Roles for State Title V Programs in Building Systems of Care for CYSHCN-ASD & Other DD: Lessons Learned in NJ

Presented by Diana MTK Autin, Executive Co-Director, Statewide Parent Advocacy Network
35 Halsey Street Newark, NJ 07102
800-654-SPAN
973-642-8100
www.spannj.org
Empowered Parents: Educated, Engaged, Effective!

Major Barriers: Core Outcomes
• Many families unaware that their children/youth have ASD or the resources available
• Average age of ASD diagnosis >4½
• Only 38.3% NJ families report having medical home (much lower for LEP, immigrant, uninsured, families of color); 23.8% report difficulties getting referrals; families receiving primary care services through FQHCs have difficulty getting affordable specialty services; many primary care providers unaware of the clinical enhancement centers
• 41.7% of CYSHCN (52% of Spanish-speaking) don’t have adequate insurance; increasing out of pocket costs
• Community providers not prepared for ASD/DD
• Only 41.8% YSHCN (17% of Latino & 25% of African American) youth receive transition services

ASD-Specific Barriers
• Only 12.7% children received standardized screen for ASD/DD
• Significant racial/ethnic disparities in prevalence of ASD between white non-Hispanic (12.5/1000) & African American children (7.7/1000)
• 60% of children/youth with identified ASD not receiving special education services in that category (instead ID, ED, SLD)
• Family-identified needs:
  o Training & employment
  o Transportation
  o Financial difficulties
  o Dependence on emergency rooms due to lack of physicians trained to treat people with ASD
  o Lack of housing, employment, and social and long-term care services in urban areas as well as the need for culturally appropriate services.
  o 30% said youth had no transition plan; another 30% said plan was not being implemented
  o 80-85% were not told of various available supports & services
SPAN Role Within Title V

- Funded 23 years for “Family WRAP”
  - FRS at county SCHS CMUs
  - Parent to Parent (including EHDI collaboration)
  - Family Voices
- Partner on all grants involving CYSHCN
- Part of MCH Block Grant Team
- Community of Care Consortium (co-convened by SPAN, AAP, & Title V)
  - Serves as stakeholder group for Title V CYSHCN
  - All workgroups co-chaired by parent

Families engaged at all levels & satisfied with services (69.2%)

- Governor’s Autism Council composed of parents of children/youth & adults with ASD, clinicians, doctors & other health professionals, state agencies, etc.
- Recommends policy changes to meet needs of people with ASD & their families.

Family Support

- Trained parents (SPAN family resource specialists) housed in 21 SCHS Case Management Units, regional Clinical Enhancement Centers, & FQHCs, to provide one-stop “wrap-around” services, information, support, and connection to resources for families including families of CYSHCN-ASD (ISG I, II & III)
- SPAN also houses Family Voices, F2F HIC, P2P, & FFCMH
Family Support - ASD/DD
- Arc of NJ (across all DD)
- Autism NJ
- Autism Family Services
- Parents of Autistic Children (POAC)
- Family Support Center (across all DD)
- Family Support Planning Councils
- NJ DHS DDD Office of Autism

Early & Continuous Screening (83.8%)
- AAP-NJ EPIC: Building capacity of practices to improve early & continuous screening, connection to resources, & medical “home-ness” for children with ASD/DD
- Advocating use of standard routine screening tools
- Informing families & providers of screening resources (e.g. EI, EPSDT)

Early & Continuous Screening
- Assuring Better Child Development pilot with AAP
- 6 clinical enhancement centers with parent support through FRs
- Regional comprehensive multidisciplinary evaluation centers: 11 Child Evaluation centers (Title V-funded)
- EI Targeted evaluation teams
Early & Continuous Screening

- Early ID of Autism Spectrum Disorders Guidelines for Healthcare Professionals in NJ (issued April 2009 by NJ DHSS Division of Family Health Services). Dissemination through ISG Learning Collaboratives
- Assessment & Service Guidelines for Children with ASD (issued by NJ DHSS EI in February 2004)

Center of Excellence on Autism (in planning stages)

- Will provide state of the art diagnosis, evaluation & management of children with ASD, and ensure training of providers in clinical best practices

Medical Home (38.3%)

