



# **Organizations and Developing Culturally Competent Parent Support Groups**

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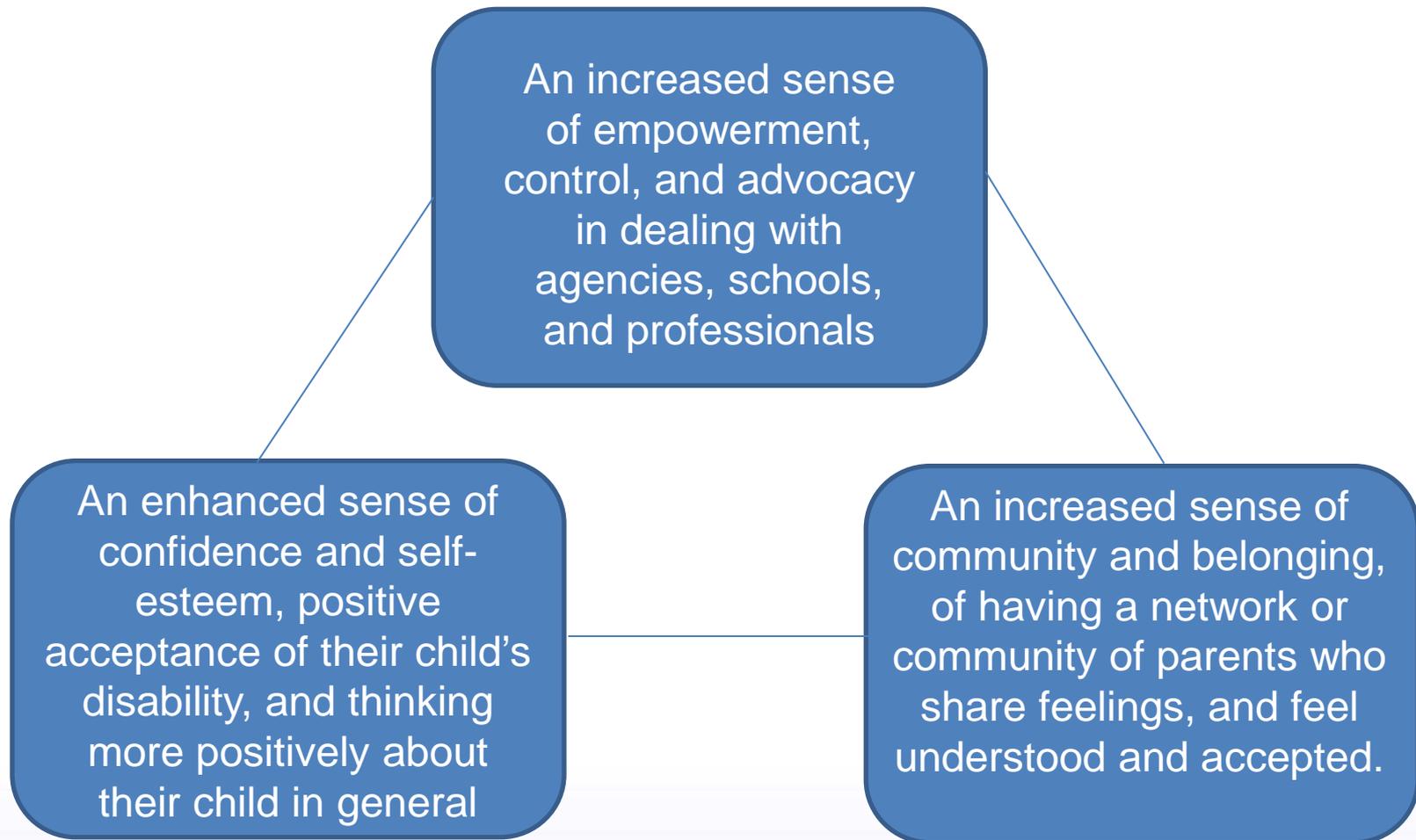
**“Hispanic Parent Support Group”**

September 16, 2013

# Establishing a Parent Support Group



# Benefits of Support Groups According to Parent Participants



# Why it Matters

Families of children with disabilities:

- Have special needs, too
- Face a variety of unique concerns and life stressors
- Have exceptional strengths and resources that must be considered in order to provide appropriate intervention and support



# Why it Matters

Meeting on a regular basis in a community of people who are going through similar experiences, sharing and receiving information, and providing mutual support are valuable tools to provide to parents.



