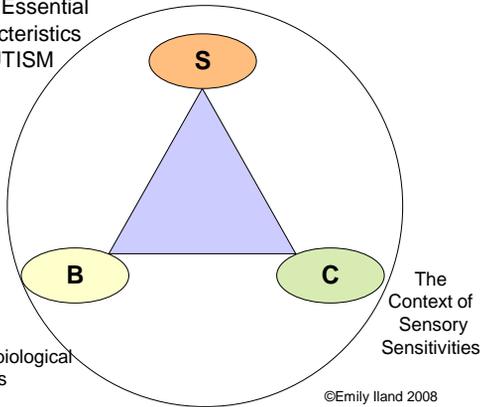
Autism & Stress

- Daily challenges are significant because of the attention and effort required to care for a child with autism.
- Most often, the mother is responsible for continuous care of the child with autism.
- Current studies show that mothers of children with autism are most at risk for stress and depression compared to mothers of children with other disabilities

Magaña, S., & Smith, M. (2006). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes toward coresidence status. *American Journal of Orthopsychiatry*, 76(3), 346-357.

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Three Essential Characteristics Of AUTISM



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Growing Incidence of Autism- Underdiagnosis of Latinos

- Autism is also on the rise.
- Fewer Latino children than expected are found to have autism: Risk Ratio of 0.5.*
- Under-diagnosis of Latino children may be related to family circumstances including limited access to medical, and educational community services.
- Inequities and disadvantages may combine to put the Latino child with autism at significant risk.

* Source: 27th Annual Report to Congress on the Implementation of the *Individuals with Disabilities Education Act*, 2005 Vol. 1, Prepared by Westat for the Office of Special Education and Rehabilitative Services, U.S. Department of Education

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**Family Needs Survey
Bailey & Simeonsson, 1988
English & Spanish**



- Information
- Family & Social Support
- Explaining to Others
- Financial
- Professional Support
- Community Services

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Family Needs Survey Bailey & Simeonsson, 1988

INSTRUCTIONS: Listed below are some of the needs expressed by parents of special children. Please read each statement and decide if you need help in this area. Then **circle** the one number: **1, 2, or 3** which represent your response to the need.

NEEDS FOR INFORMATION	Definitely DO NOT need help with this	NOT SURE	Definitely DO need help with this
1. I need more information about my child's condition or disability.	1	2	3
2. I need more information about how to handle my child's behavior.	1	2	3
3. I need more information about how to teach my child.	1	2	3
4. I need more information on how to play with or talk to my child.	1	2	3
5. I need more information about the services that my child might receive in the future.	1	2	3
6. I need more information on the services that are presently available for my child.	1	2	3
7. I need more information about how children grow and develop.	1	2	3

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**Unparalleled Level of Unmet Needs
Iland, E.D., Weiner, I., & Murawski, W.W. (2012).**

- 35/35 needs unmet for 50% of mothers
- 28/35 needs unmet for 70% of mothers = common needs
- 77 mothers added unmet needs not mentioned in the FNS:
 - Securing services and ASD-specific therapies
 - Advocacy, navigating the education system
 - Social & community inclusion

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Obstacles Faced by Latina Mothers

Iland, E.D., Weiner, I., & Murawski, W.W. (2012). Obstacles faced by Latina mothers of children with autism. *Californian Journal of Health Promotion, Special Issue: Health Disparities in Latino Communities (10)*, 25-36.

Provider barriers

- Navigating the education and service systems (Lack of information about services & supports)
- Paperwork at clinics, schools and agencies
- Did not know where to go for help

Professional barriers

- Finding a professional to make a diagnosis
- Doctor told me nothing was wrong
- Doctor gave a different dx
- Doctor did not listen/was discourteous

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Obstacles Faced by Latina Mothers

http://www.cjhp.org/SpecialIssue2_2012/documents/25-36Iland.pdf



Personal & Family level

- Family thought nothing was wrong
- I did not know the signs
- Read or write English
- Speak or understand English
- Time

Socio-economic-political

- Getting childcare for other children to go to appts.
- Transportation
- Cost of medical care
- Insurance
- Discrimination
- Immigration Status

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Cultural Sensitivity & Competence

