

# **Protection and Advocacy for Individuals with Developmental Disabilities (PADD)**

Annual Statement of Goals and Priorities (SGP)  
Annual Program Performance Report (PPR)

*Revised September 3, 2015*

Administration on Intellectual and Developmental Disabilities (AIDD)

Administration for Community Living  
U.S. Department of Health and Human Services

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# Part I: Demographics

## Interventions on behalf of Individuals

The following subsections include demographic information for the seven intervention strategy types listed in Part I.F.

### A. Individuals Served

Count individual once per fiscal year (FY). Multiple counts not permitted for lines A1 –A3.

What to Count	Number
1. Individuals served as of October 1 (Carried over from previous FY).	39
2. Additional individuals served during the year.	162
3. Total individuals served during the year (Add lines A1 and A2).	201
4. Individuals with more than one (1) intervention opened/closed FY.	13
5. Individuals served as of September 30 (Carry over to next FY; ≤ A3).	43

### B. Problem Areas/Complaints of Individuals Served

Problem Area/Complaint	Number
Complaint	
1. Abuse (total)	11
1. Inappropriate Use of Restraint & Seclusion	
2. Involuntary Treatment	
3. Physical, Verbal, & Sexual Assault	
4. Excessive Medication	
5. Financial Exploitation	
6. Other	
2. Access to Administrative or Judicial Processes	
3. Access to Records	
4. Advance Directives	42
5. Architectural Accessibility	1
6. Assistive Technology (total)	
1. Augmentative Communication Devices	
2. Durable Medical Equipment	
3. Vehicle Modification/Transportation	
4. Other	
7. Aversives (including ECT)	
8. Civil Commitment	
9. Criminal Justice	
10. Custody/Parental Rights	
11. Education (total)	53
1. FAPE: IEP/IFSP Planning/Development/Implementation	
2. FAPE: Discipline/Procedural Safeguards	
3. FAPE: Eligibility	
4. FAPE: Least Restrictive Environment	

5. FAPE: Multi-disciplinary Evaluation/Assessments	
6. FAPE: Transition Services	
7. Other	
12. Employment Discrimination (total)	
1. Benefits	
2. Hiring/Termination	
3. Reasonable Accommodations	
4. Service Provider Issues	
5. Supported Employment	
6. Wage and Hour Issues	
7. Other	
13. Employment Preparation	
14. Financial Benefits (total)	
1. SSDI Work Incentives	
2. SSI Eligibility	
3. SSI Work Incentives	
4. Social Security Benefits Cessation	
5. Work Related Overpayments	
6. Welfare Reform	
7. Other Financial Entitlements	
15. Forensic Commitment	
16. Government Benefits/Services	21
17. Guardianship/Conservatorship/Substitute Decision Maker	4
18. Home & Community Based Services including Discharge Planning Transition Follow-up	6
19. Healthcare (total)	4
1. General Healthcare	
2. Medicaid	
3. Medicare	
4. Private Medical Insurance	
5. Other	
20. Housing (total)	
1. Accommodations	
2. Architectural Barriers	
3. Landlord/Tenant	
4. Modifications	
5. Rental Denial/Termination	
6. Sales/Contracts/Ownership	
7. Subsidized Housing/Section 8	
8. Zoning/Restrictive Covenants	
9. Other	
21. Immigration	
22. Juvenile Justice	
23. Neglect (total)	5
1. Failure to Provide Necessary or Appropriate Medical Treatment	4

2. Failure to Provide Necessary or Appropriate Mental Health Treatment	
3. Failure to Provide Necessary or Appropriate Personal Care & Safety	1
4. Other	
24. Post-Secondary Education	
25. Non-Medical Insurance	
26. Privacy Rights	
27. Public Accommodations	
28. Rehabilitation Services (total)	
1. Communications Problems (Individuals/Counselor)	
2. Conflict About Services To Be Provided	
3. Individual Request Information	
4. Non-Rehabilitation Act	
5. Private Providers	
6. Related to Application/Eligibility Process	
7. Related to IWRP Development/Implementation	
8. Related to Title I of ADA	
9. Other Rehabilitation Act-related problems	
29. Suspicious Death	17
30. Transportation (total)	2
1. Air Carrier	
2. Paratransit	
3. Public Transportation	
4. Other	
31. Unnecessary Institutionalization including identification and assessment	
32. Voting (total)	
1. Accessible Polling Place/Equipment	
2. Registration	
3. Other	
33. Other	

### C. Gender of Individuals Served

Gender	Number
1. Female	56
2. Male	145
<b>TOTAL</b>	201

## D. Living Arrangements of Individuals Served

Living Arrangement	Number
1. Independent	6
2. Parental r Other Family Home	129
3. Community Residential Home for Children/Youth (0-18 Yrs.)	2
4. Community Residential Home for Adults	15
5. Non-Medical Community Base Residential Facility for Children and Youth	1
6. Foster Care	
7. Nursing Homes, Including Skilled Nursing Facilities (SNF)	3
8. Intermediate Care Facilities (Icf)	1
9. Public And Private General Hospitals including Emergency Rooms	
10. Public Institutional Living Arrangement	39
11. Private Institutional Living Arrangement	3
12. Psychiatric Wards (Public Or Private)	
13. Jail	
14. State Prison	
15. Federal Detention Center	1
16. Federal Prison	
17. Veterans Administration Hospital	
18. Other Federal Facility	
19. Homeless	
20. Unknown	1
<b>TOTAL</b>	<b>201</b>

## E. Reasons for Closing Individual Intervention Files

Reasons for Closing Individual Advocacy Case File	Number
1. Number of Closed Cases in which Client's Objective Was Partially or Fully Met	121
3. Other Representation Found	2
4. Individual Withdrew Complaint	13
5. Services Were Not Needed Due To Client's Death or Relocation	4
6. P&A Withdrew Because Individual or Client Would Not Cooperate	5
7. Individual's Case Lacked Merit	18
8. Individual's Issue Not Favorably Resolved	2
9. Appeal(s) Unsuccessful	1
<b>TOTAL</b>	<b>166</b>

## F. Intervention Strategies Used in Serving Individuals

Individual Advocacy Service	Number
1. Self-Advocacy Assistance	54
2. Limited Advocacy	69
3. Administrative Remedies	5
4. Negotiation	13
5. Mediation/Alternative Dispute Resolution	4
6. Litigation	4
<b>TOTAL (1-6)</b>	<b>Total (1-6)</b>
Individual Investigation Service	
7. Individual Investigation	<b>1</b>
<b>TOTAL (1-7)</b>	

## G. Age Range of Individuals Served

Range	Number
1. 0 – 2	0
2. 3 – 5	0
3. 5 – 10	3
4. 11 – 22	125
5. 23 – 64	58
6. 65 & Over	15
<b>TOTAL</b>	<b>201</b>

## H. Primary Disability of Individuals Served

Primary Disability	Number
Disabling Condition	
1. Absence of Extremities	
2. Acquired Brain Injury	
3. ADD/ADHD	10
4. AIDS/HIV Positive	
5. All Other Disabilities	3
6. Autism	
7. Auto-immune (non-AIDS/HIV)	
8. Blindness (Both Eyes)	
9. Cancer	
10. Cerebral Palsy	12
11. Deafness	1
12. Deaf-Blind	2
13. Diabetes	
14. Digestive Disorders	
15. Epilepsy	
16. Genitourinary Conditions	1
17. Hearing Impaired (Not Deaf)/Hard of Hearing	
18. Heart & Other Circulatory Conditions	



19. Intellectual Disability	67
20. Mental Illness	8
21. Multiple Sclerosis	
22. Muscular Dystrophy	1
23. Muscular/Skeletal Impairment	1
24. Orthopedic Impairments	3
25. Other Emotional/Behavioral	
26. Other Visual Impairments (not blind)	
27. Neurological Disorders/Impairments	3
28. Respiratory Disorders/Impairments	
29. Skin Conditions	
30. Specific Learning Disabilities (SLD)	7
31. Speech Impairments	
32. Spina Bifida	
33. Substance Abuse (Alcohol or Drugs)	
34. Tourette Syndrome	
35. Traumatic Brain Injury (TBI)	
<b>TOTAL</b>	<b>201</b>

## Race and Ethnicity

### I. Racial and Ethnic Diversity of Individuals Served

Race/Ethnicity	State %	Individual Advocacy #	Individual Advocacy %
1. Hispanic/Latino ( <i>of any race</i> )	Auto calculated	5	Auto calculated
	Auto calculated		Auto calculated

Race/Ethnicity ( <i>NOT Hispanic/Latino</i> )	State %	Individual Advocacy #	Individual Advocacy %
2. American Indian/Alaskan Native	Auto calculated		Auto calculated
3. Asian	Auto calculated	3	Auto calculated
4. Black/African American	Auto calculated	58	Auto calculated
5. Native Hawaiian/Other Pacific Islander	Auto calculated		Auto calculated
6. White	Auto calculated	126	Auto calculated
7. Two or more races	Auto calculated	6	Auto calculated
8. Race/Ethnicity Unknown	Auto calculated	3	Auto calculated

## Intervention Benefitting Groups

### J. Groups Served

*Multiple counts not permitted for lines J1 –J3 and J6.*

What to Count	Number
1. Group cases/projects still open at October 1. (Carried over from prior FY(s))	
2. New group cases/projects opened during the year.	
3. Total group cases/projects worked on during the year. (Add lines I1 and I2)	
4. Total group cases/projects as of September 30. (Carry over to next FY)	
5. Group cases/projects targeted at serving racial/ethnic minority(ies).	
6. Total # of individuals potentially impacted by the line I.J.3 projects/cases.	

### K. Problem Areas/Complaints of Groups Served

*Indicate the number of group cases/projects addressing each of the problem areas/complaints below.*

Problem Area/Complaint	Number
1. Abuse	
2. Access to Administrative or Judicial Processes	
3. Access to Records	
4. Advance Directives	
5. Architectural Accessibility	
6. Assistive Technology	
7. Aversives (including ECT)	
8. Civil Commitment	
9. Custody/Parental Rights	
10. Education	
11. Employment Discrimination	
12. Employment Preparation	
13. Financial Benefits	
14. Forensic Commitment	
15. Government Benefits/Services	
16. Guardianship/Conservatorship/Substitute Decision Maker	
17. Home & Community Based Services including Discharge Planning Transition Follow-up	
18. Healthcare	
19. Housing	
20. Immigration	
21. Neglect	
22. Post-Secondary Education	
23. Non-Medical Insurance	
24. Privacy Rights	
25. Rehabilitation Services	
26. Suspicious Death	
27. Transportation	

28. Unnecessary Institutionalization including Identification and Assessment	
29. Voting	

### L. Living Arrangements Targeted by Groups Interventions

Indicate number of group advocacy cases/projects targeted at people in each of the living arrangements listed below. Cases/projects not targeting by living arrangement should be counted under "Not Applicable".

Living Arrangement	Number
1. Independent	
2. Parental or Other Family Home	
3. Community Residential Home for Children/youth (0-18 yrs.)	
4. Community Residential Home for Adults	
5. Non-medical Community Base Residential Facility for Children andY	
6. Foster care	
7. Nursing Homes, including Skilled Nursing Facilities (SNF)	
8. Intermediate Care Facilities (ICF)	
9. Public and Private General Hospitals including Emergency Rooms	
10. Public Institutional Living Arrangement	
11. Private Institutional Living Arrangement	
12. Psychiatric Wards (Public Or Private)	
13. Jail	
14. State Prison	
15. Federal Detention Center	
16. Federal Prison	
17. Veterans Administration Hospital	
18. Other Federal Facility	
19. Homeless	
20. Not Applicable – Intervention not Focused on a Particular Living Arrangement	
<b>TOTAL</b>	

### M. Reasons for Closing Group Cases/Projects

Reason	Number
1. Concluded Successfully	
2. Concluded Unsuccessfully	
3. Other	
<b>TOTAL</b>	

### N. Intervention Strategies Used in Group Cases/Projects

Intervention Strategy	Number
1. Abuse and Neglect Investigation	
2. Systemic Litigation	
3. Educating Policymakers	
4. Other Systemic Advocacy	
<b>TOTAL</b>	

## O. Age Ranges Targeted by Interventions for Groups

Indicate number of cases/projects focused on people in each of the age ranges listed below. If a cases/project is not focused on age range, count it on the line 5 (not applicable).

