Fairfax County, Virginia

System of Care
Developmental Disabilities Committee
Report and Recommendations

June 2010

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Membership

Ronald Alf, Long-Term Care Coordinating Council and Parent Advocate
Janet Bessmer, Ph.D., Fairfax County, Comprehensive Services Act
Jim Gaynor, President & CEO, Grafton Inc.
Kelly Greenwood, Parent Advocate
Shelia Peters-Lee, MS, Assistant Director – Support Coordination, Fairfax-Falls Church Community Services Board ~ Intellectual Disability Services
Johnny Powell, Northern Virginia Training Center
Susie Quinn, Phillips Programs, Family Worker and Intake Coordinator, Trainer
Abdul Rahim, George Mason University Student Intern
Patricia J. Rohrer, Long-Term Care Program Development, Long-Term Care Council Facilitator, Fairfax County
Cherie Takemoto, Executive Director, Parent Educational Advocacy Training Center (PEATC),
Cheryl Wietz, LCSW, Executive Director, Improving Outcomes, LLC
Maggie Wilkinson, MS, Program Manager for Special Foster Care, Therapeutic Respite Care, and Adoption Programs, Northern Virginia Family Service

Project Management and Facilitation:
Elisa Lueck, Department of Systems Management for Human Services
Marie Custode, Department of Systems Management for Human Services

Contributors:
Thank you to the following individuals who offered additional information about services, supports, needs and barriers in our system in order to better serve youth with developmental disabilities and their families:

Susan Sigler, Infant and Toddler Connection, Fairfax-Falls Church CSB
Kiran Shahani, LICSW, FCPS Social Work
Heidi Scharlat, LCSW, FCPS Social Work, Kilmer Center
Elizabeth Matthews-Jolley, FCPS Social Work
Howard Johnson, Ed.D., Multi-agency Services, FCPS

Background of the System of Care (SOC) Reform Initiative

In November 2008, a System of Care initiative was undertaken by Fairfax County child-serving agencies and the public schools in partnership with the provider community and families to address the growth in expenditures for services and supports to at-risk youth and their families served through the Comprehensive Services Act for At-Risk Youth (CSA). CSA was established by the Virginia General Assembly in 1992 to offer coordinated services and programs to children at risk of, or experiencing, emotional or behavioral problems. This funding stream is one component of several supports available to serve youth and families, and is generally concentrated in service delivery to the highest need youth in communities. Services are offered to children and families in the jurisdictions served by Fairfax County government and schools. In addition to county residents and those residing in towns within the boundaries of Fairfax County, residents of the cities of Fairfax and Falls Church are provided services under contract with the county.

The initiative was guided by the community System of Care Reform group, comprised of public agencies/departments charged with meeting the needs of at-risk youth and families. Staff from Fairfax County Public Schools, members of the private provider community representing the continuum of care for youth and families, family representatives and county departments were convened to plan for new strategies.

The following goals and guiding principles were adopted by the group in December 2008:

Goals of the System of Care Reform Initiative

- Reduce the number of Fairfax-Falls Church children in long-term residential and group home placements by 33% between January 1, 2009 and January 1, 2010 by creating sustainable community-based services and individualized services planning (Defined as: point in time count of youth in residential and group home placements).
- Limit lengths of stay in residential/group home placements to an average of 6-9 months or less for children with serious emotional disturbances
- Limit FY 2009 and FY 2010 expenditures to FY 2008 actual expenditures by:
  - Maximizing use Medicaid, Title IV-E and other revenue sources to offset county costs for residential and community services; and
  - Implementing approved cost containment measures to reduce use of residential placements

System Change Goals

- Develop a seamless, improved and cost-effective system of care service approach for all youth by creating and implementing new community based resources in Fairfax-Falls Church and immediate region

- Create a comprehensive system of care for children with developmental or intellectual disabilities, including pervasive developmental disorders such as autism, supported by alternative revenue sources including Medicaid and third party funding

Measuring System Change

- Serve 90% or more of children in CSA in the community annually (defined as no placements in out-of county congregate care).

- Reduce the total county-funded residential treatment bed days through focus on the appropriate development and use of in- community treatment and services and improvement of treatment and transition options when residential placements are used.

To accomplish the system change goals, consistent with stated guiding principles, the following design and implementation committees were created:

SOC Sponsor Group – to oversee public agency participation and project management

Services Committee – to create methods and recommendations for:
- *Screening, Assessment and Evaluation*
- *Care Coordination/Case Management*
- *Home and Community-Based Services*

Developmental Disabilities Committee – to create a comprehensive system of care for children with developmental or intellectual disabilities including pervasive developmental disorders such as autism, supported by alternative revenue sources including Medicaid and third party funding

Family and Youth Advocacy/Engagement Committee – to design and implement a formal system of engagement of families and youth in system of care efforts in order to promote family and youth involvement at all levels in the planning and delivery of SOC services

Financing and Administrative Implementation Committee – to develop an inter-agency strategy for maximizing use of County dollars to leverage Medicaid, Title IV-E, CSA, other state and federal funding and private resources to maintain and enhance the community-based system of care.

This report incorporates work from the members of the Developmental Disabilities Committee, to respond to the deliverables and tasks assigned to the Committee.

Developmental Disabilities Committee: Purpose and Work Plan

Members of the committee were charged with creating a comprehensive system of care for children with developmental or intellectual disabilities including pervasive developmental disorders such as autism, supported by alternative revenue sources including Medicaid and third party funding

The following Work Plan was adopted to guide the work of the Developmental Disabilities Committee:

- Solicit feedback on the Services Committee Report as related to serving youth with developmental disabilities in the following areas:
    - Screening Tool and Criteria for individuals at risk of residential placement - Review screening tool and criteria and validate for developmental disabilities population. Determine what modifications, if any, are necessary.
    - Assessment Process - Review ICC assessment process and validate for developmental disabilities population.
    - Implementation Framework - Review ICC Implementation Framework (pages 18-25 in the Services Committee report) and validate for developmental disabilities population
- Services and Supports - Define community services and supports that would be needed to successfully transition members of developmental disabilities population from residential back into the community
- System Barriers - Review system barriers and validate for developmental disabilities population. Are there others specific to this population that currently exist and prevent successful treatment of developmental disabilities population in our community?
- Family Outreach and Education - Define strategies that can be used to educate families about funding streams to support children with developmental disabilities.
- Evidence-Based Practices - Explore and report on evidence-based practices that exist for the developmental disabilities population in terms of treatment options and transitioning from youth to adult services.

Overview of Developmental Disabilities

Person-Centered Model of Care

The Developmental Disabilities committee supports the adoption of a system-wide person-centered approach to service delivery for individuals with developmental disabilities. The person-centered approach is a set of principles and philosophies, consistent with Systems of Care, but more readily recognized within the field of developmental disabilities. This approach emphasizes recovery-oriented care that requires services be maximally responsive to each individual's unique needs, values, and preferences. The model supports youth and families taking greater control over their treatment and life decisions and is consistent with system of care principles, such as valuing enhanced collaboration with consumer advocacy and advisory groups, increased recognition of, and funding for, peer-run services, and the promotion of tools which promote consumer self-determination. Finally, the model provides culturally responsive care, in that it goes beyond an appreciation of culture and ethnicity as group phenomenon to appreciate the specific influence each may have on the individual's unique sense of identity, values, needs, and preferences[1]. The committee's goal for our service delivery system is to increase functional autonomy of families through staff training and equipping professionals and families with tools and resources that increase independence of families.

Definition of developmental disabilities

Developmental disabilities are severe, life-long disabilities attributable to mental and/or physical impairments which manifest themselves before the age of 22 years and are likely to continue indefinitely. They result in substantial limitations in three or more of the following areas:

- self-care
- comprehension and language
- skills (receptive and expressive language)
- learning
- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency
- ability to function independently without coordinated services (continuous need for individually planned and coordinated services).

Persons with developmental disabilities use individually planned and coordinated services and supports of their choosing (e.g., housing, employment, education, civil and human rights protection, health care) to live in and to participate in activities in the community.[2]

For the purposes of this report, the term "Developmental Disabilities" will be used broadly to describe a range of disorders to include Autism Spectrum Disorders (ASD), Intellectual Disability formerly referred to as Mental Retardation, Pervasive Developmental Disorder, and youth with physical and other neuro-developmental disorders such as Asperger's syndrome, Rett syndrome and Childhood Disintegrative Disorder.

[1] Connecticut Implementation of Person-Centered Care http://www.ct.gov/dmhas/LIB/dmhas/Recovery/personcentered.pdf

[2] US Dept of Health and Human Services, Administration for Children and Families, http://www.acf.hhs.gov/opa/fact_sheets/add_factsheet.html

Physical Health issues
Individuals with developmental disabilities are more likely to experience physical health issues such as seizure disorders, obesity, poor dental health. Some of these physical health issues may be inherent in the condition such as heart problems in Down Syndrome or a result of difficulty accessing health care. Communication problems may also contribute so that the individual is not able to fully participate in their health care planning with the physician.

Mental Health issues/ Dual Diagnosis
Mental health issues, and psychiatric illnesses, are more likely to occur in people with developmental disabilities than in the general population. A number of factors are attributed to the high incidence rate of dual diagnoses:

- the high likelihood of encountering traumatic events throughout their lifetime (such as abandonment by loved ones, abuse, bullying and harassment)
- the social restrictions placed upon people with developmental disabilities (such as lack of education, poverty, limited employment opportunities, limited opportunities for fulfilling relationships, boredom)
- biological factors (such as brain injury, epilepsy, illicit and prescribed drug and alcohol misuse)
- developmental factors (such as lack of understanding of social norms and appropriate behavior, inability of those around to allow/ understand expressions of grief and other human emotions)
- External monitoring factor: all people with developmental disabilities that are in a Federal or State funded residence require the residence to have some form of behavioral monitoring for each person with developmental disability at the residence. With this information psychological diagnosis are more easily given than with the general population that has less consistent monitoring.

Abuse Vulnerability
Abuse is a significant issue for people with developmental disabilities, and as a group they are regarded as vulnerable people in most jurisdictions. Common types of abuse include:

- Physical abuse (withholding food, hitting, punching, pushing, etc.)
- Neglect (withholding help when required, e.g., assistance with personal hygiene)
- Sexual abuse
- Psychological or emotional abuse (verbal abuse, shaming and belittling)
- Constraint and restrictive practices (turning off an electric wheelchair so a person cannot move)
- Financial abuse (charging unnecessary fees, holding onto pensions, wages, etc.)
- Legal or civil abuse (restricted access to services)
- Systemic abuse (denied access to an appropriate service due to perceived support needs)
- Passive neglect (a caregiver's failure to provide adequate food, shelter)

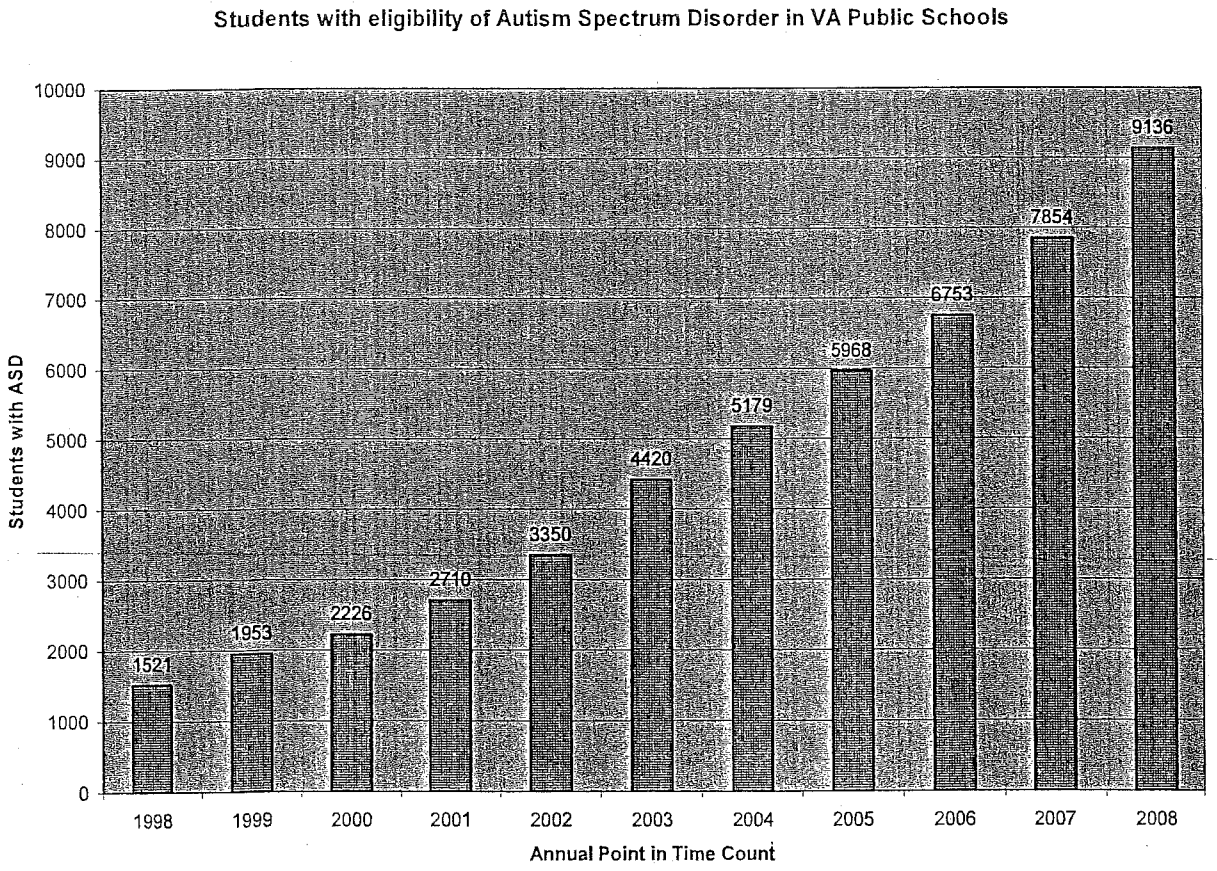
A number of factors contribute to the higher incidence of abuse among individuals with disabilities to include communication difficulties, less understanding of social norms and appropriate behavior and difficulties with self-advocacy.

