

Thinking **BIG** about ASD

Developing Systems of Care to Improve Early Identification & Support

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My background

- As a father
- As a clinician
- As a teacher
- As a researcher
- As a program leader

- No conflict of interests



CHALLENGES AND OPPORTUNITIES

Working as a team

CHILDREN are supported by
their **FAMILIES**

Who are directly supported by
Clinicians, Educators, & Parent Groups in
their local communities

Who are themselves supported by
Trainers, Researchers, & Program Leaders
at the regional and state level

Whose efforts are coordinated by an
Act Early State Team



CHALLENGES

I. For families of children with ASD

- Getting an early and accurate diagnosis is a critical first step for the families of children with ASD
- For most, this is the beginning of an odyssey that presents many challenges that can include
 - Significant functional impairment & maladaptive behaviors
 - Patchy services and confusing treatment options
 - Debate about the cause, and an uncertain future
- Many families will remain significantly involved in their child's care for their entire lifetime
- Can we make sure families get off to the right start?



OPPORTUNITIES

I. For families of children with ASD

- Families that are guided & supported can make ALL the difference in the life of a child with ASD b/c they
 - Are exquisitely sensitive to their child's needs
 - Bridge & coordinate care across many providers
 - When resilient, mobilize resources, make positive meaning of disability, becoming united and closer, building friendships, and rediscover pride as parents
 - With new insights offered by adults with ASD, can voice the goals and dreams for themselves and their children
 - Join with parents of children with other developmental disabilities to advocate for change that benefits all



CHALLENGES & OPPORTUNITIES

II. For Direct Service Providers

- Our challenges: As clinicians and educators, can we support families by assuring that
 - ASD identification is timely, accurate, & accessible?
 - Other related child & family needs are addressed?
 - Families know how to access services we recommend?
 - Care is coordinated and family centered?
- Our opportunities: We already have
 - Clear guidelines regarding identification
 - Models of coordinated, family-centered care
 - Research beginning to describe the range of needs



CHALLENGES & OPPORTUNITIES

III. For Trainers, Researchers, & Leaders

- Our challenges: Can we support families and service providers by
 - Providing the necessary training and supports?
 - Making sure services reach ALL families?
 - Identifying & targeting other gaps in services?
- Our opportunities: We already have
 - Agencies identified for many of these tasks
 - Model programs for training in ASD identification
 - Research beginning to describe gaps and service options



CHALLENGES & OPPORTUNITIES

IV. For Act Early State Teams

- Can we address the challenges faced by children, families, and those who support them by
 - Developing a shared vision to address these and other challenges, by thinking BIG about the system change needed at the local, regional, and statewide levels?
 - Translating this vision into a State Plan with specific action steps, measurable goals, and timelines?
- Our opportunities: We already have
 - Examples of effective programs for improving early identification, and that often just need be scaled up
 - Entities designated for many of the needed tasks
 - Mechanisms via these summits to develop effective plans