Focus	Number
1. Group Cases/Projects Focused on Children Approximately 0-2 yrs. old	
2. Group Cases/Projects Focused on Children Approximately 3-5 yrs. old	
3. Group Cases/Projects Focused on Young People Approximately 5-10 yrs. old	
4. Group Cases/Projects Focused on Young People Approximately 11-23 yrs. old	
3. Group Cases/Projects Focused on Adults Approximately 23—64 yrs. old	
4. Group Cases/Projects Focused on Seniors Approximately 65 yrs. & older	
5. Not Applicable – Intervention Not Focused on Any Particular Age Range Grouping	
<b>TOTAL</b>	

## P. Race/Ethnicity of Groups Served

Cases/projects where the number of people in the group served for any of the categories listed below is disproportionately high in comparison to a state or territory's census data. More than one category per project/case may be counted.

Race/Ethnicity	Number
1. Hispanic/Latino (of any race)	
2. American Indian/ Alaskan Native	
3. Asian	
4. Black/African American	
5. Native Hawaiian/Other Pacific Islander	
6. White	
7. Two or more races	
8. Unknown	

# Part II: Statement of Goals and Priorities

## A. Report on FY 2015 Statement of Goals and Priorities (SGP)

<b>Goal Number:</b> 1			
<b>Goal Statement:</b> People with Disabilities are Free from Abuse and Neglect			
<b>2. Priorities</b> <i>(Add rows below if needed)</i>			
<b>#</b>	<b>Priority</b>		
1	Protection from Harm in Institutions		
2	Protection from Harm in Community Settings		
3	Protection from Harm in Community or Institutional Settings Serving Children or Adolescents		
<b>3. Strategies Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>			
X Collaboration		<input type="checkbox"/> Systemic Litigation	
X Rights-Based Individual Advocacy Services		X Educating Policy Makers	
X Investigations of Abuse and Neglect		X Other Systemic Advocacy	
X Monitoring		X Training/Outreach	
<b>4. Extent to Which Goal was Achieved</b> <i>(Check one below)</i>			
<input type="checkbox"/> Not Achieved	<input checked="" type="checkbox"/> Partially Achieved	<input type="checkbox"/> Achieved	<input type="checkbox"/> No Results This Year
<b>5. Stage of Implementation</b> <i>(Check one below)</i>			
<input type="checkbox"/> Planning	<input type="checkbox"/> Initiation	<input checked="" type="checkbox"/> Implementation	Outcome/Fully Integrated
<b>6. Results Narratives of P&amp;A Activities and Accomplishments Related to Above Goal</b>			
<i>List goal and priority #(s) addressed in the activity described in the narrative below.</i>			
Goal #(s): 1	Priority # 1: <b>Protection from Harm in Institutions</b>		
Collaborator(s): <i>across all projects and SRs:</i> Virginia Department of Behavioral Health and Developmental Services (DBHDS); United States Department of Justice; US v. VA Settlement Agreement Independent Reviewer; Local Human Rights Committees; Medical Examiners			
Underserved/Unserviced/Minorities Targeted? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <i>(If yes, describe in narrative).</i>			
<p>The disAbility Law Center of Virginia (dLCV) addressed the priority of “Protection from Harm in Institutions” by strenuous monitoring, casework, and efforts towards systemic change. In the Commonwealth of Virginia, the Virginia Department of Behavioral Health and Developmental Services (DBHDS) currently operates four “Training Centers,” which are institutions that house large numbers of individuals with intellectual disabilities (ID) or developmental disabilities (DD). DBHDS operates an additional facility, Hiram Davis Medical Center (HDMC), which is a large facility that provides nursing home-level care to individuals with Mental Illness, ID, or DD who have additional significant medical needs.</p> <p>In 2012, the Commonwealth of Virginia and the U.S. Department of Justice (DOJ) reached a settlement agreement which anticipated that DBHDS would to close all but one of its Training Centers and transition the individuals affected to community-based services. dLCV has closely monitored the progress of this Settlement Agreement during the year through site visits, analysis</p>			

of pertinent data, and communication with stakeholders.

During Fiscal Year 2015 (FY15), we completed 48 visits to the 4 training centers and 9 visits to HDMC. dLCV targeted the underserved, rural area of Southwestern Virginia by conducting 22 of the 48 Training Center visits at Southwestern Virginia Training Center (SWVTC), which serves that area.

DBHDS regularly provides dLCV with reports on “critical incidents” at state-operated facilities. These Critical Incident Reports (CIRs) detail incidents in which residents suffered injuries that required evaluation by a physician or physician extender. We reviewed 524 CIRs from DBHDS. This is an increase of 21 over last year’s reports. Although a modest increase, this occurred as the Training Center census was reduced nearly 25% in the same time. We regularly analyze data from CIRs and support that analysis by reviewing restraint data and census data. We monitored for any trends that might be of concern. dLCV also routinely requests autopsies and death summaries to provide additional review on unanticipated or suspicious deaths.

During meetings with DBHDS personnel, we identified errors and omissions in some reports and stressed the importance of timely and accurate reporting. The aforesaid DOJ settlement agreement includes language requiring DBHDS to conduct a review of all deaths; both in DBHDS facilities and in DBHDS licensed community programs. In three instances, dLCV found that DBHDS was not properly conducting Mortality Reviews.

#### “Untethered”

On the outside, this Training Center didn’t seem *that* bad. Unlike other Training Centers, it was newly-renovated and looked like a small, contemporary gated community. We monitored this facility regularly and none of the residents had anything bad to say. But something seemed... off. They congregated residents with behavioral problems in a small number of poorly staffed “homes.” During a monitoring visit in December, we noticed that Wallace—a resident of one of these “behavioral homes”—had a bed with metal loops on the sides. We asked Wallace about the loops, but all he would say is “they don’t like me.” After that visit, dLCV started requesting restraint data regularly. We charted this data over time and noticed that the facility was reporting a large number of “mechanical restraints.” dLCV contacted the facility and asked what “mechanical restraint” meant. The facility confirmed that this was code for Bed Restraint, or, the practice of using devices to essentially tie someone to their bed during a behavioral emergency. We were concerned: the other Training Centers didn’t report anywhere near this rate of bed restraint. Even if they had, bed restraint is a dangerous practice. Individuals restrained in this way can develop blood clots or other serious complications. We took our concerns to the facility’s director and advocated for less restrictive behavioral interventions. Thankfully, the director understood dLCV’s position and agreed that the facility should not be placing individuals in bed restraints. Shortly after voicing concerns, this Training Center ended their regular practice of bed restraint.

#### “Negligent Care and Inadequate Oversight: The Deaths of Jackie, Leo and Don”

In October of 2014, dLCV learned about the death of Leo, a long term resident of one of the Training Centers, through the CIR system. Leo was relatively young—only 48 years old—and his death raised alarms for dLCV advocates. dLCV obtained a copy of Leo’s autopsy report from the Office of the Chief Medical Examiner, and the results were shocking. Leo died of a hemoperitoneum—blood leaking into his abdomen—due to rectal perforation. The Medical Examiner noted that this perforation was consistent with the improper administration of a fleet’s

enema. We requested a Mortality Review from DBHDS to explain *exactly* how Leo sustained the rectal perforation that killed him. Both the Settlement Agreement and the Department's own internal policies require DBHDS to conduct a Mortality Review within 90 days of a death. Eight months after Leo's death, DBHDS still had not reported the findings of the Mortality Review Committee to dLCV or the Training Center. Leo is not alone. Mortality Review Process repeated these failures in both institutions and the community.

A month after Leo died, dLCV also learned about the death of Jackie, an 88-year-old long term resident of a DBHDS-Operated Nursing Facility. We had concerns about the death and opened an investigation into the matter. Jackie's autopsy from the Office of the Chief Medical Examiner listed her cause of death as "dehydration due to gastroenteritis." Despite the 90 day window, DBHDS waited four months to conduct the Mortality Review. When they finally met, the Mortality Review Committee determined that the Nursing Facility was feeding Jackie "too much food" through her tube; they also determined that Jackie had two separate orders for food. The Committee further concluded that no one followed up with Jackie's identified problems with swallowing food and liquid. Despite these significant findings, the Nursing Facility reported to dLCV that corrective action plans were not required as a result of Jackie's death and Mortality Review. dLCV conducted interviews, reviewed records, and ultimately determined that, again, DBHDS failed to complete Jackie's Mortality Review within the required 90-day window.

DBHDS' failures were not limited to large institutions. Only days after Jackie died, Don, a 29-year old man living in a DBHDS-licensed group home, died unexpectedly. The Medical Examiner determined that Don's cause of death was a stroke, with epilepsy being an underlying factor. Although he died in November, DBHDS waited until late February to initiate their Mortality Review. When they finally convened, the DBHDS Mortality Review Committee determined that neither the group home nor Emergency Services gave Don coumadin—an anti-clotting medication touted as "the standard of care" for someone having a stroke. They also found that the group home failed to get his medications filled during the 8-day period between his admission to the group home and the time he died. In spite of these significant findings, the DBHDS licensing specialist overseeing the group home reported to dLCV that she was unaware of any needed follow-up or corrective action resulting from Don's Mortality Review. Don was a long-time client of dLCV. Without this existing relationship, dLCV may have never known that Don had died, much less died under such worrying circumstances. The idea that there could be hundreds more people like Don—failed by both their providers and DBHDS oversight—has driven much of dLCV's systemic work over the past year.

dLCV determined that these failures were indicative of a larger systemic trend and addressed them that way. dLCV wrote a scathing letter to the Commissioner of DBHDS, notifying her of our findings and requesting immediate corrective action. We also shared Jackie and Leo's stories with the Department of Justice and Independent Reviewer—the entities responsible for overseeing the Settlement Agreement. The Department of Justice recognized the monumental nature of these failures and incorporated dLCV's findings into their recent arguments before the court on the timeline of the Settlement Agreement.

By disseminating their findings to the stakeholders involved, dLCV shed light on the systemic quagmire that is DBHDS Mortality Review system. Change is in motion. Without dLCV's intervention, the authorities responsible for licensing, overseeing, and regulating the facilities that killed Don, Jackie and Leo would not be aware of the problems that led their deaths to be "swept under the rug." dLCV can't bring Don, Jackie and Leo back, but we have done everything

possible to make sure that their deaths were not in vain.	
<i>Choose performance measures from Part III here for activity described above in this Results Narrative</i>	
<b>Performance measurement</b>	<b>Number</b>
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

**6. Results Narratives (cont.)**

*List goal and priority #(s) addressed in the activity described in the narrative below.*

Goal #(s): 1	Priority # 2: <b>Protection from Harm in Community Settings</b>
Collaborator(s): Virginia Department of Behavioral Health and Developmental Services (DBHDS); United States Department of Justice; US v. VA Settlement Agreement Independent Reviewer, Group Home staff, Adult Protective Services Agencies	
Underserved/Unserved/Minorities Targeted? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <i>(If yes, describe in narrative).</i>	

**Unnecessary and Dangerous Use of Force**

In FY 2013, George’s mother asked dLCV to assist her when her son was tasered repeatedly at a local emergency room. George, a young man with autism, resides in a community residential home. Group home staff transported him to the emergency room for stitches and while waiting, he became impatient in the strange environment and began making loud noises and pacing. An off-duty officer from the local police department was in the emergency room and ordered George to sit down and remain quiet, despite the fact that George was not harming anyone. The officer’s stern commands further escalated George’s behavior and George crawled under a desk in the waiting room. The officer yelled at him to come out and be quiet. George did not comply and the officer used his taser repeatedly on him. dLCV investigated the incident and determined there was a general lack of communication from all parties that led to this unfortunate and preventable situation. dLCV collaborated with the group home provider and the hospital staff creating a policy requiring the group home to communicate with the hospital prior to arrival with its residents to discuss any necessary accommodations. This policy ensures humane and adequate treatment at the hospital for George and many others. dLCV connected the local police department with Crisis Intervention Training for its officers as well.

**Can Anybody Hear Me?**

Abigail is an individual with an intellectual disability, deafness, and cerebral palsy. In FY 2014, Abigail’s sister called to report that Abigail refused to return to her group home because of alleged abuse there. The sister also reported that she witnessed staff acting in an inappropriate manner and making threats of using corporal punishment. Abigail went to a START (Systemic, Therapeutic, Assessment, Respite, and Treatment) home as a safe alternative while dLCV and Abigail’s interdisciplinary team figured out how to resolve the issues.