Prevalence of Developmental Disabilities

Autism

According to data released by the U.S. Centers for Disease Control and Prevention (CDC) in 2007, about 1 in 150 8-year-old children in multiple areas of the United States had Autism Spectrum Disorder (ASD). ASDs occur in all racial, ethnic, and socioeconomic groups, but are four times more likely to occur in boys than girls.[3] More recent CDC estimates have indicated that the prevalence is as high as 1 in 110 children or 1% of the U.S. population[4]. Over the last decade, diagnoses of Autism have grown 173% while the population has only grown 13% and other non-autism-related disabilities have grown 16%.

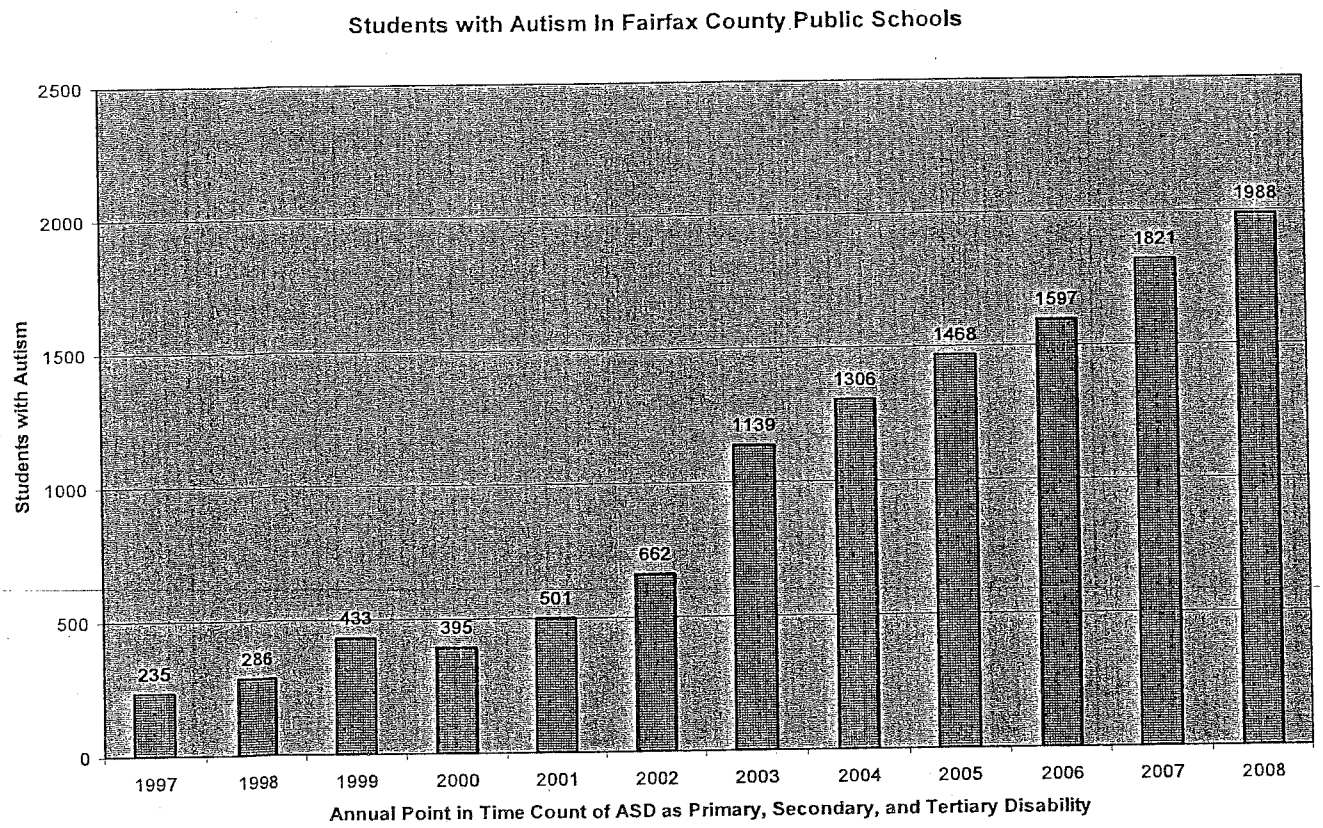
In Virginia, these national data trends regarding Autism Spectrum Disorder are reflected in state-wide data reported by each school jurisdiction to the Virginia Department of Education (VDOE). Local school jurisdictions provide the VDOE with "Child Count" data, a point in time count conducted annually on December 1. The most current Child Count from December, 2008 of the special education eligibility for enrolled students ages 0 – 22 provide a picture of the increasing incidence within Virginia's public schools as shown in the table below[5].



[3] http://www.cdc.gov/media/subtopic/fact-sheets/Autism-Fact-Sheet.pdf
[4] www.autismva.org/statistics.php
[5] http://www.autismva.org/statistics.php

Within the Fairfax County Public Schools (FCPS), students receiving special education services will make up 14.0% of the total FCPS membership in FY 2010 or 24,274 students out of the total projected enrollment of 173,573 students[6]. Students who are eligible for Level 1 special education services (i.e., less than 50% of the instructional day) comprise 5.8% of the FY 2010 total, and 8.2 % of the students receive Level 2 special education services (i.e., greater than 50% of the instructional day).

Mirroring the state trend, the number of students eligible for special education services under the disability category of Autism has been increasing in our locality as well. As shown in the following table, the most current published "Child Count" data reported by FCPS indicates that 1,988 youth have Autism as their primary, secondary or tertiary category for special education eligibility as of December 1, 2008.[7]



[6] www.fcps.edu/about/stats.htm
[7] http://www.autismva.org/statistics.php

Developmental Disabilities

The data related to Autism only conveys a part of the information about numbers of youth in our community with developmental disabilities. Youth who might not have the educational label of Autism, but who fall under the broader criteria for developmental disabilities, may be eligible for special education services in the categories of Intellectual Disability/ Mental Retardation, Severe Disability, Multiple Disability, and sometimes Emotional Disability for students who fall on the less impaired range of the autism spectrum (e.g., Asperger's syndrome)[8]. When these other eligibility categories including physical disabilities are included, the number of children and youth in Fairfax with developmental disabilities is greater than the ASD data suggests. The table on the following page from the FCPS FY2011 Proposed Budget provides additional current information about the number of youth receiving special education services in FY 2009 and FY 2010 across eligibility categories.

Although the data provided by the school system currently yields the best estimate of the incidence of developmental disabilities in our community's youth, there remain challenges associated with using the special education eligibility and labeling process to obtain a real count of youth representing this population. The eligibility category is determined by the IEP team with parental input. It differs from a diagnosis which is provided by a mental health professional using objective clinical criteria. Even when objective clinical criteria are used, there may also be variation in the diagnostic categorization from one clinician to another. These figures then represent the best estimate based on available data.

[8] http://www.doe.virginia.gov/special_ed/disabilities/

Special Education Services

	FY 2009 Actual	FY 2010 Actual	FY 2011 Proposed	Change FY 2010-FY 2011 Amount	Change FY 2010-FY 2011 Percent
Category A Services					
Level 1 [1]					
Emotionally Disabled	1,123	1,015	986	(29)	-2.9%
Learning Disabled	5,530	5,546	5,258	(288)	-5.2%
Level 2 [2]					
Emotionally Disabled	1,088	1,052	1,098	46	4.4%
Learning Disabled	7,569	7,597	7,883	286	3.8%
Subtotal Category A Services	**15,310**	**15,210**	**15,225**	**15**	**0.1%**
Category B Services					
Level 1 [1]					
Autism	398	428	440	12	2.8%
Davis and Pulley Center Services	3	2	6	4	200.0%
Intellectually Disabled [3]	0	39	0	(39)	-100.0%
Mild Retardation	76	53	84	31	58.5%
Moderate Retardation/Severely Disabled	26	32	28	(4)	-12.5%
Physically Disabled	47	55	50	(5)	-9.1%
Noncategorical	240	256	268	12	4.7%
Level 2 [2]					
Autism	1,167	1,272	1,379	107	8.4%
Davis and Pulley Center Services	265	239	255	16	6.7%
Intellectually Disabled [3]	0	204	0	(204)	-100.0%
Mild Retardation	544	389	556	167	42.9%
Moderate Retardation/Severely Disabled	414	349	388	39	11.2%
Physically Disabled	156	146	154	8	5.5%
Noncategorical	792	816	867	51	6.3%
Subtotal Category B Services	**4,128**	**4,280**	**4,475**	**195**	**4.6%**
Other Services					
Level 1 [1]					
Preschool Resource	827	889	826	(63)	-7.1%
Deaf/Hard-of-Hearing	320	313	325	12	3.8%
Vision-Impaired	281	296	284	(12)	-4.1%
Speech and Language Impaired	10,352	10,178	10,329	151	1.5%
Level 2 [2]					
Preschool	942	894	983	89	10.0%
Preschool Autism	166	178	191	13	7.3%
Deaf/Hard-of-Hearing	132	122	123	1	0.8%
Vision-Impaired	9	10	10	0	0.0%
Subtotal Other Services	**13,029**	**12,880**	**13,071**	**191**	**1.5%**
Related Services					
Adaptive Physical Education	1,290	1,337	1,337	0	0.0%
Audiology Services	331	320	363	43	13.4%
Career and Transition Services	2,990	3,047	3,018	(29)	-1.0%
Instructional Technology Services	3,556	3,382	3,528	146	4.3%
Therapy Services	3,046	2,961	3,048	87	2.9%
Subtotal Related Services	**11,213**	**11,047**	**11,294**	**247**	**2.2%**
Total Services	**43,680**	**43,417**	**43,065**	**648**	**1.5%**
Unduplicated Special Education Membership					
Students Enrolled in FCPS	23,518	23,717	24,078	361	1.5%
Contract Services Students	302	289	272	(17)	-5.9%
Private School Students	174	143	128	(15)	-10.5%
Other	23	24	24	0	0.0%
Unduplicated Membership Count [4]	**24,017**	**24,173**	**24,502**	**329**	**1.4%**

[1] Level 1 services are those which are provided for less than 50 percent of the instructional day.

[2] Level 2 services are those which are provided for 50 percent or more of the instructional day.

[3] Intellectually disabled (ID) service was added in FY 2010 and replaces mild retardation, moderate retardation, and severely disabled services. The existing services will be phased out as services on student's IEP's are updated to the new ID service.

[4] Total number of students receiving one or more special education services for whom FCPS is responsible.