# The Parent Support Group's Goals

1. Help parents of children with disabilities cope more effectively with the many demands of child rearing in an unfamiliar country with different cultural values.
2. Help families understand concept of disabilities and offer parenting tips and educational resources
3. Recognize the importance of child-first language (the disability does not define the child)



# The Parent Support Group creates a place for mothers and fathers to:

- Give and receive both emotional and practical support
- Receive parenting tips and tools
- Exchange information
- Utilize social networking opportunities
- Recognize cultural barriers they may be facing



# Content of Meetings

- Information about disabilities
- Advocacy Training
- Instruction on navigating service delivery systems (specifically addressing cultural and other barriers)
- Parent-parent emotional support
- Stress management techniques
- Effective behavioral techniques and strategies for children
- Information on child development
- Information about community resources
- Resources regarding assimilation and acculturation into American life

# **Steps in Developing a Support Group for Spanish-Speaking Parents of Children with Disabilities**

1. Target potential members
2. Secure a safe and convenient location
3. Establish reliable child care
4. Recruit a facilitator

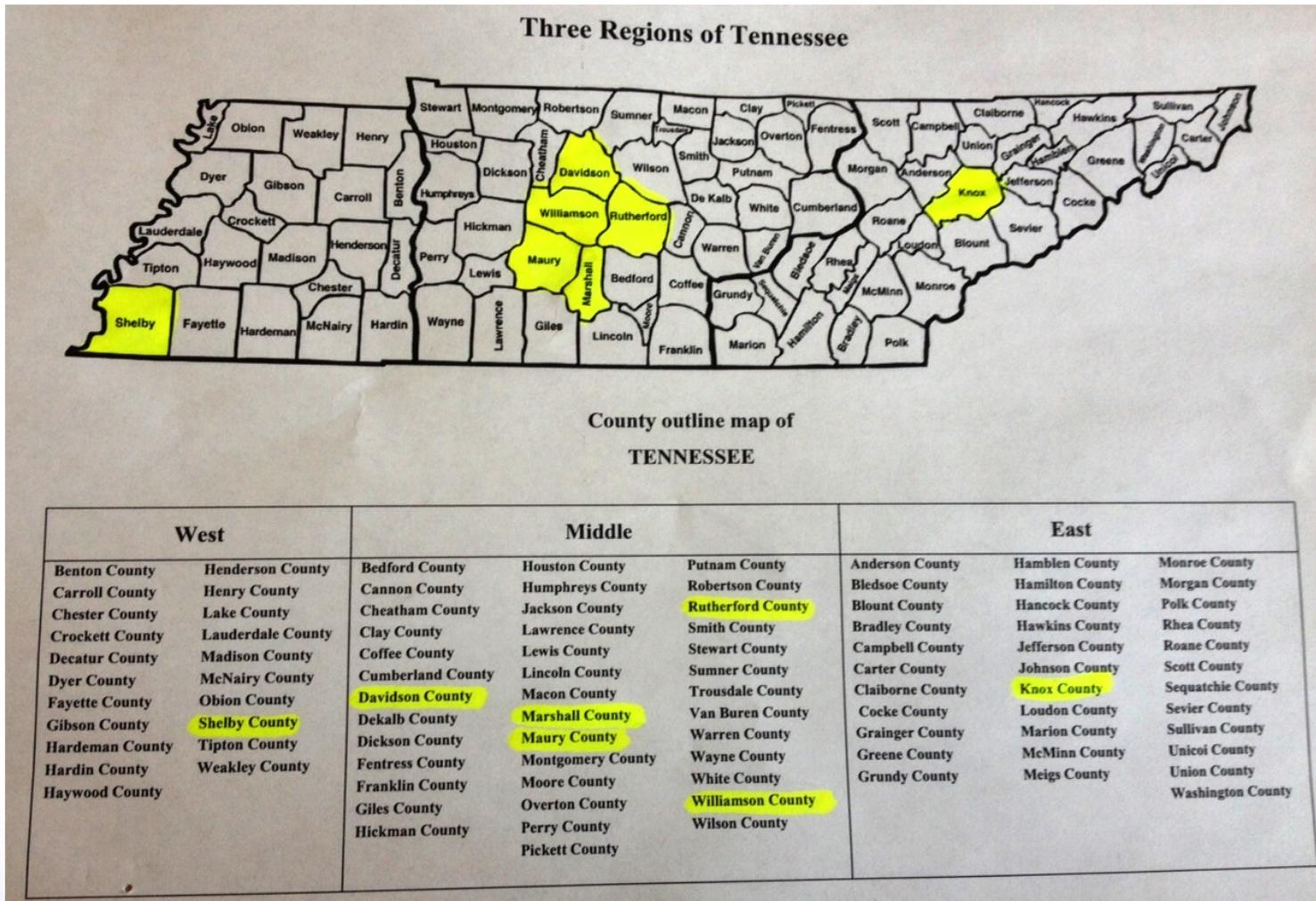
# 1. Target Potential Members

- Post fliers
  - Early intervention agencies, disability agencies, health centers, private therapists, community clinics, schools, etc.
- Network
  - Share information at community meetings as well as by parent to parent contact.

## 2. Secure a Safe and Convenient Location

- A safe, comfortable, and accessible environment promotes trust
- Meet within an area that is familiar or a “common place” for targeted members.
  - Faith-based organizations, schools, community centers
  - Choosing a faith-based organization may not be the best choice. Keep in mind differences in religious perspectives.
  - Be aware of liability concerns within the chosen place

# Support Group Representation



# 3. Establish Reliable Child Care

- Opportunity to create an inclusive environment
- Opportunity to introduce new activities or therapies (music, art, yoga)
- Ensures better attendance
- Child care workers should be knowledgeable about:
  - Child development, safe and appropriate activities, effective caregiving of young children including those with disabilities
- Try to secure the same child care workers each session to promote trust and safety for families
- The ratio of child care workers needed depends on:
  - number of children, types of disabilities, age ranges, siblings



# 4. Recruit a Facilitator

- The facilitator should be:
  - Committed
  - Flexible
  - Bilingual
  - Culturally Aware