In the course of our investigation, we determined that the group home had violated Abigail’s rights in several ways, including failing to provide a sign language interpreter or having staff who communicate through American Sign Language. dLCV worked with Abigail’s team to find a suitable group home to communicate with her in her primary language and monitor that transition to her new environment. dLCV continues to monitor the original group home for violations of civil and human rights.



Choose performance measures from Part III here for activity described above in this Results Narrative

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

**6. Results Narratives (cont.)**

List goal and priority #(s) addressed in the activity described in the narrative below.

Goal #(s): 1	Priority # 3: <b>Protection from Harm in Community or Institutional Settings Serving Children or Adolescents</b>
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Collaborator(s): Office of Licensure, DBHDS Office of Human Rights, Local Human Rights Committees, The U.S. Department of Education

Underserved/Unservd/Minorities Targeted?  Yes  No (If yes, describe in narrative).

dLCV conducted monitoring visits at all long-term care residential facilities for children, met with leadership, and toured each facility across Virginia during FY15. dLCV educated each long-term care residential facility about dLCV’s mission and services, including dLCV’s Children’s Facility Monitoring Program. Through education and outreach, dLCV advocates provided information to approximately 160 staff and 140 children and youth. Federal regulations for Psychiatric Residential Treatment Facilities (PRTFs)—which serve children with mental illness, intellectual disability, developmental disability, or some combination of these diagnoses—require reporting of serious incidents to dLCV. As a result of dLCV outreach, incident reporting by PRTFs increased by 50% this year. dLCV’s diligent work with clients in institutions and community settings not only benefitted individual clients, but led to larger, systemic reforms helping children and adolescents across the Commonwealth.

“A Child’s Right to Safety and Dignity”

A 7-year-old’s life should be full of fun, playtime and daydreaming. Keith, a 7 year old boy diagnosed with developmental, intellectual, and physical disabilities, lived a life of suffering, loneliness, and fear. Keith’s mother called dLCV to report that a long term care residential facility in the Tidewater area neglected and abused her son. They restrained Keith in his bed day and night for staff convenience. As a result, Keith hurt himself and ate things that weren’t food and were dangerous to consume out of boredom, loneliness, and frustration. dLCV investigated and substantiated physical abuse, neglect, and a plethora of other rights violations, including violations of basic human dignity.

dLCV filed a formal Human Rights Complaint on behalf of Keith and represented him through the formal Human Rights Complaint Process. We acquired a corrective action plan for Keith’s care. The facility agreed to no longer leave Keith in his bed during non-sleep hours; provided him with a one-on-one aide; collected data on his eating and sleeping schedules and worked to facilitate normal schedules. Finally, they transitioned Keith to a less restrictive bed. This corrective action plan addressed the individual needs of the client, the lack of staff interaction and use of restraint on a systemic level.

Because of dLCV’s intervention, Keith was able to stabilize in a safe, therapeutic environment. dLCV also gave Keith’s mother the tools she needed to continue to advocate for her son.

“Negotiating for an Effective Transportation Plan”

Lynn requested help for her grandson, Logan, a 14-year old boy using a wheelchair for mobility

issues from cerebral palsy. Aides and the driver on his bus repeatedly abused and neglected Logan. According to Lynn, on the first day of school, the driver and aide moved Logan's wheelchair ramp before he was entirely on the bus. This caused him to flip backwards and hit his head. Lynn told us that staff on the bus frequently restrained Logan, which was contrary to his doctor's advice and led to wounds and skin irritation. Despite Lynn's strenuous advocacy for her grandson, the school refused to fix the situation. Lynn needed an ally.

dLCV met with the school and Lynn to negotiate an effective transportation plan. We successfully helped Lynn advocate for better safety and support on the school bus. The school agreed to inspect the bus and make sure that the ramp and safety straps were adequate. They set up a time for Lynn to come to the school and inspect Logan's safety herself. Finally, Logan received a special blanket from home to use on the bus, adding to his sense of security and safety. A strong communication plan is in place for any future issues. Logan now feels safe and supported at school.

*Choose performance measures from Part III here for activity described above in this Results Narrative*

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

## Other Qualitative Narrative Related to the Above Goal

*Significant activity for which there were no quantifiable results goes here.*

### Describe any other significant activity related to this goal

dLCV filed a complaint with the Office of Licensing concerning one long-term care residential facility. We will address conditions and safety hazards at this facility in the next fiscal year. Nine (9) PRTFs did not report any critical incidents, which indicates they are not in compliance with the federal regulations. dLCV will follow-up with these facilities to address this apparent failure to report.

dLCV reviewed and analyzed all reports from PRTFs to identify any trends or patterns to guide our outreach and monitoring.

dLCV receives reports of Adult Protective Services (APS) investigations from many local Social Services and each of these reports are reviewed by at least one staff person for viable cases, possible areas of collaboration with Social Services, and trends in the community. We review APS reports stemming from investigations of incidents in community day programs and in congregate residential settings. We use this information to open investigations or cases where Social Services cannot intervene to bring about change and also to inform our community monitoring activities throughout the year. We opened five service requests based on APS reports in FY 15.

dLCV conducted monitoring visits at four of the five local crisis services programs operated under START (Systemic, Therapeutic, Assessment, Respite, and Treatment) or REACH (Regional Educational Assessment Crisis Response) to evaluate the programs for safety and community integration. Through our work in these programs and the contacts we made through our visits, we determined that a major inadequacy that impacts a large number of individuals is a lack of understanding and services for individuals with dual diagnosis of intellectual disability and mental health issues. As a result of this work in FY 15, we created a major impact project in FY 2016 focusing on dually diagnosed individuals.

### 1. Goal Number: 2

**Goal Statement:** Children with Disabilities Receive an Appropriate Education

### 2. Priorities *(Add rows below if needed)*

#	Priority
1	<b>Educational Services</b>
2	<b>Children who are Suspended</b>

### 3. Strategies Used to Implement Goal and Address Priorities *(Check all that apply below)*

<input type="checkbox"/> Collaboration	<input type="checkbox"/> Systemic Litigation
<input checked="" type="checkbox"/> X Rights-Based Individual Advocacy Services	<input type="checkbox"/> Educating Policy Makers

<input type="checkbox"/> Investigations of Abuse and Neglect	<input checked="" type="checkbox"/> Other Systemic Advocacy		
<input type="checkbox"/> Monitoring	<input checked="" type="checkbox"/> Training/Outreach		
<b>4. Extent to Which Goal was Achieved</b> (Check one below)			
<input type="checkbox"/> Not Achieved	<input checked="" type="checkbox"/> Partially Achieved	<input type="checkbox"/> Achieved	<input type="checkbox"/> No Results This Year
<b>5. Stage of Implementation</b> (Check one below)			
<input type="checkbox"/> Planning	<input type="checkbox"/> Initiation	<input checked="" type="checkbox"/> Implementation	Outcome/Fully Integrated

**6. Results Narratives (cont.)**

List goal and priority #(s) addressed in the activity described in the narrative below.

Goal #(s): 2	Priority #1: <b>Educational Services</b>
Collaborator(s): Independence Empowerment Center, Manassas Park Transition Fair, Commonwealth Connects Resource Fair, Amelia Street School	
Underserved/Unserved/Minorities Targeted? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No (If yes, describe in narrative).	
<p><b>Restraint Is Not in the Curriculum</b>  John is a 7-year-old with ADHD and ODD. John’s mother contacted dLCV after he was reportedly dragged down the hallway by his gym teacher, pulled by the arms by two teachers, pushed into a classroom, and then restrained by his special education teacher. The principal called his mother to pick John up after the special education teacher had been holding John in a chair with his arms and legs wrapped around him for over 20 minutes. The school staff could not explain what started the incident. The school suspended John for 4 days. This was his second suspension this school year, totaling 7 days, with no Functional Behavioral Assessment or Behavior Intervention Plan in place. The school also failed to convene an IEP meeting as requested by John’s mother.</p> <p>dLCV provided John’s mother with extensive assistance empowering her to file an Office of Civil Rights (OCR) complaint of abuse, prepare for the pending Individualized Education Program (IEP) meeting, and negotiate with the school. At the IEP meeting, the school admitted to the abuse and acknowledged that the Manifestation Determination Review (MDR) team found the behavior was a manifestation of disability based on the school's failure to appropriately implement the IEP. John now has adequate behavioral supports to avoid incidents in the future.</p> <p><b>1:1 Means 1:1</b>  James is a nine-year-old boy with autism who does not communicate verbally. James engages in self- injurious behavior (SIB) at school, including head banging and hitting his head with his fists causing many severe injuries, including fractures. Due to his severe and dangerous behaviors, James spent 4 weeks at the Kennedy Krieger Institute’s self-injury program and received intensive evaluation and treatment. The team there developed a comprehensive Applied Behavior Analysis (ABA) program to appropriately address his needs. With dLCV’s assistance, James’ teachers and IEP team agreed to fully incorporate this new ABA plan into his IEP along with the requirement that James have a 1:1 aide with dLCV’s assistance. Due to dLCV’s advocacy, James received appropriate behavioral supports and services.</p> <p><b>Finding a Happy Place</b>  Andrew is a 6<sup>th</sup>-grade student diagnosed with Autism, ADHD, and Pediatric Bipolar Disorder. He received multiple suspensions because the school failed to follow his Behavior Intervention Plan (BIP) or his IEP. dLCV intervened and the school determined Andrew’s behavior incident was a manifestation of his disability. dLCV also advocated for a more appropriate placement for the</p>	

child that met his needs. Andrew is thriving in his new placement with a trained 1:1 aide.

**Let's Get All the Facts Before We Bus Him Across Town**

Martin is a kindergartner diagnosed with Autism and speech disorder. He experienced several episodes of restraint in school before the school proposed placement in an autism class in a non-neighborhood school. The school proposed this restrictive placement despite the fact that they had not done a Functional Behavioral Assessment (FBA) and Martin was only in the school for 15 incomplete days. Martin's mother did not agree with the plan for placement in a more restrictive environment and the school requested mediation to resolve the issues. dLCV represented Martin and his mother and advocated for revising the IEP to include measurable goals and data-collection protocols, advocated for more positive behavior interventions, and secured a comprehensive FBA and assistive technology evaluation. Due to dLCV's advocacy at the mediation meeting, the school and Martin's mother produced a written agreement and an addendum to his IEP and Martin successfully transitioned from home-bound instruction to regular school attendance. dLCV monitored the transition until Martin returned to school. His mother reports that, after meeting Martin's new teacher and staff, she is confident that the new teacher and staff know what they are doing and Martin is excited about going to school for the first time this school year.

*Choose performance measures from Part III here for activity described above in this Results Narrative*

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

**6. Results Narratives (cont.)**

*List goal and priority #(s) addressed in the activity described in the narrative below.*

Goal #(s): 2	Priority #2: <b>Children who are Suspended</b>
Collaborator(s): None	
Underserved/Unserved/Minorities Targeted? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <i>(If yes, describe in narrative).</i>	

**The Right Placement Makes All the Difference**

Zachary, a 9-year-old boy with Autism and mental health issues, attended an alternative school after he left an inpatient mental health facility. His mother called dLCV with concerns over the school's failure to follow Zachary's BIP, his regression since starting at the alternative school and the school's frequent use of seclusion to deal with his behavior. dLCV reviewed records, assisted Zachary's mother in requesting a Functional Behavioral Assessment and a classroom observation for possible placement in an Autism classroom, and attended an IEP meeting to advocate for the appropriate placement for Zachary. The IEP team placed Zachary in a classroom for children with Autism that meets all of his needs and he successfully transitioned into his new placement.

**Manifestation Determination Failures**

Millard is a 4<sup>th</sup>-grade student with behavior challenges in the school setting associated with ADHD. The school conducted a FBA and implemented a BIP to address Millard's aggressive behaviors after 10 suspensions in one semester. The school proposed an alternative placement and Millard's mother refused. Recent MDRs found Millard's behavior not to be a manifestation of

his disability, even though his BIP addresses the exact aggressive behavior he demonstrated. Millard’s mother contacted dLCV to represent her in challenging the MDRs through due process and advocate against the school’s recommendation for a restrictive placement through mediation. dLCV filed for a due process hearing to challenge two MDRs and the school division offered an administrative review of the two MDRs as an alternative to due process. dLCV withdrew the request for due process and represented Millard at the administrative review and successfully overturned both MDRs. dLCV represented Millard in mediation and successfully negotiated for him to receive a fresh start in his elementary school. dLCV also successfully negotiated an independent FBA to draft an appropriate BIP to support Millard as he moves forward in a safe environment with the right supports in place.