- Collaboration to expand medical homes in children’s hospitals, FQHCs, pediatric & family practices
- Parents as partners on medical home teams
- Expand use of medical home tools (including screening for ASD)
- ASD resources for practices & families
Medical Home

- 20 community health centers & FQHCs provide access to primary care on sliding fee scale (including for undocumented immigrant families)
- FRS onsite part-time to provide support

Community Services Organized for Easy Use by Families (62.3%)

- Expanded Birth Defects & Autism Reporting System (registry):
  - Record of all reported cases of ASD
  - Automatic connection to county SCHS case management units
  - Tracking to determine services offered to registered children & families
  - Training for primary care practices

Community Services Organized for Easy Use by Families

- County SCHS CMUs (with SPAN FRS)
- County Family Support Organizations & Care Management Organizations (CY w/ mental health &/or dually diagnosed with mental health & DD)
- FSOs connect schools to resources for children with challenging behavior (MH & DD)
- Mobile response for crisis situations; mandatory DD training for first responders
**Community Services Organized for Easy Use by Families**

- SPAN NJ Inclusive Child Care Project: onsite training & TA on red flags in child development & inclusion of children with challenging behavior including ASD
- Inclusive After-School Resources
- POAC workshops for child care centers on identifying ASD/DD; resources

**Community Services Organized for Easy Use by Families**

- *Through the Maze: A Family Guide to Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders and other Developmental Disabilities* (collaborative guide from NJ Departments of Human Services, Children & Families, Community Affairs, Education, Labor, & Health & Senior Services)

**Adequate Public & Private Insurance & Health Financing (54.9%)**

- Insurers must pay for therapies for children with ASD/DD
  - Maximizing Reimbursement Under NJ’s Autism/DD Insurance Mandate guide
  - County workshops & online webinar
- SCHIP covers children up to 350% of FPL; families with higher incomes may purchase health insurance comparable to NJ Family Care at state’s cost
  - SPAN CHIPRA Immigrant Outreach & Enrollment project (CMS-funded)
- EI services at no cost to families up to 300% FPL; sliding fee scale for others
**Adequate Public & Private Insurance & Health Financing**

- Catastrophic Illness in Children Relief Fund reimburses families for uncovered medical debt
- Child behavioral health services (CMOs in every county); includes CY with dual diagnosis of mental health & ASD/DD
- Young adults up to age 30 can stay on parents’ health insurance

---

**Adequate Insurance & Health Financing**

- Healthcare Financing Fact Sheet Series (one pagers on healthcare financing resources)
- Printing & Dissemination of My Health Passport; Being a Healthy Adult: How to Advocate for your Health & Healthcare; Healthcare Advocacy Across the Lifespan: What Parents of Children with Disabilities Need to Know; & Transition Resources for Health Practitioners (one page fact sheets including on healthcare financing)
- Arc’s Mainstreaming Medical Care Project (newsletter, conf., advocacy)

---

**Effective Transition to Adult Systems of Care (41.8%)**

- SPAN TA Specialists
- Pathways to Adult Life
- Division of Disability Services Office of Information & Assistance Services
- County DVRS Transition Counselors who assist youth at IEP meetings & assist young adults with ASD/DD to secure employment
- Network of county CILs & Statewide CIL
Effective Transition to Adult Systems of Care: Info & Training

- Information & Resources
  - County & web transition workshops & mini-conferences for families & professionals (SPAN)
  - Being a Healthy Adult (Transition to Adult Health guide) (UCEDD)
  - Transition CD & Tip Sheet for youth; Transition Resources for Health Practitioners; Transition Guide for parents

Effective Transition to Adult Systems of Care: Self-Advocacy

- “YELL: Youth Engaged in Learning & Leading” - Statewide Youth Advisory Council
- Autistic Self-Advocacy Network
- NJ DDC Youth Leadership Project

Sustaining Our Efforts

- Building activities into Title V Block Grant
- Cross-training SPAN staff to provide ongoing TA & support
- Providing train-the-trainers, archived webinars, & links on partner websites to project resources so information & training available after grant ends
- Building capacity of practices
- Building parent leaders
- Peer supports
- Targeted medical home parent partner training, support parent orientations, SRPs
- Writing grant applications