



Developmental Services Advocacy

Annual Report

July 1, 2017 through June 30, 2018

Table of Contents

INTRODUCTION.....	2
DSA CLIENT DEMOGRAPHICS	3
REPORTABLE EVENTS & CASES.....	4
SAMPLE REPORTABLE EVENTS	8
SAMPLE INDIVIDUAL CASES	10
Abuse, Neglect & Other Rights Violations	10
Due Process	12
Guardianship	14
Housing.....	15
Person-Centered Planning	16
Transportation.....	18
BEHAVIOR MANAGEMENT REVIEW TEAMS	19
SUMMARY OF SYSTEMIC ACTIVITIES.....	23

INTRODUCTION

Disability Rights Maine (DRM) is Maine’s federally funded protection and advocacy agency for people with disabilities and has provided legally based advocacy services to people with developmental disabilities since 1977. DRM’s mission is to ensure autonomy, inclusion, equality, and access for people with disabilities in Maine.

With funding provided by the Maine Department of Health and Human Services (DHHS), DRM has Developmental Services Advocates (DSA) who work out of DHHS offices in Caribou, Bangor, Lewiston, Portland, and Rockland, as well as DRM’s main office in Augusta.

DSA advocates provide direct representation, respond to rights violations, attend behavior management review team meetings to advocate for our clients with regard to the use of behavior and safety plans, attend Person-Centered Planning meetings, and conduct regular outreach and training throughout Maine.

Data provided by the Department shows the following breakdown of individuals receiving Developmental Services:

DISTRICT	ACTIVE DS CLIENTS
Districts 1&2 (York, Cumberland)	2,161
District 3 (Androscoggin, Oxford, Franklin)	1,032
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	560
District 5 (Somerset, Kennebec)	861
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	1,412
District 8 (Aroostook)	506
Total	6,532

DSA CLIENT DEMOGRAPHICS AND CASE INFORMATION

CLIENT DEMOGRAPHICS	
LIVING ARRANGEMENT	
Adult Community Residential Home	570
Community Residential Home for Children/Youth	11
Foster Care	1
Homeless	3
Independent Housing	83
Intermediate Care Facilities	9
Legal Detention	1
Nursing Home	5
Parental/Guardian or Other Family Home	173
Public and Private General Hospitals	5
Public State Operated Institutional Living Arrangement/Setting	2
Total	863
CLIENT AGE	
17	1
18 to 25	181
26 to 64	600
65 and Over	81
Total	863

CLIENT GENDER	
Female	393
Male	470
Total	863
RACE	
American Indian / Alaskan Native	5
Black / African American	2
Race Unknown	407
Two or more races	4
White	445
Total	863
ETHNICITY	
Ethnicity Unknown	532
Hispanic / Latino	3
Not Hispanic / Latino	328
Total	863

REPORTABLE EVENTS & CASES

The two primary ways DSA advocates open individual advocacy cases is through intakes (requests for information or services) and reportable events. All cases are supervised by an attorney.

Intakes

DRM fields intake calls from our central office in Augusta, Maine, and coordinates the referral of new cases to staff in offices in the developmental services regions (Portland, Lewiston, Rockland, Bangor, and Caribou). People with disabilities can, of course, make direct requests for assistance to our community developmental disabilities advocates, but those requests also generate service requests that become part of our data system.

Reportable Events

DSA receives notification of potential rights violations through the State's Enterprise Information System (EIS). DSA investigates all rights violation reportable events that we receive through the EIS system, unless we refer them to another appropriate DHHS entity for follow-up, such as Adult Protective Services, DHHS Licensing, or OADS District Management, etc. In the numbers that follow, these are reflected as "I&Rs." The largest category of reportable events that become I&Rs are provider daily reports of the on-going use of rights restrictions while awaiting the approval of a safety device or a behavior management plan. For example, 997 of the reportable events concerned 15 individuals, each of whom had at least 30 reportable events filed on their behalf. Four individuals had over 50 reportable events and a single individual had 130 reportable events filed on their behalf for the unapproved use of a safety device. For these duplicate reportable events, the first in time report becomes a "case," which the DSA advocate actively works on to resolve all of the associated rights violation reportable events. The other associated reportable events are "I&Rs."

As part of our investigation of rights violation reportable events, DSA makes a documented attempt to contact the individual within five business days. We work with individuals to resolve the rights violation. The intervention strategy we use and the remedy we seek depends on the particular issues presented and the direction of the individual affected. This work is reflected in the "cases" that follow.