Service Costs and Funding for Developmental Disabilities

Currently, the Autism Society estimates that the lifetime cost of caring for a child with autism ranges from $3.5 million to $5 million, and that the United States is facing almost $90 billion annually in costs for autism (this figure includes research, insurance costs and non-covered expenses, Medicaid waivers for autism, educational spending, housing, transportation, employment, in addition to related therapeutic services and caregiver costs).[9] In a survey conducted by JLARC staff, caregivers of individuals with ASDs reported spending an average of $12,000 per year on ASD-related services using their own resources such as savings, second mortgages on their homes and retirement funds.[10]

Funding sources for youth with developmental disabilities include private insurance, Medicaid programs (e.g., Waiver programs and Early Periodic Screening, Diagnosis, and Treatment – EPSDT), the public schools, and in Virginia, the Comprehensive Services Act pooled funding. While there is no single data source to obtain the costs for serving youth with developmental disabilities, it is clear that these costs are significant and increasing as the numbers of youth requiring public agency services are increasing.

Medicaid Waivers

There are three primary Medicaid waiver programs for youth with developmental disabilities. These programs are summarized in Appendix B. Youth may apply through the Department of Family Services for the Elderly or Disabled with Consumer Direction (EDCD) waiver for in-home assistance. Families may apply online with the Department of Medical Assistance (DMAS) for the DD waiver. Youth with intellectual disabilities may apply to the Community Services Board for the ID waiver. In Fairfax County as of May, 2010, there are 89 individuals under the age of 22 receiving the ID Waiver and 46 of them are under the age of 18.

Comprehensive Services Act Pooled Funding

According to analyses conducted by the Office for Comprehensive Services and the Virginia Department of Education in 2008, the fastest growing population in special education, and in private day school placements, is the students with autism. The number of students with autism as a primary disability in 2007 increased 91% from 2003. In addition, the number of students with autism placed through CSA into private day schools in 2007 (n = 243) almost tripled since 2003 (n= 83) across Virginia. Despite a 2.5% decrease in the overall special education population in Virginia over the past five years, there has been an increase of 13% in the number of CSA funded special education private day placements in that time period. State and local net expenditures for CSA Pool funded special education private day placements increased from $37,834,777 in FY03 to $60,961,422 in FY07, representing a 61% increase in total net expenditures. The unit cost for CSA special education private day school placements increased 42% from 2003 to 2007 ($19,234 in 2003 compared to $27,398 in 2007)[11].

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[9] http://www.healthnews.com/family-health/child-health/prevalence-autism-estimated-more-than-1-all-children-3744.html Prevalence of Autism Estimated at More Than 1% of All Children, Madeline Ellis, , 6 October 2009

[10] Assessment of Services for Virginians with Autism Spectrum Disorders, Report of JLARC, June 8, 2009. www. *jlarc.state.va.us/meetings/June09/**Autism**.pdf*

[11] Schools and CSA Executive Summary Special Education Placements. State Executive Council (SEC) Comprehensive Services Act For At Risk Youth And Families, Minutes, September 26, 2008.

In the Fairfax-Falls Church CSA program, similar utilization trends have been noted regarding increasing numbers of youth with developmental disabilities specifically those students with autism being served in Private Day programs. As shown in the table below, the number of youth enrolled in Private Day programs that specialize in serving youth with developmental disabilities has increased while enrollment in more traditional Private Day programs has declined slightly.

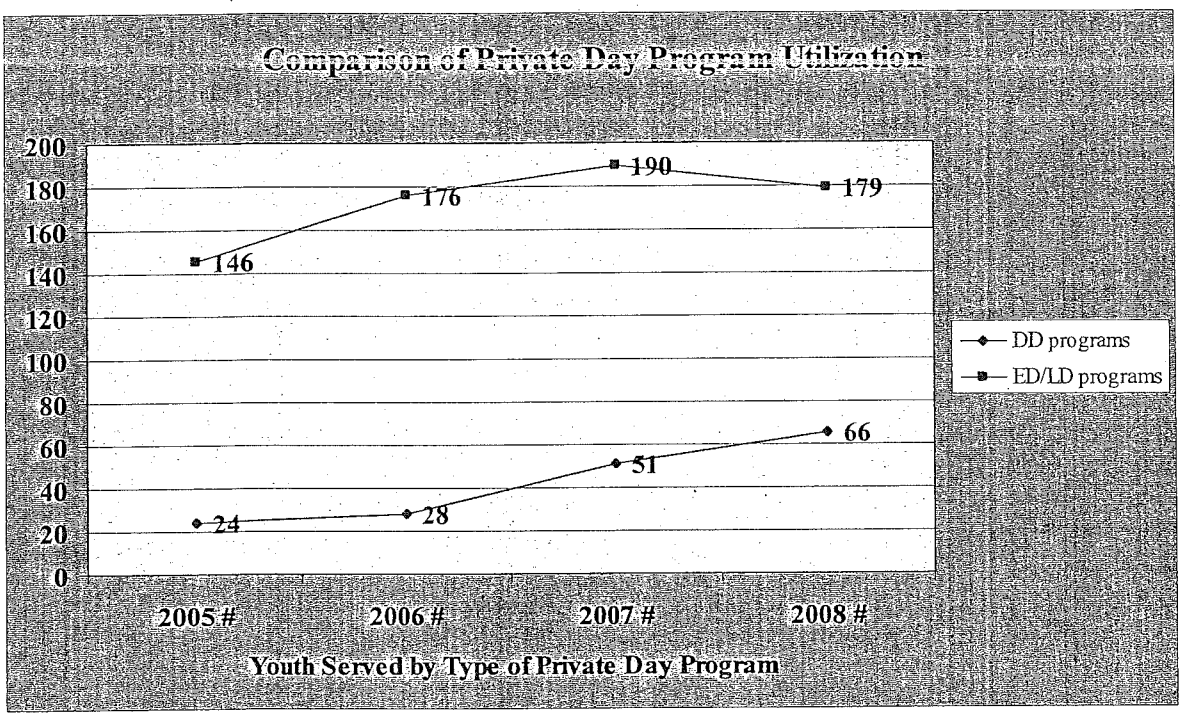
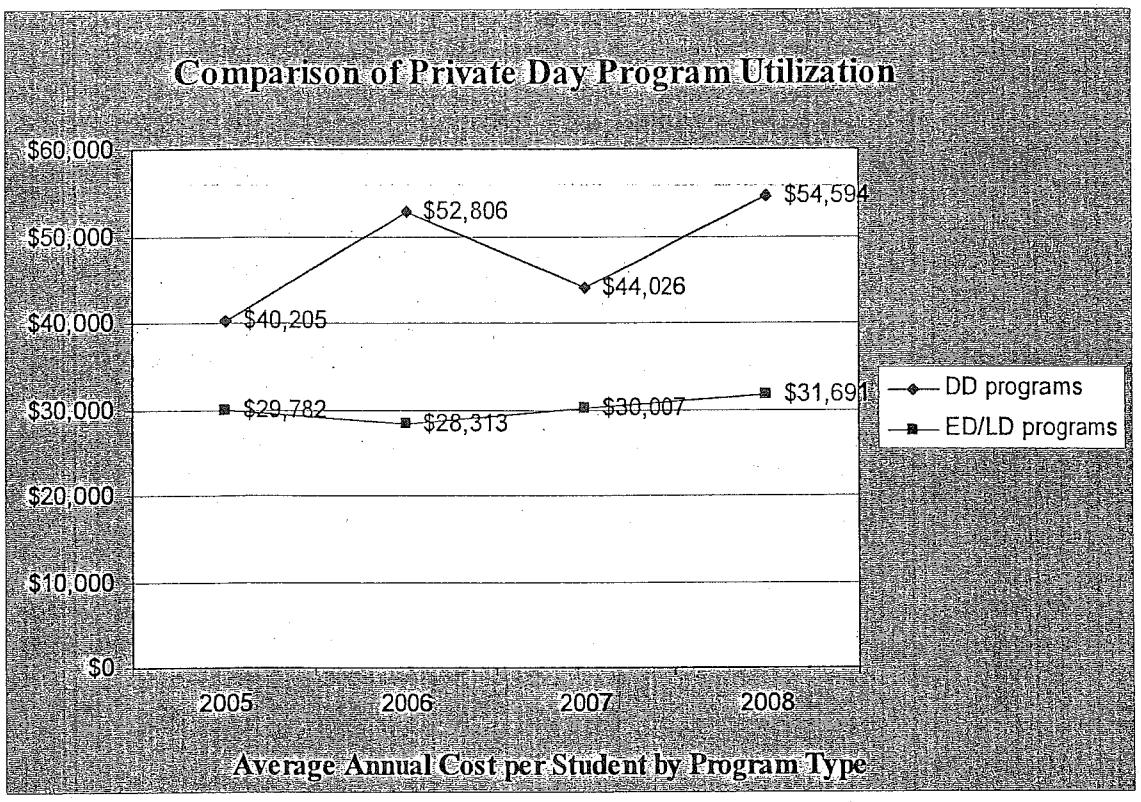
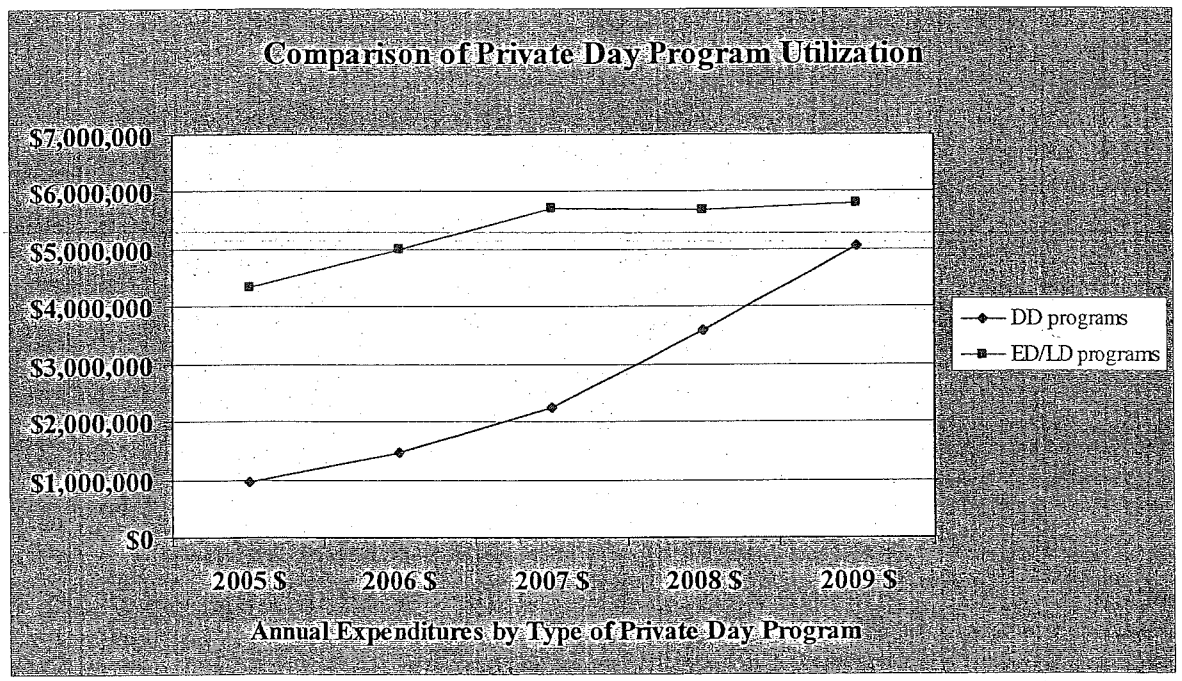


Figure 1: Types of Private Day Programs – Private Day programs were divided into two types based on the primary disability of youth enrolled from Fairfax-Falls Church. DD programs were defined as containing > 50% youth with special education eligibility of MR/ID, AUT, SD, and MD.

While the overall number of youth served in Private Day programs is relatively stable, the percentage increase in youth with developmental disabilities has a significant fiscal impact. The average annual cost per student for those enrolled in more traditional "ED/LD" Private Day programs has shown modest increases across fiscal years ranging from $29,782 in FY 2005 to 31,691 in FY 2008. In contrast, the average annual cost per student for private day programs specializing in serving youth with developmental disabilities rose from $40,205 to $54,594 since FY 2005. See the table below for the average annual costs per student comparing different program types.



The staff to student ratios and additional staff training and qualifications combined with other intensive behavioral supports likely contributes to the DD population being more expensive to serve.