CHALLENGES AND OPPORTUNITIES

Working as a team

CLINICIANS

Identification of
ASD & related
needs

PARENT GROUPS

Guidance

EDUCATORS

Coordinated, family-
centered care

CHILDREN
I. FAMILIES

II. Directly Supporting Children & Families

Training &
Support

TRAINERS

Reaching all families

LEADERS

Identifying other
gaps & goals

RESEARCHERS

III. Supporting Service Providers

IV. Act Early State Team



II. TIMELY, ACCURATE, ACCESSIBLE DIAGNOSIS

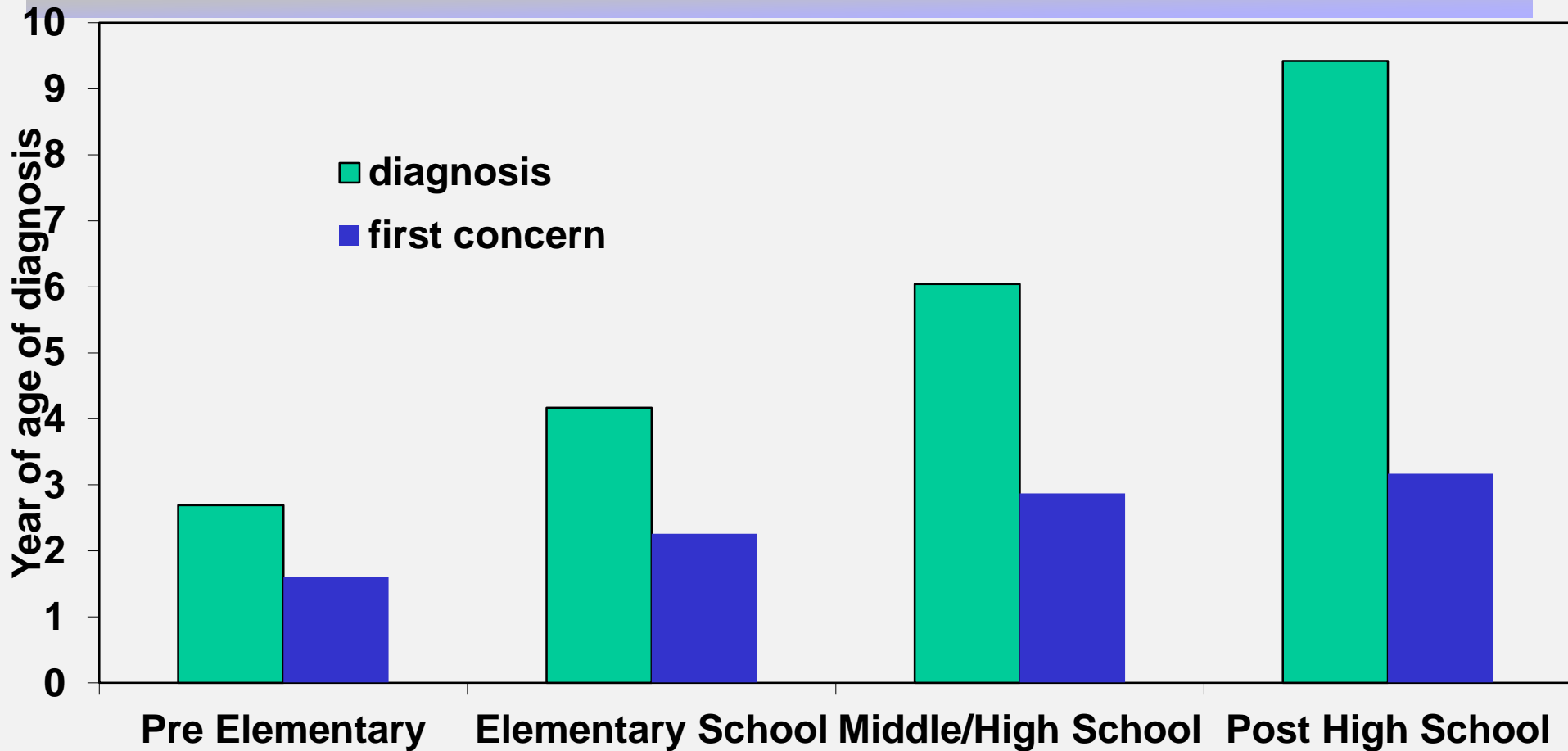
What is not working?

- Families are reporting that the initial diagnosis is not always timely, accurate, or accessible
 - 40% report that they are not satisfied with the process involved in getting an ASD diagnosis
 - They see multiple clinicians en route to a diagnosis
 - Early developmental concerns minimized or dismissed
 - The perceived delay in diagnosis is 9 -18 months, and there are long waiting lists at diagnostic centers
 - But there is evidence that children are being identified earlier, and without being seen by as many professionals



PA AUTISM NEEDS ASSESSMENT

Age of Diagnosis and First Concern



II. TIMELY, ACCURATE, ACCESSIBLE DIAGNOSIS

What are some solutions?

