

# URBAN, UNDERSERVED & UNBELIEVABLY POWERFUL! Parent Leaders of CYSHCN

Presented at the Family Voices National Conference 2009  
By Parents Place of Maryland & Statewide Parent Advocacy  
Network of New Jersey



# Why do parents get involved?

- We believe the issue is important to us and our family
- We believe we have something to contribute
- We believe that we will be listened to and our contributions respected
- We believe that our participation will make a difference



# How do parents stay involved?



- Multiple opportunities for participation, from a small contribution of time to progressively larger contributions of time and effort
- The level of our participation can vary depending on our life circumstances.

# How do parents stay involved?

- Families receive sufficient advance notice
- Family participation is facilitated:
  - Child care
  - Transportation
  - Dinner
  - Compensation for time
  - Education & information in understandable language & formats
  - Mentoring/pairing with experienced family member



# How do families stay involved?



Families are listened to;  
our ideas are supported &  
respected

Families do not experience  
retribution as a result of  
our participation

Family participation has an  
impact

Family participation is  
consciously & visibly  
appreciated

# Pathways to Parent Leadership

- Critical supports:
  - Contact with other parents in leadership roles
  - Opportunities to take on leadership roles, however small, & safe settings to practice them
  - Relationship with respected & trusted person who provides feedback & support
  - Sense of belonging



# B'More LEADers



# Baltimore

- Low income, urban, minority population
- School system has many problems!
  - Highest drop out rate in state, 4<sup>th</sup> in nation (34% graduate)
  - Highest % kids in special ed
  - 20 yr special ed system reform lawsuit
  - Special ed taken over by state in 2005
- Parents marginalized by systems, confused, angry, unsure of what to do, no organized parent voice

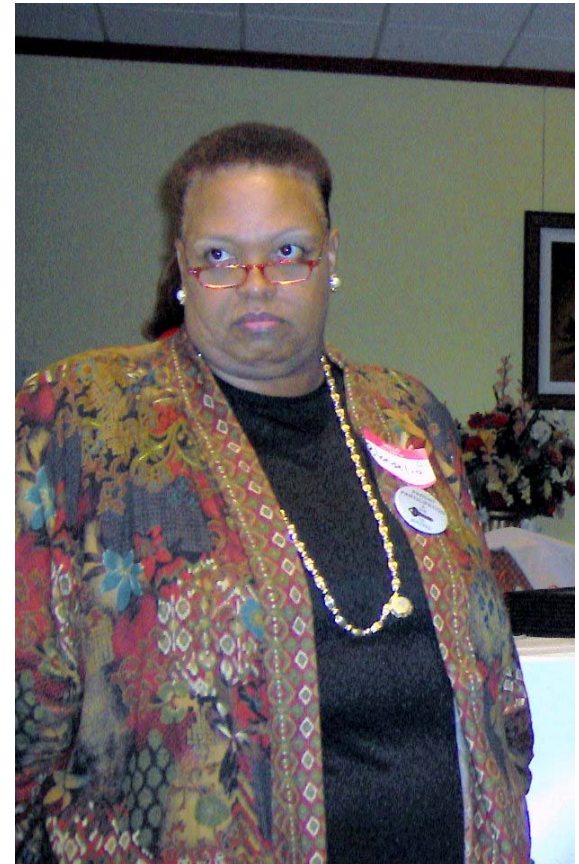


# Program

- Outreach to the community
- Application process
- 6 wks intensive training
- Ongoing mentoring & training
- Bi-Monthly meetings after graduation
- Social events - Sunday Social, picnic
- Bi-monthly Newsletter

# What Works

- Establish relationships with community and neighborhood leaders.
- Listen to families from the community -- base agendas and curriculum on community-defined needs.



# What Works

- Remove barriers to participation: offer meals, transportation, compensation, and child care.
- Identify appropriate community locations for activities.
- Have staff who engage in one-to-one relationships.



# What Works

- Get families involved right away.
- Create a leadership pyramid - graduates mentor new leaders.
- Turn over the running of the program as much as possible.



# What Works

- Allow for differences. If we want to create a safe and diverse community, we have to allow for the ambivalence and judgment that may surface.



# What Works



- We are all families - enter conversations based on common experiences rather than what separates us.

# What Works



- Find ways to include and support men and fathers.

# What Works

- Allow time for stories, generational history, and dreams.





# What Works



- Do what you say you are going to do.
- Be transparent

# What Works



- Express and show appreciation
- Remember - it's long term!

# B'More Accomplishments 2008



- Helped more than 300 parents
- Conducted outreach
- Participated in ongoing training
- Conducted workshops
- Actively involved with more than 50 local schools, city/state advisory councils & boards

# Celebrate!



# Low-Income Urban Immigrant LEP Families



- Parenting a child with special healthcare needs or disabilities frequently causes isolation, confusion & fear
- With a language barrier, little communication occurs which makes the family even more isolated
- Families live in low-income urban areas with few resources
- Communication requires an investment of time & effort but it can be done!