With the average annual cost for DD Private Day programs being nearly double per student than for more traditional ED/LD programs, the overall annual expenditures for DD program is quickly approaching the total amount for traditional Private Day programming. In FY 2009, the expenditures for both DD programs and traditional ED/LD programs were over $5 million each for a combined expenditure on Private Day services of $10,968,866. Our CSA program has seen our overall expenditures for Private Day programs rise from $7,539,739 in FY 2006, to $8,772,438 in FY 2007, and to $10,049,605 in FY 2008. These cost increases are likely due in part to the changing nature of who is served in Private Day and which programs are being utilized.

In addition to describing factors related to fiscal increases seen in recent years, the data regarding Private Day utilization is also important to understand how many youth may be at risk of a more restrictive educational placement. Residential IEPs are one of the means for youth to be placed in out-of-home settings. Youth with developmental disabilities may also be placed in congregate care settings using other mandated and non-mandated CSA pooled funding.

Review of Current CSA Residential Placements for Youth with Developmental Disabilities

When the DD committee first began meeting in 2009, there were 32 youth placed by the various child-serving agencies into a residential level of care. In the latest point in time count, the total youth with developmental disabilities placed with CSA funding is 34. The following tables provide information about these youth based on a point in time count from April 1, 2010.

Placements by Mandate Type	
Foster Care	16
Schools - IEP	17
Foster Care Prevention	1
Non-mandated	0
Total	**34**

Average length of stay - # Days	
Children with developmental disabilities	912 days
Children with emotional and behavioral problems	281 days

These tables show that youth with developmental disabilities are often placed in residential either as part of their individualized education program or as their foster care placement. The data regarding length of stay clearly demonstrates a significant difference in how long youth with developmental disabilities remain in residential programs compared to youth with primarily emotional and behavioral disorders.

Youth who are placed in Virginia facilities have the benefit of being closer to their families and home community. The selection of an in-state facility also has an additional benefit to our system. In-state facilities are more likely to be Medicaid-enrolled which offers a cost-sharing between federal, state and local governments for the cost of services. Placements out of state are generally funded solely by the CSA program at the match rate for IEP residential placements of 46% and for other placements such as for youth in foster care of 58% of the total cost.

Placement Location – Virginia vs. Out of State	
In state residential or group home facilities	23
Out of state residential facilities	11
Total	**34**

Some placements in out of state programs are selected due to the nature of a youth's specific developmental disability or the severity of the disability, and for IEP placements, parents have been granted additional legal authority in the selection of the program compared to previous years.

When youth can be served in a Virginia facility, the opportunities for Medicaid reimbursement offer significant local savings. The VDOE has provided policy clarification that IEP services are eligible for Medicaid-reimbursement and that parents may voluntarily participate in submitting the Medicaid application with the assistance of school and local government staff. Some families have found that the application for Medicaid offers them additional financial support for their child with medication and services that are not covered under the primary health care policies and are non-educational. Youth who are eligible for disability under the federal Supplemental Security Income (SSI) program are also eligible for Medicaid enrollment.

Of the 34 youth placed in residential facilities for DD, 19 were placed at Grafton School in FY09 and 26 were being served in FY10. Grafton School has been successful in applying for and receiving reimbursement from the EPSDT program for residential services. 21 of these youth were able to access EPSDT funding for services during FY 2009 and 2010. The EPSDT program does not require a local match, unlike the Medicaid psychiatric residential program for youth with primarily mental health disorders. The costs for the residential services would otherwise be covered using CSA pooled funds.

Summary of EPSDT Reimbursement

EPSDT Reimbursable	FY 2009 (Feb – June)	FY 2010 (Jul – Oct)	FY 2010 (additional projected)
Grafton School (n= 21)	$1,667,339.08	$801,995.48	$772,661.50

Data provided by Grafton based on actual Medicaid payments as of October, 2009.

Current Public Agency Continuum of Care in Fairfax-Falls Church

Infant and Toddler Connection of Fairfax-Falls Church

To fulfill the federal mandate of IDEA, part C, the Infant and Toddler Connection of Fairfax-Falls Church provides evaluations and early intervention services to eligible infants and toddlers who have at least a 25% developmental delay in one or more area and who are less than three years old. Early Intervention supports and services focus on increasing the child's participation in family and community activities. Services and supports focus on helping parents and other caregivers know how to find ways to help the child learn during everyday activities, such as play.

These supports and services are available for all eligible children and their families regardless of the family's ability to pay. Families do share a cost of the services, but service coordination is offered free of charge. The child and family are typically seen one to two times per week, typically in their home. Services are federally mandated to occur in the natural environment and not center-based. Family support groups are offered in central locations so that families may meet other caregivers and develop social supports. For more information about this program, see www.infantva.org.

Fairfax County Public Schools

- Early Identification and Educational Services- transition from Infant and Toddler to Preschool by age 2, IDEA, part B
  - Assessment & Diagnostic program/ Child Find
  - Preschool Autism Class (PAC), Noncategorical

- Instructional Support, K – 12
  - Enhanced Autism Services and Applied Behavioral Analysis (ABA)
  - Special Education in neighborhood schools (e.g., Union Mill)
  - Inclusive School resource support
  - Kilmer, Key, Pulley, Davis

- Transition to Post-school
  - Transition linkages from high school to adult services

Fairfax-Falls Church Community Services Board, Intellectual Disability Services

- Care Coordination,
- ID Waiver program
- Residential, Day supports

- Governance and Oversight
  - Fairfax Long Term Care Coordinating Council
  - Board of Supervisors, Human Services committee
  - Disability Board

- Non-profit organizations serving Fairfax-Falls Church community
  - ARC – Nancy Mercer
  - PEATC – Cherie Takemoto

Deliverable A: Screening Tool and Criteria for youth at-risk of Residential and/or Group Home Care placement - Review and Comment

The Developmental Disabilities Committee reviewed the following Services Committee recommendation as presented in its November 2009 report:

Screening process for youth at risk of residential or group home care:
It is not required that children at risk for residential/group home placement be screened for ICC. It is, however, a legal requirement that prior to placing a child outside Fairfax County or the cities of Fairfax and Falls Church FAPT must explore all appropriate community services for the child and document that no appropriate placement is available in the locality. ICC using a wraparound approach is a best practice in coordinating community services for youth at-risk of residential placement.

The screening process is completed by a public agency staff person otherwise eligible to refer and manage CSA cases. To meet screening criteria for ICC at least one of the significant incidents listed in section 1 below must have occurred within the past 60 days, **and** the youth must have serious behavioral/emotional needs and/or risk behaviors, as identified in section 2.

1. **Significant incidents**

- Relief of custody petition/ request
- Second Juvenile Detention Center (JDC) or Less Secure placement
- Psychiatric hospitalization
- Leland placement
- Entry into foster care or notice to Department of Family Services (DFS) thereof
- Threatened foster home disruption
- Recommended for homebound instructional services due to severe, disabling anxiety or depression
- Consideration of more restrictive setting for special education student who is not adjusting to current setting
- Ten days of suspension within a school
- Ten unexcused absences within a school year
- Recommendation for expulsion
- Sexually aggressive/reactive behavior
- Pattern of running away accompanied by risk behaviors; most recent incident of runaway within 60 days
- Behavior requiring 911 involvement

The Developmental Disabilities Committee recommends that ***threatened disruption to living situation*** be added to the list of qualifying significant incidents. Parents/caregivers with special needs children have long-term parenting challenges and may seek an out of home placement as a source of relief from the on-going demands of parenting. It would be important to identify families who need additional support prior to them asking for relief of custody or a long-term out-of-home placement.

2. Child Behavioral/Emotional Needs and Risk Behaviors Screening

The Developmental Disabilities Committee reviewed the following Services Committee recommendation as presented in its November 2009 report:

Two CANS dimensions – Child Behavioral/Emotional Needs and Risk Behaviors - will be used to screen youth for ICC. Case managers will rate youth on these two dimensions to determine if the youth might benefit from and qualify for ICC. Youth who meet the screening criteria can be referred to CSA UR staff.

CANS screening criteria:

- A "3" on any Risk Behavior OR
- A total of 6 or greater when all 2's and 3's are added for Behavioral/ Emotional Needs and Risk Behaviors

CHILD BEHAVIORAL/ EMOTIONAL NEEDS				
0 = No evidence of problems 1 = History, Watch/Prevent 2 = Causing problems consistent with diagnosable disorder		3 = Causing severe, dangerous problems		
	0	1	2	3
Psychosis				
Impulse / Hyper				
Depression				
Anxiety				
Oppositional				
Conduct				
Adjustment to Trauma				
Anger Control				
Substance Use				
Eating Disturbance				

CHILD RISK BEHAVIORS				
0 = No evidence of problems 1= History, Watch/Prevent		2 = Recent, Act 3 = Acute, Act Immediately		
	0	1	2	3
Suicide Risk				
Self-Mutilation				
Other Self-Harm				
Danger to Others				
Sexual Aggression				
Runaway				
Delinquent Behavior				
Fire setting				
Social Behavior				

Sexual Reactive Behavior				
Bullying				

The Developmental Disabilities Committee recommends the addition of a subset of items from the ***Life Domain functioning dimension*** from the CANS for youth with developmental disabilities:

LIFE DOMAIN FUNCTIONING				
0 = No evidence of problems 1= History, Mild		2 = Moderate 3 = Severe		
	0	1	2	3
Living Situation				
Sleep				
Social Functioning				
Communication				
Medical				
Daily Functioning				

In addition, the Developmental Disabilities committee recommends that the CANS screening criteria proposed in the Services committee report of November 2009 be revised, as follows:

CANS screening criteria:

- A "3" on any Risk Behavior OR
- A total of 6 or greater when all 2's and 3's are added for Behavioral/ Emotional Needs and Risk Behaviors

OR

If DD/Autism/ID exists, then

- **A total of 3 or more "3's" on Life Domain OR**
- **A total of 9 or greater when all 2's and 3's are added across all 3 domains (Behavioral/Emotional Needs, Risk Behaviors, and Life Domain functioning)**

Deliverable B: ICC Assessment Process - Review and Comment

The Committee agreed that this section appeared very comprehensive and did not have specific recommendations, other than those recommended for the ICC Screening Tool outlined in Deliverable A.

Deliverable C: ICC Implementation Framework – Review and Comment

The Developmental Disabilities Committee reviewed the Services Committee Proposed ICC Implementation Framework, as presented in its November 2009 report. As a result of this review, the Developmental Disabilities Committee recommends the following:

- In addition to staff and service providers, family members should also be trained on ICC and should have access to training in multiple languages.
- ICC should allow for different modes of client/family participation (e.g., telephone conferencing)
- "Developmental needs" should be added to the list of required knowledge and expertise for the Intensive Care Coordinator (i.e., knowledge of the behavioral/emotional/ ***developmental*** needs and risk behaviors that place children at risk of residential placement and the services and treatments that may be effective in addressing them).
- The following language should be added to the Intensive Care Coordinator responsibilities: The ICC process includes identification and connection with FCPS personnel that can serve as point of contact for the individual with developmental disabilities and their caregivers to assist with transitioning back into school system so that a continuum of care may seamlessly occur. Similarly, it is important that the ICC identify a school contact for ongoing support as the child transitions out of ICC.

