DRM I/DD Statement of Goals & Priorities 2016-2017

**Priority Setting Process**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Public Hearing❑ | Public Comment🗹 | Experience🗹 | Focus Groups❑ | Advisory Council❑ | Monitoring Visits🗹 | Research/Data🗹 |

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

With the DD Coalition, DRM closely monitors DDA's budget, waiting list, the numbers of people who are waitlisted and in crisis and the numbers of people remaining in state institutions, both the ICFs and the forensic DD facility. DRM meets people with disabilities by conducting monitoring visits and rights trainings. We have analyzed the state abuse and neglect reporting system to determine trends in reporting for all types of incidents including abuse, neglect, death, restraint, unplanned hospitalizations, and others. DRM analyzed I&Rs received in the past fiscal year by type of request to review trends in demand for our services by people with DD and people calling on their behalf. We also analyzed the pattern of open cases. DRM has not had a practice of identifying that specific I&Rs and cases are closed due to lack of resources. Changes in our database will permit us to identify cases that close due to lack of resources, but not I&Rs. We are in the process of improving our case handlers’ use of this capability to collect more accurate information. It is apparent that the demand for our services is greater than our staff can responsibly take on and still deliver quality legal advocacy.

**2. Number of days for public comment: (**by November 1, 2016)

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

The data that we have tracked includes all people with DD in all geographic areas.

**4. 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

**5. Summary of Findings**

**Waiting List**

The DDA waiting list numbers over 7900, with over 100 people annually in crisis. In FY 2016, advocacy secured funding for 100 people in the highest priority category, Crisis Resolution. Each year DDA has funding for approximately 600 transitioning youth.

**DDA Transformation**

DDA is responding to intense funding and administrative challenges and is undergoing a “Transformation” to change all of its Medicaid waiver services, promote Employment First, increase opportunities for self-direction, improve person centered planning and require new health screenings as well as working to comply with the Home and Community Based Service integration mandates that are required by March 2019. These changes will require Medicaid waiver amendments, new regulations and new policies and will require substantial education efforts throughout the DD system as well as individuals and families and other government agencies.

DDA itself collects little data about people and services. For many years DDA collected client satisfaction data through the Ask Me! Project which hired people with DD to administer surveys directly to people receiving services. Though this project was considered a success, DDA suddenly ended the contract in 2014 and is now using the National Core Indicators survey which is administered primarily through surveys of family members or legal guardians of people with disabilities. The data collected through this survey is too general to help DRM identify where advocacy services are most needed.

After representing several clients who were badly injured at a provider agency that supports people with intensive behavior support needs, DRM asked for data on DDA’s behavior support system and we interviewed 12 provider agencies that deliver behavior support services or support people with intensive behavior support needs. (see PPR) Though we received some data, we did not receive what we requested about usage statistics. Our study resulted in a public report and conclusions about the need for DDA to redesign its behavior support services with stakeholder involvement.

Self-advocates with DD have continued to work toward competitive integrated employment, and, in this fiscal year, secured legislation to phase out subminimum wages under Fair Labor Standards Act 14(c) certificates in Maryland. DDA has developed a strategic plan to transition its services to deliver competitive integrated employment.

**Eligibility**

This year, DDA terminated targeted case management services for 2,770 people who were deemed not to have a DD. Due to flaws in the eligibility determination process, it was likely that many of the people terminated in fact have a DD and were wrongfully terminated. See the PPR for more information and data from this process that spurred DRM to advise many clients on eligibility. DRM obtained information through a public information act request and the MCDD performed some data analysis that helped confirm some trends and patterns of regional variation in eligibility determinations. The data helped support DRM advocacy and helped inform the DD Coalition. (see PPR)

DDA’s consultant studied the data and found similar trends and patterns of regional variation in eligibility determinations. The consultant found:

We reviewed CY2015 statewide applicant data gathered by the Western Regional Office for the entire state. This included data on all 1,415 applicants for the 12 months in CY2015. We analyzed the data by regions to determine if variability existed in the eligibility determination process. While a certain amount of variability is expected across jurisdictions due to issues such as urban- rural- suburban, under served, density of services, etc., the variability illustrated in Table II on the next page suggests a reliability problem due to an absence of common measures. For example, an applicant’s chances of being determined as eligible are twice as good in the Southern Region as in the Western Region. In other words, the odds of being determined as eligible in the Southern Region are nearly two in three (60%), in contrast to the odds in the Western Region of about one in three (30%). Again, variability (2-5%) around a statewide average of 50% is to be expected; however, the processes that result in these disparities between the regions are in need of improved reliability.



