

Joint Legislative Audit and Review Commission



**Assessment of Services
For Virginians With
Autism Spectrum Disorders**

Senate Finance Subcommittees on Education and
Health and Human Resources

September 17, 2009



JLARC

Study Mandate

- House Joint Resolution 105 (2008) directs staff to
 - Compare services provided to individuals with autism spectrum disorders (ASDs) in Virginia to other states
 - Identify best practices and ways to improve delivery of services to Virginians with ASDs
 - Assess availability of ASD training for public safety personnel

Research Activities

- 4 public input sessions around Virginia
- Survey responses from
 - 436 Virginia public schools
 - 600 Virginians with ASDs or their caregivers
 - 27 criminal justice academies
- Site visits to 8 Virginia areas to interview local staff
 - Early intervention programs
 - School division and regional program
 - Department of Rehabilitative Services field offices
- Structured interview with State agency personnel
- Extensive review of literature & other states' practices

In This Presentation

- Overview of Autism Spectrum Disorders (ASDs)
- Several Publicly Supported Programs Serve Virginians With ASDs
- Publicly Supported Programs Often Inadequately Coordinated
- ASDs Frequently Diagnosed and Addressed Later Than Recommended
- Early Intervention Programs Not Designed or Structured to Effectively Address ASDs
- Many Schools Unable to Fully Meet the Needs of Students With ASDs
- Limited Supports Exist to Facilitate Independence of Adults With ASDs
- Conclusions and Funding Options

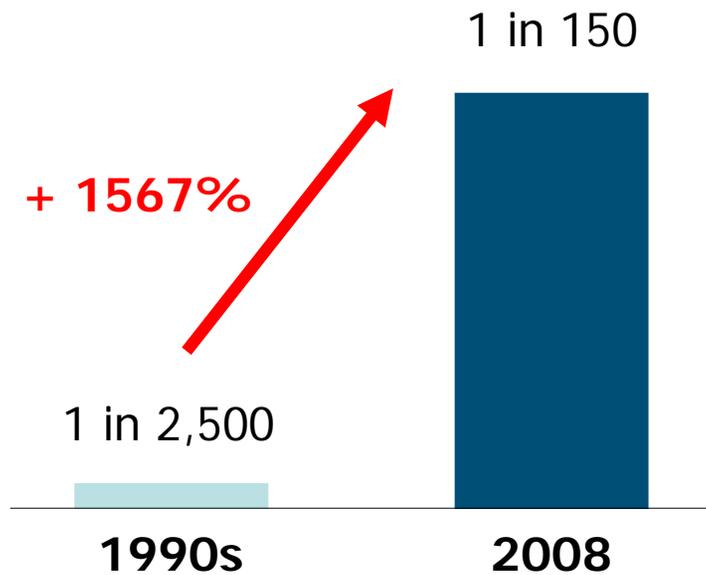
What Are Autism Spectrum Disorders (ASDs)?



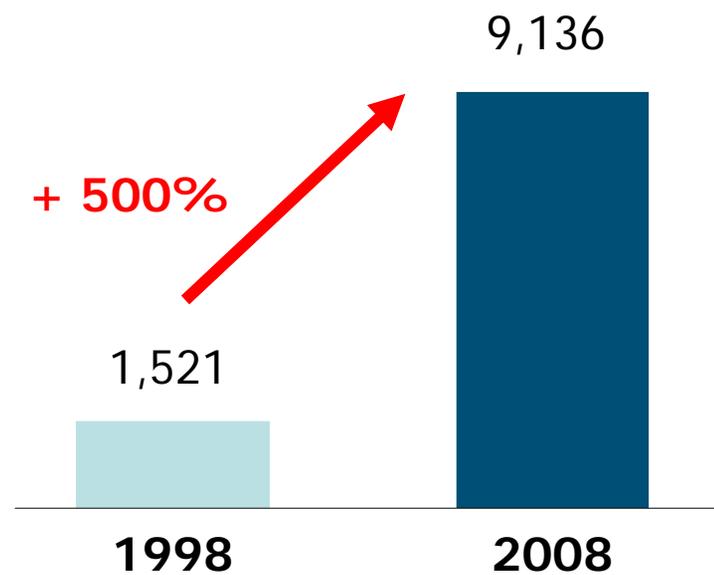
- Symptoms vary greatly between individuals, but usually appear by age 3 and affect
 - Social skills
 - Communication skills
 - Behavior