*Choose performance measures from Part III here for activity described above in this Results Narrative*

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

### Other Qualitative Narrative Related to the Above Goal

*Significant activity for which there were no quantifiable results goes here.*

#### Describe any other significant activity related to this goal

dLCV developed a special education online advocacy guide for parents involved in Virginia's special education system. This online resource walks parents through the steps of identification, evaluation, IEP drafting, effectiveness of services, discipline issues, and assists parents to understand these processes and gain self-advocacy skills. The resource also assists on-duty advocates as they provide valuable information to parents navigating this complex system.

dLCV provided training to over 200 parents, students, and advocates through 5 presentations around the state. Audiences included a group of Spanish-speaking parents at the Independence Empowerment Center, a group of parents at the James Street County Library, a group at the Manassas Park Transition Fair, a group at the Commonwealth Connects Resource Fair, and a group at the Amelia Street School Open House. The presentations provided participants with practical information on challenges acquiring appropriate special education services and supports, parent rights, student rights and school division responsibilities.

#### 1. Goal Number: 3

**Goal Statement: People with Disabilities have Equal Access to Government Services**

#### 2. Priorities *(Add rows below if needed)*

#	Priority
1	<b>Access to State and Federal Government Services</b>

<b>3. Strategies Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>			
<input type="checkbox"/> Collaboration	<input type="checkbox"/> Systemic Litigation		
X Rights-Based Individual Advocacy Services	<input type="checkbox"/> Educating Policy Makers		
<input type="checkbox"/> Investigations of Abuse and Neglect	X Other Systemic Advocacy		
<input type="checkbox"/> Monitoring	<input type="checkbox"/> Training/Outreach		
<b>4. Extent to Which Goal was Achieved</b> <i>(Check one below)</i>			
<input type="checkbox"/> Not Achieved	<input type="checkbox"/> Partially Achieved	X Achieved	<input type="checkbox"/> No Results This Year
<b>5. Stage of Implementation</b> <i>(Check one below)</i>			
<input type="checkbox"/> Planning	<input type="checkbox"/> Initiation	X Implementation	<input type="checkbox"/> Outcome/Fully Integrated

**6. Results Narratives** (cont.)

List goal and priority #(s) addressed in the activity described in the narrative below.

Goal #(s): 3	Priority #(s): <b>Access to State and Federal Government Services</b>
Collaborator(s): None	
Underserved/Unserved/Minorities Targeted? X Yes <input type="checkbox"/> No <i>(If yes, describe in narrative).</i>	
<p>During FY15, dLCV worked to help individuals with intellectual and developmental disabilities access government benefits. An area of great need is access to Social Security. For these individuals—many of whom are not able to work 40 hours per week—Social Security benefits are truly a lifeline. Throughout the year, we receive hundreds of calls from Virginians with disabilities who want to know about their right to Social Security Benefits, as well as the benefit determination process. While we provide case services and short term assistance to many of these callers, the community’s need for information is so great that we had to broaden our reach.</p> <p>dLCV created a series of Social Security Self-Help Guides to educate new and prospective beneficiaries. These guides provide in-depth information about the typical stages of a Social Security income disability claim and tips on how to apply and appeal; how the Social Security Administration makes the decision; tips on how to improve your claim; and how to maintain benefits. We posted this guide to the dLCV website under a new publication category called Social Security Self-Help, with direct links to key SSA webpages for easy interface.</p> <p>“Now That He's 18, is He Still Disabled?”  Social Security completes an “Age 18 Redetermination” when a child on Supplemental Security Income (SSI) turns 18 and becomes a legal adult. As an adult, the Social Security Administration (SSA) determines if the individual is eligible for this benefit, based on the <i>adult</i> rules. This process is stressful under the best of circumstances, but especially so when it comes at a time when the young person is graduating from high school and beginning to explore the world of work.</p> <p>Duncan, a young man with a developmental disability, had a hard time navigating this redetermination process. He simply wanted to work. He participated in a supported employment program, but SSA said this made him ineligible for benefits. After redetermination, SSA denied Duncan any further benefits. He appealed this decision, but SSA turned them down again. Duncan needed help from an advocate. dLCV worked with Duncan and his mom to understand his situation and educate them on the next steps of the Redetermination process. Duncan</p>	

appealed the second denial and dLCV helped him prepare for the appellate hearing. He awaits the decision with knowledge he completed the strongest application possible thanks to dLCV.

*Choose performance measures from Part III here for activity described above in this Results Narrative*

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

### Other Qualitative Narrative Related to the Above Goal

#### Describe any other significant activity related to this goal

How do I get in?

dLCV identified five voter registrar's offices with accessibility issues and negotiated resolution.

Prince Edward County addressed several barriers to access, including fixing a steep slope that threatened the safety of individuals using a wheelchair and creating a new, unobstructed path through the grass to make it easier for individuals to get from accessible parking spots to the entrance.

Isle of Wight County administration accepted suggestions for making their space more accessible, including putting signs that point individuals in the direction of accessible entrances.

Alleghany County is in the process of repaving and restriping the parking lot so that they will be in compliance with ADA requirements. They are constructing an ADA compliant entrance ramp to the building. The county also indicated anticipated upgrades to the bathrooms as budgeted in the fiscal year 2017 capital improvements cycle.

The Charles City County Administrator agreed to address concerns regarding accessible parking spaces, and accessible parking signage including penalty language.

The City of Danville indicated that their office is now compliant with ADA Accessibility Guidelines and Virginians with Disabilities Act.

dLCV was able to educate and develop relationships with county administrators and actually provoke physical structure change to improve accessibility for everyone.

**1. Goal Number: 4**

**Goal Statement: People with Disabilities Live in the Most Integrated Environment**

**2. Priorities** *(Add rows below if needed)*



#	Priority		
1	<b>Settlement Agreement in U.S. vs. Commonwealth of Virginia</b>		
2	<b>Maximize Individual Choice and Self-Direction</b>		
<b>3. Strategies Used to Implement Goal and Address Priorities (Check all that apply below)</b>			
X Collaboration	<input type="checkbox"/> Systemic Litigation		
X Rights-Based Individual Advocacy Services	<input type="checkbox"/> Educating Policy Makers		
<input type="checkbox"/> Investigations of Abuse and Neglect	X Other Systemic Advocacy		
X Monitoring	X Training/Outreach		
<b>4. Extent to Which Goal was Achieved (Check one below)</b>			
<input type="checkbox"/> Not Achieved	X Partially Achieved	<input type="checkbox"/> Achieved	<input type="checkbox"/> No Results This Year
<b>5. Stage of Implementation (Check one below)</b>			
<input type="checkbox"/> Planning	<input type="checkbox"/> Initiation	X Implementation	<input type="checkbox"/> Outcome/Fully Integrated

**6. Results Narratives (cont.)**

List goal and priority #(s) addressed in the activity described in the narrative below.

Goal #(s): 4	Priority #(s): <b>Settlement Agreement in U.S. vs. Commonwealth of Virginia</b>
Collaborator(s): Virginia Department of Behavioral Health and Developmental Services (DBHDS); United States Department of Justice; US v. VA Settlement Agreement Independent Reviewer, Group Home staff, Adult Protective Services Agencies	
Underserved/Unserved/Minorities Targeted? X Yes <input type="checkbox"/> No (If yes, describe in narrative).	
<p>dLCV conducted monitoring visits at over 30 community residential and day support programs located throughout the state from far southwestern Virginia to the Eastern Shore, from Winchester to Franklin and the Northern Neck. We selected the programs based on geography, the number of individuals served (approximately 350) and previous reports or concerns. During the visits, staff completed a survey about physical safety and community integration through observation and interviewing staff and participants. We provided information on dLCV, the client assistance program (CAP) and assistive technology (AT) services. dLCV used the information gathered during these visits to draft a report detailing problems in the community. Issues discovered included community oversight, funding for specialized services, basic physical accessibility, and true community integration.</p> <p>dLCV conducted monitoring visits in 10 licensed vocational, work, or prevocational programs provide services to more than 300 people. These programs are located in all parts of the state from northern Virginia to southwest Virginia and the Shenandoah Valley. One-third of the locations come from reports we received from Adult Protective Services. Our observations indicate that the programs, for the most part, are not truly community integrated. Some programs demonstrated an attempt to convert to a more community-integrated model and others operate both a segregated day and vocational program.</p>	
Choose performance measures from Part III here for activity described above in this Results Narrative	
<b>Performance measurement</b>	<b>Number</b>
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

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**6. Results Narratives (cont.)**

List goal and priority #(s) addressed in the activity described in the narrative below.

Goal #(s): 4	Priority #(s): <b>Maximize Individual Choice and Self-Direction</b>
Collaborator(s): Children’s Hospital of Richmond, Partnership for People with Disabilities, Region Ten Community Services Board, Charlottesville High School	
Underserved/Unserved/Minorities Targeted? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No (If yes, describe in narrative).	
<p>The Eyes Have It! Woodrow has lived in a children’s nursing home since a car accident at the age of 7 caused quadriplegia and ventilator and g-tube dependency. He is 18-years-old, communicates via eye blinks, and uses an eye-controlled computer system. As he approached the age of majority, his mother and staff at the children’s facility began to discuss options for his future, including supported or substitute decision-making options. His mother adamantly opposed guardianship even though Woodrow needs significant support in all areas of daily living, including decision-making and communication. Although his mother and his attending staff at the facility can communicate with Woodrow, once he leaves the facility, he faces many obstacles to get his needs understood and met. The chaplain at the facility referred the family to dLCV after learning about us through the Partnership for People with Disabilities, Virginia’s university center for excellence in developmental disabilities. dLCV met with Woodrow and his mother to discuss their options for supported decision-making as an alternative to guardianship. After learning Woodrow’s communication system, we found that he is able to communicate quite effectively with eye movements, blinking and facial expressions. He was very clear about what he wanted regarding a Power of Attorney. We drafted his advance directive based on his stated wishes and helped him avoid an unnecessary guardianship. After the meeting with Woodrow, we met with the facility’s chaplain and social worker to discuss how they can better assist other patients with needs similar to Woodrow’s. We provided them with forms and information to help other young individuals avoid unnecessary guardianship.</p> <p>Just Because I Cannot Speak Does Not Mean I Have Nothing to Say! Lucy called dLCV to discuss alternatives to guardianship for her granddaughter Lucretia as she neared the age of majority. Lucy has been Lucretia’s primary caretaker since birth and she assumed she would always make decisions for her due to Lucretia’s significant disabilities, including Autism, Intellectual and Cognitive Disabilities, and inability to communicate verbally. She was shocked to learn that at the age of 18, she could no longer legally make decisions for Lucretia without some sort of legal document such as a Power of Attorney or guardianship. We met with Lucretia, her grandmother and her case manager to educate them on the legal rights of an adult in Virginia and options for supported decision making. At this meeting, dLCV was unable to establish any system to communicate with Lucretia and it seemed that any alternative based on her capacity to consent, such as Power of Attorney, would not be possible. Lucy agreed and thought it was a waste of time to even try to talk about such options with Lucretia. The case manager stated that Lucretia’s teacher had recently referred her to the school’s speech therapist to explore assistive technology (AT) options for communication. She offered to talk to the therapist to see if we could try using AT to assist in this process. A few weeks later, dLCV attorney met with Lucretia, Lucy, the case manager and the therapist at the school to talk about supported decision-making options again. Based on the previous meeting, dLCV did not expect the meeting to be very productive. However, using an iPad and an augmentive communication program, Lucretia was able to “voice” her choices several times in response to varying questions asked by the dLCV attorney. After answering the questions several times,</p>	

Lucretia very clearly indicated she had had enough and wanted to take a walk! There was not a dry eye in the room! We drafted a Health Care Power of Attorney based on Lucretia's beautifully stated wishes.

**Sometimes "No" Is the Best Answer**

Caroline requested assistance drafting a healthcare power of attorney. Staff met with Caroline and her mother Eleanor at their home in Northern Virginia to discuss what Caroline wanted. Caroline clearly stated her preferences for agent designations and other medical issues. When Caroline left the room to go the bathroom, Eleanor looked at dLCV's blank advance directive document and stated, "This isn't what I asked for." She then stated that she wanted a power of attorney document that would give her authority to make ALL of Caroline's medical decisions, even those that Caroline had the capacity to make. dLCV explained that under the Virginia Healthcare Decisions Act, an agent's authority under a health care power of attorney does not engage unless the principal lacks capacity to make a decision. dLCV refused to create a document directed by a third party and inconsistent with dLCV's goal of maximizing individual choice and self-direction. Eleanor quickly ended the meeting and said that she would "find someone else" to write the document she wanted. We hope she does not.

