



Key Accomplishments of SIG-I

Community of Care Consortium

- ✓ Established & facilitate Community of Care Consortium for CYSHCN and their families
 - Key partners include SPAN, American Academy of Pediatrics-NJ/NJ Council on Pediatric Research & Education; NJ Departments of Health (early intervention, Special Child Health Services, Governor’s Council on Autism), Children & Families (includes Child Behavioral Health, child protection, & family support/prevention), Human Services (includes Medicaid & CHIPRA, Developmental Disabilities, child care, TANF), & Labor (includes Vocational Rehabilitation Services)
 - Other important partners include the major family & disability organizations, the three DD Act agencies (Boggs Center University Center on Developmental Disabilities, DD Council, & Disability Rights NJ), NJ Hospital Association, NJ Association of Teaching & Children’s Hospitals, NJ Primary Care Association representing FQHCs, NJ Immigration Policy Network & Hispanic Directors Association)
 - Over 60 statewide organizations representing almost 200 individual organizations, and 75+ parent leaders
 - Quarterly meetings with 50-60 participants at each meeting
 - Workgroups focused on all six core outcomes that are co-chaired by a parent and a professional
- ✓ Held statewide summit for 100 stakeholder invitees focused on all six core outcomes that developed action briefs to be implemented over the life of the project
- ✓ Funded 10 mini-grants focused on a variety of core outcomes at the community level, all representing collaboration between parents, health professionals, and community resources
- ✓ Established a section on the SPAN website with resources about the six core outcomes; AAP developed a section on their website

Family Engagement & Satisfaction with Services

- ✓ Families are engaged in all aspects of the project including leadership at all levels

- ✓ Trained 75 parent partners & are engaging internal parent partners from practices involved in the medical home initiative
- ✓ Trained over 75 SPAN Resource Parents last year alone to provide information & support to other families, staff display tables, etc.
- ✓ County workshops for families on health advocacy; transition to adulthood; health & education rights of CYSHCN in child welfare & juvenile justice; & range of other topics
- ✓ Established 3 pilot County Family Councils of families involved in various systems in collaboration with NJ Alliance of Family Support Organizations & Parents Anonymous; meet every other month to build leadership and engage as parent leaders in county advisory committees, etc.
- ✓ Held a parent leadership conference with 340 parent leaders!
- ✓ Providing training to professionals on how to work more effectively with families
- ✓ Developing a brochure for families on health information technology
- ✓ Provided direct TA to thousands of families last year through trained SPAN Family Resource Specialists housed at county Special Child Health Services Case Management Units

Medical Home

- ✓ Trained 75 diverse parents of CYSHCN to be medical home parent partners, to participate on medical home visits and provide information and resources as well as be a support to the practice's internal parent partners
- ✓ Collaborate with AAP-NJ on medical home visits
- ✓ Held a series of learning collaboratives with the initial pilot practices in Monmouth County
- ✓ Held our first Learning Collaborative for the practices in the three southern counties
- ✓ All medical home communities will include a children's hospital, FQHC, and 6-8 individual practices
- ✓ Pre-post surveys from our pilot counties show improvements in medical home-ness across all indicators
- ✓ Developed a fact sheet on medical home for parents and one for professionals

Community Resources Organized for Easy Access

- ✓ Worked with the SCHS Case Management Unit in Monmouth County (our pilot county) to develop a county resource guide for practices; will use that model in new counties
- ✓ Other SPAN projects are supporting this effort to make community-based services easier to access and more effective for CYSHCN and their families (some examples):
 - NJ Association of Child Care Resource & Referral Agencies is represented on the COCC. SPAN's NJ Inclusive Child Care Project trains county Child Care Resource & Referral Agencies to be able to more effectively communicate with & support families of CSHCN, and to be able to help the child care centers in their county include CSHCN. The NJ Inclusive Child Care Project also works intensively with 25 child care centers each year to improve their capacity to include CSHCN. We

disseminate a guide for parents and professionals on inclusive child care as well as a brochure on resources for including children in child care.

