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, 4th 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\textsuperscript{th} 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!