# Action Plan Summary

- Monthly activities facilitated by immigrant, bilingual staff
  - Support group
  - Workshops on critical issues
  - Parent to Parent orientation
  - SRP intensive training
  - Attendance at SPAN conference & other conferences
  - Participation in other focus groups



# Action Plan Summary

- Families learned about:
  - Parent rights & tips on how to advocate @ IEP meetings, with doctors, etc.
  - Government, non-profit, & community resources
- Connected to web & email through Traducelo Ahora



# Conferences Provided Learning Opportunities

- Facilitating transportation for families to attend learning events created opportunities for families to learn about different resources that can help them & their children become more independent
- Asking questions & interacting with panel members challenged families & gave them hope





# Connecting Families with Other Families



- Weekend mini-conferences/trainings included extensive opportunities to gain new educational information, network with other parents, & connect with professionals & with each other

# Action Plan Summary

- Other activities
  - Home visits
  - Attendance at IEP meetings
  - Signing families up for health insurance
  - Finding better doctors, clinics, specialists
  - Ongoing communication
  - Connecting families to other service providers & to each other



# Building Leadership



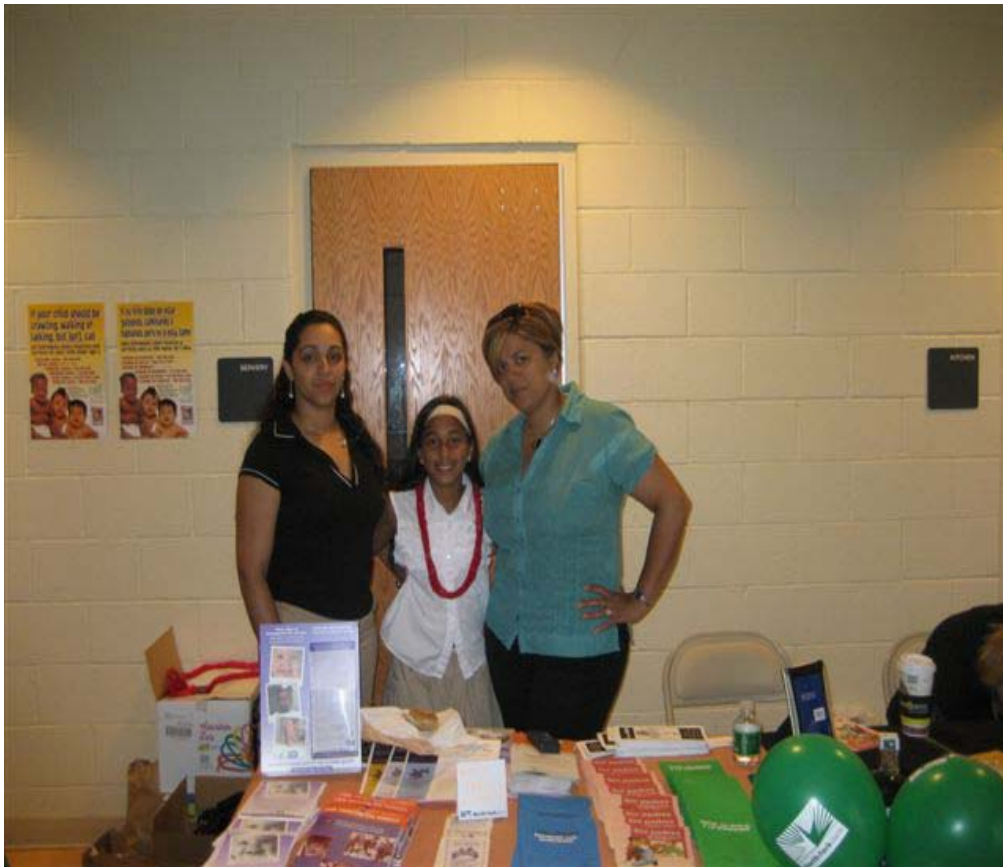
- Building leadership requires:
  - Trust
  - Honesty
  - Hope
  - Shared relationships
  - Openness
  - Flexibility
  - Love

# Building Trust



- Trust is not automatic; it must be earned and it can be lost.
- Trust must be two-way: those who are not trusted, do not trust.
- Trust leads to belief in each other and in a cause.

# Developing Trust & Being Clear



- Be honest about the problems, the barriers, the potential negative consequences - as well as the potential benefit
- What can you offer? What can't you offer?