Though DDA has responded to Coalition pressure to make changes to ensure the integrity of eligibility determinations, the systems issues have not yet been resolved. DRM assisted 54 people in eligibility determination cases, many of which are still unresolved.

**Institutions**

The state of Maryland has two remaining ICFs/IID: Holly Center with 61 residents and Potomac Center with 39 residents. The state also has about 30 people in short term stay Secure Evaluation and Therapeutic Treatment (SETT) facilities for people involved with the criminal justice system. Though the number of residents in the ICFs/IID is gradually falling and the SETTs have stayed under capacity in recent years, people with DD are still facing unnecessary institutionalization in nursing facilities and psychiatric hospitals. Though we don’t have numbers, we continue to receive intakes for these clients, and when we try to obtain discharges to community based services, we encounter systemic barriers that prevent our clients from leaving.

**Abuse/Neglect**

DRM analyzed data for provider-reported incidents of abuse, neglect, deaths, medication errors, hospital admissions, restraint, etc. Last year we reported that in a six month period, incident reports increased 15% and specifically there was:

• A 10% increase in each of the following categories: abuse, hospital admissions and emergency room visits, and injuries;

• A 20% increase in reported medication errors;

• A 25% increase in reported neglect;

• A 22% increase in unauthorized restraints; and

• A 67% increase in chemical restraints in state institutions.

This year, for a 12 month period, significant changes in numbers were:

* A 13% increase in the number of abuse reports
* A 15% increase in the number of psychiatric admissions
* A 7% reduction in medication errors
* A 40% reduction in the use of chemical restrains (which are almost exclusively in one state institution); and
* A 41% increase in the use of unauthorized restraints.

DRM has long been concerned about the steady increases in psychiatric admissions, which signal a possible failure of adequate community supports. The leap in unauthorized restraints requires further investigation in the next fiscal year as does the steady growth rate of abuse reports.

The Office of Health Care Quality (OHCQ) is responsible for regulating nursing facilities, assisted living, numerous medical facilities as well as DD provider agencies and institutions. OHCQ is required to perform annual licensure and regulatory compliance monitoring of each site operated by over 200 DDA provider agencies. The total annual OHCQ budget for all of its operations is just over $20 million compared DDA’s annual budget of over $1 billion. OHCQ has recently strengthened its DD Unit oversight capability but its annual report in December 2015 documented on-site OHCQ investigations for only 6.5% of the combined complaints received and provider reported incidents. OHCQ’s DD unit performed 77 relicensure surveys and 66 initial site surveys.

**Children: Education and Inclusive Child Care**

Though DRM represented 32 children in special education and inclusive child care cases from October 1, 2015 to August 31, 2016, we also received 103 calls for help but could only provide information and referral to these families.

**Medicaid**

From November 1, 2015 through August 22, 2016, the HOMES Project has handled approximately 100 Service Requests coded as cases and provided I&R in 74 additional service requests.

DRM has been advocating for Maryland Medicaid to cover Applied Behavior Analysis (ABA) therapy since CMS released a Bulletin in July 2014 on Medicaid services for children with Autism Spectrum Disorder.  Maryland’s Medicaid Program is now moving ahead with plans to add this service to its State Plan in January 2017 and has just released proposed regulations.  The estimate is that 700 children on Medicaid will be eligible to receive ABA treatment in the first 6 months increasing to approximately 1,400 children by the end of the fiscal year.  The State has projected additional expenditures of $13,390,440 over one year to cover these services.

More than 18% of Maryland’s population – over 1,084,000 low-income children and adults (over 272,000 in Baltimore City) – are Medical Assistance recipients, legally entitled to a range of essential health care services. It is estimated that 13.4% of Marylanders have a disability (15.5% in Baltimore City, a percentage that has been increasing).