*Choose performance measures from Part III here for activity described above in this Results Narrative*

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

**Other Qualitative Narrative Related to the Above Goal**

*Significant activity for which there were no quantifiable results goes here.*

**Describe any other significant activity related to this goal**

dLCV completed extensive monitoring of community residences, day support programs, 14(c) certificate holders, and adult protective services reports and analyzed this data in conjunction with expectations under the settlement. dLCV prepared a report on its findings for submission to the Independent Reviewer and the oversight agency. From our monitoring work, dLCV has determined that the primary issues with community oversight are the organizational structure of the oversight agency, insufficient regulations and inadequate training. The system of community oversight is overstretched and insufficient to provide ample oversight.

We provided three presentations reaching 53 individuals at day support, community residential and 14(c) locations with information on dLCV services, general rights in the community, community integration, and assistive technology. We discussed examples of community integration at each program we visited, as well as ideas for innovative options. We shared our bag of assistive technology samples and discussed ways to enhance community integration.

**1. Goal Number: 5**

**Goal Statement: People with Disabilities have Equal Access to Appropriate and Necessary Healthcare**

<b>2. Priorities</b> <i>(Add rows below if needed)</i>			
<b>#</b>	<b>Priority</b>		
1	<b>Denial of Medicaid Services</b>		
2	<b>Access to Healthcare</b>		
<b>3. Strategies Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>			
<input type="checkbox"/> Collaboration		<input type="checkbox"/> Systemic Litigation	
<input checked="" type="checkbox"/> Rights-Based Individual Advocacy Services		<input type="checkbox"/> Educating Policy Makers	
<input type="checkbox"/> Investigations of Abuse and Neglect		<input checked="" type="checkbox"/> Other Systemic Advocacy	
<input type="checkbox"/> Monitoring		<input checked="" type="checkbox"/> Training/Outreach	
<b>4. Extent to Which Goal was Achieved</b> <i>(Check one below)</i>			
<input type="checkbox"/> Not Achieved	<input checked="" type="checkbox"/> Partially Achieved	<input type="checkbox"/> Achieved	<input type="checkbox"/> No Results This Year
<b>5. Stage of Implementation</b> <i>(Check one below)</i>			
<input type="checkbox"/> Planning	<input type="checkbox"/> Initiation	<input checked="" type="checkbox"/> Implementation	<input type="checkbox"/> Outcome/Fully Integrated

**6. Results Narratives** (cont.)

List goal and priority #(s) addressed in the activity described in the narrative below.

Goal #(s): 5	Priority #(s): <b>Denial of Medicaid Services</b>
Collaborator(s): None	
Underserved/Unservd/Minorities Targeted? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <i>(If yes, describe in narrative).</i>	
<p><b>Garden Variety Bathroom</b>  Warren’s parent contacted dLCV when the Department of Medical Assistance Services (DMAS) denied needed environmental modifications to his bathroom. Warren is a young man with multiple disabilities who cannot safely get in or out of his family’s bathtub. DMAS determined that it is more cost effective to provide a shower chair with a hand-held spray nozzle than to approve the modifications recommended by Warren’s physician. dLCV worked with Warren’s doctors and case manager to draft a letter of medical necessity justifying why a shower chair and hand-held shower head are not appropriate. After a year of trying to get the request processed, DMAS approved the modification. Now, rather than climbing over the edge of the family’s garden tub - something very dangerous not only for him but for his caregivers - Warren has a walk-in shower recommended by his doctors and is safe in his home.</p> <p><b>Double Trouble</b>  The mother of three children with a variety of disabilities came to our “Office Hours” program, expressing concern with barriers to the Elderly or Disabled with Consumer Direction (EDCD) Waiver. The mother received denial letters for both children and lost her appeal rights when the county provided the denial notice outside of the 30-day appeal period. dLCV worked with the parent to set up a new screening for the children, worked with the family to obtain letters regarding risk of nursing placement and attended the screening with her and her children. Two weeks after the screening, both children received approval for the waiver. Once approved, the little girl was able to begin ABA Therapy and her brother began receiving much-needed Occupational Therapy.</p>	

<i>Choose performance measures from Part III here for activity described above in this Results Narrative</i>	
<b>Performance measurement</b>	<b>Number</b>
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

**6. Results Narratives (cont.)**

*List goal and priority #(s) addressed in the activity described in the narrative below.*

Goal #(s): 5	Priority #(s): <b>Access to Healthcare</b>
Collaborator(s): the VA Association for Blind and Vision Impaired; VA Association for Deaf and Hard of Hearing; VA Medical Law Report; VA Board of Medicine; VA NAMI, VA ARC; and VOCAL Self-Advocacy	
Underserved/Unserved/Minorities Targeted? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <i>(If yes, describe in narrative).</i>	

dLCV worked to ensure access to healthcare for Virginians with disabilities and focused on education and systemic change. dLCV authored a comprehensive publication on effective communication in healthcare. dLCV distributed this publication to a number of community and professional organizations—including the Arc of Virginia, the Virginia Medical Law Report, and the Virginia Board of Medicine—for dissemination to their members and the community at large. dLCV and stakeholder groups distributed the publication to over 1500 individuals with disabilities, family members, and medical professionals. In addition to systemic work, dLCV provided a number of individuals with assistance and advocacy for their right to access healthcare.

**“EmPowering Veronica”**

Veronica had cancer and needed treatment. Despite her intellectual disability, she had been proactive and decided to make a Power of Attorney (POA) document, to help guide her doctors and consent to medical treatment, in case she became unable to communicate these decisions. In the State of Virginia, a POA only needs the author’s signature and two witnesses in order to be valid. Veronica’s Intellectual Disability didn’t make her ineligible to make a POA—in fact, her long history with healthcare providers probably made her *more* qualified to know what she would need in an emergency.

Despite Veronica’s dedicated preparation for a worst-case-scenario, Veronica’s providers failed her by refusing to honor her POA when it mattered. Veronica’s case manager, Lilly, contacted dLCV and informed us that Veronica’s doctor (and the medical center where he worked) refused to treat Veronica, claiming that she didn’t have a valid POA. They claimed that they didn’t have to honor the POA because it did not have ‘POA’ in the document’s heading and an attorney did not sign it. You, dear reader, may remember that *neither* of these things are required for the POA to be legally valid.

dLCV contacted the doctor and medical center and explained Veronica’s rights. While the provider was cagey and reluctant to provide treatment, dLCV ultimately swayed them. We spoke to the Risk Manager at the medical center and answered questions she had about the document until she felt comfortable with having Veronica reschedule her treatment at the facility. Thanks to dLCV’s advocacy, Veronica got the cancer treatment she needed.

*Choose performance measures from Part III here for activity described above in this Results Narrative*

Performance measurement	Number
N/A- Reports unavailable to detail splits- numbers consolidated in Section III	N/A

**Other Qualitative Narrative Related to the Above Goal**

*Significant activity for which there were no quantifiable results goes here.*

**Describe any other significant activity related to this goal**

dLCV developed a fact sheet on rights to health and mental health treatment in jail. We posted this information on the agency web page and shared it widely.

dLCV provided information and referral to many residents of Virginia’s Training Centers and their families, who were concerned about access to dental care in the community.

**Strength of Family**

Wraparound services are those designed to help children with serious mental health issues and behavior problems remain in the community. These children are at risk of placement in residential care for their own safety or that of family member. Through research and review of the Children's Services Act, dLCV put together a fact sheet outlining wraparound services to give families an introduction to the purpose, availability and funding available through this program. The fact sheet was published to dLCV’s website, distributed at conferences, and provided to families who receive services from dLCV.

dLCV provided an educational article on effective communication to five different community organizations for purposes of dissemination to their members and community at large: Virginia Association for Blind and Visually Impaired, Virginia Association for Deaf and Hard of Hearing, National Alliance on Mental Illness of Virginia, Arc of Virginia, and Virginia Organization of Consumers Asserting Leadership. These five organizations are statewide and have a far reach. The Virginia Medical Law Report and Virginia Board of Medicine also disseminated the article.

## B. Priority Setting Process<sup>1</sup>

Complete this section by providing a thorough description of how the P&A conducts priority setting process (e.g., methods) used to develop the goals and priorities for the fiscal years covered in your multiyear plan. Revise based on public input on an annual basis with the idea that major changes will be made when it is time for a new multiyear plan.

### 1. Means by which the P&A conducted data-driven strategic planning, including formal public input

(Check all that apply below)

Public Hearing	Public Comment	Experience	Focus Groups	Advisory Council(s)	Monitoring Visits	Research/Data
<input type="checkbox"/>	X	X	<input type="checkbox"/>	X	X	X

Narrative (describe how the P&A conducted data driven strategic planning):

dLCV launched a public input survey in FY 15 to obtain feedback on the FY 16 goals and focus areas. From 5/17/15 through 7/24/15, dLCV received 340 responses to our survey. This is an increase from the number of responses in previous years. dLCV's web-based survey continues to gain momentum. Twenty-two percent of responses came directly from individuals with disabilities. Twenty-six percent of responses were from parents or guardians. The remaining groups represented included family members, teachers, mental health professionals, and providers.

dLCV distributed surveys to the public via web, mailings and at facilities. dLCV staff, with input from the dLCV Board, PAIMI Advisory Council, public input survey, and past year work experience, also helped to develop Fiscal Year 2016 Goals, Focus Areas, and Objectives. The dLCV Board approved the Fiscal Year 2016 Goals and Focus Areas in September 2015.

The dLCV Board also held a Strategic Planning Retreat in the third quarter mediated by NDRN and discussed the future direction of the agency. A general consensus led us to develop long term goals for effective systemic advocacy and effective communication through the agency.

### 2. Number of days for public comment: 68

### 3. A copy of the proposed SGP for comment was provided to the:

State Council on Developmental Disabilities: Yes

The University Centers for Excellence in Developmental Disabilities Education, Research and Service: Yes

### 4. Describe efforts to assure diversity (disability, geographic, racial, etc.) in the data-driven strategic planning process

dLCV develops our work plan based upon the needs of the entire Commonwealth. We reached out to all of our active clients and multiple collaborators in all regions of the state to develop or plan.



For example, the monitoring work we complete at the Department for Behavioral Health and Developmental Services (DBHDS) Mental Health Hospitals and Training Centers allows us to keep track of the major developmental disability service providers and individuals' transition to the community.

### **3. Summary of Findings**

When it came to the issues most important to our survey respondents, access to quality mental health care services (14 %) comprised the largest and most significant percentage. Tied for second place are access to community programs and government services (10 %), housing (10 %), and access to assistive technology and health care (10 %). Following those were: special education (8 %), effective vocational rehabilitation services (7 %), employment rights (7 %), transportation (7 %), abuse and neglect in schools (5 %), access to buildings and community activities (4%), guardianship (4 %), abuse and neglect in the juvenile justice system (3 %), abuse and neglect in jails and prisons (1 %), and voter rights (1%).

### **4. Summary of How Data was used to Develop P&A Goals and Priorities (include how priority input used, including input from the DDC and UCEDD)**

The DDC and UCEDD received copies of our public input survey and distributed it to their networks. The input provided by the agencies and their constituents is valuable in planning our Goals and Focus Areas.

dLCV created a survey outcome report and provided it to all staff and the dLCV Board Public Input and Priorities Committee who used it to develop meaningful Goals, Focus Areas, and Priorities.

### **5. List of topic areas of additional priorities that would be listed but are not due to lack of resources.**

dLCV could complete work in many areas including transportation, increased monitoring, and housing if lack of resources were not an issue.