- Public awareness about ASD has already increased tremendously over the past decade
- There are excellent instruments and guidelines already in place for ASD screening & diagnosis
 - Possible gaps: Comfort in identifying ASD before 3, and the mismatch between recommended protocols and what community-based professionals have time for / can bill for



II. RECOGNIZING OTHER RELATED CONDITIONS

- Other prevalent, co-occurring conditions
 - May more problematic for families than ASD itself – i.e., challenging behaviors, sleep problems, Feeding / GI concerns, & anxiety
 - Parents report that PCPs lack expertise in ASD management, are uninformed /unsupportive of Complementary & Alternative Medicine, & specialists are difficult to access
- Some solutions
 - New research-based algorithms from the Autism Treatment Networks are on the horizon
 - Can interventions effective with other children be readily adapted for children with ASD?



II. PROVIDING GUIDANCE

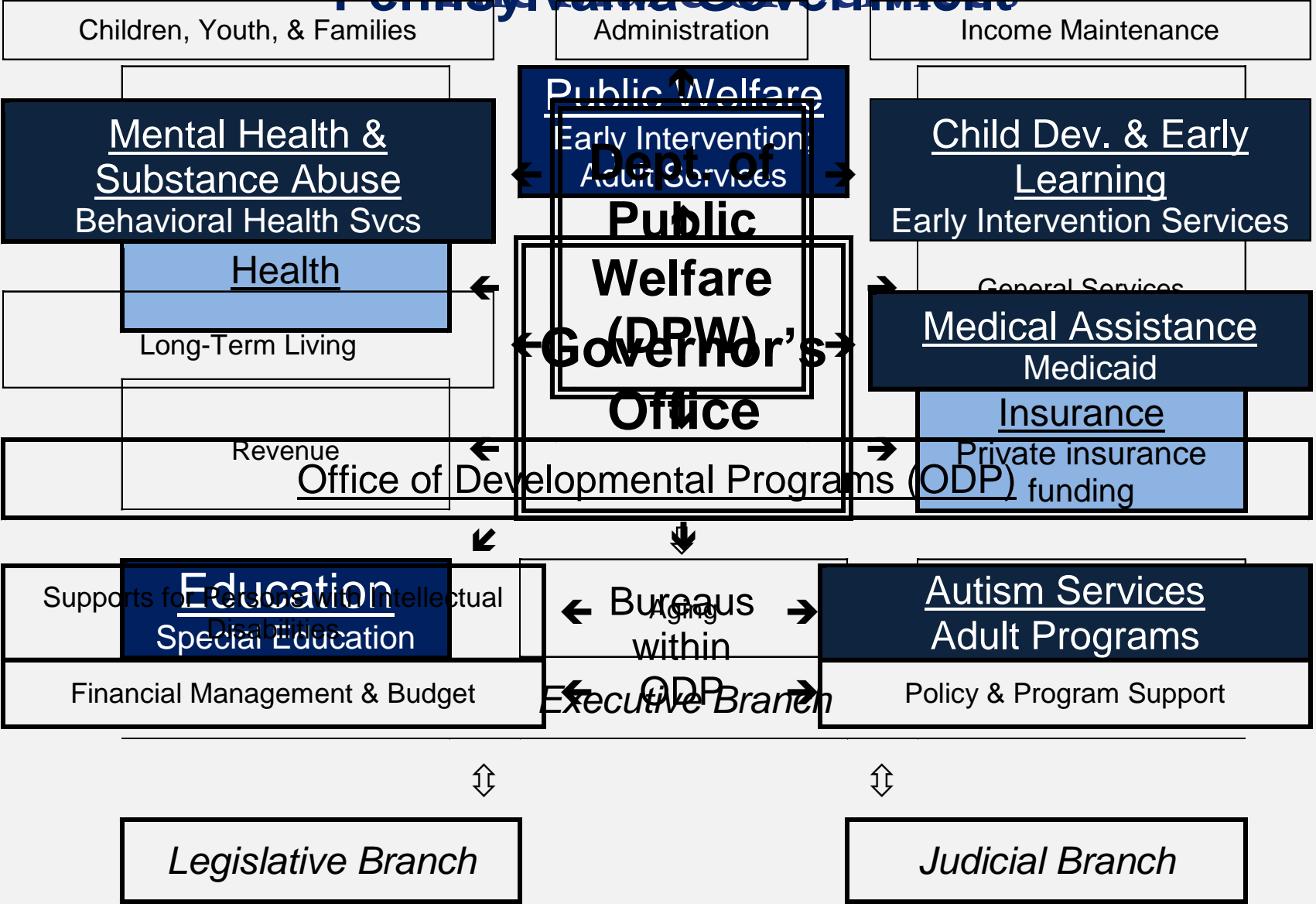
- Problems
 - Almost too much information about ASD for parents
 - Children with ASD often require the involvement of multiple professionals, agencies, & service systems
 - Professionals also are confused about where to refer
 - Families cannot always get services they are entitled to
- Solutions: Ensure that
 - You create simple roadmaps describing the path to services, tailoring it to different audiences
 - Professionals understand the service network, and how to find services in their communities