CASES – SUMMARY	
Number of Individuals Served During the Period (Cases)	863
Number of Cases Closed During the Period	692
Individuals Still Being Served at the End of the Period	516
Number of Service Requests (Cases) Opened During Period	1,040
REPORTABLE EVENTS	
Follow-up Remedy Pursued (Cases)	803
Preliminary Investigations Conducted – Multiple Reportable Events Regarding Same Matter/Referred to Other Appropriate Entity (I&Rs)	1,728
Total Reportable Events	2,487
CASE INFORMATION	
GEOGRAPHIC LOCATION	
District 1: York	62
District 2: Cumberland	127
District 3: Androscoggin, Oxford, Franklin	127
District 4: Lincoln, Knox, Waldo, Sagadahoc	37
District 5: Somerset, Kennebec	119
District 6: Piscataquis, Penobscot	141
District 7: Washington, Hancock	16
District 8: Aroostook	63
Total	692

PROBLEM AREAS / COMPLAINTS	
Abuse	25
Assistive Technology	4
Custody/Parental Rights	1
Employment	3
Government Benefits/Services	6
Guardianship/Conservatorship	46
Healthcare	16
Home- and Community-Based Services	531
Housing	5
Neglect	11
Privacy Rights	8
Transportation	36
Total	692
REASONS FOR CLOSING SERVICE REQUESTS	
Appeal(s) Unsuccessful	1
Case Lacked Legal Merit	16
Individual Withdrew Complaint	27
Individual's Issue Not Favorably Resolved	20
Issues Resolved Partially or Completely in the Individual's Favor	618
Other Representation Obtained	3

Services Not Needed Due to Death, Relocation, Etc.	1
Withdrew Because Individual Would Not Cooperate	6
Total	692
INTERVENTION STRATEGIES/CLOSED CASES	
Administrative Remedies	11
Individual Investigation	17
Legal Remedy/Litigation	4
Limited Advocacy	354
Mediation/Alternative Dispute Resolution	2
Negotiation	4
Self-Advocacy Assistance	300
Total	692

SAMPLE REPORTABLE EVENTS

DRM and Client Co-Train Staff on Rights Following Impermissible Restraint

DRM received a reportable event that a 28-year-old woman with autism and an intellectual disability was physically restrained by her staff due to “health and safety.” The woman was upset with her staff and went to her room and closed her door. Staff followed and opened her bedroom door, and restrained her when she tried to push them out of the room. DRM met with the individual and her staff, and co-trained staff on the individual’s rights. DRM also met with the individual separately to discuss issues she was having in the home. As a result of the training, client’s staff have a better understanding of client’s rights and are able to do a better job of serving her.

Staff Who Poured Water on Client's Face Terminated

A woman with an intellectual disability was denied humane treatment by her staff when they attempted to wake her up by pouring water on her face and banging pots and pans. DRM contacted the Executive Director of the agency and discussed the violation of the individual's rights and requested information on the internal response. The advocate educated staff on client rights and discussed the individual's requests with the Executive Director, who reached out to the individual directly to apologize and inform her that the staff member was let go from the agency as a result of their actions. The individual accepted this resolution.

DRM Assures Access to Crisis Services for Client

DRM received a reportable event alleging a woman with an intellectual disability was denied the opportunity to contact crisis services and was told she would be fined if she did so. The DRM advocate attended a scheduled Individual Support Team meeting at the request of the client and crisis services. During the meeting the DRM advocate assured the client that she could contact the DHHS Crisis Team at any time for assistance and support without being assessed a fine for doing so.

DRM Protects Religious Freedom of Client

DRM received a reportable event that the guardian of a 26-year-old woman with an intellectual disability told the client that she was not allowed to participate in holidays that are against the guardian's own religion. DRM met with the client, her guardian, and her support staff and informed the guardian that she did not have the right to infringe on the individual's freedom of religion. The guardian relented and agreed that she would not block the person from participating in the upcoming holidays in a manner of her own choosing.

DRM Clarifies Client's Rights Regarding Access to the Community

DRM received a reportable event in which a client with an intellectual disability was prohibited by staff from going out into the community due to unsafe behaviors. At a team meeting that included the client, his mother/guardian, his case manager, and his staff, DRM explained that unless a person is being actively unsafe, staff cannot withhold community time. If a person is prevented from going out into the community for unsafe behaviors, the person must be permitted to go into the community as soon as the crisis has passed. DRM followed up and the client reported no further issues with this matter.

DRM Does Rights Training Following Rights Violation

DRM received a reportable event detailing staff taking away food from a 29-year-old woman with developmental disabilities while at the Special Olympics. DRM met with the woman and her staff and discussed her rights. DRM also trained the staff and agency administration on rights of persons receiving services. The woman reports that staff is no longer taking away her food.

DRM Vindicates Right of Client to Have His Food

DRM received a reportable event that a 57-year-old man who receives developmental services was having his rights violated by the agency because the agency maintained a locked file cabinet in the individual's home that contained his medication and food. The administration of the agency could not answer any specific questions or show any documentation on why this was necessary, only stating that the individual had been subject to this violation for years due to concern he may overeat or run out of food. DRM told the agency to immediately unlock the cabinets and to keep them unlocked. The individual stated that he had wanted them unlocked and was happy that he no longer had to wait for staff in order to access his food.