## **C. FY 2016 Statement of Goals and Priorities (SGP)**

*There are no changes to the SGP from prior year.*     *There are changes to the SGP (see below).*

<b>1. Goal Number: 1</b>	
<b>Goal Statement:</b>	
<b>People with Disabilities Free from Abuse and Neglect</b>	
<b>2. Priorities</b> <i>(Add rows below if needed)</i>	
<b>#</b>	<b>Priority</b>
1	<b>Protection from Harm in Adult Institutions</b>
2	<b>Protection from Harm in Adult Community Settings</b>
3	<b>Protection from Harm in Community or Institutional Settings Serving Children and Adolescents</b>
4	<b>Appropriate Services in Juvenile Correctional Facilities</b>
<b>3. Strategies to Be Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>	
X Collaboration	X Systemic Litigation
X Rights-Based Individual Advocacy Services	X Educating Policy Makers
X Investigations of abuse and neglect	X Other Systemic Advocacy
X Monitoring	X Training/Outreach
<b>4. Rationale for Adding/Changing Goal</b>	
N/A	
<b>5. Rationale for Adding/Changing Priorities</b>	
Priority 4 was added as a response to need in the community we received from public input	

<b>1. Goal Number: 2</b>	
<b>Goal Statement: Children with Disabilities Receive an Appropriate Education</b>	
<b>2. Priorities</b> <i>(Add rows below if needed)</i>	
<b>#</b>	<b>Priority</b>
1	<b>Educational Services</b>
2	<b>Children who are Suspended, Secluded or Restrained</b>
<b>3. Strategies to Be Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>	
<input type="checkbox"/> Collaboration	<input type="checkbox"/> Systemic Litigation
x Rights-Based Individual Advocacy Services	x Educating Policy Makers
<input type="checkbox"/> Investigations of abuse and neglect	x Other Systemic Advocacy
<input type="checkbox"/> Monitoring	x Training/Outreach
<b>4. Rationale for Adding/Changing Goal</b>	
N/A	
<b>5. Rationale for Adding/Changing Priorities</b>	
Priority 2 was modified to allow dLCV to stay active with the Virginia Department of Education development and implementation of regulations for seclusion and restraint in the school system. We intend to redirect individuals to our web based resources and reduce the number of total cases accepted.	

<b>1. Goal Number: 3</b> <b>Goal Statement: People with Disabilities have Equal Access to Government Services</b>	
<b>2. Priorities</b> <i>(Add rows below if needed)</i>	
<b>#</b>	<b>Priority</b>
1	<b>Architectural Barriers and Reasonable Accommodations</b>
2	<b>Access to Social Security Benefits</b>
<b>3. Strategies to Be Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>	
<input type="checkbox"/> Collaboration	<input type="checkbox"/> Systemic Litigation
<input checked="" type="checkbox"/> Rights-Based Individual Advocacy Services	<input type="checkbox"/> Educating Policy Makers
<input type="checkbox"/> Investigations of abuse and neglect	<input type="checkbox"/> Other Systemic Advocacy
<input type="checkbox"/> Monitoring	<input checked="" type="checkbox"/> Training/Outreach
<b>4. Rationale for Adding/Changing Goal</b>	
N/A	
<b>5. Rationale Adding/Changing Priorities</b>	
Public feedback and staff expertise led us to modify our priorities under this goal.	

<b>1. Goal Number: 4</b> <b>Goal Statement: People with Disabilities Live in the Most Integrated Environment</b>	
<b>2. Priorities</b> <i>(Add rows below if needed)</i>	
<b>#</b>	<b>Priority</b>
1	<b>Settlement Agreement in U.S. vs. Commonwealth of Virginia</b>
2	<b>Maximize Individual Choice</b>
<b>3. Strategies to Be Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>	
<input checked="" type="checkbox"/> Collaboration	<input checked="" type="checkbox"/> Systemic Litigation
<input checked="" type="checkbox"/> Rights-Based Individual Advocacy Services	<input checked="" type="checkbox"/> Educating Policy Makers
<input type="checkbox"/> Investigations of abuse and neglect	<input type="checkbox"/> Other Systemic Advocacy
<input type="checkbox"/> Monitoring	<input checked="" type="checkbox"/> Training/Outreach
<b>4. Rationale for Adding/Changing Goal</b>	
N/A	
<b>5. Rationale for Adding/Changing Priorities</b>	
N/A	

<b>1. Goal Number: 5</b> <b>Goal Statement: People with Disabilities have Equal Access to Appropriate and Necessary</b>
--

Healthcare	
<b>2. Priorities</b> <i>(Add rows below if needed)</i>	
#	Priority
1	<b>Denial of Medicaid Services</b>
2	<b>Access to Healthcare</b>
<b>3. Strategies to Be Used to Implement Goal and Address Priorities</b> <i>(Check all that apply below)</i>	
<input checked="" type="checkbox"/> Collaboration	<input type="checkbox"/> Systemic Litigation
<input checked="" type="checkbox"/> Rights-Based Individual Advocacy Services	<input type="checkbox"/> Educating Policy Makers
<input checked="" type="checkbox"/> Investigations of abuse and neglect	<input type="checkbox"/> Other Systemic Advocacy
<input type="checkbox"/> Monitoring	<input type="checkbox"/> Training/Outreach
<b>4. Rationale for Adding/Changing Goal</b>	
N/A	
<b>5. Rationale for Adding/Changing Priorities</b>	
N/A	

## D. Description of P&A Operations

**1. Provide a description of how the P&A operates. Include information on how the P&A coordinates the PADD program with other Protection and Advocacy programs administered by the State Protection and Advocacy System. This description must include the System's processes for intake, internal and external referrals, and streamlining of advocacy services.**

dLCV provides PADD advocacy services across all agency Units. Many projects and outreach efforts utilize multiple funding streams including PADD.

dLCV accepts requests for services on Mondays, Wednesdays and Fridays from 8:30am-4:00pm and during other outreach programs like 'Office Hours' at Centers for Independent Living and monitoring visits to Training Centers and community residential and day programs.

Requests come in via phone, in person, via e-mail, fax, and accepted in any other requested alternate formats including through the language line.

If the service request falls within the scope of our work plan in the fiscal year, the staff completing the request for services forwards it to the Team Manager who manages that specific priority category. For example, an abuse or neglect case involving a child is typically sent to the Children's Advocacy Unit. An abuse or neglect case in a large facility is typically sent to the Institutions Unit. Our Community Resources Unit typically manages an abuse or neglect case involving a small residential home (less than 6 residents).

Team leaders assign the service requests and projects to advocates and attorneys. Team

Leaders monitor and balance staff caseloads and project work.

dLCV refers issues or concerns outside of the P&As work plan to other community advocacy and legal entities. Advocates provide all individuals requesting assistance information and referral at a minimum.

**2. Will the System will be requesting or requiring fees or donations from clients as part of the intake process?**

- a. Yes
- b. No

**3. Collaboration and Coordination:**

- a. Describe how the P&A is collaborating with others in the State, including the DDC and UCEDD.

dLCV solicits feedback from the Partnership for People with Disabilities and Virginia Board for People with Disabilities during our public input survey effort. We also review public comment provided by the Board on DD issues to other state agencies.

The DDC (Virginia Board for People with Disabilities) and UCEDD (The Partnership for People with Disabilities) have pledged to support specific objectives and projects during FY 16. We anticipate close collaboration as we begin to develop an improved system for community monitoring and we develop extensive self-advocacy tool for youth who are coming of age.

- b. Describe how the P&A is reducing duplication and overlap of services and sharing of information on service needs.

The DDC, UCEDD and Protection and Advocacy System work closely together during the Virginia Legislative Session.

We participate in the Board's Youth Leadership Program providing an advocate to educate attendees on rights topics not covered by the other collaborators.

dLCV reviews the Board's public comment on regulatory actions and in some cases jointly participates in multi-agency feedback on actions utilizing non-federal funding.

All 3 network agencies share news and developments coming from sister agencies through social media contacts.

## Part III: Results of P&A Activity<sup>2</sup>

### Overarching Outcome Statement:

*People with disabilities exercise their civil, human, and legal rights.*

### A. End Outcomes of P&A Activity

By End Outcome

Performance Measurement	Number
1. People with disabilities who are provided with appropriate community based services resulting in community integration and independence.	16,752
2. People with disabilities who accessed benefits.	459
3. People with disabilities who live in a healthier, safer or otherwise improved environment.	590
4. People with disabilities who were able to stay in their own home.	1,093
5. People with disabilities who work in safer and more humane conditions.	0
6. People with disabilities who go to school in safer and more humane conditions.	15,055
7. Students with disabilities who stayed in school.	15,057
8. Children with disabilities receiving appropriate services in most integrated settings.	296
9. People with disabilities who had their other rights enforced, retained, restored and/or expanded.	746
10. Public and private places/services made more accessible.	46

By Intervention Type

End Outcome	Technical Assistance	Individual Advocacy <sup>3</sup>	Abuse & Neglect Investigations	Systemic Litigation	Educating Policy Makers	Other Systemic Advocacy
<i>On row below insert # from line to right</i>	Line III.I.2	Line I.A.3	Line I.N.1	Line 1.N.2	Line 1.N.3	Line 1.N.4
T.A.'s/Cases/Projects						
1	0	5	N/A	0	0	16,747
2	0	459	N/A	0	0	0
3	0	106	18			466
4	0	13	N/A	0	0	1,080
5	0	0	0	0	0	0
6	0	12	0	0	15,043	0
7	0	14	N/A	0	0	15,043

<sup>2</sup> Only those measures and subsections with data will be displayed when the report is submitted.

<sup>3</sup> Individual advocacy includes self-advocacy assistance, limited advocacy, administrative remedies, negotiation, mediation/alternative dispute resolution and litigation.

8	0	21	N/A	0	0	275
9	0	46	N/A	0	0	700
10	0	1	0	0	0	45
Total	0	697	12	0	15,043	34,356

## B. Overview of How Many People with Disabilities Served

Performance Measurement	Number
1. People with disabilities receiving individual advocacy services to exercise their civil, human and legal rights.	201
2. Abuse and neglect investigations to protect people with disabilities from abuse and neglect.	18
3. People with disabilities receiving information, technical assistance and referral services.	766
4. People with disabilities trained to become active participants in making decisions that affect their lives.	16,165
5. People whose rights were advanced through class and/or systemic impact litigation.	0
6. People with disabilities whose rights were enforced, protected or restored as a result of non-litigation group advocacy.	0
7. People with disabilities who received a lower level of services due to lack of P&A resources.	52
8. People with disabilities impacted by one or more provision(s) in law modified or prevented.	0

## C. Rights-Based Individual Advocacy Services

### Outcome Statements

- People with disabilities exercised their rights because of access to rights-based and/or legal advocacy services.
- The P&A protected rights of individuals with disabilities through legal and rights-based advocacy in accordance with the retainer agreement or similar agreement between the client and the P&A.<sup>4</sup>
- The P&A took action to protect the rights of people with disabilities to be free from abuse, neglect or discrimination.

Performance Measurement	Number
1. People with disabilities who had their rights enforced and/or restored.	121
2. People with disabilities who were assisted in obtaining access to administrative or	37

<sup>4</sup> As developed in the P&A Standards, it is understood that all client representation is provided consistent with applicable rules of professional conduct including rules regarding ethics and requirements for continuing education.

judicial processes.	
3. Closed cases in which client objective was met or partially met.	121

## D. Investigations of Abuse and Neglect

### Outcome Statement

- The P&A takes action to protect the rights of people with disabilities to be free from abuse and neglect.

Performance Measurement	Number
1. Investigations (not death related).	1
2. Investigations of abuse and neglect completed with a finding or determination ( <i>not including death investigations</i> ).	1
3. Death investigations.	17
4. Death investigations completed with a finding or determination.	17
5. People with disabilities who benefitted from the findings of investigations of abuse and neglect.	468
6. Provisions in policy added or prevented.	10

### Other Qualitative Narrative

Report additional information related to investigations not already reported in Part II.

N/A

## E. Monitoring

### Outcome Statements

- People with disabilities live, work and go to school in safe and humane conditions.
- People with disabilities are provided with appropriate community-based services so that they can live as independently as possible.

### Facilities/Programs Monitored

Unique Facility	Facility Type	Facility Capacity	Location (By County)	# of Visits	Court Ordered Monitoring? Yes/No
Central Virginia Training Center	DD Training Center	288	Amherst	10	No
Southeastern	"	75	Chesapeake	7	No



Virginia Training Center					
Southwestern Virginia Training Center	“	144	Carroll	22	No
Northern Virginia Training Center		107	Fairfax	9	No
Hiram Davis Medical Center		67	Dinwiddie	9	No
30 Community ID Day Support and Residential Providers	Waiver ID Residential and Day Support Providers	350	statewide	60	No

Total Number of Unique Facilities: 35

<b>Performance Measurement</b>	<b>Number</b>
1. People with disabilities whose living, working and/or other circumstances were monitored by P&A.	1031
2. Cases opened for health and safety issue investigation.	16
3. Health and/or safety violations validated by the P&A.	16
4. Rights violations (not health or safety and including quality of life) identified and addressed as a result of P&A monitoring.	6
5. Complaints referred to regulatory agencies or investigative organizations.	504
6. Times P&A access was denied during a monitoring/access attempt.	2
7. Times denial of P&A access was successfully resolved.	2

### **Other Qualitative Narrative**

A description of dLCV’s monitoring activities is in Part II of this report.