- NJ School Age Child Care Coalition is represented on the COCC. SPAN's Inclusive After-School Champions partners with NJ SACC on training administrators of multi-site after-school programs in communities with significant poverty and high numbers of immigrant families to include youth with SHCN in after-school programs, and provides direct on-site TA to participating after-school programs. We helped to develop a fact sheet on the laws regarding inclusion in after school and summer programs, resources to support inclusion, and a guide on how to do it with real-life examples, and disseminate it to parents and professionals.
- NJ Alliance of Family Support Organizations is represented on the COCC. County Family Support Organizations host SPAN workshops on health advocacy, the education and health rights of CYSHCN in the child welfare and juvenile justice systems, and transition to adult life. FSO parent leaders are part of the Medical Home Parent Partner team.
- NJ Primary Care Association is represented on the COCC. SPAN's CHIPRA Immigrant Outreach & Enrollment project staff go onsite to FQHCs to share resources and information about services and supports available to CYSHCN and their families.
- NJ Statewide Independent Living Council is represented on the COCC. SPAN's transition to adult life project trains the transition staff of the county Centers for Independent Living so they can effectively support youth in the transition process.
- Regional Early Intervention Collaboratives are represented on the COCC. SPAN Family Resource Specialists collaborate with REIC staff on county workshops for families about the transition to preschool.
- Partnership for Family Success is represented on the COCC. Various SPAN projects provide training to staff of community-based Family Success Centers on topics such as health advocacy, resources for families of CYSHCN, & helping families navigate the early intervention, preschool, and special education system.
- NJ Immigration Policy Network & Hispanic Directors' Association is represented on the COCC. SPAN's NJ Inclusive Child Care Project provided training to staff of the HDA on red flags in child development, rights of CYSHCN and their families under ADA & 504, & resources available to support families of CYSHCN.
- ✓ Contracted with Parents of Autistic Children to do county workshops for child care centers on red flags in child development & resources for children with ASD & other DD
- ✓ Contracted with NJ Alliance of Family Support Organizations to support Family Support organizations going into schools to train them about resources available for children with challenging behavior (whether it's based on mental health, ASD, or other DD) to reduce the calling of police, arresting of children, or sending children to out-of-district segregated placements or alternative schools
- ✓ Collaboration with the three DD Act partners on bi-annual conferences for underserved families of CYSHCN & disability providers (so far have completed one on Latino families, one on African-American families, & one on South Asian families; this coming year we will

be doing one on Arab-American families); bring together immigrant organizations, disability providers, and families for a full day conference

Early & Continuous Screening

- ✓ Collaborated with AAP-NJ in working with 30 pilot practices in Monmouth County on using validated screening for autism & other DD; lessons learned will be used in new counties through the medical home expansion
- ✓ Developed resources for families whose children fail the first hearing screening; hold a bi-annual conference for families of children with deafness & hearing loss
- ✓ Share information with a variety of community organizations about resources for early & continuous screening such as early intervention, EPSDT, etc.
- ✓ Developed resources for child care centers on early intervention & preschool special education and how to help families access evaluations & services from those sources

Adequate Public & Private Insurance

- ✓ Share information with families, pediatric practices, FQHCs, and community organizations about available public & private insurance & other health care financing such as Catastrophic Illness in Children Relief Fund, Federally Qualified Health Centers, state legislation requiring insurers to cover costs of services for children with autism & other DD (contracted with Autism NJ to develop a family & professional guide & to do regional workshops)
- ✓ CHIPRA Immigrant Outreach & Enrollment Project works to enroll eligible children of immigrant parents into Medicaid &/or CHIPRA
- ✓ Joined as amicus in a lawsuit aimed at reversing the Governor's elimination of ALL immigrant parents who hadn't been in the US at least 5 years from coverage under our CHIPRA program, NJ Family Care (lawsuit ongoing)
- ✓ We disseminate our 6 part fact sheet series on Medicaid Managed Care (one of the most popular set of materials on our website, in English and Spanish)

Effective Transition to Adult Systems of Care

- ✓ Widely disseminate the tools we developed including:
 - Interactive Transition CD for youth (parents & professionals use it too!)
 - Mini-guide on transition for parents
 - Transition Resources for Health practitioners (parents use it too!)
- ✓ Annual transition teleconference series that are recorded & available on website
- ✓ Series of annual mini-conferences on transition held in underserved communities
- ✓ Recruited and are establishing a 23-member Youth Advisory Council that includes diverse youth with and without special needs as per their interest
- ✓ County workshops on transition
- ✓ Piloting collaboration between pediatric and adult health practitioners at a hospital that is also an FQHC in New Brunswick, an underserved community with high rate of poverty and

immigrant families; will use what we learn as we expand our medical home efforts.

Facilitated a “train the trainer” for 50 pediatric & general medicine interns on transition.

- ✓ Youth developing a Facebook page for YAC and other youth