SAMPLE INDIVIDUAL CASES

ABUSE, NEGLECT & OTHER RIGHTS VIOLATIONS

DRM Thwarts Client's Sterilization

DRM received a reportable event in which a case manager reported that the guardian and doctor of a woman with an intellectual disability were recommending she be sterilized. After DRM spoke with the guardian, it became clear that the main reason the procedure was being recommended was because of the client's disability. DRM researched the issue and informed the guardian that such a procedure would be illegal absent a court order. DRM also wrote a letter to the client's doctor indicating the need for a court order. Finally, the advocate met with the client and explained the client's rights to the client and her staff.

DRM Assisted Client with Enforcing Right to Community and Family

An adult with an intellectual disability and profound hearing loss who has worked with an agency that has provided him in-home supports for over 14 years, and has lived in his current group home for 5 years, enjoys a close relationship with his parents, visiting with them every other weekend and taking yearly vacations with them, as he has done for years. The client's parents contacted DRM after receiving a letter from the agency stating that the client's visitation schedule with his family was problematic because it was a financial loss for the agency, who could not bill for the client's time away from the home. DRM met with the client and his parents and the client indicated he enjoyed spending time with his parents and his extended family, and wished to continue to do so. DRM attended a team meeting at the agency and expressed concern about the agency's decision to place financial concerns over the client's rights to access family and community as he wished. The agency eventually stated that the parents could continue the visits as they always have, and the agency would not take any action against them. Also of concern was the agency's statement that it, and possibly other providers, had sent similar letters to other families for whom they provide support. DRM spoke with staff at DHHS who were put on alert about this improper practice.

DRM Investigates Neglect Concerns

Upon receiving a call from the community case manager, the DSA advocate urged the CCM to file a reportable event on behalf of an individual with autism. The individual's house manager cancelled the individual's medical appointment at his discretion without any consultation with the individual or his guardian. Due to concerns about the individual's rapid decline in weight due to his diet at his home, the CCM contacted the DSA advocate and informed her of the individual's right to medical care being violated. After the DSA advocate visited with the individual at his home, investigated directly with the house administrator, raised this violation before the regional review committee, and met with the guardian and case manager, the guardian moved the individual to another home and outside of the care of this provider. The individual is now living a better, healthier life and is receiving the medical attention he needs.

Client Rights Restored after More than 20 Years

The case manager of a man with an intellectual disability contacted DRM to request attendance at a team meeting to discuss the client's request for lifting

certain rights restrictions. Upon attending the meeting, DRM discovered that the client had been subjected to significant rights restrictions for his entire adult life, going back decades. The restrictions included limits on internet access and a prohibition on being unsupervised in the community. The rights restrictions were not pursuant to any approved behavior management plan, and were based upon an isolated incident that occurred when the client was a juvenile--well over 20 years prior. DRM advised the client of his rights, and reviewed some records provided by his planning team. DRM discussed concerns about these restrictions with the case manager and advised that they needed to lift the restrictions as soon as possible and at the client's comfort level. DRM convened a second team meeting a few months later. The team reported the restrictions had largely been lifted, and that the client was learning to use the internet (with support at the client's request), and was allowed access to the community, including some alone time, and with support at the client's request. The advocate spoke privately with the client, who reported that he was happy with the developments, although he did at times continue to feel as if he were being watched too closely. The advocate explained his right to privacy and his right to request privacy from staff when he wanted it.

DUE PROCESS

Agency Attempts to Evict Client; Agrees to Move Client to Another Home Due to DRM Intervention

DRM received a reportable that an older woman with an intellectual disability had been told she needed to move without being provided with proper notice. A new agency had taken over the client's assisted living facility and had notified all of the residents that they were closing the home. Initially, the client was given the option to move to another location much further away, which the client declined. DRM spoke with the case manager and reviewed the defective notice of eviction. Ultimately, the agency offered the client a placement in another home that was much closer, and the client chose to move to the closer location. The advocate spoke with the client over the course of a few weeks after her move to ensure she was happy and that the move went smoothly.

Client Appeals Adverse Determinations and Found Eligible After DRM Submits Additional Evidence Demonstrating Client had ID prior to Age 18

An adult with an intellectual disability contacted DRM after appealing a determination that the client was not eligible for developmental services. The client had been diagnosed by 2 providers with Autism Spectrum Disorder as an adult. The Department deemed the client ineligible for services, citing lack of documentation that the disability presented itself during the developmental period (i.e., prior to age 18), as required by the regulations. DRM reviewed extensive records and spoke with one of the diagnosing providers, who then submitted an addendum indicating that the diagnosis is by definition a developmental disability, and that the diagnosis would have been present prior to age 18 based on records reviewed. After DRM submitted the additional paperwork to the Department, the client was determined eligible for developmental services without the need for a hearing.