## F. Systemic Litigation

### Outcome Statements

- Rights of individuals with disabilities are advanced through class and/or systemic and/or systemic impact litigation.
- Through systemic or class litigation, obtain changes in policy, regulations and law that will benefit individuals with disabilities and/or prevent creation or implementation of policy, regulations or law that would harm individuals with disabilities.
- Settlements or judgments resulting from P&A systemic litigation positively impact the rights and interests of people with disabilities.

<b>Performance Measurement</b>	<b>Number</b>
1. Systemic or class action lawsuits handled for the benefit of people with disabilities.	0
2. Provisions in policy modified or prevented.	3
3. Provisions in regulation modified or prevented.	2
4. Provisions in law modified or prevented.	0
5. Lawsuits addressing systemic issues resolved by settlement.	0
6. Lawsuits addressing systemic issues resolved by judgment.	0
7. Amicus briefs signed onto or filed.	0
8. People with disabilities whose rights were advanced as a result of amicus participation.	0

## G. Educating Policymakers<sup>5</sup>

### Outcome Statement

- Statutes, ordinances and regulations will benefit individuals with disabilities.

<b>Performance Measurement</b>	<b>Number</b>
1. Communications to people with disabilities explaining a policy initiative.	15,043
2. People with disabilities supported in expressing their own viewpoint on a policy related matter.	85
3. Times written comments were submitted regarding proposed legislation or regulations.	0
4. Times testimony was provided at a legislative hearing.	15
5. Provisions in regulation modified or prevented.	0
6. People with disabilities impacted by the regulation provision(s) modified or prevented.	0
7. Provisions in law modified or prevented.	0
8. People with disabilities impacted by one or more provision(s) in law modified or prevented.	0
9. Provisions in ordinances modified or prevented.	0

## H. Other Systemic Advocacy

### Outcome Statement

The rights of individuals with disabilities are advanced through non-litigation group advocacy.

Performance Measurement	Number
1. Changes in practices made or prevented.	No report
2. Provisions in policy modified or prevented.	No report

## I. Information, Technical Assistance and Referrals

### Outcome Statement

- People with disabilities, family members and others will receive basic disability related information and referral services.

Performance Measurement	Number
1. People receiving information and referral services.	504
2. People receiving technical assistance.	262
3. Self-advocacy materials published or revised.	4
4. Self-advocacy materials distributed.	15,050

## J. Training

### Outcome Statements

- People with disabilities have the skills necessary to conduct effective self-advocacy.
- People with disabilities have knowledge necessary to be an effective self-advocate.
- Family members and additional groups are provided information about laws and policies affecting individuals with disabilities as the P&A determines useful.

Performance Measure	Number
1. People who report the training enhanced their knowledge and/or skill (was beneficial) at the completion of the training.	1,285
2. People with disabilities who received advocacy skills training.	1,122
3. People with disabilities who received rights training.	1,122

## K. Public Relations and Outreach

### Outcome Statements

- The public will become more aware of the existence and mission of the P&A.
- The public will become more aware of the content of disability rights laws and regulation and of disability rights issues.

Performance Measure	Number
1. Press releases issued.	5
2. Times a P&A representative was interviewed or featured on TV or radio.	0
3. Articles about the P&A or its work in external mass media such as newspapers, radio, podcasts, blogs or television.	13
4. Social media followers.	831
5. Absolute unique visitors to blogs/web pages where information about the P&A is posted.	15,043
6. Circulation of the P&A's newsletter and/or listserv updates.	0
7. Articles by the P&A about disability rights issues published in newspapers, books, journals or magazines.	0
8. Links to other disability rights related information sources published on the P&A website.	124
9. Times the P&A exhibited at conferences, community fairs, etc.	6
10. Presentations made to community groups.	42

### Other Qualitative Narrative

Describe any innovative or significant P&A activity related to public relations and/or outreach (to include unserved and underserved populations/communities, and outreach to self-advocates)

dLCV launched a video series this fiscal year titled 'Ask the Expert.' It focuses on providing information on important disability advocacy topics to the public. Our first two videos aired in FY 15 were 'Vocational Rehabilitation Rights and Services' and 'Employment Rights.' Although funded under other grants, these videos are invaluable to the DD population.

## Part IV: Collaborations

Use the boxes below to report on collaborative and coordination efforts with the following client assistance program (unless housed within the P&A), long term care ombudsman (unless housed within the P&A), developmental disabilities council, center(s) for excellence (university affiliated program) and any parent training centers. This is another place to describe collaboration with unserved/underserved communities/groups/populations and discuss collaboration with self-advocates. Optional: Add boxes to report on other major collaborations.

Check one or more of the following boxes if the P&A houses any of these programs.

<input checked="" type="checkbox"/> Client Assistance Program	<input type="checkbox"/> Long Term Care Ombudsman	<input type="checkbox"/> Parent Training Center
---	---	---

Name of Collaboration	Long Term Care Ombudsman
<p><b>Description of collaboration</b>            The Long-Term Care Ombudsman Program consists of the Office of the State Long-Term Care Ombudsman and 20 local offices located in area agencies on aging throughout the state providing direct service in their communities. The mission of</p>	

Virginia’s State Long Term Care Ombudsman Program is to serve as an advocate for older persons receiving long-term care services. Virginia Local Ombudsmen provide older Virginians and their families with information, advocacy, complaint counseling, and assistance in resolving care problems. The program also represents the interests of long-term care consumers before state and federal government agencies and the General Assembly. dLCV and the Ombudsman frequently educate and refer potential clients and families with issues regarding community barriers, discharge and abuse and neglect to each other for services.

**Role of P&A within the collaboration**

As Virginia’s training centers continue on the path to closure, dLCV remains committed to monitoring individuals discharged from these facilities and offer advocacy in coordination with the Long Term Care Ombudsman to ensure individuals understand their rights as they navigate a new world of community choices and independence.

<b>Name of Collaboration</b>	<b>DD Council</b>
<p><b>Description of collaboration</b>            The DD Council (Virginia Board for People with Disabilities, Partnership for People with Disabilities and dLCV) collaborate during Virginia’s General Assembly session regarding proposed legislation and budget issues that impacting people with disabilities.</p> <p><b>Role of P&amp;A within the collaboration</b>            Educating our partners and the public about dLCV and our continued mission to act as the protection and advocacy system for Virginia opens the door to serve the advocacy needs of Virginians with disabilities.</p>	

<b>Name of Collaboration</b>	<b>Disability Law Center of Virginia Foundation</b>
<p><b>Description of collaboration</b>            dLCV has partnered with the <b>Disability Law Center of Virginia Foundation</b> to develop a Special Education Manual and training curriculum to educate parents about navigating the special education system. Phase one of this project, completed in fiscal year 2013, resulted in the production of a pilot special education manual paired with a training. Phase two in FY 14 included a training in Virginia Beach to an estimated 13 parents and advocates. Phase three in FY 15 created a Special Education Rights publication to allow parents, students, and advocates to understand their rights.</p> <p><b>Role of P&amp;A within the collaboration</b></p>	

dLCV provided the presentations and created the materials to allow this program to grow. We are committed to continuing to provide opportunities to educate parents on understanding the complex special education system so students may be successful in the classroom.

*Add boxes as needed*

## Part V: Governance and Compliance

### A. Board, staff and advisory council race and ethnicity

Race/Ethnicity	Board	Employees	Advisory Council
1) Hispanic/Latino ( <i>of any race</i> )			N/A

Race/Ethnicity ( <i>NOT Latino/Hispanic</i> )			N/A
2) American Indian/ Alaskan Native			
3) Asian			
4) Black/African American	2	7	
5) Native Hawaiian/ Other Pacific Islander			
6) White	8	25	
7) Two or more races		1	
8) Race/Ethnicity Unknown			
<b>TOTAL</b>	10	33	

Describe advisory council if applicable

N/A

### B. Consumer involvement in P&A governance

	Board	Advisory Council

		<i>If Applicable</i>
PADD Eligible Primary Consumers	1	N/A
PADD Eligible Secondary Consumers	4	
Other Eligible Primary Consumers	3	
Other Eligible Secondary Consumers	2	
<b>TOTAL Membership</b>	10	

## Part VI: General Program Information

### A. P&A Identification

Name of state, territory or jurisdiction	Virginia
Name of P&A system	disAbility Law Center of Virginia

### B. Main Office

Mailing Address & Phone Number of Main Office	1512 Willow Lawn Drive, Suite 100, Richmond, VA. 23230  804-225-2042
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### C. Satellite Offices (If Any) (Add rows if needed)

Name, Mailing Address	N/A

### D. CEO Contact Information

Name, phone number, and email address of P&A CEO	<b>Colleen Miller</b> <b>804-225-2042</b> <b>Colleen.Miller@dclcv.org</b>
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### E. PPR Preparer Contact Information

Name, title, phone number, and email address of P&A Preparer	<b>Robert Gray</b> <b>804-225-2042</b> <b>Robert.Gray@dclcv.org</b>
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## Part VII: Definitions

### **Absolute Unique Visitor** (*pertaining to websites, blogs, etc.*)

The phrase “absolute unique visitor” is a term of art used in Google Analytics and similar applications. It represents the number of different people that visit a particular website or blog during a period of time specified by the user.

### **Abuse**

The term “abuse” means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes but is not limited to such acts as: verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations, or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue. In addition, the P&A may determine, in its discretion that a violation of an individual’s legal rights amounts to abuse, such as if an individual is subject to significant financial exploitation.

### **Administrative Hearing**

An administrative hearing is a case level of intervention where an individual is represented by the P&A in requesting, preparing for, or participating in a formal proceeding to challenge a decision within an agency or facility, or between agencies, which does not involve adjudication by a court of law.

### **Administrative Remedy**

An administrative remedy is where the P&A represents the client in any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative remedy processes are generally simpler, less formal, and less technical than the judicial process.

### **Advocacy Activities**

The term “advocacy activities” means active support of policies and practices that promote systems change efforts and other activities that further advance self-determination and inclusion in all aspects of community living (including housing, education, employment, and other aspects) for individuals with developmental disabilities, and their families.

### **Alternative Dispute Resolution**

Alternative Dispute Resolution (ADR) describes any process for settling a contested matter outside of the formal judicial process. ADR includes, but is not limited to negotiation, conciliation, mediation, and arbitration. ADR often includes the aid of a third, neutral party to guide the parties to a settlement.

### **Areas of Emphasis**

The term “areas of emphasis” means the areas related to quality assurance activities, education activities and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-



related activities, and other services available or offered to individuals in a community, including formal and informal community supports that affect their quality of life.

### **Case**

A matter in which a significant service is provided that is intended to benefit one or more eligible individuals with developmental disabilities. A case file must be established and maintained by the P&A in each such matter. Each case must have a documented client goal.

### **Capacity Building Activities**

The term “capacity building activities” means activities (e.g. training and technical assistance) that expand and/or improve the ability of individuals with developmental disabilities, families, supports, services and/or systems to promote, support and enhance self-determination, independence, productivity and inclusion in community life.

### **Client**

For the purposes of the PPR (but not necessarily for determining a client-attorney relationship), a client is an individual or group of individuals who meets three criteria: 1) he/she is eligible for the PADD program; 2) a file/service record has been opened which includes at least the name, address, age, race, disability, signed release of information form (if appropriate), the concern or complaint and the goal of the action to be taken; and 3) he/she has been provided at least one significant service.

### **Client Objective**

The result(s) a client(s) desires and the P&A has agreed to pursue as documented in a retainer agreement between the client(s) and the P&A.

### **Client Objective Met**

The result(s) a client(s) desired and the P&A agreed to pursue as documented in a retainer agreement was achieved, at least in part.

### **Closed Case**

The status of a case when the issue has been addressed through the provision of some level of service, the service is no longer needed, or the client is no longer available to address the issue(s) and the closed status is documented in the P&A case management system.