- Through your service to families, you can help remove some of the barriers faced by Latino families and help them access the information, services and support they need to care for their child with special needs.
- Apply similar approaches to serve other populations

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Identify Unmet Needs



- Use Bailey or other similar tools
- Encourage addition of other needs

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Create a New Tool: Tie Survey Items to Local Resources, generic & specific



- Create a resource guide, match needs with options
- Customize by neighborhood, language etc.
 1. Information
 2. Support
 3. Explaining to Others
 4. Community Services
 5. Family Functioning
 6. Financial Needs
 7. Other

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Five Sensitivities



1. Información
2. Personalismo & respeto
3. Familismo
4. Perspectiva Cultural
5. Socio-económica

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1. Información

- Many families do not understand what autism is or why their child has the diagnosis.
- The service systems may be foreign and confusing

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1. Información

- The language barrier may often lead to frustration, misunderstanding or dissatisfaction in efforts by Latino families to access services and supports.
- Language barriers can result in exclusion, delays or denial of services from agencies and contractors, which is a form of discrimination.

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Communicate to Close the Information Gap



- Avoid jargon and acronyms
- Put instructions in writing
- Clarify follow-up steps and directions
- Check for understanding

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Communicate to Close the Information Gap



- Provide informative materials in Spanish
- Whenever possible provide Spanish-speaking or bilingual staff
- Use qualified translators for formal purposes
- Provide translation of personal documents
- Parent mentors

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2. Personalismo & respeto

Personalismo means “formal friendliness.”

- Latino families value warm and friendly relationships with the professionals and staff they meet.
- Latino families want to develop rapport before they feel comfortable enough to open up and talk about their personal issues.

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Personalismo & respeto

Respeto is respect, a highly valued trait.

- In studies Latina mothers have reported that they want professionals to listen to them.
- Especially when there is a language barrier, non-verbal signs of interest and caring can very important to Latinos.
- Latino families tend to respect professionals and authorities, so realize that your words and instructions may carry great weight and importance.

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Show personalismo and respeto

- Take time to establish trust and rapport before getting down to business.
- Be a good listener.
- Respect and acknowledge the mother or parent's point of view and intimate knowledge of the child.
- Demonstrate a sincere desire to help.

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Show personalismo and respeto

- Use eye contact, facial expression, and body language to show interest.
- Use caring gestures including close proximity, handshakes, and pats on the back.
- Extend professional courtesy to all members of the family, particularly to elders.

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3. Familismo

Latino families value interdependence and loyalty

- The extended family is included in decision making and solving problems.
- The role of elders is respected and their views and wishes are followed.
- The family often acts as a unit. When an appointment is made, the whole family may attend.

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Latino Family Values

- *Allocentrismo*: Willingness to sacrifice for others, and orientation to the welfare of the group over the individual.
- *Marianismo*- Mothers model self-sacrifice, suffering, high moral values, and maternal devotion to their child on the example of Mary

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Gender Roles in the family

- Latino families may follow traditional gender roles, with the mother taking on all responsibility for the child with autism.
- Fathers may not have an active parenting role.

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Understand the family dynamic



- Identify and address the head of the family when talking.
- Be sure to include the whole family in discussions.
- Give them time to decide among themselves what course of action to take. Any plan may need to be approved or "authorized" by the elders or men in the family.
- A mother may be struggling if she does not have the support or understanding of family members regarding how to deal with her child.

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Understand the family dynamic

- The family can be a wonderful source of support. Be sure to help educate and inform all family members so that they can be supportive of the mother and child.
- Encourage all family members to take an active role in caring for the child so with autism so that the mother is not overburdened.
- Research finds that religious coping can be helpful to Latina mothers (among others). Encourage families who wish to use their religion as a source of coping.
- Caution: Erosion of family support (immigrant status, disagreement within the family)

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4. Perspectiva Cultural

- Traditional beliefs that are unique to Mexico and Latin American countries may affect Latino views of health, illness and treatment
- All societies have a complex system of beliefs concerning disability, including explanations of why some individuals have disabilities and others do not
- This affects the, understanding of cause, reaction to the diagnosis, and decisions about treatment

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Beliefs About Cause of Disability