DRM Works to Successfully Transfer Client from Jail to Psych Hospital

DRM met an adult with an intellectual disability while conducting outreach at a regional jail. The client was being held on serious charges. DRM contacted the court, and, despite the fact that the client had already been brought before a judge for an initial appearance, no attorney had been appointed to represent the client. The court clerk appointed a criminal defense attorney, and DRM worked with the attorney to advise on services that might be available in order to have the client transferred. At the jail, the client was being kept in isolation to keep him safe, due in part to the perceived vulnerability of his apparent intellectual disability. Numerous advocates at DRM communicated with the defense attorney and personnel at a psychiatric hospital, and the client was eventually transferred to a secured unit of a psychiatric hospital for further evaluation and treatment.

Hearing Officer Finds that Broker Must Accommodate Client after DRM Files for Administrative Hearing

DRM successfully represented a woman with autism in an administrative hearing who needed an accommodation in order to access MaineCare non-emergency transportation (NET). The woman was utilizing a NET to get from her home to her day program. On a couple of occasions, and as a result of her disability, the client began unbuckling her seatbelt prior to arriving at her destination. As a result of this, the client was told she could no longer independently access van transportation; instead she would need a friend or family member to ride on the van with her to day program and then wait four hours at her day program and then ride back on the van with her. Alternatively, her family was told they could

drive her. Both of these options prevented her family member from working. The hearing officer found that the NET transportation broker was required to accommodate her disability and have an attendant support her on the van to ensure her safe access to transportation.

GUARDIANSHIP

DRM Explains Guardianship and the Process for Challenging a Guardianship

A case manager contacted DRM on behalf of her client, who was interested in learning more about possibly terminating her mother's guardianship of her. The case manager had concerns about possible emotional abuse by the mother/guardian, or neglect. DRM met with the client and her support staff, answering questions about the client's rights and limitations of guardian authority. DRM explained the client's right to challenge guardianship at any time, and went over the process and then followed up with a letter to the client explaining how to write to the court to challenge the guardianship and how to request a court-appointed lawyer to assist.

DRM Provides Technical Assistance on Supported Decision-Making

A 17-year-old client and her mother contacted DRM seeking information on alternatives to guardianship. The client would be reaching the age of majority within the next 6 months. DRM met with the client, her mother, and her sister at her home and discussed guardianship and alternatives to guardianship, such as Supported Decision-Making and Powers of Attorney. DRM provided printed materials on SDM, POAs, transition services for minors entering adulthood, and DRM's various programs. DRM also answered questions about the rights of people with disabilities, particularly with respect to voting and employment. The family had concerns about the client's ability to make her own decisions, but they were very open to considering guardianship alternatives. Although no decision was made at the meeting, the family was especially interested in utilizing SDM in conjunction with a Power of Attorney, and the client was happy with the discussion.

HOUSING

Eviction Dismissed and Client Reimbursed Fees Due to DRM Intervention

DRM was contacted by a 25-year-old woman with an intellectual disability who was facing eviction because of the alleged re-infestation of bedbugs in her apartment. DRM requested a reasonable accommodation and represented the person in an eviction hearing, seeking to have the case dismissed, as the heat treatments that were being used by the property management company were not in compliance with Maine statute. The property management company dismissed the eviction and reimbursed our client the \$12,750 in treatment-related fees they had charged her.

DRM Successfully Negotiates for Client to Avoid Eviction

A 36-year-old woman with an intellectual disability that was facing eviction and had been issued a Notice of Termination requested DRM assistance. DRM met the client's case manager and determined what was needed to create a successful tenancy. DRM then negotiated with the Property Manager and requested a Reasonable Accommodation because her in-home services had ended and the client needed time in order for new supports to be put into place. The property manager created an agreement allowing the client to stay in the property with the stipulation that certain lease requirements were followed moving forward. DRM reviewed the agreement, negotiated other terms of the agreement, and the client agreed to the negotiated terms and signed the agreement, preserving her tenancy.

Client Gets Out of Nursing Facility and Into Apartment Due to DRM Advocacy

An adult with a developmental disability contacted DRM for assistance with housing. The client had been residing in a nursing facility for a number of years, but had been medically cleared to leave for over a year. She was still in the nursing facility because a primary landlord in the region refused to rent to the client. The client had been a former tenant in good standing of the landlord. DRM reached out to the apartment association, who cited a number of impermissible reasons for the refusal, ranging from unsubstantiated claims of breaking her lease, to concerns about her health. DRM talked with the landlord, and attended a team meeting with the landlord, who eventually agreed to rent to the client. In addition, the landlord agreed to backdate the client's application to rent and placed her at the top of the waitlist for available wheelchair accessible units. Although there were some subsequent delays in moving due to health

issues, the landlord has agreed to keep the client at the top of the waitlist until she is able to accept an apartment when one becomes available.

Client Moves to Shared Living After DRM Intervenes

The legal guardian for a 21-year-old woman with autism living in a camp with no running water and receiving intermittent services through Section 17, contacted DRM. The client had been approved and was waiting for Section 21 services. The individual briefly went into a Crisis Stabilization Unit. DRM teleconferenced with the department's resource manager and the individual's case manager, and a residential transition plan for the individual was created. The individual left the crisis unit, moved into a respite house, and started services with a shared living provider.