### **Collaboration**

An activity or set of activities the P&A undertakes with a community partner(s) to pursue a shared advocacy goal. For purpose of this report it includes working with federally funded entities identified in the P&A mandates to assure coordination of the activities between the entities and to avoid inappropriate or wasteful duplication of services. These entities include a state’s or territory’s client assistance program, long term care ombudsman, developmental disabilities council, center(s) for excellence (university affiliated program) and mental health agency. Reporting on these collaborations is mandatory.

It also includes coalitions, task forces, councils, etc. in which a P&A participates for the purpose of advocating for systemic reform. These can be ongoing or time limited collaborations. Reporting on these collaborations is optional.

### **Community Residential Setting**

A community residential setting optimizes autonomy, independence, and access to services and supports in the community in compliance with new Medicaid Home and Community Based Services regulations.

### **Complaint**

The term “complaint” includes, but is not limited to, any report or communication, whether formal or informal, written or oral, received by the P&A system, including media accounts, newspaper articles, electronic communications, telephone calls (including anonymous calls) from any source alleging abuse or neglect of an individual with a developmental disability.

### **Culturally Competent**

The term “culturally competent,” used with respect to services, supports, and other assistance means that services, supports, or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

### **Direct Representation**

Legally advocacy provided pursuant to a retainer agreement between a client and a P&A. The intervention types employed by the P&A in representing its client may include negotiation, administrative hearings and/or litigation.

### **Developmental Disability**

The term “developmental disability” means a severe, chronic disability of an individual that:

- (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (2) Is manifested before the individual attains age 22;
- (3) Is likely to continue indefinitely;
- (4) Results in substantial functional limitations in three or more of the following areas of major life activity:
  - (i) Self-care;
  - (ii) Receptive and expressive language;
  - (iii) Learning;
  - (iv) Mobility;
  - (vi) Self-direction;
  - (vii) Capacity for independent living; and
  - (viii) Economic self-sufficiency.
- (5) Reflects the individual’s need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
- (6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in paragraphs (1) through (5) of this definition, if the individual, without services and supports, has a high probability of meeting those criteria later in life.

### **Educating Policy Makers**

An essential strategy used to achieve systems change. Policy Makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individuals makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

### **End Outcome**

An end outcome is a quantitative performance measurement that expresses the ultimate benefit to the client.

### **Full Investigation** *(see also Investigation)*

The term “full investigation” means access to service providers, individuals with developmental disabilities and records authorized under these regulations, that are necessary for a P&A system to make a determination about whether alleged or suspected instances of abuse and neglect are taking place or have taken place. Full investigations may be conducted independently or in cooperation with other agencies authorized to conduct similar investigations.

### **Goal Statement**

A goal statement is a general but measurable declaration that describes a future state and gives the general direction, purpose or intent of what should be achieved. A goal statement explains the end result or specific desired outcome. A goal should include a description of the result and the entity/group for whom the result applies. Goals should ultimately be achievable.

### **Group Advocacy Services**

Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors.

### **Group Number Impacted** *(And the “At Least” Method of calculating an estimate)*

A specific unduplicated number of people impacted should be used with a “number impacted” performance measure when the number is known or a very close estimate is possible based on available data. For instance, you know all of the people on a particular ward of a hospital will benefit but the number of people on that ward varies slightly from day to day. Then a number close to the number usually present on that ward can be used.

If a close estimate is not possible based on available data but the range the number falls within can be determined and supported by available data, a number followed by a plus sign (+) from the following chart should be used in the “number impacted” performance measure. This method of estimation should also be used when a certain number of people could be impacted but it is not clear that they all will be impacted.

If the number is unknown and there is no available data to support the estimation, then a “number impacted” performance measure should not be used.

<b>Estimate</b>	<b>Range</b>
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<b>to Put in PPR</b>	<b>for what the estimate means</b>
1+	1-9
10+	10-99
100+	100-999
1,000+	1,000-9,999
10,000+	≥ 10,000

### **Inclusion**

The term "inclusion", used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enable individuals with developmental disabilities to have friendships and relationships with individuals and families of their own choice; live in homes close to community resources, with regular contact with individuals without disabilities in their communities; enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

### **Individual Advocacy Service**

Legal work on behalf of a client using one or more of the following intervention types: Self-advocacy assistance, limited advocacy, administrative remedies, negotiation, mediation/alternative dispute resolution, and/or litigation.

### **Individualized Supports**

The term "individualized supports" means supports that: enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life; designed to enable such individual to control such individual's environment, permitting the most independent life possible; and prevent placement into a more restrictive living arrangement than is necessary and enable such individual to live, learn, work, and enjoy life in the community; and include early intervention services, respite care, personal assistance services, family support services, supported employment services support services for families headed by aging caregivers of individuals with developmental disabilities, and provision of rehabilitation technology and assistive technology, and assistive technology services.

### **Information and Referral Service**

Information and referral includes responses to individuals at meetings, one-time telephone discussions, and follow-up mailings of letters, brochures and/or pamphlets per an individual's request. I&R includes brief written or oral information, such as, generic information about the P&A, including information about additional programs and resources external to the P&A relating to the individual's service needs and statutory or constitutional rights as a person with a disability. The agency generally would not have personal identifying information about the individuals who request and/or receive I&R services, except for possibly the name, address and telephone number.

### **Institutional Living Arrangement**

In keeping with the Medicaid Home and Community Based Services regulations, any facilities that does not optimize autonomy, independence, and access to services and supports in the community.

### **Investigation**

An investigation is a methodological and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations require a significant allocation of time and resources including such activities as interviewing witnesses, record review, gathering evidence and generating a written report, which may or may not be made public. An investigation is distinct from advocacy. A P&A may choose to pursue an individual advocacy service for direct representation (except when a death has occurred) arising from an investigation, i.e. consistent with the terms of a retainer agreement, and distinct from the investigation itself.

### **Law** (*see also regulation and policy*)

For the purpose of completing this report, “law” refers to the body of federal or state common law, statutory law, regulations, and policy prescribing action or directing forbearance, usually attaching a legal consequence for failure to adhere.

Statutory law is created by enactments of legislative bodies declaring, commanding, or prohibiting something. Common law is developed from judicial decisions based on custom and precedent, unwritten in statute or code.

### **Legal Guardian, Conservator, and Legal Representative**

The terms “legal guardian,” “conservator,” and “legal representative” all mean a parent of a minor, unless the State has appointed another legal guardian under applicable State law, or an individual appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers, and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, persons acting only to handle financial payments, executors and administrators of estates, attorneys or other persons acting on behalf of an individual with developmental disabilities only in individual legal matters, or officials or their designees responsible for the provision of services, supports, and other assistance to an individual with developmental disabilities.

### **Limited Advocacy**

Limited advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited advocacy can include communications by letter, telephone or other means to a third party, preparation of a simple legal document, or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.

### **Litigation**

Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

### **Mediation**

Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.

### **Monitoring**

Monitoring includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

### **Neglect**

The term "neglect" means a negligent act or omission by an individual responsible for providing services, supports or other assistance which caused or may have caused injury or death to an individual with a developmental disability(ies) or which placed an individual with developmental disability(ies) at risk of injury or death, and includes acts or omissions such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; or provide a safe environment which also includes failure to maintain adequate numbers of trained staff or failure to take appropriate steps to prevent self-abuse, harassment, or assault by a peer.

### **Negotiation**

Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences with a third party in an attempt to reach a joint decision on their common concerns.

### **Number Impacted Performance Measure**

A number impacted performance measure is one that asks for the number of people with disabilities in a group that was the target of a P&A's advocacy.

### **Other Systemic Advocacy**

Other systemic advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form. Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

### **Outcome**

An outcome is a quantifiable performance measure expressed in terms of any result achieved for a client or group of clients.

### **Output**

An output is a performance measure that describes something quantifiable and concrete that is not descriptive of an end result desired by a client or group of clients but rather an incremental or interim step along the way. It can also be used to capture P&A engagement in an ongoing intervention.

### **Outreach**

Outreach is an activity that provides targeted information to specific populations regarding the activities of the P&A or one of its programs.

### **Performance Measure Menu**

Each advocacy intervention type has an associated list of outcome and output performance measures. It is not expected that a P&A would use every performance measure on every menu.

### **Policy** *(see regulation and law)*

For the purposes of completing this report, a policy is a basic principle and associated guideline, formulated in writing and enforced by the governing body of an entity, to direct and limit its actions.

### **Priority**

For purposes of this report, a priority is a subset of and related to a larger goal statement which the P&A plans to work on during the reporting period. Priorities are allocated resources so that a measurable result can be documented. Priorities as established through the SGP serve as the basis for the P&A to determine which cases are selected in a given fiscal year. P&As have the authority to turn down a request for assistance when it is outside the scope of the SGP, but they must inform individuals when this is the basis for turning them down.

### **Probable Cause**

The term “probable cause” means a reasonable ground for belief that an individual with developmental disability(ies) has been, or may be, subject to abuse or neglect, or that the health or safety of the individual is in serious and immediate jeopardy. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect.

### **Provision**

For the purpose of completing this report, a provision is a clause in statute, regulation or policy that explains a specific condition, effect, implication, qualification, or requirement that would result in benefit or detriment to people with disabilities.

### **Qualitative Results**

The result of advocacy efforts expressed primarily through a narrative describing what was accomplished and includes the specifics of the outcomes and outputs reported in the quantitative results.

### **Quantitative Results**

The result of advocacy efforts expressed using outcome or output performance measures.

### **Regulation** *(see policy, and law)*

For the purpose of completing this report, a “regulation “ is a rule or order, usually promulgated by federal or state administrative agencies or governmental departments, designed to implement, interpret, or prescribe the procedures or practice requirements of an agency to carry out the intent of statutory enactments of the legislature.

### **Results Narrative**

A qualitative results narrative describes the specifics of what the P&A achieved in response to a direct representation service request or in a group advocacy project in a way that illustrates and humanizes the associated quantitative performance measures. The narrative includes:

- Headline capturing the gist of what follows (optional but helpful to the AIDD reviewer)
- Priority addressed if applicable
- The results narratives document (provide story of) how the advocacy elements worked together to achieve outcomes for our clients in a more efficient and coherent way than in the current program performance reports. The story/results narrative:
  - Describe the problem presented, what the P&A did and what was accomplished
  - Give specifics to general terms in performance measures
  - Description of how targeted toward unserved/underserved minority population, if applicable
  - Next steps, if applicable
  - Mention collaborators and partners, if applicable, including a cross reference to where a collaboration is described elsewhere in the report (Collaborations Section)
- Completed quantitative performance measures accomplished

### **Self-Advocacy Assistance**

Self-advocacy assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.

### **Self-determination Activities**

The term “self-determination activities” means activities that result in individuals with developmental disabilities, with appropriate assistance, having the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and contribute to, their communities; and support, including financial support, to advocate for themselves and others to develop leadership skills through training in self-advocacy to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

### **Significant Service**

Includes self-advocacy assistance, limited advocacy, negotiation, administrative hearings/alternative dispute resolution, or litigation on behalf of P&A client.



**Substantive Work**

Work performed by a P&A that can reasonably be interpreted as having contributed to a result measurable using one or more of the End Outcomes performance measures listed in Part III.A.

**Standardized Performance Measure**

A standardized performance measure is one that is to be used when doing like activity and reporting like results. For the purpose of this report it refers to both the outcome and output performance measures included in the result sections.

**Systemic change activities**

The term “systemic change activities” means a sustainable, transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

**Systemic Litigation**

Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

**Technical Assistance**

Technical assistance is provided to family members, non-legal guardians, professionals or other advocates in consultation regarding an area of the law in which the P&A has expertise. It is considered a non-client directed activity.

**Tier 1 Review Tool**

The Tier I Review Tool is used by AIDD in the compliance and outcome review process of the SGP and PPR and will be used, in part, to determine whether a P&A needs a higher level of review (Tier II). It is used annually by AIDD staff to conduct high level program compliance and outcome reviews of the P&A PPR and SGP. The compliance review verifies through review of the PPRs and SGPs that the P&A is compliant with DD Act requirements. The outcome review uses narrative information and measures (data) to evaluate performance based on data analysis. The outcome review focuses on data and narrative results of outcomes/results achieved. The outcome and output data is reviewed for each P&A program and across all P&A programs to understand results.

**Training**

Training is an activity that builds skills and knowledge of target populations. Training may be provided to individuals with disabilities and others.

**Unserved and Underserved**

The term “unserved and underserved” includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in community life.