II. PROVIDING GUIDANCE

Diagram of Departmental Relationships with the ODP

Pennsylvania Government



II. PROVIDING COORDINATED CARE

- Some problems: Parents report that primary care providers
 - Do not coordinate care with other providers
 - Do not ask about transition plans
- Some solutions
 - IEP & IFSP are mandated in state and federal law, though neither requires PCP involvement
 - Medical Homes: a model for coordinating care with PCPs
- Ongoing problem: In most cases, no one but the parent can assume the role of the case manager



Who is the case manager?



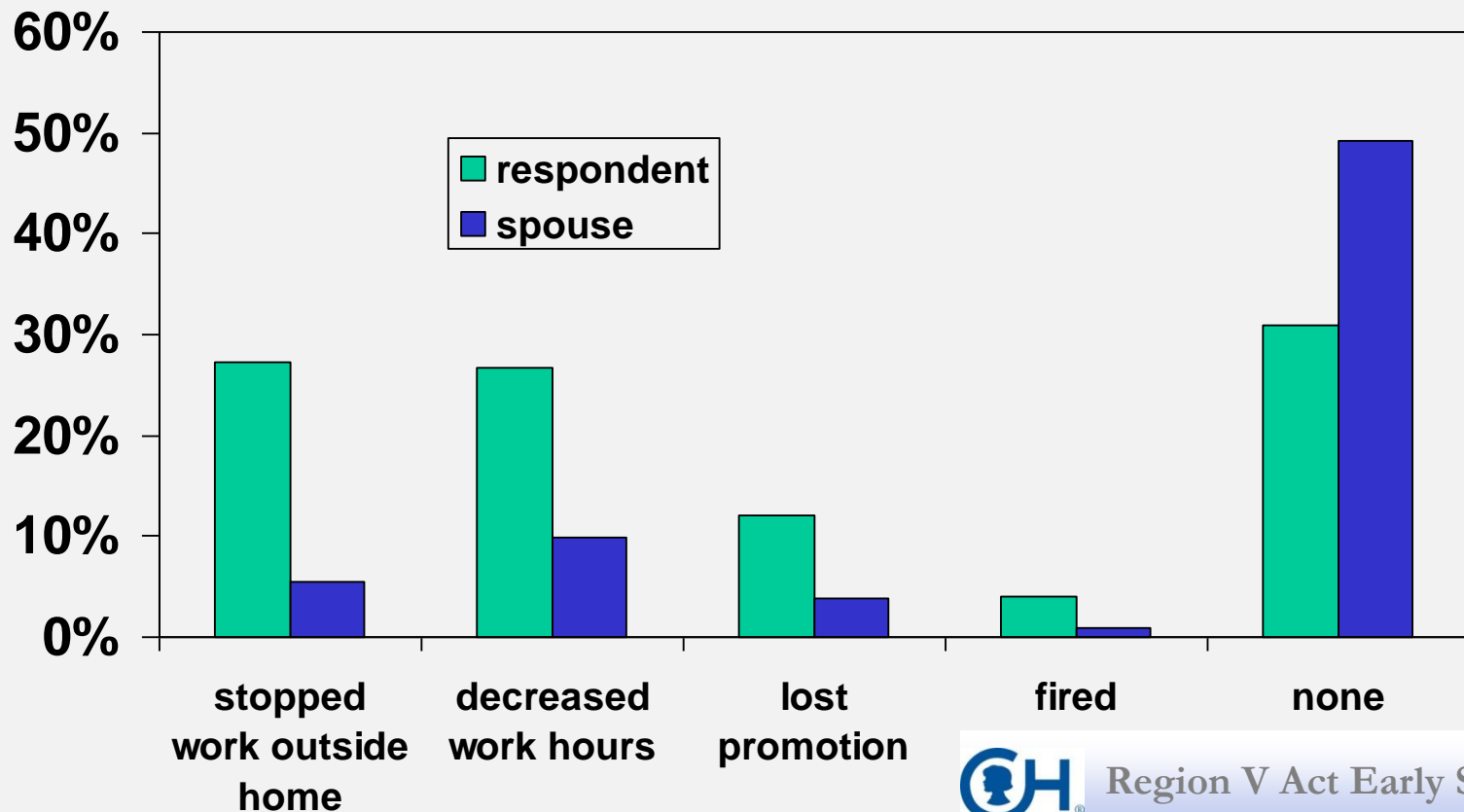
II. PROVIDING FAMILY-CENTERED CARE

- Some problems
 - Autism has a significant impact on the family's finances, health, and well-being that can limit their future options
 - Parents report that primary care providers do not ask about how autism affects other family members, and medical care is not family centered
- Some solutions
 - Supports like summer programs & respite can sometimes be publicly funded though might not be available
 - A role for private agencies and non-profits?



Changes in workforce participation

Workforce participation changes resulting from having a child with ASD



The daily impact



Recreating a family life



III. TRAINING & SUPPORTING PROVIDERS

What are some problems?

- Excellent guidelines for screening & diagnosis are available, though have not been universally adopted
- Specialized positions like Developmental Pediatricians & Speech Language Pathologists remain difficult to fill in rural regions



III. TRAINING & SUPPORTING PROVIDERS

What are some solutions?

- Identify and target barriers to implementing screening / diagnosis guidelines
 - Provide training in streamlined, research-based protocols for less complex cases, and that can lean on other, often more available professionals(e.g., nurses)
- Build on existing training programs like LEND
 - Multidisciplinary, family focused, culturally sensitive, and community-based focus is a perfect fit (NextSteps)
- Develop new training programs with a specific ASD focus (internships, fellowships)



III. REACHING ALL FAMILIES

- Problems? Well-documented disparities in access for rural populations & racial/ethnic minorities
 - Delays in identification, and are likely to have received other diagnoses first
- Solutions
 - Many excellent materials have been translated, and various programs available to fund their dissemination
 - Closely track / document local disparities, and develop specific programs to reach under-served groups