DRM Worked to Get Improperly Discharged Client into New Living Arrangement

A young adult with an intellectual disability contacted DRM after his shared living provider improperly discharged him to the hospital and refused to take him back. The client had been in the hospital for a month even though he had been cleared by the hospital for discharge the day after he arrived at the hospital. By the time DRM got involved, he had been at the hospital for a month. The client did not want to return to the former provider. Another shared living provider agreed to work with the client after the client had spent a weekend there. Despite an identified placement, administrative procedures held up the client from moving into the new placement for another month. DRM worked with the case manager, the client, DS crisis services, and members of OADS, and the Case Coordination Unit at DHHS to try to get what was essentially a data entry process expedited. During his stay at the hospital, the client had to be moved from bed to bed because the ED was overrun with a flu epidemic. Finally, after just under 2 months of unnecessary hospitalization, the client was able to move into his new home. The advocate followed up with the client a few weeks later and confirmed that the move had gone smoothly.

PERSON-CENTERED PLANNING

DRM Attends PCP Ensuring Client Remains In Home Until New Placement Found

The family of a young man with an intellectual disability who resides in a group home contacted DRM when they learned that the client's agency was closing the client's home. His family was requesting assistance to ensure a suitable new

placement was found before the young man was discharged from his home. DRM attended a team meeting with the provider, the case manager, and the client's family to discuss expectations around discharge. DRM assured that the client was able to remain in his home until a new placement was identified and the client was able to safely transition there.

DRM Advocate Shares Strategies to Avoid Coercion

DRM received a reportable event alleging a rights violation of a 35-year-old female with an intellectual disability. The reportable event stated that the former owner of the client's shared living agency was pressuring the client to move. The advocate met with the client to discuss staff concerns that client was being coerced. Client stated that she used to feel coerced, but she is managing the situation now. Advocate and client reviewed client's support network and available strategies should she feel coerced in the future.

DRM Assists Client in Making Sure His PCP Is About Him

A man with intellectual disabilities contacted DRM for an advocate to be present at his PCP. He has some issues around hoarding and spending money. DRM attended, and at the meeting, was able to keep the group focused on what the client wanted and clarified that his money was his to spend as he liked.

DRM Assists with Transition after Client Dumped in Emergency Department

DRM received a request to attend a meeting for a 30-year-old female client with an intellectual disability to assist in advocating for appropriate discharge services from a local hospital. The client's provider refused to allow her to return home after she was evaluated at the local emergency room. DSA intervened and determined the client did not wish to return to the program, and therefore efforts to compel that were not appropriate. The DSA advocate assisted the hospital advocate in obtaining a referral for community case management services, an updated occupational and physical therapy evaluation, and a psychological exam to assist in developing appropriate support services in the community for the client. Ultimately, the client was discharged from the emergency room and placed in a local waiver home. The client reports she is adjusting to her new home and learning to get along with staff and her new roommates.

DRM Keeps Team Focused on Avoiding a Behavior Management Plan

DRM received a reportable event alleging that the rights of a 22-year-old male client with an intellectual disability were violated by agency staff when they refused to take the client back out into the community. The advocate spoke with the client who said the issue had been resolved. He requested a follow-up meeting with the support of the advocate. The client was very concerned that he would have a behavioral support plan. At the meeting, the team discussed the client's concerns, his rights to privacy and personal property, and the client's right to access the community, social activity, and his right to participate in planning that concerns him. The advocate supported the client's self-advocacy in the team problem solving session. The case manager and residential staff confirmed that a BMP is not necessary at this time.

TRANSPORTATION

Transportation Services Restored After DRM Involved

DRM received a report that an elderly man with an intellectual disability, who resided in a nursing facility, had his transportation to day program abruptly cancelled without notice. The nursing home provided transportation for a short period of time but was unable to continue, citing costs. Because of the lack of transportation, the client was unable to attend the day program that he had been attending for more than 35 years. DRM worked extensively with the long-term care ombudsman and the client's guardian and service provider on the issue of getting transportation reinstated. DRM demanded that the client receive an updated and accurate screening for needs and services (called a PASRR), and then worked extensively with DHHS to ensure the plan of care outlined in the PASRR was carried out. The PASRR specifically recommended the client's day program be reinstated, and that the nursing facility make it a priority. DRM worked with licensing to ensure the nursing facility carried out its responsibility to ensure the client was receiving appropriate services. After over seven months without community supports, transportation was reinstated and the client was able to resume attending his day program. The guardian is now in the process of seeking a less restrictive placement for the client.

DRM Successfully Negotiates to Restore Transportation Services for Client

The parent/legal guardian of a 20-year-old man with an intellectual disability contacted DRM after the individual's transportation services had been cancelled.

The transportation broker alleged that he behaved inappropriately towards a driver and decided that the client required an escort in order to continue receiving transportation services. The client's parents are both elderly and neither was able to be an escort. The client also lived in a remote area and depended on day program for socialization. DRM encouraged the parents to fill out the paperwork to receive mileage for self-transport while a reinstatement of services was being negotiated. DRM contacted MaineCare and negotiated with the transportation broker to determine next steps in re-applying and securing transportation. The broker agreed to reinstate transportation after negotiation.