Deliverable D: Services and Supports: A Gaps and Needs Analysis

The Developmental Disabilities Committee was tasked with defining community services and supports that would be needed to successfully transition members of the developmental disabilities population from residential back into the community. The Committee recommends the following additions, **noted in bold and underline**, to the nine service gap needs as identified by the Services Committee in its November 2009 report:

1. Increase Case Management Capacity

- Intensive Care Coordination is appropriate for any youth at risk of residential treatment placement
- Appropriate, high quality case management is needed for youth who don't qualify for intensive care coordination through the assessment process
- "Hot Potato" cases – those that are between system eligibility requirements or cases that are multi-agency/system in nature - require additional trained, available case management services
- **For youth with DD, families need access to on-going case management services.**
- **Particular need for agency DD/ID case managers specific to younger children**

2. *Increase number of child and adolescent psychiatrists*

- Additional Medicaid providers are needed
- Providers who serve special populations - examples include services to those with developmental disabilities, experiencing trauma, and child with co-occurring mental health and substance abuse issues
- **Availability of medical and psychiatric care could be major factors in stabilizing behaviors allowing a youth to transition from residential back to the community**
- **Consider increasing capacity for these services by contracting with developmental pediatricians and child neurologists. Consider other specialty care groups, particularly those that accept Medicaid.**

3. *Supervised activities and customized programming for special populations* of at-risk youth*

- After-school, holidays, summer recreation **(particularly month of August)**, socialization, and normalized developmental experiences
- Supervised vocational training and experiences, job coaches**
- **Strong network of jobs that utilize the strengths of the DD population as they transition into adulthood**

** Consistent with recommendations, 2/24/2005 final report of Northern Virginia Regional Workgroup on Gaps and Barriers in Services for Sexually Abusive Youth*
***Consistent with recommendations, 10/12/2007 presentation to CPMT, Ensuring Effective Transitions for Youth*

4. Transportation

- Access to community services and supports is critical to the success of community-based care plans
- **For the DD population, there is a critical need for transportation aides to accompany youth with behavioral challenges or medically fragile conditions, particularly youth with a history of exiting moving vehicles.**
- **There is a need for additional outreach and training for the community on transportation, including information about utilizing paratransit programs such as Metro Access and taxi services provided by Medicaid.**

5. Support to Families to Meet Basic Needs

- Basic goods and supports (e.g., registration fees, sports equipment, camps, utility payment, transportation, food, clothing, copayments for meds, incentives for meeting goals, etc.) funded through:
  - *Coordinated charitable giving*
  - *flexible public funds*
- **For youth with DD, there is a need for on-going assistance for goods not adequately covered by Medicaid or other payers such as supplemental nutrition like Ensure, adult diapers, home repairs from damage caused by youth**

6. In-community crisis supports, including:

• Mobile crisis response for youth • **Crisis stabilization** • Crisis out-of-home, community settings/Crisis residential settings (for young children) • Intensive outpatient services	• Intensive home-based intervention • Day treatment • Partial hospitalization program • Acute psychiatric hospitalization

The DD Committee consistently noted in its discussions that there is a particular lack of supports for children with DD/ID/Autism that accompanies a mental health crisis. The current array of crisis services is not designed for youth with DD nor are these programs able to admit youth with dual diagnosis. Caregivers have noted a particular gap regarding the need for acute psychiatric hospitalization for DD youth having a mental health-related crisis.

7. *Respite for caregivers*

- In-home and out of home
- Planned and crisis
- Daily, hourly, overnight
- Capacity for special populations, such as:
  - **DD youth who elope, who use communication devices, with atypical behavior management needs, and/or aggressive behavior**
  - **Young adults aged 19-21 years old – CSA-funded respite services provided by agencies/facilities licensed for youth < 18 years old; facilities used for respite provided by the ID waiver have not been CSA vendors**

For youth under the age of 18, more licensed, affordable, geographically dispersed respite options, including residential facilities, are needed. There are limited resources available for families for this much-needed service.

8. *In-community home settings for the following special populations:*

- Adolescents with chronic emotional/behavioral problems who have gained maximum benefit from treatment but continue to require ongoing structure and supports
- Adolescent sex offenders*
- Adolescents with chronic/severe substance abuse and co-occurring mental health needs (trauma, conduct disorder)
- Adolescent mothers with chronic emotional/ behavioral problems (with custody of their infants/ toddlers) who require ongoing structure and supports
- Youth transitioning into adult services** (e.g., apartment program)
- **Adolescents with DD/Autism/brain injury who have gained maximum benefit from treatment but continue to require ongoing structure and supports**

** Consistent with recommendations, 2/24/2005 final report of Northern Virginia Regional Workgroup on Gaps and Barriers in Services for Sexually Abusive Youth*
***Consistent with recommendations, 10/12/2007 presentation to CPMT, Ensuring Effective Transitions for Youth*

9. *Linguistic and cultural competence*

- Expertise exists in the community that is not accessed
- Ongoing commitment needed for continued improvement of competencies throughout the system
- **Need for providers with expertise in DD/ID/Autism who also have ability to communicate in other languages**
- **Increase access to translators/interpreters for DD population and their caregivers**

10. Implement Family Navigator program

- **The Family Navigator program would assist families:**
  - **traverse complex systems, especially in situations in which the child has concurrent developmental and mental health needs;**
  - **troubleshoot when it is not clear who has lead responsibility**
  - **connect with the agency responsible for long-term case management; (for families who need services, but who do not have an entry agency for service linkage);**
  - **find relevant information, referral and linkage to appropriate services through one-to-one support and advocacy;**
  - **complete forms, applications, and appeals for services and benefits, including SSI, SSDI, Medicaid, waivers, Department of Rehabilitation Services, Exceptional Family Member Services;**
  - **negotiate the special education process, including attending eligibility or IEP meetings;**
  - **support at meetings related to the child; and**
  - **prepare for transition to post-secondary and adult services, programs and benefits.**

The DD Committee recommends developing a Family Navigator program to assist families through outreach and linkage with existing resources. In other jurisdictions' systems of care, Family Navigators are typically parents or primary caregivers who have cared for a child or youth with special needs and who are trained to help other families obtain the appropriate services and supports for their child and family. Similar to the parent liaison role in the school system, Family Navigators can connect with other parents and caregivers and offer families an easily approachable contact person who knows the "system" but is not seen as a part of county government.

Family Navigators would also work in partnership with local agencies and participate on planning and advisory boards to provide a family perspective on policies and programs for children with special needs, and work with families with children who don't have ID (autism or physical disability) or who are not currently on a waiver program or county service system. This program

could assist our system in meeting critical case management gaps in the current service system by supplementing the work of county case management staff.

The Family Navigators are not case managers and are typically connected to a community-based agency for training and oversight. The community-based agency housing this program would need to demonstrate knowledge and expertise in special education, the Fairfax service systems, waiver programs, insurance appeals processes, and military programs and services for exceptional family members.

In addition to meeting a need for outreach and linkage with families in the current system of care for children with developmental disabilities, there is an anticipated savings associated with this initiative including prevention of residential placements for youth and adults; lessened staff time spent walking families through processes and in meetings held with multiple agency representatives to sort out available services and funding; and increased utilization of benefits and services that will decrease county spending on services that might otherwise be provided through funds such as Medicaid, special education, TANF, private insurance, and military services. This increased utilization will also result in more effective family and child services that can be used to stabilize crises and maintain the child in the community.

It is estimated that at least three (3) Family Navigators would be necessary to begin a pilot program. It is recommended that a cost/benefit study be conducted by Fairfax County to further justify the costs and benefits of this program.

11. Transition into Adulthood

- **Need for sustained, coordinated initiative between families, the schools, and state and local agencies to address the lifelong needs of individuals with developmental disabilities within our community**

While the work of the committee focused on services for youth, people with developmental disabilities have lifelong needs. Schools and youth agencies provide mandated services until a person reaches 18-22 years of age, depending on the program. During adulthood, the whole service system changes from mandated to discretionary services, with the most funding and services reserved for adults who meet specific eligibility criteria. However, there remain children, youth and adults with significant disabilities and care needs who remain under the care of their family or community networks, without county services. Many adults with developmental disabilities who live successfully in their communities or at home, have had families who have prepared for their long-term needs and planned for benefits, services, employment and community living during their childhood and adolescent years. Fairfax County needs to provide services and supports that consider the lifespan needs of people with disabilities, promoting maximum independence and reducing the need for county-funded care.

Areas for action include:

- Collaboration with schools and community groups to make parents aware of issues related to transition, including the cessation of mandated services for adults with developmental disabilities and information on services and supports available to help children achieve maximum independence in adulthood

- Access to benefits planning for SSI or SSDI, including work incentives and economic self-sufficiency programs; information about adult eligibility for Medicaid or Medicare, waiver applications that can provide funding for services, CSB ID/MH services, and Department of Rehabilitative Services programs

- Increased availability of social/leisure programs for youth/adults without ID (such as individuals with autism or physical disabilities) who are not eligible for waiver services; these programs should include social and life skill building activities to promote an independent lifestyle in the community

- Expanded cooperative agreements among agencies related to preparing for transition services, particularly for youth/adults with autism, concurrent mental health and/or substance abuse issues, physical disabilities, and others ineligible for ID services in adulthood

- Early permanency planning in the community, including increased number of in-home adult care programs, for young adults with developmental disabilities in foster care and FCPS contract./multi-agency services

- Increased therapeutic residential options for youth (including foster homes, resource parents, adult foster homes) with providers who are trained in non-aversive behavioral techniques, and can care for young adults and adults with complex care needs

- Increased options for housing and community-based living supports (e.g. home attendants, supervised apartment living, co-housing options with personal care support)

- Individualized, long-term behavioral support services in combination with traditional vocational rehabilitation programming to maintain continuous successful employment

The Developmental Disabilities Committee recognizes the work of organizations and current county initiatives underway to address the needs of youth transitioning to adulthood. The Fairfax Long-Term Care Coordinating Council, for example, has identified unmet needs of young adults with autism. The LTCCC has formed partnerships with county agencies, non-profit organizations, the business community, and faith-based organizations and has leveraged available resources to pilot a program which will provide behavioral supports in vocational and leisure environments to young adults with autism. The committee recommends that these existing initiatives are supported and linked with the System of Care efforts directed at the youth with developmental disabilities.

Deliverable E: Systems Barriers

The Developmental Disabilities Committee identified systems barriers in its discussions regarding service provision. Many of the barriers can be addressed by adopting the recommendations contained in the Service and Supports section of the report. Additional recommendations are offered to address systems barriers where needed.

Conceptualization

a. "Person Centered" approach to services is not fully endorsed across agencies, professional, and services
b. Perceptions about people with disabilities limit/bias broad exploration of client needs for services and interventions

Service Coordination and Integration

Participants noted a lack of integration and coordination between the various public agencies and programs who offer services to youth with developmental disabilities in our community. While the programs themselves offer high quality services and the staff are knowledgeable about resources, from a family perspective or from the perspective of someone attempting to access services, the lack of a unified entry point and lack of integration of services creates a system barrier. There is no overarching local entity responsible for oversight and coordination of services for children, youth and adults with developmental disabilities.

a. Agencies and providers with the most contact with the ID/DD population have different ways to conceptualize the needs of ID/DD children and youth. These agencies often lack the broader overview of needs these populations experience. For example, schools address behavioral problems as they impact access to education but may not refer for mental health/behavioral health services.
b. Services are organized in categories (MH, SA, SPED) which address sets of conditions. There are times when the identified condition of the child or youth is not the presenting problem but the initial assessment is focused on the category. Ex., a child with moderate ID is traumatized by abuse by an outsider. A call to MH reveals the child has ID and the family is sent to another service for children with ID.
c. Children with ID may not access those specialized services until 18 and so are not served by an agency with the expertise in issues related to ID – especially case management.
d. Lack of communication between agencies, or at least direct service staff, leaves the workforce unaware of the range of service available to DD/ID service needs at public and private agencies.

Service delivery

a. Focus tends to be on level of care/placement type vs intervention type. As we move towards a system that is more informed about evidence-informed intervention, service plans can become more sophisticated around matching the intervention to the strengths, needs and preferences of the youth and family.
b. Services are implemented that are not effective and/or poor fits for the ID/DD populations. Service delivery will need to shift towards a more outcome-oriented process.
c. Lack a focus on outcomes, resulting in drift or possibly deterioration of the client's overall function

d. Lack of evidence-based levels of care criteria (appropriate level of care) that meet needs of child in appropriate amounts at appropriate time
e. Providers lacking awareness of and training in the strengths and needs of ID/DD populations may implement interventions that worsen a problem or simply be ineffective
f. Too few after school programs for students with ID/DD
g. An over-focus on interventions focusing on the individual leaves families on the sideline thus not developing the family's capacity to care for its members with ID/DD

Funding

a. Tends to be more utilized for emergency and crisis intervention than developmental, preventive, or maintaining interventions.
b. Youth "fail up" into more intensive services if funding not available for early intervention/ prevention and when criteria not clear for levels of care.
c. Medicaid reimbursement rates in the waiver programs are low. Providers have difficulty hiring and retaining well-qualified staff to provide waiver services. Families complain of poor quality care and sometime prefer not to utilize waiver services even when they are eligible for them.

Workforce

a. Job descriptions may make the priority of case management a lower priority than the delivery of a more clinical service. Thus, time constraints lead to less time and focus on the case management function. Families may not receive referrals to additional services until a crisis is underway.
b. Professional attitudes toward the ID/DD populations may influence consideration of effective interventions
c. Professional training and the interests of professionals seeking training may not include training that informs about the strengths and needs of the ID/DD population
d. Professionals with limited experience with ID/DD populations may not have the skills and knowledge necessary for assessment and effective intervention

Deliverable F: Family Outreach and Education

The Committee identified a system barrier that it is difficult for families to learn of resources given the state and Fairfax County's large, somewhat non-integrated system of service delivery. As noted in the 2009 report on Autism Spectrum Disorders drafted by the Joint Legislative Audit and Review Commission (JLARC) to the Governor and General Assembly, "...no coordinated source of information comprehensively addresses all key concerns of individuals with ASDs and their caregivers[12]." Therefore, the Committee recommends a local public information campaign, an electronic source of information on the System of Care on county website, and/or implementation of the Family Navigator concept, to be provided by a family organization.