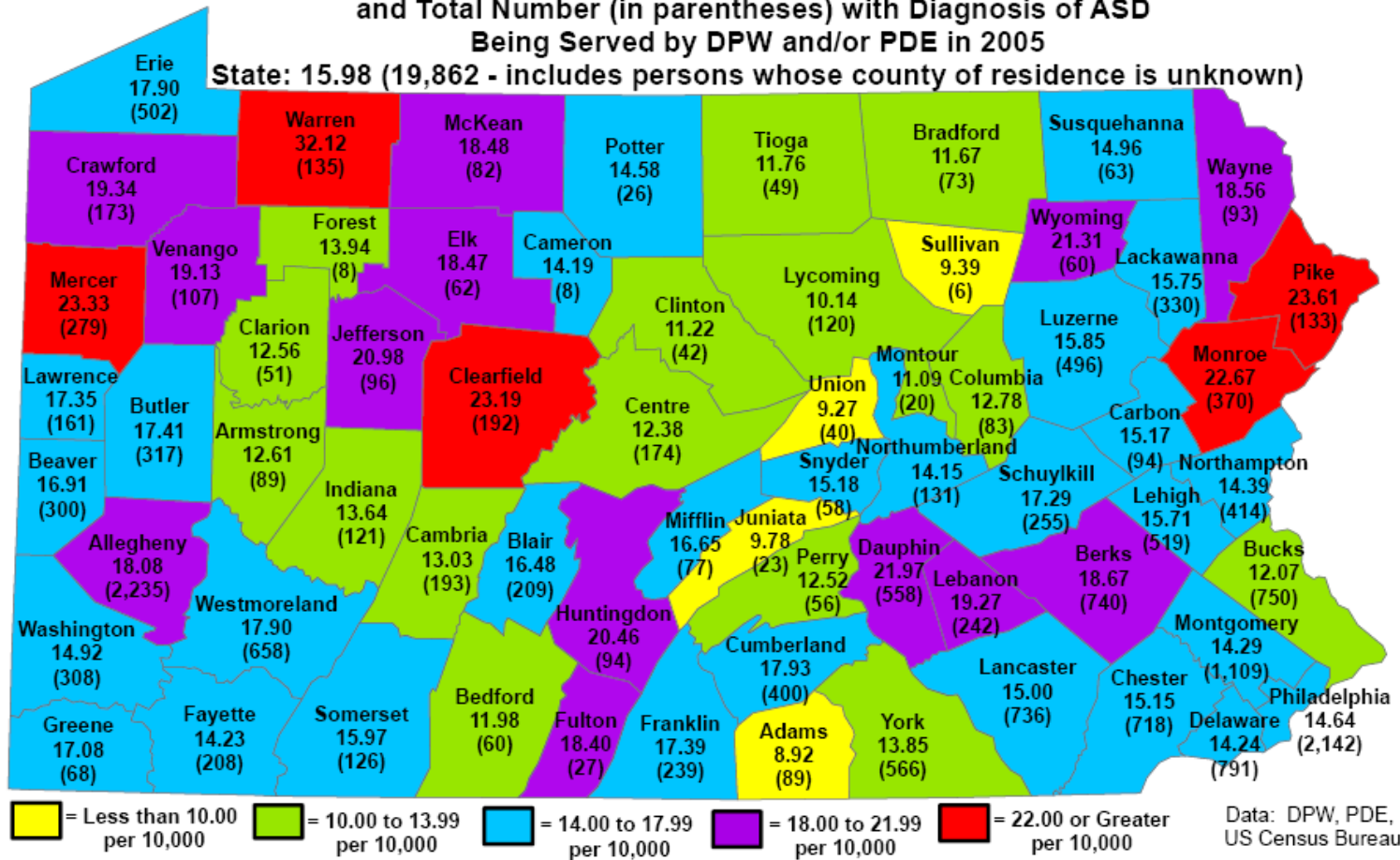


PA AUTISM CENSUS

Regional variation in identification

County Autism Prevalence - Rate per 10,000 of County Population
and Total Number (in parentheses) with Diagnosis of ASD
Being Served by DPW and/or PDE in 2005

State: 15.98 (19,862 - includes persons whose county of residence is unknown)



III. IDENTIFYING & TARGETING OTHER GAPS

- Some problems
 - Services are organized in silos that lead to confusion and important gaps
- Some solutions: Gather data regarding
 - gaps and to document the family's struggles, that can be used to guide policymakers
 - Consider a re-organization to develop more specialized regional supports and programs