Prevalence of Diagnosed ASDs Rose Dramatically During Last Decade

National Estimated Prevalence Rate of ASDs
(Centers for Disease Control)



Virginia Students With ASDs in Special Education



Multiple Theories Attempt to Explain Increased Prevalence in Diagnosed ASDs

- Formerly diagnosed as other conditions
- Broader autism spectrum
- True rise in incidence
 - Unclear because causes of ASDs are unknown
 - Would result in increasing need for public supports

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Major Publicly Supported Programs Serving Virginians With ASDs

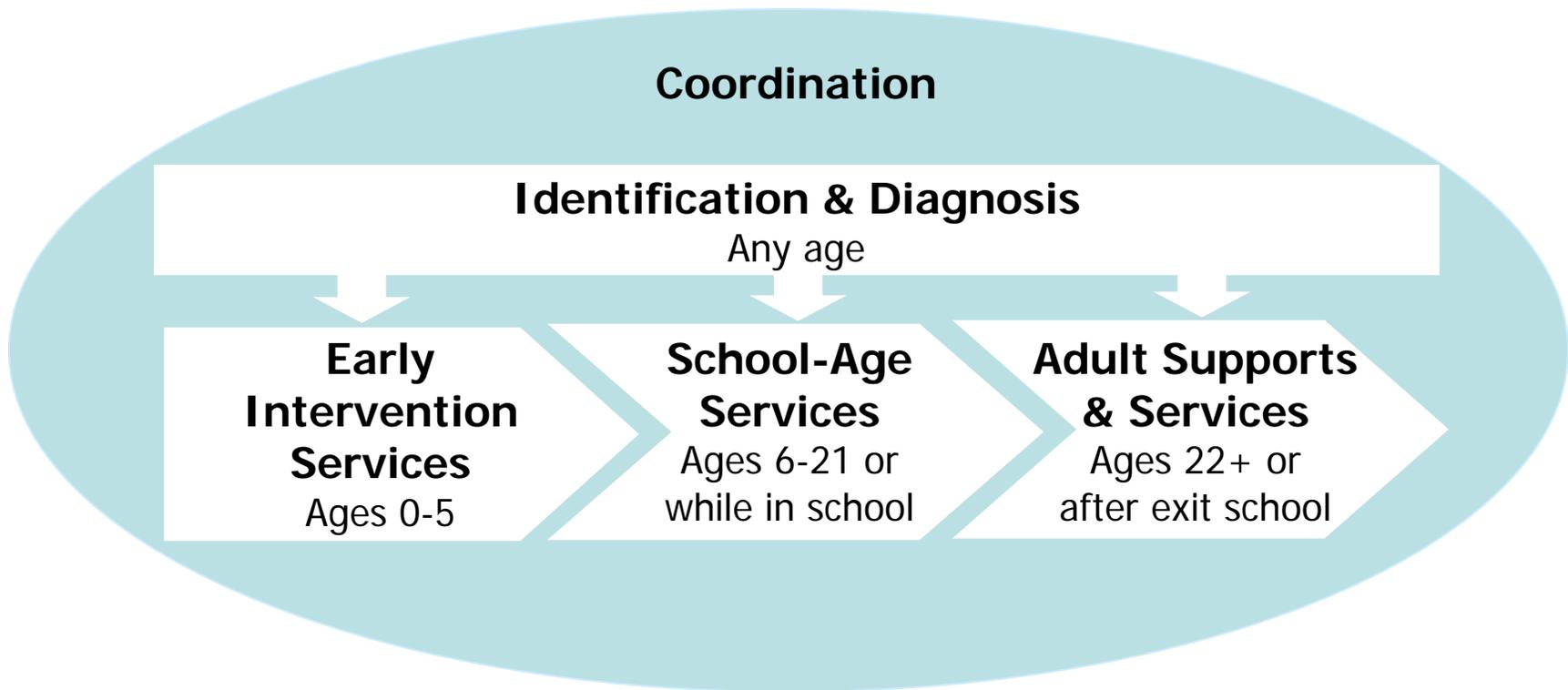
Department	Program	Services & Population
DMAS	Medicaid Waivers	Community-based services as alternative to institutionalization, - any age
Behavioral Health & Developmental Svcs.	Medicaid Waivers	
	DOE	Early Intervention Part C
DOE		School Part B
Comprehensive Services	Comprehensive Services Act	Children with severe emotional or behavioral problems, 0-21
	DRS	
DRS	Woodrow Wilson Rehab. Center	Vocational and life skills training, age 18+