  - Open to receiving new ideas with an empathetic ear
  - Experienced in the mental health field such as counseling, social work, psychology, or group facilitation
    - These backgrounds are useful for a facilitator to have in order to understand group dynamics and interpersonal communication.
    - These backgrounds understand how to assess if participants need to be referred to a mental health professional

# 4. Recruit a Facilitator (Continued)

- An effective facilitator will:
  - Ensure equal opportunity for members to share within the group
  - Gently encourage less assertive parents
  - Provide consistent attention and resolution of issues as they arise to promote trust and increase group cohesion
  - Will Discourage criticism, judgment, and unsolicited advice



# 1. Administrative Activities (Continued)

- Create a flier each month with information regarding meetings, trainings, discussion groups, topics, dates, location, and times.
- Be sure to include information about child care

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FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

TENNESSEE COUNCIL ON  
DEVELOPMENTAL  
DISABILITIES

### Tennessee Disability Pathfinder

**Organiza Un Grupo Para Padres Con Hijos  
Que Tienen Capacidades Diferentes**

El segundo lunes de cada mes  
De 6-7:30 PM

En la iglesia South Minster Presbyterian  
643 Harding Place, Nashville, TN 37211

Para más información puede llamar a  
Carolina al 615-400-4422. Se ofrece  
servicio de guardería si confirma su  
asistencia. Y no tiene costo, es gratuito!!!!

(615) 400-4422 | [www.familypathfinder.org](http://www.familypathfinder.org)

## 2. Role of Facilitator in Group Meetings

- Must attend group regularly
- Draw people into the group and keep the conversation moving in a positive direction
  - Act as a “friendly traffic cop” to ensure everyone is heard
- Help parents feel valued, respected, and safe by treating them with dignity and consideration, refraining from judgmental statements, and encourage others to the same

## 2. Role of Facilitator in Group Meetings (Continued)

- Never assume you know what a parent feels
- Remember, parents who have children with special needs are “parents” first and foremost
- Protect parents by stepping in if someone is being critical or disrespectful
- Direct parents to additional services and community resources

# Conclusion

- The goal of the support group is to help parents of children with disabilities cope more effectively with the many demands of child rearing in an unfamiliar country with language barriers and different cultural values.
- It is common to feel somewhat lost trying to navigate a world of unknown services and experiences.
- To be surrounded by people who have “been there” and who know exactly what a person is going through can alleviate stress, empower, and return a sense of control.