DRM Works to Resolve Statewide Transportation Issue

Adults with an intellectual disability residing in group homes and attending community support programs contacted DRM because brokers, responsible for arranging transportation, said they were reducing their reimbursement rates to home agencies providing transportation to the community support programs. The brokers further said the agencies were responsible to provide transportation. The agencies subsequently reported they needed to cut off transportation due to the insufficient reimbursement rates offered by the brokers. DRM spoke with a number of client guardians, various providers, and with brokers. As this was an issue affecting numerous other clients, DRM met with DHHS/OADS officials to resolve the issue statewide. OADS' position was that it was the broker's responsibility to arrange transportation. OADS advised the brokers of their duty pursuant to contract, and eventually the parties were able to reach an agreement on reimbursement rates, thus ensuring that clients would have reliable transportation to day program.

BEHAVIOR MANAGEMENT REVIEW TEAMS

The Behavior Management Review Team is required by statute (34-B M.R.S. § 5605(13)(B)(2)) to review Behavior Management Plans after they been approved by the individual's planning team and an overseeing psychologist. Behavior management plans can only be used to correct behavior that is more harmful to the individual than the proposed intervention.

The Department of Health and Human Services has also adopted regulations (14-197 C.M.R. Ch. 5, § 6) requiring Behavior Management Review Teams to review

the use of safety devices as part of a Safety Device approval process. Safety devices are devices which reduce or inhibit a person’s movement in any way with the sole purpose of maintaining safety. If there is any component of behavior management, the device may only be approved as part of a Behavior Management Plan. The Review Team must ensure that the plan is the least possible restriction consistent with maintaining safety and does not act as a substitute for a Behavior Management Plan.

In addition, DRM, the Office of Aging and Disability Services (OADS), and the Maine Developmental Services Oversight and Advisory Board (MDSOAB) have formed a Statewide Review Panel (the “Panel”) as required by regulation. The Panel is tasked with monitoring Level 4 & 5 Behavior Management Plans (BMPs) throughout the state for quality and consistency. The Panel also provides recommendations to the Department regarding interventions that may put individuals at risk and assures that applicable policies, regulations, and laws are being followed.

Behavior Management Plans by Geographic Location	
Districts 1&2 (York, Cumberland)	31
District 3 (Androscoggin, Oxford, Franklin)	31
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	7
District 5 (Somerset, Kennebec)	6
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	19
District 8 (Aroostook)	4
Total	98

Safety Plans by Geographic Location	
Districts 1&2 (York, Cumberland)	80
District 3 (Androscoggin, Oxford, Franklin)	94
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	24
District 5 (Somerset, Kennebec)	44
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	105
District 8 (Aroostook)	68
Total	415

Regional Review Team Meetings

DRM advocates participated in all regional review team meetings as non-voting members. At these meetings, the advocates raised concerns about the individuals' due process rights and assisted individuals in advocating for their own rights, including their presence and participation in Review Team meetings. The individuals subject to plans who participated in the meetings were able to speak directly to the Review Teams about their plan and were able to have their questions answered. Often, individuals articulated reasonable requests involving decreasing the plans, which their teams agreed to consider. DRM advocates have made concerted efforts to reach out to individuals so that they have the opportunity to attend meetings where their plans are reviewed.

During the meetings, DRM advocates also encouraged the voting members of the team to require detailed and attainable discontinuation criteria. Likewise, the advocates continued to emphasize the regulatory requirement for the use of positive supports, and continued to express significant concern for extreme measures such as restraints, restrictions on phone and computer access, helmet usage, food restrictions, and non-emergency rights restrictions being implemented outside of approved behavior management plans.

Most Behavior Management Plans reviewed this year were plan renewals, but there were several new plans reviewed. Several plans were not approved, most often because of the lack of documentation to justify their need. Additionally, several of the submitted plans were ultimately reduced to less intrusive means, with at least two Level Three Behavior Management Plans that were converted to Positive Support Plans.

Statewide Review Panel

The DSA Managing Attorney sits on the Statewide Panel as a non-voting member, and advocates for the least restrictive intervention, raising systemic concerns about the overuse of physical restraint in behavior management, the lack of due process, and the inconsistencies of BMP implementation by agencies. The DSA Managing Attorney was successful in raising awareness on issues of due process and rights violations for multiple plans and successfully advocated for the exploration of more comprehensive services and fewer restrictions. The comments sent to the Commissioner of the Department of Health and Human Services reflected the concerns raised by DRM. The Panel has continued to discuss best practices for the Statewide Panel and the Regional Review Teams.