**DRM Experience**

DRM experience working with people with disabilities, families, advocates, professionals, and state agencies has been extremely informative about the specific wants and needs of people with DD, how they are treated, and whether state agencies are complying with legal requirements to deliver safe appropriate services in integrated settings. For example, after working on several administrative appeals of DDA eligibility denials, DRM learned that DDA has been changing its eligibility criteria and does not have an objective means of assessing eligibility. Our view was vindicated by an expert hired by DDA. We also learned from experience that DDA has been systematically denying eligibility to children. Through advocacy by DRM and the DD Coalition, DDA agreed to review the eligibility denials of 1,245 children. Of the 1,008 children reviewed so far, DDA has reversed 353 denials so these children are now eligible for services. For more on this topic, see PPR.

DRM is not able to meet the demand for our services. There is no private bar that can deliver the type of legal advocacy that DRM can provide in representing people in abuse and neglect issues and Medicaid waiver eligibility and access cases, though there are two or three private attorneys in the state of Maryland we believe are competent to handle such Medicaid cases. However, these attorneys charge fees that most individuals and families cannot afford.

Our conclusions about systemic issues were corroborated by a series of public meetings held by DDA last fiscal year to gather public comment and input on DDA services, particularly its Medicaid waiver. Individuals and family members consistently complained about lack of access to the system, inadequate services for people with more intensive needs, and poor communication from DDA so that people do not understand their status or benefits.

**6. 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)**

**Collaborative Project with DDC and MCDD**

DRM conferred with the DD Council and UCEDD about our priorities. Because so many people with DD, families and professionals are confused about eligibility and access to services in the state service delivery system, DRM has been developing public education materials to help people to understand the system and provide some self-help materials so we can have a broader reach with our limited staff. However, we believe the materials need to be edited to be more easily used. The DDC and MCDD agreed that they could work together to develop documents that will be more usable. The DDC and MCDD will establish a group of people receiving services and family members to consult about what subjects they need, DRM will develop any additional substantive material that is needed, and the DDC and MCDD will edit the documents and work on accessibility and appearance. DRM will maintain responsibility for the accuracy of the documents.

**DDA Transformation**

Services and Policies. DDA is planning changes to most of its services and policies, which will have widespread effect on all of our clients. DRM plans to comment on as many of the services and policies and proposed regulations that will be promulgated, in order to advocate for our clients’ ability to live in the community with needed supports, obtain services with reasonable promptness and choose from an adequate array of provider agencies. As a result of our experience with the Employment First work groups, the HCBS Transition Work Group, and the Individual Plan work group, our advocacy is needed to ensure the individual experience is adequately represented.

Eligibility. To ensure individuals with DD are not barred from the system due to erroneous eligibility determinations, our study and experience with DDA eligibility issues have confirmed that people need DRM advocacy to protect their interests as DDA changes the eligibility system as well as the accompanying Medicaid waiver level of care issues that need to be addressed in Maryland.

Waiting List. With thousands of people with DD waiting for services, DRM has prioritized helping them to establish their correct eligibility and priority status. We will continue to work on individual cases as well as the systems reform issues that we have identified. DRM has been working with the DD Coalition and DDA to study and consider advocacy strategies for obtaining more funding for the waiting list.

**Institutions**

Because of our experience and the lack of alternative representation, DRM will continue to prioritize representation of individuals with DD who become inappropriately “stuck” in institutions and, with DRM’s nursing facility project, to attempt to resolve the systems issues that prevent people from leaving with home and community based services.

**Abuse and Neglect**

DRM is the primary non-state entity with adequate information and access to be an effective advocate for individuals and for systemic reform. Therefore, DRM will continue to advocate for improvements in the state quality system, and represent individual clients who are victims of abuse and neglect.

**Children: Education and Inclusive Child Care**

DRM also continues to receive far more requests for assistance for children in special education, infants and toddlers services, health care, and child care than we can provide. Because we lack adequate staffing to provide individual representation except in targeted projects, we will primarily focus our efforts for children on systemic reform.

**Medical Assistance**

Demand for DRM advocacy to help people with DD access Medicaid services such as Community First Choice continues to rise. DRM will respond to this need since we are the only legal resource for most people with DD who cannot afford or even find private representation.

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

People with DD need housing and transportation. While in most communities these are not legal entitlements, they are issues that continually arise in public meetings. DRM would also provide more individual representation in our selected areas if we had more resources.