Access to services and supports may be improved by changing the requirements for the Child-Specific Team (CST) process. Currently, a public agency case manager must sponsor the CST and facilitate the meeting. The committee recommends that families be able to request a CST directly to learn more about existing public agency services and resources. Access to CSA-funded services would still require an agency case manager; however, there are a significant number of CSTs that provide sufficient information and linkage to families that a referral to the FAPT is not deemed necessary.

The Committee also discussed the stigma associated with DD. The Committee recommends additional training and outreach to the community, so that individuals become less hesitant to adopt a community model of care, where, for instance, their child is placed in the same class as a child with behavioral issues.

The Committee also discussed how many parents are either afraid of the system, or have "given up", based in large part on their frustration with the system and the child. The Committee believes that the key to closing this gap in understanding is outreach and education to both family members of those with developmental disabilities, as well as the community at large.

In summary, the committee recommends the following:

- A public information campaign to assist parents/caregivers in locating resources
- The development of an electronic source of information such as the Senior Navigator but designed for children and families with developmental disabilities
- Implementation of the Family Navigator program, which may be contracted to a private, non-profit community organization
- Changes in the policy regarding access to the CST process to assist with information and referral for families

[12] Assessment of Services for Virginians with Autism Spectrum Disorders, Report of JLARC, June 8, 2009. www. *jlarc.state.va.us/meetings/June09/Autism.pdf*

Summary of Developmental Disabilities Committee Recommendations	
Deliverable	**Recommendations**
Review of screening for Intensive Care Coordination (Deliverable A)	Amend screening criteria with following elements: • Add significant incidents -"Threatened disruption to current living situation" • Add items from Life Domain Functioning • Adjust threshold score to include new items
Review of Intensive Coordination model as it affects children with developmental disabilities (Deliverable C)	Provide training and information on ICC to families
	Allow families to participate in ICC through multiple communication means (e.g., telephone conferencing)
	Add knowledge of "developmental needs" to qualifications and expertise for ICC staff Add to ICC responsibilities: • develop comprehensive transition plans for youth returning to schools from residential treatment settings • identify FCPS point of contact for ongoing supports when youth transition out of ICC
Identification of needed community supports and services for youth with developmental disabilities (Deliverable D)	Increase **Case Management** for youth (under age 18) with developmental disabilities ***CSB:*** • Increase CSB case management capacity for youth with developmental and/or intellectual disabilities. ***FCPS:*** • Enhance collaboration with key FCPS personnel to identify and refer youth with DD/ID and their families to existing community resources.

Summary of Developmental Disabilities Committee Recommendations	
Deliverable	**Recommendations**
	Fill the following service gaps for youth with ID/DD by contracting for: 1. Enhanced access to translators and interpreters in specialized services contracts 2. Recruit and fund additional specialists in youth with developmental disabilities for both primary health and psychiatric care, including: • child and adolescent psychiatrists • pediatricians • child neurologists 3. Establish a contract with medical and dental specialists providing care at the Northern Virginia Training Center for outpatient services to youth with developmental disabilities
Identification of needed community supports and services for youth with developmental disabilities (Deliverable D) *continued*	4. Medication management with medical specialists through use of Medicaid (CSB to explore billing opportunities) 5. Expand specialized programming for youth with developmental disabilities in therapeutic recreation, SACC, after school ands summer programs 6. Transportation services -- - transportation aides for youth with behavioral challenges or medically fragile conditions -develop consumer information on paratransit, Metro Access and taxi services provided by Medicaid. 7. Increase vocational training and opportunities for youth with DD (focus on ages 18-22) 8. Increase use of respite services

Summary of Developmental Disabilities Committee Recommendations	
Deliverable	**Recommendations**
Identification of needed community supports and services for youth with developmental disabilities (Deliverable D) *continued*	Create Family Navigator program using paid para-professionals to increase outreach to families and linkage to existing resources
	Establish procedures for parents/caregivers to self-refer for services/child specific team process to obtain information and referral/supports
	Transition into Adulthood • Address lifelong needs of individuals with developmental disabilities - involve county agencies, FCPS, state and local agencies • Support for current county initiatives focused on transition and services to young adults with DD
Address Systems Barriers (Deliverable E)	Address systems barriers identified by committee members
Family Outreach and Education (Deliverable F)	• Create public information campaign to assist parents/caregivers in locating resources • Develop an electronic source of information (ex: Senior Navigator) for families and public use
	Research implementation of following promising practices/Evidence Based programs for children with developmental disabilities • DIR®/ Floortime™ • Positive Behavioral Support • Applied Behavior Analysis (ABA) • Picture Exchange Communication System (PECS) • Relationship Development Intervention (RDI) • Pivotal Response Training • Collaborative Problem solving

Appendix A: Promising Practices for youth with developmental disabilities and their families

Members of the developmental disabilities committee focused on the need for services and interventions to be individualized to meet the varying needs of youth with developmental disabilities. In other words, a person-centered approach is the best practice model, rather than adopting a few models for use with all. Committee members support the use of evidence-informed, research-based, and promising practices in service delivery with the goal of maintaining youth in their families, homes and community. The committee supports the increase in availability and capacity for service providers with specialized training and expertise to offer empirically-supported interventions and services. In keeping with this philosophy, committee members discussed the following models of intervention that have shown promise for this population:

- Developmental, Individual Difference, Relationship-based (DIR)® Model - Floortime™
- Family Psycho-educational Support and Counseling
- Collaborative Problem Solving
- Relationship Development Intervention
- Pivotal Response Training
- Early Start Denver Model
- Positive Behavior Support
- Applied Behavior Analysis (ABA)
- Picture Exchange Communication System (PECS)

DIR®/ Floortime™

The Developmental, Individual Difference, Relationship-based (*DIR®/Floortime™*) Model is a framework that helps clinicians, parents and educators conduct a comprehensive assessment and develop an intervention program tailored to the unique challenges and strengths of children with Autism Spectrum Disorders (ASD) and other developmental challenges. The objectives of the *DIR®/Floortime™* Model are to build healthy foundations for social, emotional, and intellectual capacities rather than focusing on skills and isolated behaviors. For a detailed overview, download 2 page flyer.

- The D *(Developmental)* part of the Model describes the building blocks of this foundation. Understanding where the child is developmentally is critical to planning a treatment program. The **Six Developmental Milestones** describes the developmental milestones that
- The I *(Individual differences)* part of the Model describes the unique biologically-based ways each child takes in, regulates, responds to, and comprehends sensations such as sound, touch, and the planning and sequencing of actions and ideas. Some children, for example, are very hyper responsive to touch and sound, while others are under-reactive, and still others seek out these sensations.
- The R *(Relationship-based)* part of the Model describes the learning relationships with caregivers, educators, therapists, peers, and others who tailor their affect based interactions to the child's individual differences and developmental capacities to enable progress in mastering the essential foundations.

For more information: http://www.icdl.com/dirFloortime/overview/index.shtml

Family Psychoeducational Support and Counseling

The data supporting the efficacy of family psychoeducation remain compelling. Such programs should remain as part of best practices guidelines and treatment recommendations. However, assessment of the appropriateness of family psychoeducation for a particular patient and family should consider (1) the interest of the family and patient; (2) the extent and quality of family and patient involvement; (3) the presence of patient outcomes that clinicians, family members, and patients can identify as goals; and (4) whether the patient and family would choose family psychoeducation instead of alternatives available in the agency to achieve outcomes identified.

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Collaborative Problem Solving

If you're new to Collaborative Problem Solving, this is a good place to start. If you're not new to the model, this is a good place to stay fresh on key concepts.

The model sets forth two major tenets. First, social, emotional, and behavioral challenges in kids are best understood as the byproduct of lagging cognitive skills in the domains of flexibility/adaptability, frustration tolerance, and problem-solving (rather than as attention-seeking, manipulative, limit-testing, or a sign of poor motivation). In other words, challenging behavior is a form of developmental delay. Second, these challenges are best addressed by collaboratively resolving the problems that are setting the stage for challenging behavior (rather than through reward and punishment programs and intensive imposition of adult will).

Organized by important tenets of the model (and in logical sequence from top to bottom), each topic area is explained by Dr. Greene via streaming video (filmed at a presentation in Regina, Saskatchewan, in April, 2009).

Why is Collaborative Problem Solving important? Because challenging kids are still very poorly understood and therefore treated in ways that are unhelpful and counterproductive...and that place them at risk for adverse long-term outcomes...and it doesn't have to be that way.

For more information, see the following website: http://www.livesinthebalance.org/what-is-collaborative-problem-solving-cps

RDI – Relationship Development Intervention

The Goals of RDI

Dr. Steven Gutstein is the creator of the RDI (Relationship Development Intervention) program. The program is parent-centered, and, according to the literature, is intended to help lay missing pathways in the brain. The claims made for RDI are extraordinary; according to the literature, by following the system parents can expect their children to develop:

- Dramatic improvement in meaningful communication,
- Desire and skills to share their experiences with others,
- Genuine curiosity and enthusiasm for other people,
- Ability to adapt easily and "go with the flow,"
- Amazing increase in the initiation of joint attention,
- Powerful improvement in perspective taking and theory of mind,
- Dramatically increased desire to seek out and interact with peers.

Costs: Certification for individual practitioners costs approximately $7,000. This fee covers the beginning and intermediate seminars as well as supervision.

For more information: http://www.rdiconnect.com/

Pivotal Response Training

What is Pivotal Response Training?

Pivotal response training (PRT) is a behavioral treatment intervention based on the principles of applied behavior analysis (ABA) and derived from the work of Koegel, Schreibman, Dunlap, Horner, and other researchers. It is a composite of the research on task interpersonal, direct reinforcement, and role of choice. Key pivotal behaviors have been identified for children with autism: motivation and responsivity to multiple cues (Koegel & Koegel). PRT has demonstrated positive changes in these "pivotal behaviors" exhibiting widespread effects on many other behaviors associated with language and social interaction. Pivotal Response Training (PRT) provides a guideline for teaching skills and has been most successful for language, play and social interaction skills in children with autism.

For more information: http://education.ucsb.edu/autism/index.html

Early Start Denver Model

- To understand patterns of growth and change in young children with developmental differences, particularly those with autism spectrum disorders and other communication disorders.
- To prevent or minimize the disability associated with developmental differences through early detection, early intervention, and family support.
- To prepare talented people for careers in research and clinical care focused on children with developmental differences and their families.
- To increase public awareness and knowledge of the abilities and needs of children and adults with developmental differences and their families.

For more information: http://www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/

Positive Behavioral Support

Positive Behavioral Support (PBS) is an empirically validated, function-based approach to eliminate challenging behaviors and replace them with prosocial skills. Use of PBS decreases the need for more intrusive or aversive interventions (i.e., punishment or suspension) and can lead to both systemic as well as individualized change.

PBS can target an individual student or an entire school, as it does not focus exclusively on the student, but also includes changing environmental variables such as the physical setting, task demands, curriculum, instructional pace and individualized reinforcement. Thus it is successful with a wide range of students, in a wide range of contexts, with a wide range of behaviors.

Blending behavioral science, empirically validated procedures, durable systems change and an emphasis on socially important outcomes, PBS always involves data-based decision making using functional behavioral assessment and ongoing monitoring of intervention impact.

According to IDEA '97, PBS is the recommended form of intervention for dealing with challenging behavior in children with disabilities. In Fiscal Year 1999, the U.S. Department of Education's Office of Special Education Programs in collaboration with Safe and Drug Free Schools supported a Center for Positive Behavioral Interventions and Supports with a grant of almost $600,000. Information from this center is available at *www.pbis.org*.

Additionally, the U.S. government continues to support a project at the University of Kansas (Beach Center on Families and Disability) to promote programs related to the personal needs of infants, toddlers, children and youth with disabilities; this program supports the use of PBS to help children with disabilities who demonstrate challenging behavior.

