

Joint Legislative Audit and Review Commission



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

Commission Briefing

June 8, 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
 - Assess availability of ASD training for public safety personnel
 - Identify best practices and ways to improve delivery of services to Virginians with ASDs

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

Prior Related JLARC Report

- Evaluation of House Bill 83: Mandated Coverage of Autism Spectrum Disorders (September 2008)
 - Found that coverage appears needed and consistent with role of insurance
 - Recommended by Special Advisory Commission on Mandated Health Insurance Benefits
 - Not enacted by the 2009 Virginia General Assembly

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
- Few ASD Training Opportunities Available to Public Safety Personnel
- Conclusions and Funding Options

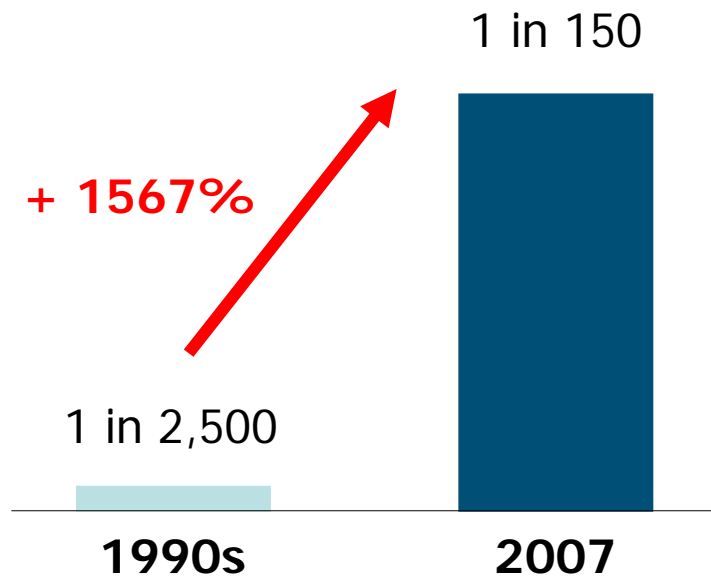
What Are Autism Spectrum Disorders (ASDs)?



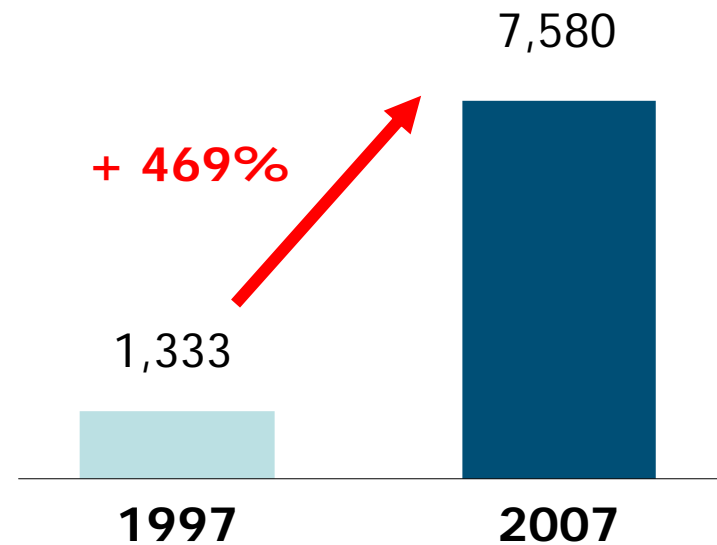
- Symptoms vary greatly between individuals, but usually appear by age 3 and affect
 - Social skills
 - Communication skills
 - Behavior

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
School Part B		Special education for students with disabilities, ages 2-21
Comprehensive Services	Comprehensive Services Act	Children with severe emotional or behavioral problems, 0-21
	DRS	Vocational Rehabilitation
Woodrow Wilson Rehab. Center		Vocational and life skills training, age 18+