C. FY 2016 [10/01/15 - 09/30/16] Statement of Goals and Priorities (SGP)

🗹There are no changes to the SGP from prior year

❑There are changes to the SGP

1. Goal Number: 1 Goal Statement: People with DD will be able to avoid or leave institutions

2. Priorities: # Priority 1 Provide legal support and advocacy to assist people to leave or avoid institutions

3. Strategies Used to Implement Goal and Address Priorities

🗹 Collaboration ❑ Systemic Litigation

🗹 Rights-Based Individual Advocacy Services 🗹 Educating Policy Makers

❑ Investigations of Abuse and Neglect 🗹 Other Systemic Advocacy

🗹 Monitoring 🗹 Training/Outreach

4. Rationale for Adding/Changing Goal This is a continued goal from FY2014-2015.

5. Rationale for Adding/Changing Priorities Priorities continue from FY2014-2015.

1. Goal Number: 2 Goal Statement: Abuse, neglect and other rights violations of people in state services will be reduced.

2. Priorities: # Priority 1 Individual/systemic advocacy on abuse, neglect or other rights violations, and service access.

3. Strategies Used to Implement Goal and Address Priorities

🗹 Collaboration ❑ Systemic Litigation

🗹 Rights-Based Individual Advocacy Services 🗹 Educating Policy Makers

🗹 Investigations of Abuse and Neglect 🗹 Other Systemic Advocacy

🗹 Monitoring 🗹 Training/Outreach

4. Rationale for Adding/Changing Goal This goal is continued from 2014-2015.

5. Rationale for Adding/Changing Priorities Priorities continue from 2014-2015

1. Goal Number: 3 Goal Statement: People with DD will have access to Medicaid services they need to live in the community.

2. Priorities: # Priority 1 Help individuals with DD to understand and acquire needed Medicaid services

3. Strategies Used to Implement Goal and Address Priorities

🗹 Collaboration ❑ Systemic Litigation

🗹 Rights-Based Individual Advocacy Services 🗹 Educating Policy Makers

❑ Investigations of Abuse and Neglect 🗹 Other Systemic Advocacy

❑ Monitoring 🗹 Training/Outreach

4. Rationale for Adding/Changing Goal Goal continues from FY 2014-2015

5. Rationale for Adding/Changing Priorities Priority remains from FY 2014-2015

1. Goal Number: 4 Goal Statement: Children with DD will be in integrated, appropriate school and day care settings.

2. Priorities: # Priority 1 Advocate to advance the rights of children with developmental disabilities to receive services in the most inclusive setting.

3. Strategies Used to Implement Goal and Address Priorities

🗹 Collaboration ❑ Systemic Litigation

🗹 Rights-Based Individual Advocacy Services 🗹 Educating Policy Makers

🗹 Investigations of Abuse and Neglect 🗹 Other Systemic Advocacy

🗹 Monitoring 🗹 Training/Outreach

4. Rationale for Adding/Changing Goal Goal continues from FY 2014-2015

5. Rationale for Adding/Changing Priorities Priority continues from FY 2014-2015

**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.**

DRM has two intake staff, one for general intake and one for special education cases. The intake staff for special education designates PADD cases, however, the special education unit staff handle all education cases regardless of the child’s disability. Most special education callers are provided with information and referral. DRM trains pro bono attorneys to represent children in special education cases. The DD unit at DRM works closely with the Medicaid unit. Many of the Medicaid unit clients, as well as the clients served by staff under the PAAT grant, have DD. Both units are cross trained to represent clients who need technical assistance or representation in Medicaid waiver service cases, although the DD unit specializes in eligibility matters. The DD unit collaborates with our CAP through the NDRN Board of Directors. DRM and the CAP trade referrals and occasionally meet to share information. DRM refers issues to the Long Term Care Ombudsman, including the conditions within a facility, rights issues, and concerns about quality of care. The Ombudsman also refers cases to DRM.

**2. Will the System will be requesting or requiring fees or donations from clients as part of the intake process?** No

**3. Collaboration and Coordination: a. Describe how the P&A is collaborating with others in the State, including the DDC and UCEDD.**

DRM’s PADD program collaborates with many others including the Developmental Disabilities Council (DDC) and UCEDD. We are a member of the Maryland DDC and are on the Community Advisory Council for the UCEDD, the Maryland Center on Developmental Disabilities (MCDD). DRM is a participant of:

• Maryland’s Developmental Disabilities Coalition which includes the DDC, People on the Go, The Arc Maryland and the Maryland Association of Community Services;

• DHMH’s transition team for the Developmental Disabilities Administration’s Medicaid waiver;

• DDA’s Waiver Quality Advisory Council;

• Maryland Coalition to Reform School Discipline;

• Maryland Disability Rights Coalition;

•DDA’s Employment First Work Group

•DDA’s Individual Planning Work Group

DRM’s PADD staff meet quarterly on quality issues with DDA, OHCQ, and the State Medicaid agency DRM PADD staff collaborate with the Legal Aid Bureau, the Office of the Public Defender and private counsel as well as the Elder Law and Disability Rights Section of the Maryland Bar Association, health care professionals, hospital staff, resource coordination entities, DDA provider agencies, public guardians DRM works with 20 programs that are part of our Out of School Time (OST) project.