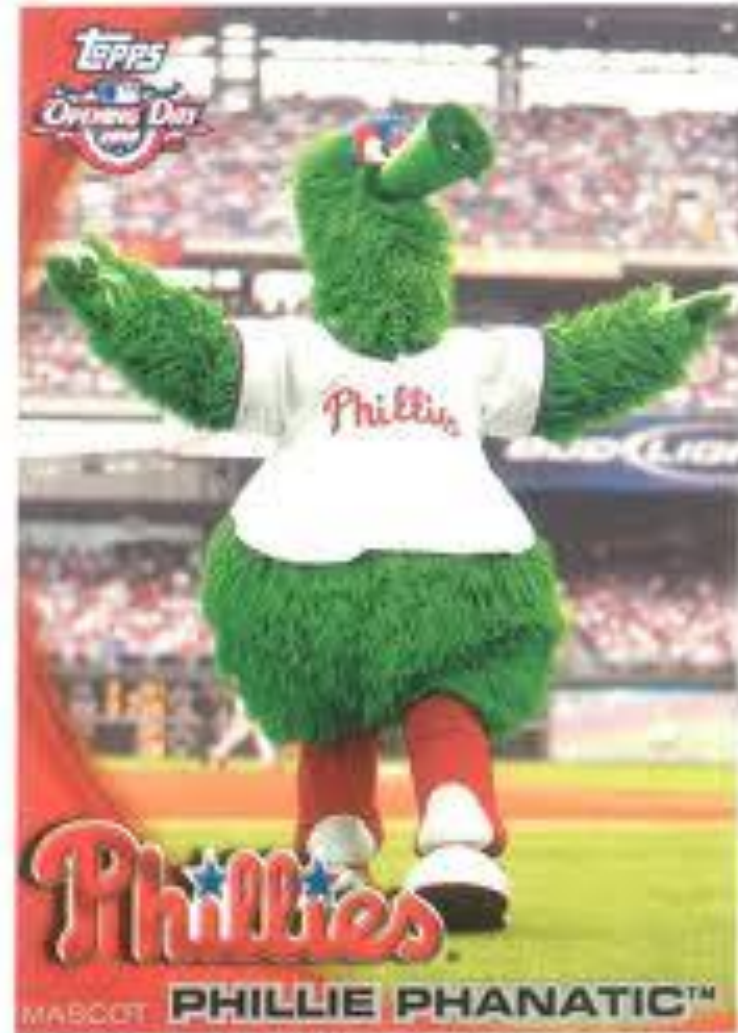
IV. DEVELOPING A SHARED VISION

- Working as a team: An opportunity AND a challenge
 - Many different stakeholders
 - Many different agencies protective of their territory
 - Funding cannot be ignored, but cannot drive the discussion



IV. DEVELOPING A SHARED VISION

- Philadelphia's founding fathers?



IV. DEVELOPING A SHARED VISION

- Solutions
 - Begin to work as a team here at the summit
 - And continue the work afterwards, perhaps with other funding supports



IV. DEVELOPING A STATE PLAN

- Opportunities: There are already
 - Other examples of excellent state plans and guidelines available: Can you draw on these?
 - Excellent resource guides and materials: CDC materials (LTSAE) , AUCD sharepoint and sites
 - Often existing partnerships with parents
- Challenges: A plan may stall if there are not
 - Actionable steps & measurable goals
 - A plan to target known barriers
 - Resources to inject new energy for training and coordination



OTHER COMPONENTS TO CONSIDER

Parent Advocacy and Support Groups

- Parent-led organizations are often a necessary and critical part of our service and support infrastructure
 - They are the most effective advocates for system change at the local, regional, state, and national levels
 - They often provide important information, support, and guidance to other families as they begin their journey
 - They are agile, and can develop and help to mobilize new services and supports that fill important gaps
- The challenges of engaging parent groups
 - Building effective & meaningful partnerships & coalitions
 - Not reacting to crises but planning for long-term needs



OTHER COMPONENTS TO CONSIDER

Children with other disabilities

- Why look beyond ASD for potential coalitions with other related developmental disabilities?
 - CAAI was also intended to address developmental disabilities other than ASD
 - The needs of children and families with ASD overlap
 - Considering the overlapping needs of a larger group may help to create a critical mass in regions with few resources
 - An example: Systems of training, services, and supports for persons with challenging behaviors



OTHER COMPONENTS TO CONSIDER

Legislative action

- There are many examples of ASD-specific laws and regulations enacted at the state level
 - Some have opened up important opportunities for children and families
 - Still more have fallen short of expectations
 - Almost all required considerable effort to pass
- So learn from what other states have done before moving ahead
 - See NCSL Autism Legislative Database



FINAL THOUGHTS

Thinking ahead to the need for services

- The challenges to improve services are even greater than those for improving identification
 - Do people fail to act early on the concerns of parents because they lack confidence that appropriate services are readily available?
- Can we capitalize on new knowledge and opportunities?
 - Greater consensus regarding evidence-based practices
 - Collaborative research networks.



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