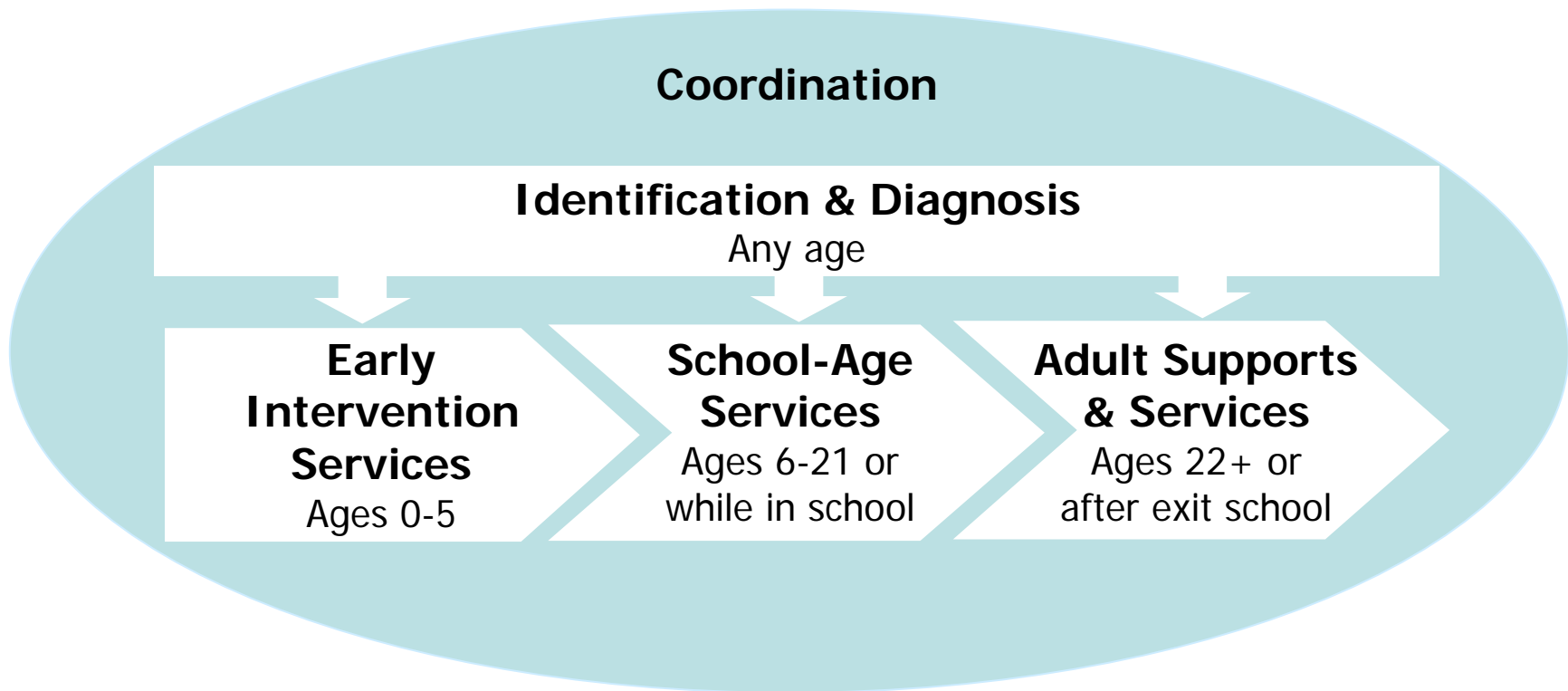


Clients and Expenditures of Primary Programs Serving Virginians With ASDs

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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Three-Pronged Coordination Facilitates System Efficiency and Effectiveness