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

DRM fills a unique role in providing free legal representation for people with DD. DRM also plays a unique role in monitoring quality oversight and services for people with disabilities. No other outside agency has the access to individuals and the systemic incident reporting system and regulatory agency reports that we have. However, many organizations play other roles and DRM avoids duplication of effort by: 1. Focusing most of our effort on the services that only DRM can perform 2. Providing limited legal advice and support to our sister advocacy organizations DRM works very closely with the DD Coalition and others. We share information in meetings but also write letters and reports to document concerns. We share this information broadly with many partners.

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| DDA Provider-Reported Abuse and Neglect Incidents  |
|  |  |  |  |  |  |
| **Incident Type** | **6/1/2013-5/31/2014** | **6/1/2014-5/31/2015** | **%change over prior year** | **6/1/2015-5/31/2016** | **%change over prior year** |
|  |  |  |  |  |  |
| Abuse I | 828 | 915 | 11 | 1035 | 13 |
|  |  |  |  |  |  |
| Death I | 236 | 245 |  | 250 | 2 |
|  |  |  |  |  |  |
| Hospital Admission/Emergency Room Visit - Type I | 2078 | 2352 |  | 2242 | -5 |
|  |  |  |  |  |  |
| Hospital Admission/Psychiatric Admission - Type I | 314 | 351 | 12 | 403 | 15 |
|  |  |  |  |  |  |
| Injury Type I | 347 | 363 |  | 348 | -4 |
|  |  |  |  |  |  |
| Medication Error - Type I | 81 | 114 | 41 | 102 | -7 |
|  |  |  |  |  |  |
| Neglect - Type I | 586 | 571 |  | 543 | -5 |
|  |  |  |  |  |  |
| Restraint - Chemical Intervention - Type II | 323 | 443 |  | 268 | -40 |
|  |  |  |  |  |  |
| Restraint - Unauthorized /Inappropriate Use of Restraints - Type II | 184 | 182 |  | 256 | 41 |
|  |  |  |  |  |  |
| Restraint - Use of Restraints that Result in Any Type of Insult - Type II | 9 | 8 |  | 8 | 0 |
|  |  |  |  |  |  |
| DRM Intake calls closed as Information and Referral **8/1/2015-7/31/2016** |  |  |
|  |  |  |  |  |

|  |  |
| --- | --- |
| Abuse | 12 |
| Access to records | 2 |
| Criminal justice | 5 |
| Custody/Parental Rights | 13 |
| Education | 97 |
| Employment | 4 |
| Financial Benefits | 12 |
| Government Benefits | 51 |
| Guardianship  | 12 |
| Health care | 20 |
| HCBS services | 43 |
| Housing | 9 |
| Neglect | 18 |
| Other | 13 |
| Quality Assurance including abuse, neglect & other violations of rights | 25 |
| Rights Violations | 3 |
| Services | 6 |
| Transportation | 3 |
| Unnecessary Institutionalization | 2 |

**Total DRM cases 8/1/2015-7/31/2016**

|  |  |
| --- | --- |
| Abuse | 8 |
| Custody/Parental Rights | 2 |
| Education | 26 |
| Employment Preparation | 2 |
| Government Benefits/Services | 72 |
| Guardianship/Conservatorship | 5 |
| Healthcare | 29 |
| Home & Community Based Services inc Discharge Planning Transition Follow-up | 32 |
| Housing | 18 |
| Neglect | 4 |
| Non-Government Services | 1 |
| Program Access | 1 |
| Quality Assurance including abuse, neglect & other violations of rights | 17 |
| Recreation | 1 |
| Rehabilitation Services | 1 |
| Rights Violations | 1 |
| Services | 3 |
| Transportation | 1 |
| Unnecessary Institutionalization | 10 |
| Total | 234 |