Statewide Regional Review Team Meetings

DRM continues to facilitate meetings of all people sitting on Regional Review Teams that review Behavior Management Plans (BMPs) and Safety Device approvals for individuals who receive Developmental Services from the state of Maine. DRM works closely with the Office of Aging and Disability Services (OADS) and the Maine Developmental Services Oversight and Advisory Board (MDSOAB) to schedule these bi-monthly meetings. The statewide group has spent a considerable amount of time discussing best practices for the successful facilitation of review team meetings and created a working draft that is currently undergoing final edits. The statewide group updated the BMP cover-sheets to reflect documentation deadlines and provide clearer instructions to planning team members and support staff. The statewide group has also discussed how to address emergency requests for plan reviews, and the procedure to follow for plans that have disappeared with no clear announcement of discontinuation. A continuing focus is on clear identification of interventions presented as safety devices that are being used to manage behavior. The group has not reached consensus on many of the particulars, though DRM continues to advocate for the

less restrictive means of support. Moving forward, the group intends to utilize the time for mutually informative trainings and collaboration.

SUMMARY OF SYSTEMIC ACTIVITIES

Developmental Services Advocacy Rights Training

DRM provides rights training statewide to individuals receiving Developmental Services, family members, guardians, and service providers. DRM provides training on the rights of individuals receiving developmental services throughout the state. DRM participated in all quarterly, regional rights trainings in conjunction with the Department of Health and Human Services. Other trainings were part of a negotiated resolution to a reportable event. Brochures and handouts on the rights of recipients were distributed to all attendees at each training. In total, the DSA team conducted 46 trainings from Aroostook to York County and all places in between. In total, DSA advocates trained more than 62 people with disabilities and nearly 1,000 providers (including case managers, DHHS employees, and home and community providers). The team continues to identify strategies to reach more individuals receiving services.

Developmental Services Advocacy Outreach

DRM's Developmental Services Advocacy Program provides ongoing, statewide outreach to individuals receiving Developmental Services, their family members, guardians and service providers. Advocates meet regularly with individuals who receive services and their families throughout the course of their work, such as attending IST meetings, Person-Centered Planning meetings, and site visits at community support programs and group homes. During these encounters, advocates will often get the opportunity to meet with not only their clients, but with other residents and staff in the home or at the program. Advocates strive to provide information about DRM in general and the DSA program in particular to individuals and their families and providers. Examples of additional outreach activity this year where we reached a large number of individuals include:

- Attending Speaking Up For Us annual conference and chapter meetings throughout the year
- Attending the Aroostook County Collaborative

- Attending “Beautiful ME” fashion show and fundraiser for the Special Olympics
- Presenting a rights training at a nursing facility
- Presenting a training to 65 parents and individuals with disabilities at the Maine Parent Federation’s Youth in Transition Conference
- Attending the Southern Maine Autism Conference
- Training Social Workers at Dorothea Dix about DD rights and DRM services
- DRM’s Disability Pride Day Event
- Regular attendance at the Maine Coalition for Housing and Quality Services and the Maine Developmental Services Oversight and Advisory Board
- Regular participation at the Maine Developmental Disabilities Council, and at the Consumer Advisory Committee at the Center for Community Inclusion and Disability Studies

Supported Decision-Making Pilot Project

Last year, DRM partnered with a provider agency to complete a Pilot Project which aimed to teach individuals with developmental disabilities how to identify areas of decision-making, practice making decisions, and seek out support when they need assistance in decision-making. Four individuals graduated from the project, and this year, one participant’s guardianship was terminated by the Probate Court in favor of Supported Decision-Making.

Supported Decision-Making Training for People with Disabilities

DRM is committed to working towards identifying and helping to implement Supported Decision-Making as an alternative to plenary guardianship. DSA advocates and attorneys conduct directed trainings and educational outreach as well as offer information about SDM as a concept, practice, and alternative to guardianship during individual meetings. DSA advocates carry SDM specific rack cards to trainings, outreach events, and meetings; SDM is included in our rights training for individuals; and DRM maintains a website where people can find resources, tools, and videos on how to integrate SDM principles into their lives and restore their rights. DSA advocates and attorneys have discussed SDM at PCP meetings, outreach events, and through scheduled trainings. This year, DRM conducted training and outreach to approximately 150 individuals with

disabilities. DRM conducted trainings at community support programs, a transition youth conference, and within various SUFU Chapter meetings around the state.

Supported Decision-Making Training for Professionals

DRM is committed to working towards identifying and helping to implement Supported Decision-Making as an alternative to plenary guardianship. Part of that work requires outreach and training to professionals in the field, including: administrators, medical providers, case managers, DSPs, agency provider personnel, and DHHS staff. The DSA managing attorney has partnered with self-advocates to conduct directed trainings and educational outreach about SDM as a concept, practice, and alternative to guardianship. Approximately 75 professionals were trained on Supported Decision-Making in partnership with a self-advocate. Trainings were held for parents of transition-aged children, legal interpreters, and hospital social workers. DRM staff was also trained by an expert in the field, Judge Kristin Booth Glen, who held a separate workshop for an additional 25 community stakeholders.