# Tennessee Disability Pathfinder

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on developmental disabilities



# Organizations and Developing Culturally Competent Parent Support Groups

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**“The Parent Stress Intervention Project”**

September 16, 2013

# Organizations and Developing Culturally Competent Parent Support Groups

This AUCD webinar will explore:

- Parent Stress Intervention - Project Description
- Kennedy Center Organizational Support
- State Demographics & Project Numbers
- Implementation
  - staffing
  - recruitment
  - accessibility
- Resources

# Parent Stress Intervention Project

- 2009 study designed to target parental wellbeing.
- Parents of children with neurodevelopmental disabilities
  - often experience poor health, high stress, anxiety and depression.
  - when stressed, are less able to implement interventions and their children make less progress.
- Last groups offered 2012.

# Parent Stress Intervention Project

- Compared the effectiveness of
  - a conventional Parent Group (PAD: Positive Adult Development) intervention
  - to Mindfulness- Based Stress Reduction (MBSR)
- Funded through NIH's National Center for Complementary Alternative Medicine Grant 5RC1AT005612.

# Parent Stress Intervention Project

- Parents of children with ASD or other disabilities were assigned to 6 weeks of a PAD group or an MBSR group.
- Data was collected on
  - parental health
  - positive and negative psychological states
  - biomarker indices of stress

# Participants Agreed To

- Be assessed for eligibility.
- Be randomly assigned to one of the groups.
- Answer questions about their child and themselves 4 times (online or paper; approximately 1 hour each).
- Come to 6 weekly meetings.
- Attend 3 follow-up meetings.
- Give us regular saliva samples to measure cortisol (a stress hormone).
- Complete a written program eval at the end of 6 wks.

# Decision to Offer Culturally Diverse Groups

- Organizational Support
  - Tawara D. Goode, PhD., Director of the National Center for Cultural Competence at Georgetown University reminds us to
    - examine our organization's world view
    - ask “How does this world view guide organizational behavior, philosophy, values & commitment to cultural competence?”
  - Grant application was written to serve our demographic.

# Organizational Support

## Evidence of Principles, Values & Commitment

- Principal Investigator for the PSIP project: Elisabeth Dykens, Ph.D., Annette Schaffer Eskind Chair and Director, Vanderbilt Kennedy Center, Co-Director, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities
- Diverse Membership on Community Advisory Council
- Diversity in student enrollment in Next Steps Post Secondary Program
- Information & Dissemination – Website, Tip sheets  
<http://kc.vanderbilt.edu/site/resources/links/page.aspx?id=4038>
- VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- A joint project with the Tennessee Council on Developmental Disabilities
- Statewide multilingual telephone HELPLine & Camino Seguro database
- A replication manual for Camino Seguro was written to assist other states in developing similar projects.

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- 30 Minute talk show series in Spanish highlighting agencies in Camino Seguro, a collaboration with Disability Law & Advocacy Center
- PSAs in Spanish, Kurdish, and Farsi/Persian
- Weekly interviews were played on Spanish radio
- Bi/tri-monthly print articles developed for Spanish newspapers, translations of materials developed by LEND trainees
- A Nigerian newspaper article on inclusive activities for people with disabilities

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- Formed the statewide Multicultural Alliance on Disability and worked with
  - The Tennessee Kindred Stories of Disability project to collect and compile stories from families with diverse cultural backgrounds.
  - TennCare MCOs to discuss solutions for ensuring that families who speak another language can access services through healthcare coverage providers.

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- Multicultural team member participation on projects:
  - Tennessee Autism Summit Team (autism)
  - TennesseeWorks (employment)
  - TRIAD (autism treatment & research)
- Participation in MyCity Academy
  - an invitation-only initiative formed by the Nashville Mayor
  - to facilitate a greater understanding of Metro government and services within Nashville's growing immigrant community.