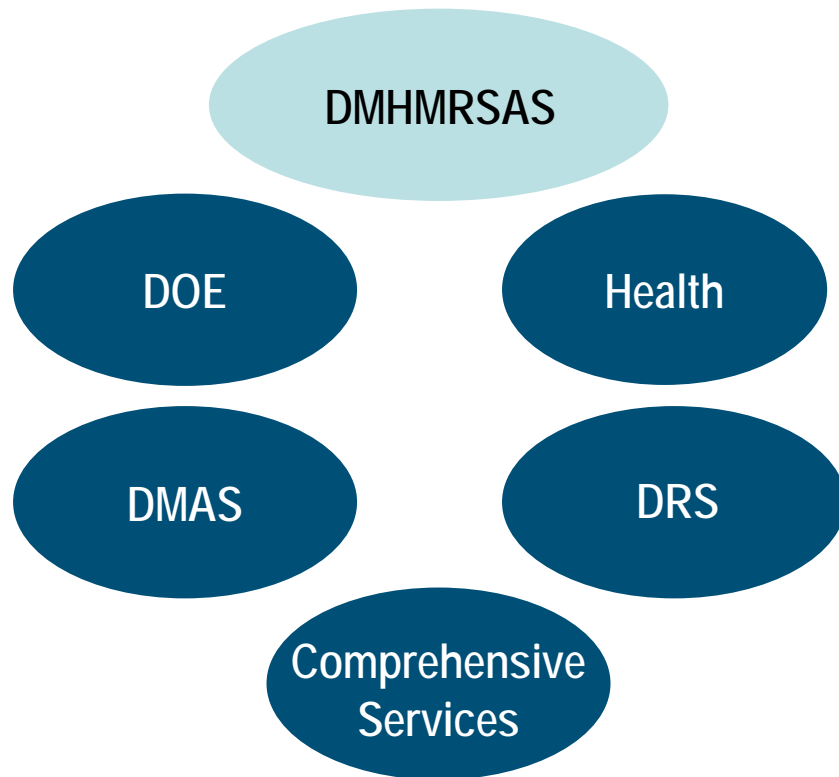
- State - efforts of multiple agencies coordinated by lead entity
- Community - information about available resources coordinated through centralized resource
- Individual - care coordinated across programs and providers

Finding

- Programs serving Virginians with ASDs tend to be inadequately coordinated at the State, community, and individual levels

No State Entity Has Coordinated Agencies and Programs for Virginians With ASDs to Date

**As Is
Prior to 7/09**

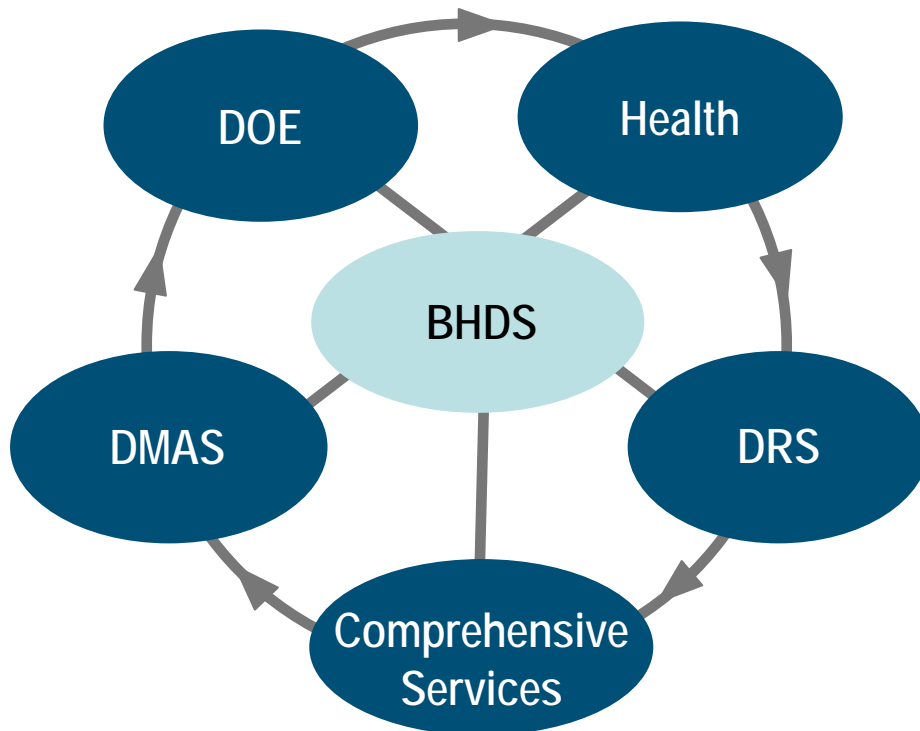


Challenges

- No State agenda or vision for system of care
- No mechanism to ensure efficiency
- No process to measure or foster program effectiveness

Behavioral Health and Developmental Services To Act as Lead Agency Beginning July 2009

