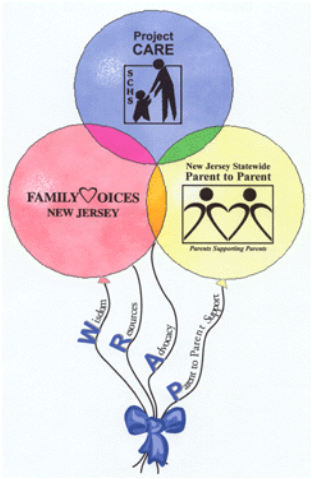
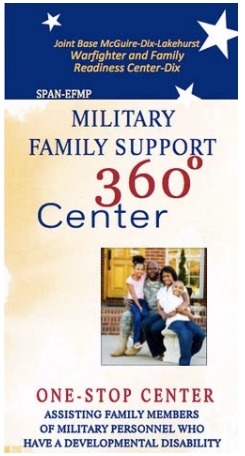
Bringing Early Screening to Immigrant Children and Making it Matter

Presented by Deepa Srinivasavaradan, SPAN



SPAN



Family Voices
New Jersey

New Jersey Statewide
Parent to Parent
Parents Supporting Parents

Center for
Parent Information
and Resources

NE-PACT
Family Centered, Parent Led

NATIONAL FEDERATION OF FAMILIES
For Children's Mental Health

The Basis of our Work

- Families have the greatest interest in ensuring that their children's and family's services meet their needs, and the most to gain in improving services and outcomes
- Parents can be powerful partners with national, state, and local agencies across systems
- SPAN is NJ's "one stop" for families of CYSHCN and is the PTI, Family Voices Chapter, Family to Family Health Information Center, and National Federation of Families for Children's Mental Health, funded by the NJ DOH to implement activities around the six core outcomes through the workgroups of the Community of Care Consortium
- Family WRAP project, funded by NJ DOH, provides Family Resource Specialists in the county Special Child Health Services Case Management Units and the NJ Statewide Parent to Parent, which provides emotional support and connection to resources to families of CYSHCN

Barriers to Accessing Services for Immigrant Families in NJ

- Immigrant families are often:
  - Less likely to have expectations of good health care for their children, especially CSHCN, because of lack of access in their country of origin
  - Unclear about the importance of early screening and screening tools, preventative care & accessing primary care or a Medical Home
  - Unaware of existing healthcare services & healthcare financing options or how to access them
  - Intimidated by anti-immigrant rhetoric
  - Mixed-immigrant families may be unaware of eligibility status
  - Scared/hesitant to talk to their child's provider
  - Not aware of healthy developmental milestones and unsure of what questions to ask
  - Unclear of coverage options and information about covered services

Other Barriers…

- Limits on language access for families with limited English proficiency (LEP) despite federal & state requirements
- Limits on immigrant parent eligibility for health coverage & other services impacts coverage & access to services for eligible children
- Lack of cultural diversity among providers impacts immigrant interest in reaching out for help or accessing services
- Immigrant families, whether documented or undocumented are frequently less likely to be aware of resources to assist their child or reach out to access those resources
- Many Immigrant families fear government authority based on their countries of origin and/or their experiences of discrimination in the US, particularly when families have one or more members without documentation

Overcoming the Barriers

- Enhancing Awareness:
  - Importance of healthy developmental milestones in infants and young children – promoting Act Early materials
  - Importance of early and periodic screening and screening tools – helping families partner with their child's providers
  - Enhanced early access to early intervention, health insurance & healthcare financing options and services for parents & children - factsheets
  - Access to quality healthcare providers for insured and uninsured
  - Increase Health Literacy so parents understand coverage, insurance plan options and covered Services

Activities to Support Families & Providers to Screen Early

- **Quick Peek Community Screenings** – in collaboration with Children's Specialized Hospital. SPAN FRS are present at the screening locations to provide 1:1 emotional support to those parents whose children "fail" developmental screening, encouraging them to (a) make appointments for needed evaluations, (b) understand the importance of following up with evaluation and accessing services, (c) address cultural implications of disability that may interfere with follow-up, and (e) connect them to SPAN and other community supports.
- **Parent led screening trainings to 15 FQHCs** – in collaboration with the Bogg's Center/NJ's Act Early Team. Developed and disseminated Community Resource Binders (by region) and flowchart of next steps and resources (by county) for families to use. Trainers reflected diversity of NJ's population & training included cultural implications for families from different backgrounds.
- **Center for Neurological & Neurodevelopmental Health (CNNH)** - Supporting families of children identified with autism spectrum disorders and other DD to partner with professionals on behalf of their children
- **Medical Home initiative** – Training (included a parent story/experience with screening and early identification of his/her child) providers on the importance of early and periodic screening and cultural competence through the MH learning collaborative.

Our Approach

- Approach
  - Strengths-based
  - Family-centered
  - Solutions-focused
- Goal
  - Enhance the leadership and advocacy skills of every parent
    - Within their family
    - Within their community
    - In systems change
- Motto
  - Empowered Parents: Educated, Engaged, Effective!