Clients and Expenditures of Primary Programs Serving Virginians With ASDs

Program	Clients With ASDs		
	Number Served	Spending (\$Millions)	% State Funding
School Part B	7,580	\$152.3	23%*
Medicaid Waivers	1,557	52.2	50
Comprehensive Services Act	831	36.1	64
Vocational Rehabilitation	794	0.5	20
Early Intervention Part C	460	unavailable	22
Woodrow Wilson Rehab. Center	123	1.0	35

* Majority of other funding comes from local governments (64%)

Components of Service Delivery System Align With Life Stages of Virginians With ASDs



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Finding

- Programs serving Virginians with ASDs tend to be inadequately coordinated
 - No state entity had coordinated agencies and programs for Virginians with ASDs prior to July '09
 - Virginia has no centralized and comprehensive source of information about ASDs
 - Comprehensive case management services are not consistently available

Potential Actions to Improve Coordination of ASD Services

- ***Recommendation:*** Department of Behavioral Health and Developmental Services (DBHDS) to facilitate development of cross-agency action plan addressing issues from JLARC report
- ***Recommendation:*** DBHDS to lead design and implementation of information source
- Train caregivers or expand case management services

Options Assessment Contained at End of Report Chapters 4-8

Major Goal	Resources Needed	Extent to Which Addressed Major Goal	Time Needed to Implement
Promoting State-Level Accountability and System Coordination			
Prioritize key steps in implementation plan	--		 
Enhancing Access to Information About Community Resources			
Develop guidebook		★ ★	
Create interactive website		★ ★ ★	 
Staff information clearinghouse		★ ★ ★	 
Improving Coordination of Individual Care			
Encourage physicians to act as medical home			 
Train individuals/caregivers on case management		★ ★	 
Expand role of existing case managers		★ ★	 
Expand and centralize case management in regional offices		★ ★ ★	  

Illustration

Least  Most
 ★ ★ ★ ★ ★ ★
 Greatly Substantially at least

< 6 Months
 6-18 Months
 > 18 Months

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Finding

- Although ASDs can generally be accurately identified and diagnosed between ages 2 and 3, Virginia children are often diagnosed well after age 3
 - 50% diagnosed after age 3, based on responses from caregivers of children under 8
 - 83% of special education students classified with an ASD after age 3, based on school records
- Many children with ASDs do not begin receiving services promptly

Delays in ASD Diagnoses and Services Appear To Result From Several Factors

- Parents waited 5 months to seek professional help after noticing warning signs, on average
- Physicians do not appear to screen as consistently as recommended by American Academy of Pediatrics
- Limited diagnostic capacity results in wait lists
- Services do not start until 1 year after consulting professional, on average
 - Professional guidance about next steps is limited

Options to Expedite ASD Diagnoses and Services

- Increase consistent and standardized ASD screening through training
- Expedite access to diagnosis by increasing capacity through regional offices
- Improve referral process by providing better information to physicians

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Intensive Early Intervention Services Can Generate Positive Outcomes and Cost Savings

- Easier to shape outcomes at young age
- Studies have demonstrated 90% of young children with ASDs improved due to intensive interventions
 - 50% reached normal or near-normal functioning
- States can achieve savings in education costs with early intensive treatment programs
 - Other states estimate \$187K to \$209K savings / child

Findings

- Virginia's primary early intervention programs lack recommended intensity and structure
 - Effective programs offer 20-25 hours of services, year-round, for 2 to 3 years starting at age 3
- Early intervention programs appear to have limited impact on functional improvements of children with ASDs

Part C Program Not Designed to Provide Intensive Services Yielding Positive Results

- Children with ASDs under 3 typically receive less than 3 hours of services/week from Part C providers
 - Program designed to coach parents to provide interventions, but some parents may lack skills and other abilities
- Caregivers report Part C services have marginal impact on outcomes
 - No meaningful improvements – 60%
 - No reduced need for special education services – 80%

Preschool Part B Programs Often Unable to Meet Needs of Students with ASDs

- Many lack recommended intensity and structure
 - 30% of preschools are part-time for students ages 2-5 with developmental disabilities
 - Child-to-staff ratios usually exceed recommended 1:1 or 2:1
- Preschools unable to provide services necessary to minimize need for special education later – 50%
 - Impact on functioning is often “poor” – 25-40% depending on functional area