Envisioned
After 7/09



Opportunities

- Determine role of State in supporting Virginians with ASDs
- Facilitate implementation of steps needed to achieve vision
- Create and enforce mechanism to foster efficiency and effectiveness
- Address service gaps

Virginia Has No Centralized and Comprehensive Source of Information About ASDs

- Most families report relying on other parents and Internet
- Lack of adequate information hinders families from
 - Understanding ASDs
 - Accessing available programs and supports
 - Using effective treatments and providers

Recommendation

- The report recommends that the Department of Behavioral Health and Developmental Services collaborate with relevant State agencies and stakeholder groups to design a centralized, comprehensive, and reliable source of information about ASDs, effective treatment approaches, and available programs and providers.

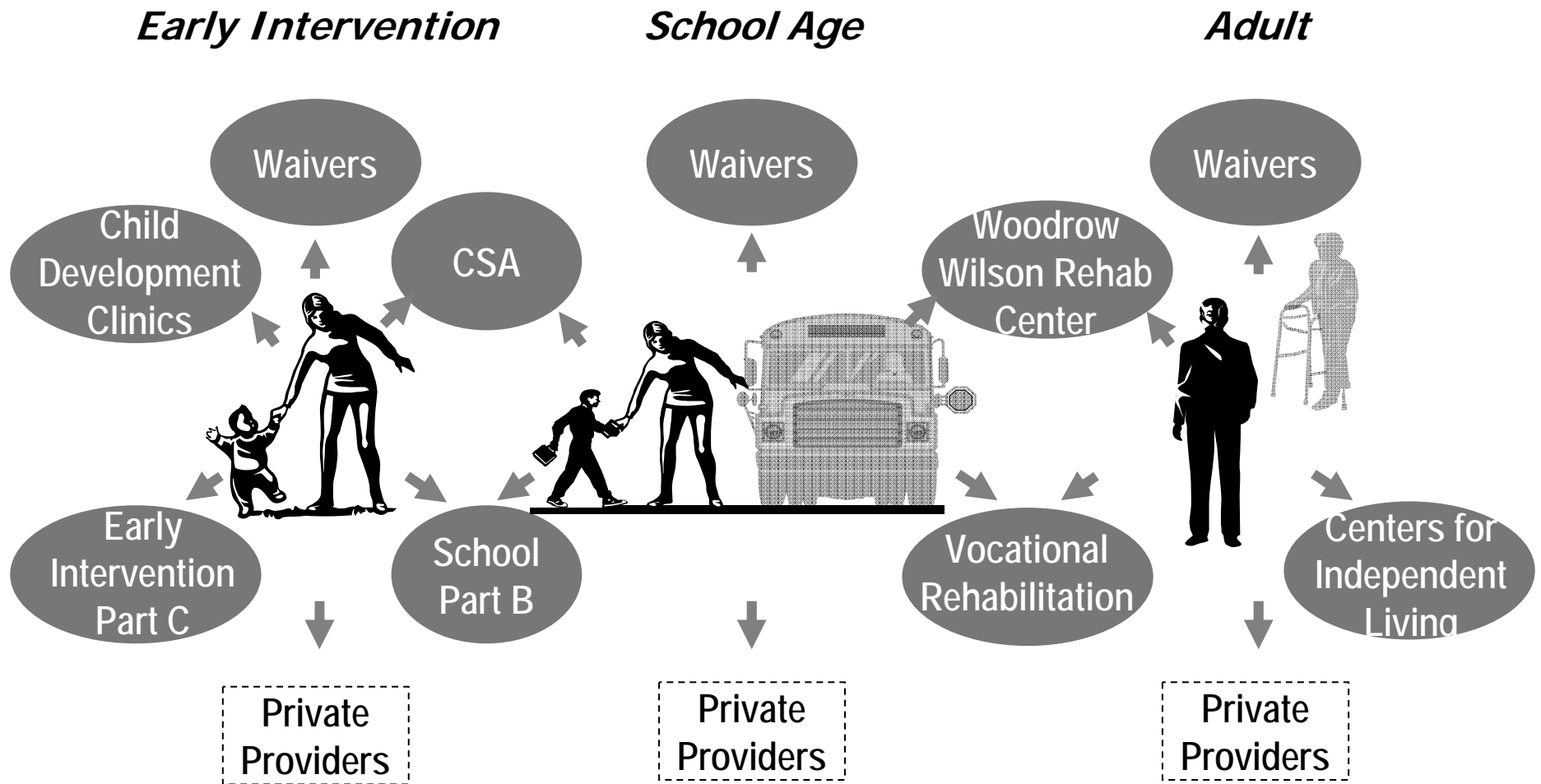
Finding

- Comprehensive case management services are not consistently available to coordinate the care of Virginians with ASDs

