

Systems of Supports & Services for CYSHCN-ASD/DD & their Families in New Jersey



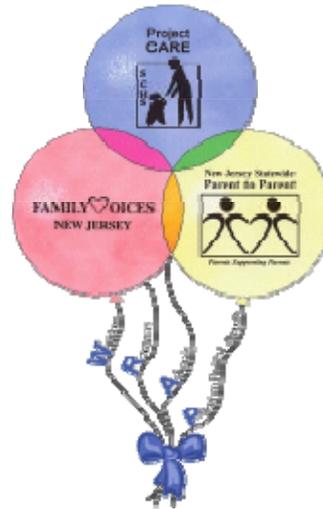
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*Empowered Parents:
Educated, Engaged, Effective!*

Collaborative Partnerships

- Community of Care Consortium for CYSHCN & their Families
- SPAN (PTI, F2F HIC, FV, P2P, FFCMH, SIG-CSHCN)
- AAP-NJ/NJ PCORE & other health partners (NJHA, NJAC&TH, NJFPA, FQHCS)
- Clinical Enhancement Programs
- NJ DHSS (EI, DFHS, SCHS CMUs), DHS (DDD), DCF (DCBHS, DCPC), DOL (DVRS)
- DD Act partners (UCEDD, P&A, DDC) & other DD advocates (Family Support Center, CILS, Arc, etc.)
- Autism advocates (Autism NJ, POAC, ASAN, NJAFSO, FSOs)



American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

New Jersey Chapter



Cover our Kids Community Campaign



department of human services **DHS**

Families engaged at all levels & satisfied with services

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



Family support

- Trained parents (SPAN Family resource specialists) housed in each of the 21 SCHS Case Management Units (& soon in the 6 regional Clinical Enhancement Centers) to provide one-stop “wrap-around” services, information, support, and connection to resources for families including families of CYSHCN-ASD
- SPAN also houses Family Voices, F2F HIC, & P2P



Family support-ASD & DD

- Autism NJ
- Autism Family Services
- Parents of Autistic Children
- Family Support Center (across all developmental disabilities)
- Family Support Planning Councils



Early & continuous screening

- EPIC: Building capacity of 30 practices in pilot county to improve early & continuous screening, connection to resources, & medical "home-ness" for children with ASD/DD
- 6 clinical enhancement centers
- Regional comprehensive multidisciplinary evaluation centers: 11 Child Evaluation centers
- EI Targeted evaluation teams



Early & continuous screening



- Assuring Better Child Development pilot with AAP
- Advocating for use of standard routine screening tools
- Informing families & providers of screening resources such as EI, EPSDT

Early & continuous screening

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



Early & continuous screening

- 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



- 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 to identify ASD)
- ASD resources for practices

Medical home



- 20 community health centers & FQHCs provide access to primary care on a sliding fee scale (including for undocumented immigrant families)

Community services organized for easy use by families

- 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 if & what services were offered to registered children & families



Community services organized for easy use by families

- County SCHS CMUs (with SPAN FRS)
- County Family Support Organizations & Care Management Organizations (children & youth with mental health &/or dually diagnosed with mental health & developmental disabilities)
- Mobile response for crisis situations



Community services organized for easy use by families

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



Adequate public & private insurance & health financing

- Insurers must pay for therapies for children with ASD & other DD
- CHIPRA covers children up to 350% of FPL; families with higher incomes may purchase health insurance comparable to NJ Family Care at the state's cost
- EI services at no cost to families up to 350% FPL; sliding fee scale for others
- Young adults *up to age 30* can stay on parents' health insurance



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 children/youth with dual diagnosis of mental health & ASD & other DD