Options to Improve Major Early Intervention Programs

- Increase intensity of services
 - Part C program: provide more hours of direct services
 - Part B program: lower child-to-staff ratios; increase access to full-day, year round preschools
- Train providers on ASD-specific interventions
- Enhance reliance on outcome measurements and data-driven service planning

Finding

- Waiting list for MR waiver hinders access to early intervention services for young Virginians
 - Average wait = 3 years
 - Usually still on waiting list past early intervention window
 - Only 11 children age 5 or younger enrolled in MR waiver in 2008

Options to Improve Access to Early Intervention Services Through Waivers

- Create ASD waiver
- Develop limited-time ASD waiver for young children
 - Focus on early intensive interventions

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Finding

- While Virginia schools report being able to provide an appropriate education, many cannot fully meet the multifaceted needs of students with ASDs
 - Ability to fully address core deficits is moderate or low – 40-50% depending on deficit
 - Unable to provide services that meaningfully improve functioning in settings outside of schools – 70%
 - Most students with ASDs require as much or more special education services over time

Inadequate Training Cited as Primary Barrier to Better Meeting Needs of Students With ASDs

- Existing technical assistance structure lacks hands-on, in-depth component
- ASD experts not consistently available to schools
- New teachers not commonly receiving ASD training in colleges and universities

Options to Improve Delivery of Services to School-Age Virginians With ASDs

- Provide greater guidance on research-based interventions
- Improve access to ASD experts at local and State levels
- Increase qualifications of new and existing teachers by requiring or encouraging ASD coursework

Finding

- Virginia students with ASDs may not receive sufficient preparation to achieve independence
 - Students with ASDs have less favorable employment outcomes than students with other disabilities
 - Schools cannot provide services to maximize future independence of all students with ASDs – 71%

Transition Planning and Services May Not Address Unique Needs of Students With ASDs

- Efforts to improve transition have not focused specifically on unique characteristics of ASDs
- Limited staff to implement plans and secure services is key barrier – 25%
- Insufficient training in life and vocational skills is key challenge – 44%
 - Attributed to insufficient resources and competing instructional priorities

Options to Improve Transition to Adulthood for School-Age Virginians With ASDs

- Develop transition guidelines
- Create transition specialist positions
- Expand vocational and life skills training

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Limited Supports Exist to Promote Independence Among Adults With ASDs

- Unlike for children, no entitlement programs exist for adults with ASDs
- Primary sources of services
 - Medicaid waivers for community-based services
 - Department of Rehabilitative Services (DRS) for employment supports

Finding

- Adults with ASDs do not appear to achieve favorable employment outcomes
 - Employment is realistic for 85% of Virginia adults with ASDs, yet only 1/3 are employed
 - Adults with ASDs are among least likely to be employed nationally (28% vs. 57% for other disabilities)

System Lacks Structure and Capacity to Provide Needed ASD-Specific Supports

- Vocational rehabilitation program not designed to build communication and social skills
- Capacity constraints limit availability of employment supports
 - Only most severely disabled individuals are eligible
 - No new cases accepted for several months in 2008-2009
- Funding for long-term supports has been decreasing

Options to Foster Independence Through Improved Employment Supports

- Provide social and communication skills training
- Reduce or eliminate waiting lists for DRS services
- Expand Long-Term Employment Support Services program
- Train DRS staff to work with clients with ASDs

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- Key Findings and Funding Options

Key Findings

- Despite existing programs, needs of some Virginians with ASDs are not met
 - Lack of coordination undermines efficiency and effectiveness of services
 - Many children appear to be diagnosed later than is possible
 - Early intervention programs do not provide intensity shown to maximize outcomes and reduce costs
 - Schools cannot consistently meet all the needs of students with ASDs or facilitate their independence
 - Limited supports exist for adults, and employment supports are hindered by capacity constraints

Key Findings

- Numerous options exist for Virginia to improve delivery of services to individuals with ASDs by
 - Enhancing efficiency through greater coordination and collaboration
 - Bolstering effectiveness of existing programs through application of best practices and outcome measures
 - Alleviating service gaps, especially in early intervention

Potential Funding Options

- Medicaid
- American Recovery and Reinvestment Act
- Health insurance coverage
- Local government funding
- Client fees
- Reinvested savings

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Copies of these slides and the complete report are available on our website.