Most Programs Offer Case Management, But Not Consistently Comprehensive or Available

- Scope may not include providers outside of program
- Available only to Virginians eligible for programs
 - Excludes many adults
- Several transitions between life stages

Virginians With ASDs and Caregivers Often Act As Care Coordinators



















Gaps in Professional Case Management May Lead to Adverse Outcomes

- Care coordination efforts may be ineffective when individuals with ASDs and caregivers lack training, ability, or time
- Employment is negatively affected for most caregivers - 80%

Options to Improve Individual Care Coordination

- Train caregivers on effective case management practices
- Expand role of existing case managers to engage all providers
- Create regional case management for all Virginians with ASDs







Options Assessment Contained at End of Report Chapters 4-8

Major Goal	Resources Needed	Extent to Which Addressed Major C	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

★ ★ ★
Substantially
Greatly

 < 6 Months
  6-18 Months
   > 18 Months

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Earlier Identification of ASDs Could Accelerate Services for Young Children

- ASDs can generally be accurately identified and diagnosed between ages 2 and 3
- American Academy of Pediatrics (AAP) recommends
 - Parents seek professional help immediately after observing warning signs of ASDs
 - Physicians conduct standardized ASD screening when concerns are raised, and at 18 and 24 months
 - Parents and physicians initiate services quickly, without waiting for formal diagnosis

Finding

- Virginia children are often diagnosed with an ASD well after age 3

Multiple Data Sources Point to Diagnoses Often Occurring After Age 3 in Virginia

- Half of children diagnosed by age 3, based on responses from caregivers of children under 8
- 17% of special education students ultimately identified with an ASD are classified with an ASD by age 3, based on school records

Delays in ASD Diagnoses 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 AAP
 - Told 1/3 of parents to “wait and see” rather than perform a screening
 - Standardized tools not used in most cases
- Limited diagnostic capacity results in wait lists
 - 20% waited more than 6 months

Finding

- Many children with ASDs do not begin receiving services promptly

Limited Professional Guidance May Hinder Prompt Access to Services

- Services do not start until 1 year after professional consulted, on average
- Professional guidance about next steps is limited
 - No useful information from diagnosing physician – 90%
 - No general information at all – 40%

Options to Facilitate Earlier Identification and Diagnosis of ASDs

- 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

Effective Early Intervention Programs for Children With ASDs Share Common Elements

Key Component	Description
Early start	< age 3
Intensity	> 20-25 hours/week, all year, for 2-3 years
Structured environment	Predictable and low child-to-staff ratios
Specialized ASD curriculum	Designed to address core deficits of ASDs
Systematic instruction	Logically planned, consistently implemented, and adjusted based on data measuring child progress
Family involvement	Structured to involve families in planning and implementing interventions
Individualized services	Based on child's abilities and needs

Findings

- Virginia's primary early intervention programs
 - Lack several key effective components
 - Appear to have limited impact on functional improvements of young children with ASDs

Part C Program Not Designed to Provide Intensive Services

- Children with ASDs under 3 typically receive 3 or fewer 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
 - Vast majority of parents find intensity of services inadequate – 90%

Caregivers Report Part C Services Have Marginal Impact on Outcomes

- No meaningful improvements – 60%
- No reduced need for special education services – 80%
- Impact on functioning is often “poor” – 30-50% depending on functional area

Preschool Part B Programs Often 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
 - Only 4% with ASDs received 1:1 instruction
 - 40% of preschools cite high staffing ratios as a challenge

Many Preschools Report Struggling to Fully Meet Needs of Students With ASDs

- 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 lists and lack of knowledge may prevent young children with ASDs from accessing existing Medicaid-funded services