Strengths-based

- Parent leadership development through peer-to-peer education, support & empowerment
- Parents can be leaders regardless of their education, literacy level, or current situation
- Build leadership, not dependence
- We measure our effectiveness in enhancing family confidence, competence, attitudes and skills in - multiple ways: focus groups, pre-post surveys, telephone call-backs

Engage Families at all Levels

- Routinely ask, listen to, & incorporate the voices of diverse families in programs, services, policy
  - Be ready to hear what families say
  - Be ready to follow where families lead
  - Provide needed supports
  - "Nothing about me, without me"

- Start with understanding
  - Diverse parents who have "been there"
  - Start where parents are
  - Multiple pathways to leadership

Targeted Services

- Target families from underserved communities for more intensive supports designed to be flexible & responsive to their specific needs
- Help build trust, self-confidence, and relationships with other parents and professionals
- Help families recognize their strengths & go where they want to go
- See potential for leadership in every parent
- Make space for new leaders

My Journey…

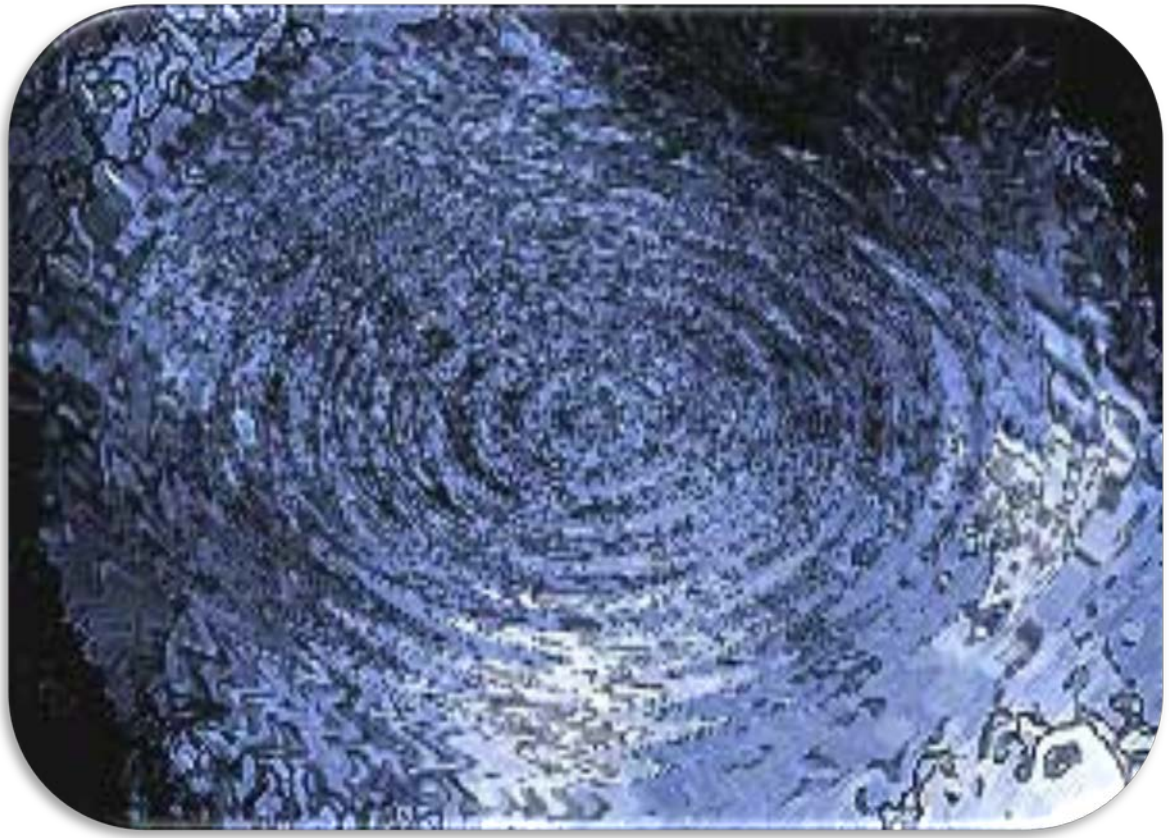
- **Year 1 – Scared to ask questions and unsure of how to navigate the different systems. Contacted SPAN and attended several workshops including the SRP training series and Medical Home Parent Partner training offered by SPAN. Started working to help enroll immigrant families into CHIP. Then became a Family Resource Specialist and started to provide advocacy information and resources to families at a Special Child Health Services unit.**
- **Year 2 – Stationed as a Family Resource Specialist at one of the Clinical Enhancement Centers for diagnosis and treatment of ASD and other DD. Was provided many opportunities to learn, and develop my leadership skills – selected as an AMCHP Family Scholar. Started working with diverse families – South Asian and Arab American support groups.**
- **Year 3 – Completed AMCHP Family Scholar program and my first Hill Visit. Invited to present to the Autism Researchers at MCHB's Strategic Planning Meeting. Became Parent to Parent coordinator and Chair of my district Special Education Parent Advisory Committee.**
- **Year 4 – Designated as AMCHP Family Delegate for NJ. Member of Help Me Grow workgroup, and Co-chair of Early and Continuous Screening Workgroup of NJ's Community of Care Consortium.**
- **Year 5 – Part of the team that presented to Dr. Michael Lu on Family Leadership. Became Project Coordinator for ACA outreach efforts. Selected as Learn the Signs - Act Early Ambassador for NJ.**

CDC's "Learn the Signs. Act Early." Ambassador Program

www.cdc.gov/ActEarly

CDC's "Learn the Signs. Act Early." Ambassador Program

CDC works with HRSA, AUCD, AMCHP and other partners to:

- Enhance the collaborative efforts to improve screening and referral to early intervention services
- Support the work of Act Early Ambassadors to promote awareness of the importance of and improve early identification efforts in their state
- As the Act Early Ambassador to NJ, my work plan includes disseminating Act Early information and materials to families and professionals in Head Start programs, NJ Association of Child Care Resource and Referral Agencies, and FQHCs throughout the state. As an immigrant parent myself, I bring the importance of understanding and addressing cultural implications of screening and culturally-appropriate approaches to the work.

We see ourselves as pebbles in a pond… causing ripples that spread in all directions