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- Two monthly support groups for Spanish-speaking parents with childcare by Spanish speaking students
- A support group replication manual and training to assist other agencies in developing parent support groups for Latino families

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- Technical Assistance to
  - West Tennessee agencies who created a group for Spanish speaking parents
    - Autism Society of the Mid-South
    - University of Tennessee Boling Center for Developmental Disabilities (UCEDD)
    - Memphis Center for Independent Living
    - STEP (Support and Training for Exceptional Parents)
  - Staff at Meharry Medical College to develop a support group for immigrants and refugees from Africa.

# VKC Multicultural Outreach Program of Tennessee Disability Pathfinder

- Annual Conferences on Cultural Diversity – past 5 years
- Community Events:
  - Opening ceremony of Tennessee Special Olympics
  - Picnics
  - Fall Festival
  - Holiday Party
- Artwork



# Demographics

- Of Tennessee's total population in 2011
  - 4.8 percent were immigrants
  - compared to 2.8% in 2000 and 1.2% in 1990.
- At the national level in 2011
  - the foreign-born population represented 13.0% of the total population
  - compared to 11.1% in 2000 and 7.9% in 1990.
- *Sources:* US Census Bureau, 2011 American Community Survey (ACS); US Census Bureau, 1990 Census of Population and Housing and Census 2000  
<http://www.migrationinformation.org/datahub/state.cfm?ID=TN>

# State Demographics

- **By Race: Native Born & Foreign Born Tennesseans, 2011**

	<u>6,403,353</u>	%
White	4,990,068	77.9
Black or African American	1,071,463	16.7
American Indian or Alaskan Native	18,732	.3
Asian	92,286	1.4
Native Hawaiian or Other Pacific Islander	2,299	.1
Other	107,031	1.7
Two or More Races	121,474	1.9
- **Hispanic Origin Residents of Tennessee 2011**

<b>Total Native-Born Population</b>	<b>6,096,677</b>	<b>100.0</b>
Hispanic or Latino (of any race)	159,784	2.6
White, not Hispanic or Latino	4,754,872	78.0
<b>Total Foreign-Born Population</b>	<b>306,676</b>	<b>100.0</b>
Hispanic or Latino (of any race)	136,523	44.5
White, not Hispanic or Latino	69,081	22.5
- *Sources:* US Census Bureau, 2011 American Community Survey (ACS); US Census Bureau, 1990 Census of Population and Housing and Census 2000  
<http://www.migrationinformation.org/datahub/state.cfm?ID=TN>

# Staffing

- Kennedy Center researchers and staff
  - Principal Investigator
  - Research Coordinator
  - Curriculum developers/clinical supervisors
- Parents of children with disabilities were hired as peer mentor group facilitators and/or recruiters.
  - Hired as research assistants, peer mentors facilitators were trained to conduct either the PAD or MBSR interventions.
  - One peer mentor facilitator was African American and also helped with recruitment.
  - One part-time parent staff member was hired for recruitment of Spanish/English bi-lingual participants.

# Recruitment

- Flyers, emailing through Middle Tennessee network of disability organizations, websites, hospitals, churches, Study Finder.

<http://kc.vanderbilt.edu/site/services/studyfinder/default.aspx>

# Recruitment

- Recruiter for bi-lingual families
  - lived in Clarksville, 45 minutes from Nashville
  - was well connected with disability organizations in Clarksville and Nashville
  - was well connected to faith organizations
- Recruiter for African American families
  - lived in Nashville
  - was well connected with disability organizations
  - was well connected to faith organizations



## Parent Stress Intervention Project

Study conducted by Elisabeth Dykens, Ph.D. and  
sponsored by the National Institutes of Health

### Do you have a child with a disability?

Developmental disabilities may include autism, Down syndrome, cerebral palsy, learning disabilities, muscular dystrophy, and many other conditions.

### Having a child with a disability can be stressful.

This research study will compare two ways to help lower stress and support parents.