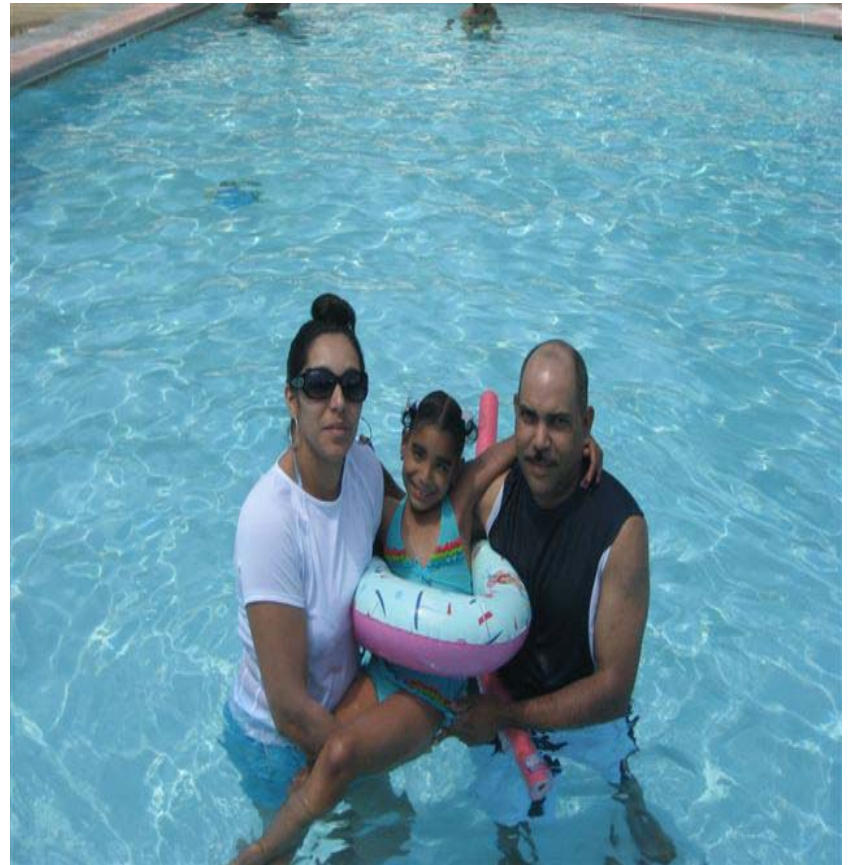
# Developing Trust

- Be in it for the long haul. Don't abandon ship after the first disappointment or failure.
- Admit mistakes.
- Ask for help!!!
- LISTEN!!!
- Acknowledge others' contributions.



# Hope

- Hope is not abstract. It is based on people's hearts and souls, their experiences, and their belief that a better life is possible - and deserved.



# Asking Questions

- Golden Rule: Do unto others as you would have them do unto you
- Platinum Rule: Do unto others as they would have you do unto them
  - How do you find out? Ask!





# Building Leadership

- Everyone's contribution is respected.
- Leadership is identified from within.
- Internal leadership is publicly recognized, supported, & validated.



# Building Leadership

- Encourage and support families to find their voice.
- Be ready to hear what family members say.
- Respect the passion of families for change.



# Looking to the Future....



- Before, the families:
  - Never heard anything from health and education professionals that they understood
  - Never spoke about their children or advocated on their behalf
  - Had little or no hope for the future

# Looking to the Future....

- Now the families
  - Eyes have been opened
  - Ears are starting to hear
  - They are speaking about their children, about their lives, about their needs
  - See a future for their children and are celebrating them
  - Have developed an extended family



# Looking to the Future....

- Families are a community not only with each other but with other families of children with a wide range of special needs
- Families are enjoying their children & celebrating their accomplishments



# Looking to the Future....

- Families are providing emotional support to other families (Parent to Parent), attending meetings with each other, connecting new families to resources (PTI, Family Voices), & sharing their experiences with policymakers



# Leadership Impacts

- Testified before:
  - NJ Department of Children & Families on Case practice model
  - NJ Department of Education on special education & bilingual education codes
  - Governor's Blue Ribbon Panel on Immigrant Affairs
- Met with:
  - Senator Menendez on health care
  - NJ Legislators on family leave insurance
  - Public Advocate & Child Advocate
  - Special Education Director
  - Title V SCHS



# Leadership Impacts

- Spoke with media on:
  - Traducelo Ahora web-based Spanish translation program in press conference with Senator Menendez (newspapers, radio & television)
  - Harassment on basis of immigrant status





# Leadership Impacts

- Spoke at SPAN 20<sup>th</sup> Anniversary Gala to 200 attendees including Senator Menendez, representatives from the Governor's office, state legislators, & advocacy organizations



# Leadership Impacts

- Participating on:
  - Partnership for Family Success Family Council
  - Local district Special Ed & Bilingual Advisory Committees



# Leadership Impacts

- Developing own non-profit parent advocacy organization, the Winning Angels!



# It's all about relationships!