Effective transition to adult systems of care: TA

- 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



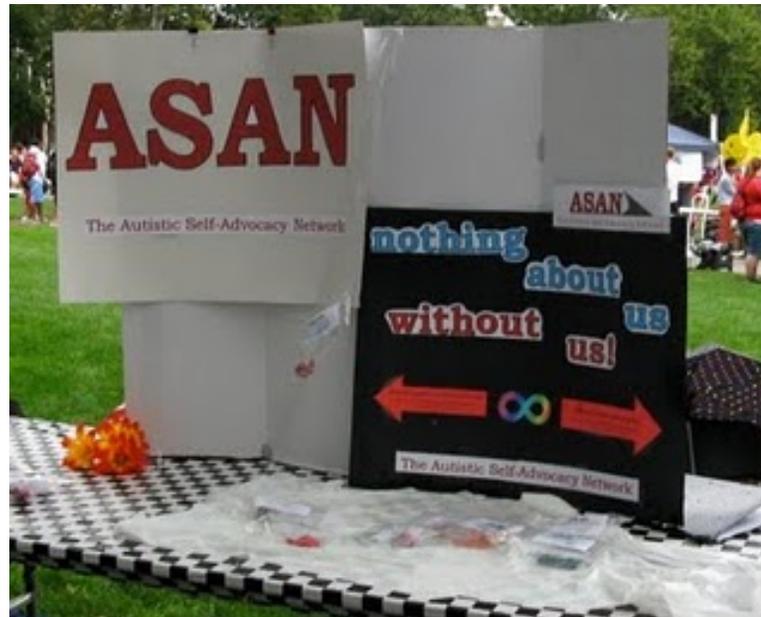
Effective transition to adult systems of care: Workshops

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



Effective transition to adult systems of care: Self-Advocacy

- Statewide Youth Advisory Council
- Autistic Self-Advocacy Network
- NJ DDC Youth Leadership Project



CAAI State Implementation Grant Webinar

“Connections”: Building Title V and LEND Partnerships to Enhance System Coordination and Outcomes

December 1, 2010

Anne Bradford Harris, Ph.D., MPH, MS, RD

Sharon Fleischfresser, MD, MPH



Waisman Center
University of Wisconsin–Madison
University Center for Excellence in Developmental Disabilities



Children and Youth with
Special Health Care Needs

State Plan

- System of Early Identification and Referral
- Assessment, Evaluation, and Diagnosis
- Intervention and Treatment
- Supports for Families
- **Overall Systems Coordination**



Systems Coordination Goals

- Strengthen **statewide infrastructure** by connecting initiatives under one umbrella
- **No wrong door** for accessing the services and supports system
- Assure everyone has **access** to information and resources
- Improve **connections** among services
- Strengthen local and regional **partnerships** for training and outreach



Collaborative Strategies

- Create and sustain state and regional communities of practice and shared work
- Inform and involve partners in new funding and developing initiatives
- Include collaborating agencies in management teams and advisory groups
- Identify products and activities that meet multiple programs' goals



Shared Work

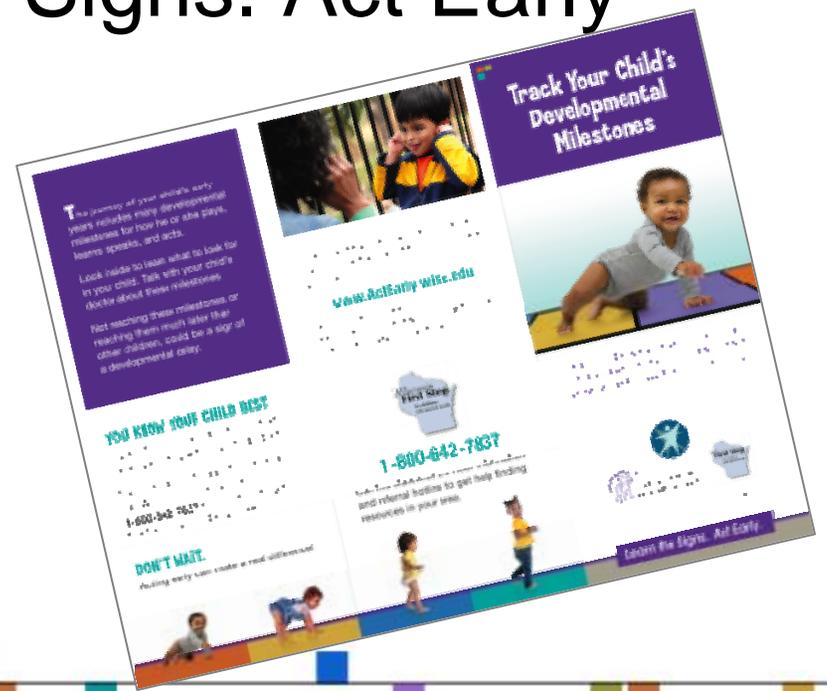
- Community of Practice on Autism Spectrum Disorder and other Developmental Disabilities
 - Practice Groups
 - 5 Regional Teams