- Many Latino families have limited information about why their child has autism.
 - Many believe in traditional/folk beliefs of cause such as illness or a fall during pregnancy, negative thoughts during pregnancy, or not eating the right food.
- Others have a religious view of the cause, believing it is a punishment or an unfair burden from God.
- Latinos may attribute the cause of an illness or disorder to biomedical and environmental causes

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Religious views of Disability

- 70% of Latinos in the U.S. are Catholics: religious beliefs may influence Latino families.
 - Many Latina mothers consider their children angels sent to them by God
- Other parents may view the child's disability as a punishment from God for their sins

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Reaction to the Diagnosis

- Misunderstanding or outdated views of cause held in the country of origin may also have a significant impact on beliefs and behavior in the U.S.
- In particular, the view of autism as mental illness, the fault of the mother, or punishment from God would cause shame or stigma to the family. As a result, the family might want to hide the problem rather than seek help (shame/blame).
- The reaction to a diagnosis may also relate to cultural values. Latino parents of children with autism may express feelings of denial, guilt, helplessness, depression, and shame that contribute to difficulty in accepting the diagnosis.

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Reaction to the Diagnosis

- Many Latino men feel that a child with a disability reflects badly on them. This may cause a father to deny that the child has a disability and reject the child.
- Some Latina women find comfort in the belief that the child with autism is a gift from God or that it is a privilege to be the mother of a child with autism. Other mothers may use religion as a means of coping.

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Treatment

- Traditional views may affect treatment options that families will try and create barriers to care.
- Some Latinos may use traditional or folk methods to treat “symptoms”
- Recent studies have shown that most Latinos rely on professional medical services.

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Inform



- Provide information about autism in Spanish and explain what it means.
- Help families give up shame and blame by understanding the facts behind autism.
- Provide information about typical development and childhood milestones to help families recognize differences.

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Inform



- Access the Bilingual Autism Guide, free at www.asdAtoZ.com or www.elAutismo.org
- Print out website material and make several binders to lend to families that do not have internet access. Include lists of state or local of organizations.

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Inform



- Purchase materials and books listed for your parent lending library.
- Be aware of differing literacy levels and needs

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Family Education Models



- Automatic referrals at time of diagnosis
- Educate all of the family- offer daycare if possible at educational events.
- Promotora de salud
- Cultural Brokers, parent mentors
- Counseling, psychological support
- Dad's groups

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5. Socio-económica

- Disenfranchisement, poverty, discrimination, marginalization and limited resources experienced by women, immigrants and ethnic groups of color are risk factors that increase the vulnerability of these populations.
- Income and level of education are predictors for wellness and access to service systems.
- Inconsistent access to care is common for poor and uninsured families.

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Socio-económica

- For Latinos who are newcomers to the United States, **immigrant status** affects the family's resources, capabilities and entitlements.
- The children of unmarried Mexican immigrant mothers are a subgroup particularly at risk.

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Socio-económica

- The process of **acculturation** (increasing interactions with people and institutions in the mainstream culture) while stressful, affects how well or how easily Latino immigrants can meet essential family needs.
- **Racism** and **discrimination** may affect families of Hispanic descent, even when the parents themselves or their children were born in the United States.

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Help Make Connections



- Connect individuals to existing Spanish language support groups.
- Create or host a Spanish language support group.
- Gather and share information about community resources for disadvantaged families.
- If possible, hire Latina staff who can serve as cultural and linguistic liaisons.
- Partner with community parent advocacy organizations that specialize in serving Latino families.

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Serving All Communities



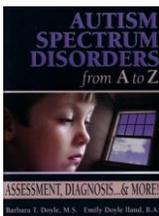
- Connect individuals to existing [insert language here] support groups.
- Create or host a [insert language here] support group.
- Gather and share information about community resources for disadvantaged families.
- If possible, hire [insert ethnicity here] staff who can serve as cultural and linguistic liaisons.
- Partner with community parent advocacy organizations that specialize in serving [insert ethnicity here] families.

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Conclusion: Individual & organizational commitment to

1. Understand the needs of diverse families
2. Create an organizational culture that promotes cultural sensitivity & competence
3. Promote equity
4. Develop new relationships and connections to work with diverse families
5. Find or create specific tools and resources to serve diverse families

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