### We will ask you to:

- Contact us and answer questions to see if this study is right for you.
- Be randomly assigned to one of the no-cost stress reduction groups.
- Answer questions about yourself and your child 4 times (online or on paper; about an hour each time)
- Come to 6 weekly meetings (child care provided)
- Attend 3 follow-up meetings
- Give us 8 saliva samples to measure cortisol (a stress hormone)

Graphics services by the Vanderbilt Kennedy Center, NICHD Grant P30HD15052. The Vanderbilt Kennedy Center is devoted to improving the lives of people with disabilities. [www.vanderbilt.edu](http://www.vanderbilt.edu)



**Contact:**  
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**(615) 875-5080**





## Parent/Child Stress Intervention Project

Study conducted by Elisabeth Dykens, Ph.D.,  
Vanderbilt Kennedy Center

**Do you have a child with a developmental disability, serious chronic health condition or mental health issue?** Developmental disabilities may include autism, Asperger's syndrome, Down syndrome, ADD/ADHD, cerebral palsy, muscular dystrophy, and many other conditions.

**Are you and your child experiencing stress? Take part in the Parent/Child Stress Intervention Project at Vanderbilt University.** We are looking for parents of children with developmental disabilities and their children (ages 5 – adult) to participate in a research study that may lower stress.

**Parent participants will:**

- Participate in Mindfulness Based Stress Reduction meetings (once per week for 6 weeks; childcare will be provided).
- Answer questions about themselves and their child several times.
- Have their cortisol (a stress hormone) measured by providing saliva samples.
- If they choose, provide two blood samples.
- Receive monetary compensation for their time.

**Child participants will:**

- Participate in Mindfulness Based Stress Reduction meetings (once per week for 6 weeks).
- Have their cortisol (a stress hormone) measured by providing saliva samples.

Research and graphic services supported by NICHD Grant P20 HD15052 to the Vanderbilt Kennedy Center, whose mission is to facilitate discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families. [lc.vanderbilt.edu](http://lc.vanderbilt.edu) (December 2011).



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# Accessibility

## Group Location & Time

- Groups were held at community locations
  - Schools
  - Churches
  - Vanderbilt University settings
  - Military base
- Day and evening groups

# Accessibility – Child Care

- For offspring with disabilities & siblings
- Students, staff, and other applicants
  - were paid
  - had background checks & were finger printed
- For groups in Clarksville that had Spanish bi-lingual parents, child care workers were primarily Spanish speaking.

# Accessibility – Language

- Bi-lingual recruiter
  - Helped with member selection, considering identification of dialects
  - helped to organize groups in Clarksville
  - acted an interpreter
    - With family members who were mono-lingual
    - With child care providers
    - With children who were mono-lingual

# Limited to Bi-lingual Participants

- We were not able to deliver to mono-speaking Hispanic parents.
  - Parent recruiter wasn't able to be a facilitator
  - Supervisors who were not bi-lingual observed
    - to check for fidelity in the research
    - to provide clinical supervision
    - co-facilitated groups when needed
  - Budget did not allow hiring additional bi-lingual staff nor translating extensive curriculum & research materials

# Parent Characteristics in MBSR versus PAD groups

	MBSR	PAD	<i>t</i> / $\chi^2$
N	94	108	
Age	42.18 (8.40)	39.75 (9.24)	1.93
Married	72.8%	73.1%	
Employed	42.4%	51.9%	1.78
Hours worked	33.09 (15.13)	32.89 (15.40)	0.06
Race			3.71
White	76.8%	63.7%	
Black	11.0%	17.7%	
Hispanic	7.3%	10.8%	
Asian, Other	4.9%	7.8%	
Education			2.15
High School	25.3%	34.0%	
2-4 year degree	47.2%	42.5%	
Professional degree	27.5%	23.5%	

# GUIDING VALUES AND PRINCIPLES

- Organizational Commitment
- Practice & Service Design
- Language Access
- Community Engagement
- Family-Centered Care
- <http://www11.georgetown.edu/research/gucchd/nccc/documents/fcclcguide.pdf>

# Georgetown University's Self Assessment Checklist

- Physical environment, materials & resources
- Communication styles
- Values & attitudes
- <http://www11.georgetown.edu/research/gucc/hd/nccc/documents/ChecklistSIDS-ID.pdf>

# Cultural Competence is a Journey

- [https://aucd.adobeconnect.com/\\_a1005431686/self\\_assessment/](https://aucd.adobeconnect.com/_a1005431686/self_assessment/) - AUCD webinar by Tawara Goode, PhD., July 16, 2013

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