Developmental Screening

- Medical Home Integrated Management Team
- Wisconsin's "Learn the Signs. Act Early" materials
- WISCU database

www.ActEarly.wisc.edu



Training and Professional Development

- Share curricula, consistent messaging and training strategies
- Involve pre-service trainees, community-based professionals and family members in Community of practice, training, and policy work
- Knowledge and resources from other projects used to inform training, outreach, and systems change
 - National Professional Development Center on ASD
 - WISADDS provides state and national prevalence estimates and findings

Enhanced Outcomes

- **Interagency collaboration**

- Communities of practice (statewide and regional)
- Integrated management teams, advisory councils and committees

- **Products**

- Wisconsin Medical Home Webcast Series

www.waisman.wisc.edu/connections/webcast.php

- Wisconsin's "Learn the Signs. Act Early" materials
- Online portal

www.waisman.wisc.edu/connections



Enhanced Outcomes

- **Systems Change and Coordination**
 - Shared database tracks participation in Medical Home training and implementation
 - CoP on ASD/DD Practice Groups assume leadership
- **Information and Training**
 - Over 500 new community resources identified for WI First Step database
 - Expanded and enhanced trainee fieldwork experiences, leadership projects, posters, and presentations
 - Increased capacity to provide distance learning



Evaluation

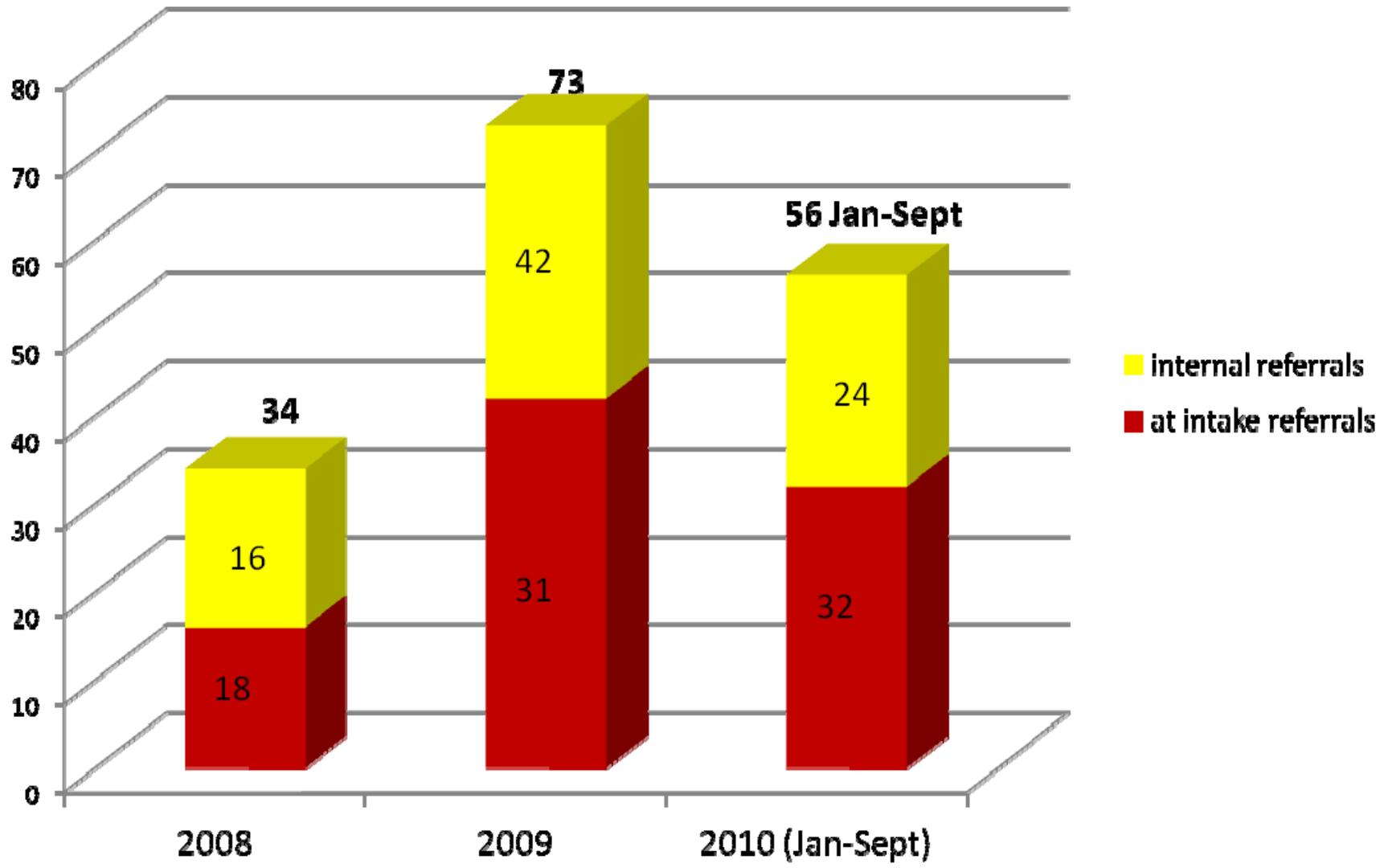
- **Evaluation team**
 - Meets every 6-8 weeks
 - Reviews plan and progress, tools and outcomes
- **3-year plan**
 - Changed/expanded as project has evolved
 - Designed and are implementing new evaluation strategies to measure enhanced outcomes