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

ASD Interventions Available Through Medicaid Waivers and EPSDT May Be Underutilized

- Enrolled children may not fully utilize intensive early intervention services
 - Few requests for ABA-based services through EPSDT*
- Only 70 young children with ASDs enrolled in EDCD** waiver
 - Only waiver with no waiting list
 - Provides access to intensive early intervention services through EPSDT

* Early periodic screening, diagnosis, and treatment

** Elderly or disabled with consumer direction



Recommendation

- The report recommends that the Department of Medical Assistance Services
 - Develop and implement a plan for educating Virginians with ASDs and their families, case managers, and relevant providers about the availability of Medicaid-funded services, particularly EDCD waiver and EPSDT services, and
 - Report on its proposed approach to the Joint Commission on Health Care by November 2009

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Federal Law Entitles Children With ASDs to Special Education Services and Supports

- Federal Individuals with Disabilities Education Act (IDEA) requires public schools to
 - Offer services and supports that meet individual needs
 - Provide a “free and appropriate public education”
 - Prepare students for “further education, employment, and independent living”

Individual Needs of Students With ASDs Vary And Are Multifaceted

- ASDs affect functioning in 5 areas
 - Behavior, communication, social skills, cognitive, and sensory development
- Functional impairments occur in all settings
 - Home, school, community