Applied Behavior Analysis (ABA)

The following information is taken from the website:
http://autism.healingthresholds.com/therapy/applied-behavior-analysis-aba

The *Applied Behavior Analysis (ABA)* approach teaches social, *motor*, and verbal behaviors as well as *reasoning* skills (1). *ABA treatment* is especially useful in teaching behaviors to children with *autism* who may otherwise not "pick up" these behaviors on their own as other children would. The *ABA* approach can be used by a *parent*, counselor, or *certified behavior analyst*.

ABA uses careful *behavioral observation* and *positive reinforcement* or *prompting* to teach each step of a behavior (2). A child's behavior is reinforced with a *reward* when he or she performs each of the steps correctly. Undesirable behaviors, or those that interfere with learning and *social skills*, are watched closely. The goal is to determine what happens to *trigger* a behavior, and what happens after that behavior that seems to *reinforce* the behavior. The *idea* is to remove these triggers and *reinforcers* from the child's *environment*. New *reinforcers* are then used to teach the child a different behavior in response to the same *trigger* (3).

ABA treatment can include any of several established teaching tools: *discrete trial training*, *incidental teaching*, *pivotal response training*, *fluency building*, and *verbal behavior* (*VB*).

In *discrete trial training*, an *ABA* practitioner gives a clear instruction about a desired behavior (e.g., "Pick up the paper."); if the child responds correctly, the behavior is reinforced (e.g., "Great job! Have a sticker."). If the child doesn't respond correctly, the practitioner gives a gentle *prompt* (e.g., places child's hand over the paper). The hope is that the child will eventually learn to *generalize* the correct response (4,5).

Pivotal response training uses *ABA* techniques to target crucial skills that are important (or pivotal) for many other skills. Thus, if the child improves on one of these pivotal skills, improvements are seen in a wide variety of behaviors that were not specifically trained. The *idea* is that this approach can help the child *generalize* behaviors from a *therapy* setting to everyday settings (4, 6, 7).

Incidental teaching uses the same ideas as *discrete trial training*, except the goal is to teach behaviors and concepts throughout a child's day-to-day experience, rather than focusing on a specific behavior (1, 7).

In *fluency building*, the practitioner helps the child build up a complex behavior by teaching each element of that behavior until it is automatic or "*fluent*," using the *ABA* approach of *behavioral observation*, *reinforcement*, and *prompting*. Then, the more complex behavior can be built from each of these *fluent* elements (8, 9).

Finally, an *ABA*-related approach for teaching *language* and *communication* is called "*verbal behavior*" or *VB* for short (10). In *VB*, the practitioner analyzes the child's *language* skills, then teaches and reinforces more useful and complex *language* skills (11).

What's it like?

Through *ABA training*, *parents* and other caretakers can learn to see the natural triggers and *reinforcers* in the child's *environment*. For example, by keeping a chart of the times and events both before and after Sammy's *tantrums*, a *parent* might discover that Sammy always throws a *tantrum* right after the lights go on at night without warning. Looking deeper at the behavior, Sammy's *mother* might also notice that her most natural response is to cuddle Sammy in order to get him to calm down. In effect, even though she is doing something completely natural, the cuddling is reinforcing Sammy's *tantrum*. According to the *ABA* approach, both the *trigger* (lights going on at night without a warning) and the *reinforcer* (cuddling) must be stopped. Then a more appropriate set of behaviors (like leaving the room or dimming the lights) can be taught to Sammy, each one being reinforced or prompted as needed. Eventually, the hope is that this kind of approach will *lead* to a time when the lights can go on without warning and Sammy still does not throw a *tantrum*.

What is the theory behind it?

Many experts believe that children with *autism* are less likely than other children to learn from the everyday *environment* (12). The *ABA* approach attempts to fill this gap by providing teaching tools that *focus* on simplified instructional steps and consistent *reinforcement*. At best, the *ABA* approach can help children with *autism lead* more independent and socially active lives (12). Research suggests that this positive outcome is more common for children who have received *early intervention*. This may be due to critical brain development that occurs during the *preschool* years and can be affected by training (3, 13).

Does it work?

ABA is considered by many researchers and clinicians to be the most effective *evidence-based therapeutic approach* demonstrated thus far for children with *autism* (14). The U.S. Surgeon General states that thirty years of research on the *ABA* approach have shown very positive outcomes when *ABA* is used as an *early intervention* tool for *autism* (15). This research includes several landmark studies showing that about 50% of children with *autism* who were treated with the *ABA* approach before the age of four had significant increases in *IQ*, *verbal* ability, and/or social functioning. Even those who did not show these dramatic improvements had significantly better improvement than matched children in the *control* groups. In addition, some children who received *ABA therapy* were eventually able to attend classes with their peers (12, 16, 17).

Parents are often trained in *ABA therapy*, and several single-subject studies have shown that *parental training* helps children with *autism* who receive *ABA therapy* (18). Larger controlled studies looking at this issue are underway (19). Studies of parental satisfaction with *ABA* indicate that *parents* believe the approach is effective (20). *Parents* also report that they experience less *stress* as a result of applying *ABA* (21).

Support is growing for increased use of *ABA* in the *classroom* (22). One study found that *ABA therapy* was as effective, and sometimes more effective, than other *special education intervention* programs (23, 24). High-intensity *ABA therapy* (for example, the *Lovaas method*) during *preschool* can be more effective than *special education* techniques (23).

There are, however, some controversies surrounding the *ABA* approach (14). Early *ABA* practice (in the 1980s and early 1990s) included the use of *aversive techniques* such as yelling at or restraining a

child. Most *ABA* practitioners no longer consider *aversive techniques* to be acceptable, and the current *ABA* approach is equally effective without these techniques (25).

Experts also disagree as to whether the *ABA* approach should be used alone or along with other *treatment* methods. While there are varied opinions (14), most practitioners agree upon the importance of *early intervention, intensive treatment* for as much time as possible each day (in the range of 25 to 40 hours per week), well-trained practitioners, and consistent application of the *ABA* approach within and outside of *school* (3).

A crucial element of the *ABA* approach that is especially important for children with *autism* is finding appropriate *reinforcement* for each child. Because praise may not be rewarding for these children, careful analysis of each child's behavior can help reveal more effective *reinforcement* tools (26). Examples of successful *reinforcers* may include access to a favorite *toy* or chair.

Is it harmful?

There are no known negative effects of the *ABA* approach. This is especially the case if gentle *prompting* is used rather than *aversive techniques*.

Cost

Although *autism* is a condition covered under the Individuals with Disabilities Education Act (*IDEA*) of 2004, whether *IDEA* covers *intensive ABA treatment* is still being considered by the courts. For *legal* information about *IDEA*, go to http://www.wrightslaw.com/.

In order to effectively implement *ABA*, both *parents* and other major caretakers are usually trained in *ABA* (19). Workshops covering the basics of *ABA treatment* can last from 2 to 7 days, and cost between $175 to $1,000 per person. Online *ABA* courses are especially useful for *parents* who do not live in a large city.

Children can also be enrolled in *schools* and clinics that specialize in *ABA treatment*. These can be found in most major cities and university towns. The cost of such *schools* can be quite high; tuition ranges from $16,000 to $25,000 per year. However, some *schools* offer scholarships to *parents* in need.

It is possible to set up *ABA treatment* at *home* using *therapists* in training or *college* students who have taken a workshop in the *ABA* approach. This can also be expensive ($5,000 to $20,000/year), and requires a great deal of time organizing and structuring the program.

A qualified, full-time (30 hours/week or more) *ABA therapist* devoted to your child costs approximately $30,000 to $50,000 per year. Because of the success of *ABA* and the *evidence* indicating that training should be *intensive* (25 to 40 hours/week), there is very high demand for *ABA*-trained *therapists*, and it may be difficult to find one who is available (see Resources).

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Picture Exchange Communication System (PECS)

The following information is taken from the website:
http://autism.healingthresholds.com/therapy/picture-exchange-communication-system-pecs

What is it?

A *picture exchange communication system (PECS)* is a form of *augmentative and alternative communication (AAC)* that uses pictures instead of words to help children *communicate*. *PECS* was designed especially for children with *autism* who have delays in speech development.

When first learning to use *PECS*, the child is given a set of pictures of favorite foods or *toys*. When the child wants one of these items, he gives the picture to a *communication partner* (a *parent*, *therapist*, caregiver, or even another child). The *communication partner* then hands the child the food or *toy*. This exchange reinforces *communication* [1-4].

PECS can also be used to make comments about things seen or heard in the *environment*. For example, a child might see an airplane overhead, and hand a picture of an airplane to his or her *parent*. As the child begins to understand the usefulness of *communication*, the hope is that he will then begin to use natural speech [5].

What's it like?

A child can be trained in *PECS* by a *parent*, caregiver, or *therapist* who has learned about the method (see Resources). An *applied behavior analysis (ABA)* approach is used, in which *prompts* are given to guide the picture exchange. Further, in the early phases of *PECS* training, the child chooses a picture of a desired food, and receives the food in exchange for the picture. Getting the food is the *positive reinforcement* for using the picture to *communicate*.

PECS is usually taught in six phases [6, 7]:

- **Phase One**: The *communication partner* makes a list of the child's favorite items (usually beginning with foods). One of these items is selected for the first training session, and a picture of the item is made. That item can be placed under a clear container, so the child can see it, but not get it. If the child looks interested in the item, the *communication partner* gives the child the picture card. Then the child is prompted (usually by holding his/her hand and guiding it) to hand the picture card back to the *communication partner*. Once the *communication partner* receives the card, the request is spoken aloud ("Oh, you want the cookie! You can have it!"). At this point, the requested item (which has become the *reinforcer*) is given to the child.
- **Phase Two**: The *communication partner* moves slightly away from the child so that the child has to move towards the *communication partner* to place the picture card in his/her hand.
- **Phase Three**: The child is given more than one picture card. Now the child must choose which one represents a desired object, and then give this card to the *communication partner*. At this point, the child may be using a *communication board* or a binder in which to hold the cards.
- **Phase Four**: The child is given a card with the phrase "I want ____" on it. This card now must be used with the picture card showing what is desired. The *idea* is that the child will learn

how to *communicate* using complete sentences. Even children who cannot yet *read* can learn to recognize the words as *symbols* on the cards.

- **Phase Five**: Before this point, the child has never been asked directly, "What do you want?" In this phase, the *communication partner* asks the child this direct question, and waits for the child to hand him/her a picture card. This builds the foundation for future *communication* when a *parent* needs to know the desires of his or her child.
- **Phase Six**: Once the child can use *PECS* with *fluency* and has generalized the system to more than one *communication partner*, the child is taught how to comment on something s/he observes. The *communication partner* holds up an interesting object, asking the child, "What do you see?" at the same time *pointing* out the "I see ____" card. The child is then prompted to place the picture card representing the object next to the "I see ____" card. The *parent* then comments on the cards ("Yes! I see the airplane too"). In this way, the child learns how to *communicate* his or her observations and experiences to others.

What is the theory behind it?

The direct *reinforcement* that comes from immediately getting what you want is the key to *PECS*. Without having to use *spoken words*, a child is able to turn an inner desire into an external *reward*. It is thought that tangible rewards are more reinforcing to children with *autism* than social rewards, at least during the first steps of *communication* learning. However, if these rewards are too difficult to receive – that is, if it is very difficult for the child to form words – then the point of *communication* may, at first, be lost on these children. This can result in *tantrums* and other undesirable behavior, because the child cannot clearly *communicate* what s/he wants. However, when children with *autism* are trained in *PECS*, *problem behaviors* often subside as the benefits of *communication* become more tangible [1, 4, 5].

PECS may also help improve social interactions in children with *autism*. Because the child is in charge of approaching the *communication partner*, the child learns how to make the first move. For children with *autism*, approaching another person socially can be difficult. However, in this case, the child is not expected to speak, so the initial approach may be less intimidating [1, 2].

Does it work?

There are several well-designed research studies showing the usefulness of *PECS* [8]. In one study of 18 *preschool* children with *language* delays, some of whom were diagnosed with *autism*, *PECS* generalized across communication partners and environments [6]. These children were able to use *PECS* to *communicate* throughout their *school* days, not just during the training sessions. Further, almost half of these children stopped using *PECS* and started using natural speech within a year [6]. One *parent* commented that "*PECS* turned on the light for *communication*" in her child [6]. Similar results were found for two smaller, but still well-designed studies [5, 7].

A larger study of *school*-aged children found significantly increased use of *PECS* when *adults* trained in the use of *PECS* were in the *classroom*. The study involved 6 half-days of *PECS intervention* per month for 5 months. While use of *PECS* by the children increased, there was no significant increase in *verbal language* use [9]. The children's use of *PECS* diminished after *classroom* visits by the trained *adults* were stopped [9].