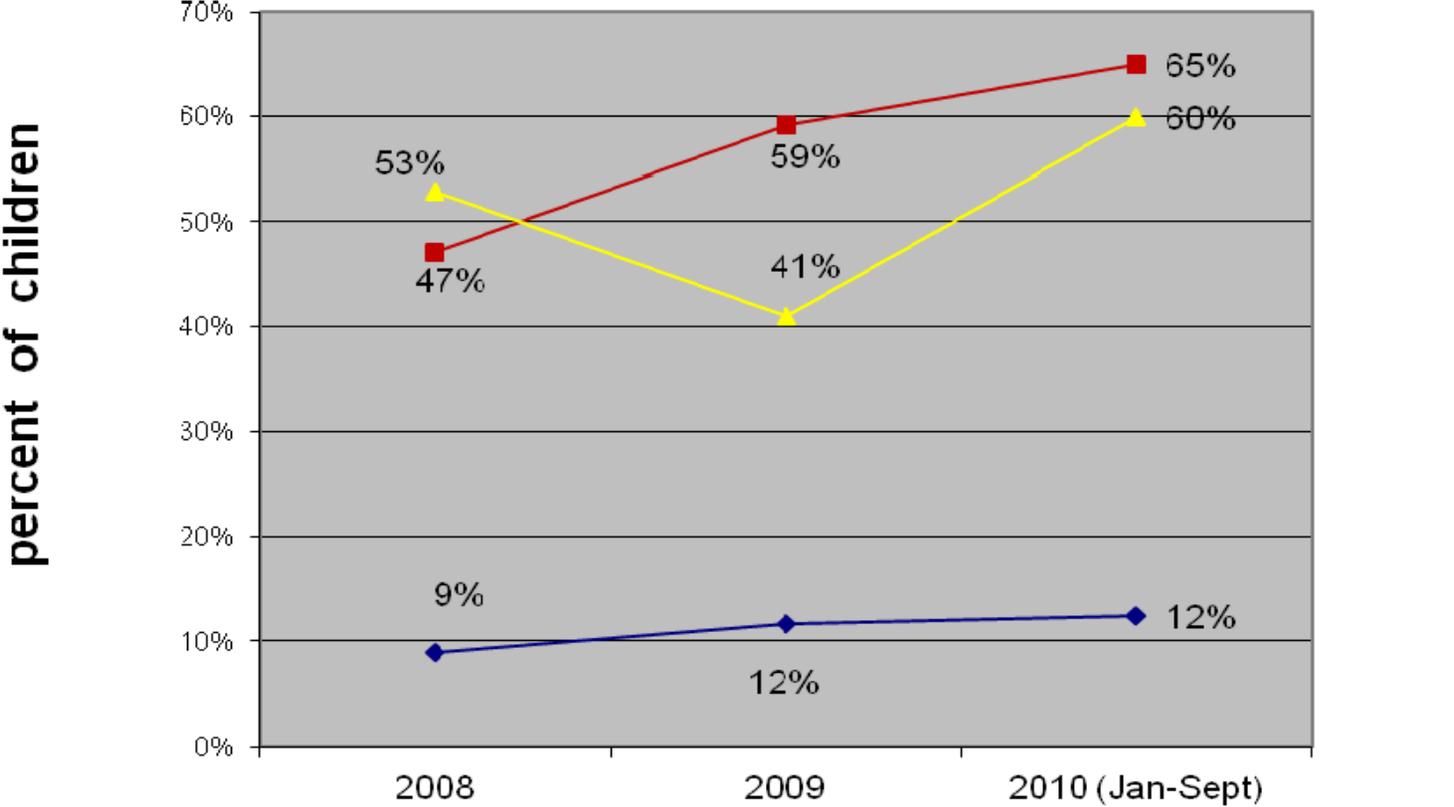
Early Recognition and Identification of ASD Concerns