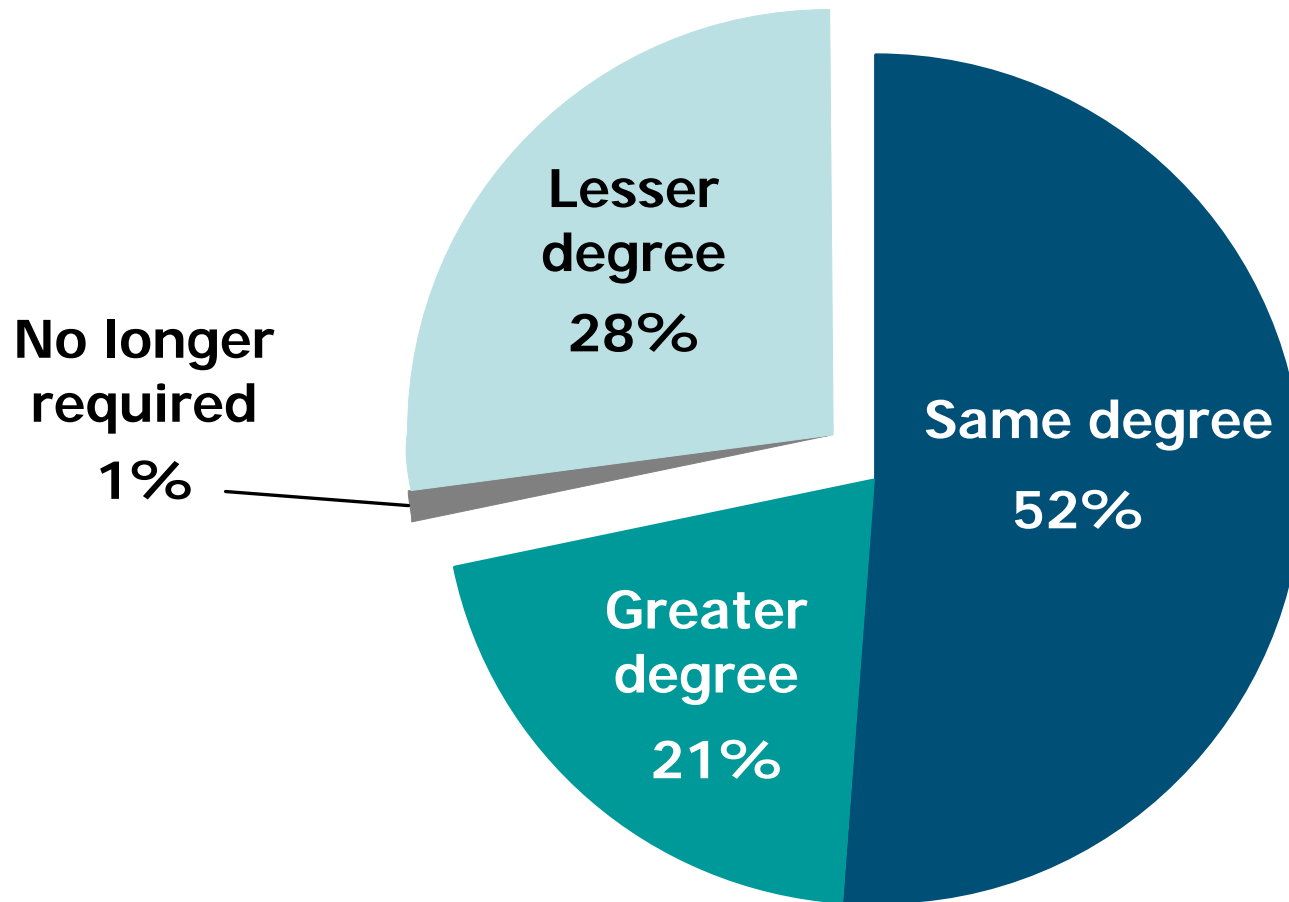
Finding

- While Virginia schools report being able to provide an appropriate education, many cannot fully meet the multifaceted needs of students with ASDs

Many Virginia Schools Struggle to Fully Address 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*