Recently, a comparison was made between *PECS* and another popular *AAC* technique, *Responsive Education and Prelinguistic Milieu Training (RPMT)*. The results showed that children with *autism* trained in *PECS* were more *verbal* than those for whom the *RPMT* approach was used [10].

Overall, the *evidence* supports the use of *PECS* as a tool for developing natural *communication* in children with *autism*, especially when it is taught before the child is six years old [3, 8].

Is it harmful?

There are no known negative effects of *PECS*. Some *parents* have been concerned that their child will become dependent on *PECS* and not move on to develop natural speech. However, this view is not supported by research studies. In fact, there is *evidence* that children with *autism* who have learned to use *PECS* develop speech more quickly than those who have not been trained in *PECS* (see Does it work?) [2, 4].

Cost

The materials used in *PECS* are relatively inexpensive. A binder for storing *PECS* pictures can be made from a 3-ring binder. A Velcro™ strip is attached to the front cover to hold the picture(s) currently being used. Each picture can be drawn by a *parent*, cut out of a magazine, or made from an actual photograph of the object glued onto a card. A Velcro™ strip can be placed on the back of each picture to hold it in place on the front cover of the binder when it is being used. Each picture can be hole-punched for storage in the binder [1].

A more expensive alternative is to purchase a *PECS* binder and several commonly used pictures (see Resources). However, even if you purchase these ready-to-use *PECS* systems, you will have to create your own pictures of preferred items that are unique to your child.

The more expensive side of *PECS* can be the expertise involved in *PECS* training. However, *PECS* can be covered in *speech therapy* under *IDEA* (see Resources). Also, *PECS* training manuals are available for $40 to $70 for *parents* and other *caregivers* (see Resources).

Resources

Healing Thresholds has partnered with Natural Learning Concepts. They have many tools that will make it easier to do *PECS* in your own *home*.

Many *PECS* resources, including commonly used pictures and *PECS* binders can be found at: http://www.pecs.org.uk/.

Several books that might be useful:

Empower! by Beth A. Soeder, M.A., *SLP*-CCC and Catharine M. Critz, Ph.D., CPNP, 2003. Pyramid Educational Products, Inc.

A Picture's Worth: PECS and Other Visual Communication Strategies in Autism (Topics in Autism) by Andy Bondy, Ph.D., and Lori Frost, M.S., CCC/*SLP*, 2001. Woodbine House.

PECS Training Manual, 2nd Edition by Lori Frost, M.S., CCC/*SLP* and Andy Bondy, Ph.D., 2002.

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Appendix B: Information on Waivers relevant for DD population

Mental Retardation/Intellectual Disability (MR/ID) Waiver

Services available:
Residential support services, day support, supported employment, prevocational services, personnel assistance (agency or consumer directed), respite, (agency or consumer directed), assistive technology, environmental modifications, skilled nursing services, therapeutic consultation, crisis stabilization, and personal emergency response systems (PERS). Support coordination is also provided.

Eligibility:
An individual must be age 6 or older and have a diagnosis of MR/ID OR be under age 6 and at developmental risk. The person must be eligible for placement in an intermediate care facility for persons with mental retardation or other related conditions (ICF-MR). This is established using the "level of functioning" survey. Children on the MR/ID Waiver who do not have a diagnosis of mental retardation should be screened at age 6 and may transfer to the DD (IFDDS) Waiver.

There are 3 types of lists for the MR/ID Waiver:

- Urgent waiting list – need waiver services immediately
- Non-urgent waiting list – need waiver services within 30 days
- Planning list – will need waiver services at some point in the future

How to apply:
For more information on the ID Waiver please call Intellectual Disability Services @
Phone: 703-324-4400; TTY: 703-324-4495 or by email @ wwwcsb@fairfaxcounty.gov

Individual and Family Developmental Disabilities Support (DD or IFDDS) Waiver

Services available:
Day support, companion services (agency or consumer directed) supported employment, in-home residential support, therapeutic consultation, personal care services (agency of consumer directed), respite care (agency or consumer directed), supported employment, skilled nursing services, attendant services, family and caregiver training, crisis supervision, environmental modifications, assistive technology, personal emergency response system (PERS), and prevocational services. Support coordination is also provided.

Eligibility:
The DD Waiver provides services to individuals 6 years of age and older who have a diagnosis of a developmental disability and do not have a diagnosis of mental retardation. Individuals also must require the level of care provided in an intermediate care facility for persons with mental retardation or other related conditions (ICF/MR). Children who do not have a diagnosis of mental retardation, and have received services through the MR/ID Waiver, become ineligible for the MR/ID Waiver when they reach the age of 6. At that time, they can be screened for eligibility for the DD Waiver; if

found eligible they will receive a DD Waiver slot without being placed on the DD waiver waiting list.

How to apply:
Download a copy of the "Request for Screening" form (available at www.dmas.virginia.gov/content/ltc-dd wvr request for services.htm –clink on link at top of the page.
Waiting list status: There is currently a waiting list for this Waiver. The DD Waiver is administered by the Department of Medical Assistance Services (DMAS).

Elderly or Disabled with Consumer Direction (EDCD) Waiver

Services available:
Personal care aide services (agency or consumer directed), adult day health care, respite care (agency or consumer directed), skilled respite care, personal emergency response system (PERS), and medication monitoring.

Eligibility:
This waiver serves the elderly and persons of all ages with disabilities. An individual must meet nursing facility eligibility criteria, including both medical needs and functional capacity needs (assistance with activities of daily living). An individual can remain on the waiting list for another waiver while being served by the EDCD Waiver and then transfer to the preferred waiver once a slot becomes available.

How to apply:
Department of Family Services, Fairfax County, 703-222-0880

Appendix C: Resources for children and families dealing with autism spectrum in Virginia

Local resources:

- The Parents of Autistic Children of Northern Virginia (POAC-NOVA) – this is a parent support group that holds monthly support group meetings and offers a number of educational workshops throughout the year. Their website is: http://www.poac-nova.org/

- The Kennedy Krieger Institute is an internationally recognized institution located in Baltimore, Maryland dedicated to improving the lives of children and adolescents with pediatric developmental disabilities through patient care, special education, research, and professional training. Their website address is: http://www.kennedykrieger.org

- Ashburn Psychological Services – with offices in Ashburn and Leesburg, offer a broad range of clinic and consultation-based services for families and individuals diagnosed with ASD, ADHD and other developmental delays. Their website is: http://www.ashburnpsych.com

Advocacy and resources re: guardianship, estate planning and more.

- ARC of Northern Virginia
  703-532-3214 www.The ArcofNoVA.org

Special Olympics

- Contact: Pat Hammeke 703-359-4301 or www.specialolympicsva.org

Therapeutic Recreation Services

- During school year (3) 5-week sessions
  Saturday 11am-4pm and summer day camp programs 703-324-5587
  www.fairfaxcounty.gov/recreation

Parent Resource Center, Advocacy

- Information and sibling program info
  Fairfax County Public Schools
  703-204-3941 www.fcps.edu//ss/prc/

Respite services:

- Mclean Bible Church
  Access Ministries
  Break Away/Break Out
  Contact: Stephanie Reding
  703-770-8654

- Northern Virginia Family Services
  Therapeutic respite care
  Contact: Maggie Wilkinson
  703-219-2126

- Students with medical issues may be eligible for the Elderly and Disabled Waiver (EDCD Waiver) administered through the Department of Family Services at 703-222-0880

- School-Aged Child Care (SACC)
  Before and after school, summer and school break programs at Kilmer Center (and other sites) Contact: Office for Children, SACC at 703-449-8989

State resources:

- The Virginia Institute of Autism (VIA) based in Charlottesville is a non-profit organization providing a day-school and other resources for families, educators and health professionals seeking services, training or information about autism and evidence-based interventions. Their website is: http://www.viaschool.org

- Autism Society of America – Northern Virginia Chapter: their aim is to improve the lives of all affected by autism. They do this by increasing public awareness about the day to day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy. They have several chapters in Virginia and in many other states. There website address is: http://www.autism-society.org

- Easter Seals Virginia – this organization is committed to being an advocate and provider for much-needed services for people with disabilities and their families. Easter Seals has partnered with the Autism Society of America in an effort to address the significant needs of individuals with autism and their families. Their website is: http://wv.easterseals.com

- The Parent Educational Advocacy Training Center (PEATC) is Virginia's parent information resource center. It is a non-profit organization that has been building positive futures for Virginia's children by working collaboratively with families, schools and communities in order to improve opportunities for excellence in education and success in school and community life. There website address is: http://www.peatc.org/

- Early & Periodic Screening, Diagnosis, and Treatment Services (EPSDT) – this is a home-based behavioral programming that offers services to increase adaptive behavioral functioning in children who demonstrate significant impairments in adaptive functioning. Services offered include:
  - Behavioral training to increase adaptive functioning and communication skills
  - Family member training in behavioral modification methods
  - Clinical service direction and involvement in the home environment
  - Clinical consultation with other agencies and schools
  - Coordination of other clinical services to increase adaptive behavior and communication skills

Who is eligible? Current Medicaid/FAMIS Plus enrolled children under the age of 21.

For more information, visit the Virginia Department of Medical Assistance Services (DMAS) website @ www.dmas.virginia.gov or call 804-225-3124 or 804786-6134.

For pre-authorization, contact Shirlene Harris @ 804-225-3124 or send email to epsdt@dmas.virginia.gov

National resources:

- The Online Asperger Syndrome Information and Support (OASIS) center has joined with MAAP Services for autism and Asperger syndrome to create a single resource for families, individuals and medical professionals who deal with the challenges of autism, Asperger's and PDD/NOS. Their website address is: http://www.aspergersyndrome.org

- The National Autism Association – its mission is to educate and empower families affected by autism and other neurological disorders, while advocating on behalf of those who cannot fight for their own rights. Their website is: http://www.nationalautismassociation.org

- The Arc is a national organization with local chapters. It advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. It works with its network members to improve systems of supports and services; connect families; inspire communities and influence public policy. Their website address is: http://www.thearc.org

- The Federation of Families for Children's Mental Health has a mission to provide advocacy at the national level for the rights of children and youth with emotional, behavioral and mental health challenges and their families. They also provide leadership and technical assistance to a nation-wide network of family run organizations. They have a local chapter located at 1101 King Street in Alexandria, Virginia. Their website address is: http://www.ffcmh.org/

- The National Alliance for the Mentally Ill (NAMI) was formed in 1979 and is dedicated to improving the lives of individuals and families affected by mental illness. NAMI continues to build on its success and to focus on three cornerstones of activity that offer hope, reform, and health to our American community: awareness, education and advocacy. They have a local chapter at 2107 Wilson Blvd in Arlington, Virginia. Their website address is: http://www.nami.org

- The National Institute of Mental Health (NIMH) envisions a world in which mental illnesses are prevented and cured. The mission of NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure. Their offices are located in Rockville, Maryland. Their website address is: http://www.nimh.nih.gov

- The National Institute on Deafness and other Communication Disorders (NIDCD) is one of the institutes that comprise the National Institutes of Health (NIH). NIDCD is mandated to conduct and support biomedical and behavioral research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech and language. The Institute also conducts and supports research and research training related to disease prevention and health promotion. Their offices are located in Bethesda, Maryland. Their website address is: http://www.nidcd.nih.gov

- The Autism Research Institute (ARI) is a non-profit world-wide network of parents and professionals concerned with autism. It was founded in 1967 to conduct and foster scientific research designed to improve the methods of diagnosing, treating and preventing autism. ARI also disseminates research findings to parents and others world-wide seeking help. Their website is: http://www.autism.com

- Autism Speaks' goal is to change the future for all who struggle with autism. It is dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raise public awareness about autism and its effect on individuals, families and society; and to bring hope to all who deal with the hardship of this disorder. Their website is: http://www.autismspeaks.org

Appendix D: References and Sources of Information

Assessment of Services For Virginians with Autism Spectrum Disorders, Report of the Joint Legislative Audit and Review Commission to the Governor and the General Assembly of Virginia, June 8, 2009. www.*jlarc.state.va.us/meetings/June09/Autism.pdf*

FY2011 Proposed Budget, Fairfax County Public Schools, Special Education Services, page 107. http://www.fcps.edu/fs/budget/documents/proposed/2011/ProposedBudget11.pdf

Trends in Autism Spectrum Disorder (ASD), Report to the Fairfax County Board of Supervisors Human Services Committee, June 9, 2008.