Objective: Pilot a systemic child find campaign using the Centers for Disease Control and Prevention (CDC) Learn the Signs/Act Early materials to increase the number of referrals for timely screening and diagnosis for ASD.

Total # of children referred for ASD assessment



Children Eligible for ASD Services



◆ ASD service eligible ■ id. at intake ▲ id. Internal referral

Impact of Campaign

- Acknowledgment and response to parental concerns
- Increase staff awareness and identification of sign and symptoms of ASD
- Increased staff skills and confidence to talk with parents about ASD
- Evaluation for ASD concerns significantly earlier
- Earlier referral for diagnostic evaluation
- Decreased time to more appropriate ASD services
- Greater likelihood of increased developmental gain
- Increase family support
- Appropriate referral to school district special education preschool program

ABCs of Autism

A Story of True
COLLABORATION

THE BEGINNING

- An idea from parents and providers
- A speech therapist URLEND trainee started it as a Leadership project
- A 12 Hour Training
 - First two pilots were live 2 hour sessions for 6 consecutive weeks
 - 2nd live series video-taped
 - Rural areas
 - On Demand
 - Expertise
- Facilitated training guide and DVD developed
 - First rural training provided as a two day conference

The Chapters (Modules)

1. Building Resilience: Healing After the Diagnosis and The Wise Consumer
2. Behavior Management
3. Introduction to Autism and Early Intervention, Pre-school Education Services
4. Communication and Sensory Integration Issues
5. Interventions – ABA, TEACCH, DIR, RDI, Social Skills Training, SCERTS and CAM
6. Finding Resources, Organized Record-Keeping and Parent Panel

The Authors (PARTNERS)

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- Autism Council of Utah
- Baby Watch
- Children's Center
- Intermountain Health Care
- Spectrum Academy
- University of Utah, Department of Pediatrics
- University of Utah Department of Psychiatry
- University of Utah, Neuro-behavior HOME Program
- Utah Department of Health, Bureau of CSHCN
- Utah Families for Early Autism Treatment
- Utah Family Voices Family to Family Health Information Center
- Utah Parent Center
- Utah State Office of Education
- Utah State University Center for Persons With Disabilities.

The Successful Ending

- A product that has had many MCHB funded projects involved, as well as community providers, parent support groups, community services and individual families.
- A user friendly tool that everyone has ownership in!
- Can be used in creative and flexible ways to get the information out to families.