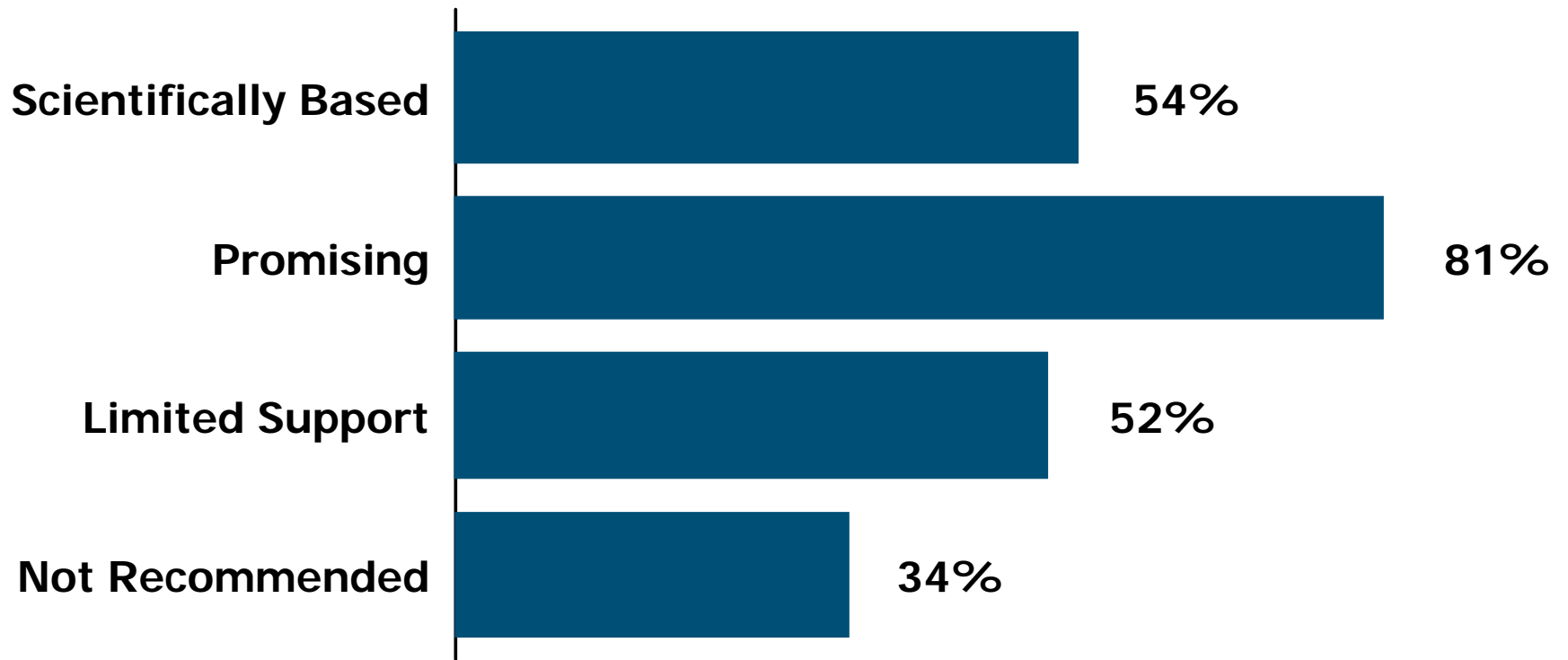


* Compared to when began receiving special education services

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

- Schools consistently report that
 - General education teachers lack basic knowledge about ASDs and behavior management
 - Special education teachers lack in-depth knowledge to identify and apply effective strategies

Nearly Half of Responding Schools Report Not Using Scientifically Based Interventions



Professional Development Opportunities Do Not Adequately Build Necessary Competencies

- Limited ASD training agenda set at local or State levels
- 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

- Identify and prioritize training needs
- Increase qualifications of new and existing teachers by requiring or encouraging ASD coursework
- Improve access to ASD experts at local and State levels

Finding

- Virginia students with ASDs may not receive sufficient preparation to achieve independence

Many Schools Cannot Provide Services Needed For Independence Among Students With ASDs

- 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%
- Children do not receive sufficient vocational or job skills training in school – 43%

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

- Medicaid waivers do not guarantee access to needed supports
- Case management services not widely available to facilitate access to existing community supports

Medicaid Waivers Cannot Provide Needed Supports to All Adults With ASDs

- Enrollment is capped for most waivers
- Only most severely disabled meet functional eligibility
- Provider shortages exist in some areas of Virginia
- DD waiver does not cover congregate care

Limited Case Management Services Available to Coordinate Access to Existing Programs

- Case management services exist only for adults enrolled in waivers or DRS programs
- Adults with ASDs may not learn about available public and community resources

Options to Improve Provision of Information and Case Management for Adults With ASDs

- Focus Olmstead Implementation Team on the development of services for adults with ASDs
- Provide case management for adults with ASDs
- Develop pilot program for comprehensive adult services

Long-Term Employment Supports Key to Independence Among Adults With ASDs

- Impaired communication and social skills often undermine ability to obtain and retain a job
 - Core deficits of ASDs
- Employment can be facilitated through on-site supports that are long term and address core deficits
- DRS is Virginia's primary source of employment supports for individuals with ASDs

Finding

- Employment programs not structured to provide supports needed by many Virginia adults with ASDs

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
 - 2/3 rely on at least one public benefit program
- 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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- **Public Safety Personnel May Need Training to Serve Individuals With ASDs, but Few Opportunities Exist**
- Conclusions and Funding Options

Individuals With ASDs Likely to Encounter Public Safety Personnel

- 7 times more likely to encounter law enforcement
 - More likely to be victimized
 - Unusual behaviors interpreted as suspicious
- Encounters can be challenging due to unexpected behaviors and characteristics
 - No obvious sign of disability
- Potential exists for encounters to result in serious injury or even death, but occurrence is rare

Finding

- ASD awareness training is not consistently available to Virginia public safety personnel

ASD Training Opportunities Limited for Virginia Public Safety Personnel

- Fewer than ½ of Virginia's criminal justice academies provide ASD awareness during basic training
- ASD training sessions offered on an ad-hoc basis for EMS and fire personnel
- No systematic ASD training available to judicial personnel

Options to Enhance Public Safety Personnel's Awareness of ASDs

- Range from a carry-card to in-depth training
- From law enforcement to all public safety personnel
- Facilitate access to mandate

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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

Recommendation

- The report recommends that the departments of Medical Assistance Services, Education, Rehabilitative Services, and Criminal Justice Services assess the options contained in this report and present recommendations to the Department of Behavioral Health and Developmental Services by March 31, 2010.

Recommendation

- The report recommends that the Department of Behavioral Health and Developmental Services
 - Develop a detailed, collaborative action plan specifying how it will address the issues contained in this report and build a system of care for Virginians with ASDs, and
 - Present its plan to the Joint Commission on Health Care, and the House Appropriations and Senate Finance committees by November 30, 2010.

Potential Funding Options

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

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and on the table by the door.