Restorative Justice Pilot Project

DRM is collaborating with DHHS and two community providers to develop a pilot project in order to teach service providers the process and principles of Restorative Justice (RJ). The pilot project would adapt traditional RJ principles to be applied to conflicts between persons with developmental disabilities and/or service providers, particularly service providers providing home support. The intention of the program would be to reduce conflict in residential programs between residents and staff, and between residents and other residents, and to promote understanding between individuals. DRM participated in meetings to discuss developing a pilot program that would enable service providers to utilize Restorative Justice principles in addressing conflicts involving individuals with DD.

This year, the group fine-tuned the pilot project and developed criteria for the pilot project, such as who will be eligible, how many cases, who would facilitate, and what areas of the state, and how this process may affect individuals facing criminal charges. Ultimately the group decided the parameters of the project. Its goal is to facilitate 12 RJ circles for individuals with developmental disabilities in the pilot year for clients in York and Cumberland counties. The group anticipates that case managers will make referrals for clients who have had enough

problematic incidents to trigger an IST meeting, which is a meeting in which the person's planning team meets with crisis services to develop a plan.

The pilot project just recently officially got underway, referral forms have been drafted and shared with case managers, and it stands ready to facilitate its first circle.

DD Partners for Positive Change

Developmental Disability Partners for Positive Change (DDPPC) is a partnership between DRM's Protection and Advocacy for Developmental Disabilities (PADD) team, including DSA advocates and attorneys, and ten self-advocates who want to make a difference through policy change. Self-advocates who participate in this group were selected through a competitive application process.

The group meets bi-monthly and had their first meeting in January. The self-advocates identified getting more control over their lives as their top priority. They want more control over: what decisions are made about their lives, where they live, who they live with, how their services are delivered, who makes decisions for them, how to get transportation where they want to go, whether to have a roommate or not, and how their money is spent. The group is working on developing strategies to move the conversation on these issues forward and to ensure that policy-makers hear directly from self-advocates, rather than those who allegedly speak for them.

Systemic Advocacy to Enforce Due Process Rights

DRM received calls and referrals from a number of individuals whose Medical Add-On Services (MAO) were significantly reduced by DHHS from years prior. Without the MAO hours, the clients faced the risk of having to move into a more restrictive institution such as a nursing facility.

Initially, DHHS asserted that the clients did not have a right to appeal the decision because it considered it a reduction of rate of pay to providers, and not a reduction of services. After DRM filed a memorandum of law arguing for the clients' rights to appeal, DHHS subsequently withdrew its claim that there was no such right, and the appeals were scheduled for hearings. DRM utilized 2 staff attorneys and 2 student attorneys to review records and contact clients, guardians, and service providers as potential witnesses. DRM also coordinated its effort with another legal services organization that was representing other

individuals in nearly identical appeals. DRM attorneys engaged in discussions with DHHS in preparation for the hearings. Ultimately, DHHS agreed to reinstate all of the original MAO hours for the clients, and DRM subsequently withdrew the appeals. The clients were able to continue to receive the level of services they required to successfully stay in their homes.

Advocacy to Ensure Reliability of Non-Emergency Transportation

DRM began receiving numerous and repeated complaints about clients who have not been able to reliably access non-emergency transportation (NET). These individuals have been deemed eligible to receive non-emergency transportation services to eligible MaineCare-funded services, and appropriate orders for transportation were requested. However, the clients were not able to access transportation, either because the ride did not show up, or because the ride arrived so late that the client missed the service. This has affected clients' abilities to attend a variety of MaineCare-funded services, including community supports, work supports, and medical appointments. DRM has advised more than 75 individuals and their case managers by letter of their right to file a complaint with the broker and how to follow up on the issue. DRM has further advised these individuals that they may contact DRM for further assistance if the problem does not get resolved.

Restraint Project

Restraints are used far too often in the name of safety for individuals with intellectual disabilities. DRM is currently developing a project aimed at the eventual elimination of the use of restraints on individuals with developmental disabilities in residential settings. DRM worked with a LEND Fellow from Maine's Center for Community and Disability Studies who conducted research on how other states have worked toward this goal of eliminating restraints with an eye toward creating a pilot project in collaboration with an agency serving individuals with Intellectual Disabilities to eliminate the use of restraints.

Anti-Human Trafficking Project

DRM continues developing and identifying strategies and practices with state, local and community allies on how to collaborate to best serve people with disabilities who are victims/survivors of human trafficking statewide through access to strategic and aggressive disability rights advocacy. DRM obtained outreach and training materials developed by a partner agency for future

trainings and development of this project and continued to identify partners. DRM published an article titled “Human Trafficking: A Call for Awareness” in its Fall 2017 newsletter. DRM worked on including incorporating information on human trafficking of people with disabilities into the DSA training. We also met with Maine Coalition Against Sexual Assault (MECASA) and strategized regarding how to collaborate in training DHHS Adult Protective Services and other agencies/partners in identifying people with disabilities who are currently victims or survivors of human trafficking, as well as how the two agencies can work together on this issue.