



## **Developmental Services Advocacy**

### **Annual Report**

**July 1, 2016 through June 30, 2017**



# TABLE OF CONTENTS

<b>INTRODUCTION.....</b>	<b>1</b>
<b>REPORTABLE EVENTS &amp; CASES .....</b>	<b>2</b>
<b>INDIVIDUAL CASE DATA.....</b>	<b>3</b>
<b>SAMPLE REPORTABLE EVENTS .....</b>	<b>3</b>
<b>INDIVIDUALS SERVED: DEMOGRAPHICS .....</b>	<b>7</b>
<b>SAMPLE INDIVIDUAL CASES.....</b>	<b>8</b>
<b>Abuse, Neglect &amp; Other Rights Violations .....</b>	<b>8</b>
<b>Due Process .....</b>	<b>10</b>
<b>Guardianship.....</b>	<b>11</b>
<b>Person-Centered Planning.....</b>	<b>13</b>
<b>Transportation .....</b>	<b>13</b>
<b>Housing.....</b>	<b>14</b>
<b>BEHAVIOR MANAGEMENT &amp; SAFETY PLANS .....</b>	<b>15</b>
<b>SUMMARY OF SYSTEMIC ACTIVITIES.....</b>	<b>17</b>

## 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 enhance and promote the equality, self-determination, independence, productivity, integration and inclusion of people with disabilities through education, strategic advocacy and legal intervention.

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

DSA advocates provide direct representation, respond to reported rights violations, attend all behavior management review team meetings the use of severely intrusive 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 in each area for fiscal year 2017:

## Developmental Services Clients By Location

Districts 1&2 (York, Cumberland)	2139
District 3 (Androscoggin, Oxford, Franklin)	1020
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	559
District 5 ( Somerset, Kennebec)	907
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	1405
District 8 (Aroostook)	550
<b>Total</b>	<b>6580</b>

## 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, Augusta, 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. In the table below, these referrals 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 or behavior management plan. For these, 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.”

For all 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” below.

## INDIVIDUAL CASE DATA

### Case Overview

Number of Individuals Served During the Period (Cases)	629
Number of Cases Closed During the Period	505
Individuals Still Being Served at the End of the Period	328
<b>Number of Service Requests (Cases) Opened During Period</b>	<b>1,112</b>

### Reportable Events

Investigations Conducted/Reports Issued (Cases)	386
Preliminary Investigations Conducted/Issues Resolved (I&Rs)	542
<b>Total Reportable Events</b>	<b>928</b>

## SAMPLE REPORTABLE EVENTS

### DRM Intervenes to Obtain Recognition of Client’s Trauma, Need for Female Staff

DRM received a reportable event concerning a 31 year old woman with an intellectual disability and brain injury. The report alleged that the woman, who had been the victim of sexual abuse, was not physically capable of cleaning her pelvic area and needed physical assistance in self-care. Despite this history, the woman was receiving physical assistance from male staff during showers. The agency allegedly responded that the agency was an ‘equal opportunity employer’

and could not accommodate the request to have only female staff members assist individuals with intellectual disabilities with showering. At an emergency crisis meeting, DRM intervened to obtain an accommodation for the woman and agency personnel agreed that female staff would provide personal care.

### **DRM Assists to Obtain Greater Community Access for Woman with Intellectual Disability**

DRM received a reportable event alleging the rights of a 58 year old woman with an intellectual disability were violated by her residential provider when they insisted she attend day program over her objections. DRM advocate met with the client, house manager, and day program director to discuss this reportable event and determined that the client had been pressured to attend day program even though she expressed interest in greater community-based activities. DRM's intervention ensured that the client's choices were honored, agency staff received DRM rights training, and that direct support professional staff would be reassigned in line with the client's wishes.

### **DRM Enforces Privacy Rights**

DRM received a reportable event that the rights of a man with an intellectual disability were violated when his staff tried to prevent him from having privacy in his room and then embarrassed him in front of his girlfriend. The advocate at DRM talked to the man and intervened with his staff about his rights, including his right to privacy and dignity and respect. The staff person involved in the reportable event apologized to the man and the supervisor at the agency provided assurances that the man will have privacy in his room or where ever else he wants it. Agency director also assured DRM that staff will be more respectful when talking to the man about sensitive issues and concerns.

### **DRM Intervenes to Enforce Communication Rights for Deaf Client**

DRM received a reportable event regarding a 29 year old Deaf man with an intellectual disability whose rights were violated by his residential provider when they continually pulled his home staff and replaced them with staff people who could not communicate with the client. The DRM advocate intervened with the agency CEO, guardian, and community case manager and attended the client's Person Centered Planning Meeting. The staffing issue has been resolved and the agency will no longer place staff in the home that cannot communicate with the

client. The agency hired an American Sign Language instructor to train staff in communicating with the client; classes are mandatory and clients are encouraged to attend. DRM led a discussion with staff regarding client rights and community integration.

**Woman with Intellectual Disability Regains Right to Participate in Community and Social Activities Due to DRM’s Intervention**

DRM received a reportable event alleging the rights of a woman with an intellectual disability were violated by a family member who removed her personal property from her home and refused to allow her to participate in community and social activities of her choice. DRM intervened with the case manager, agency staff, the client and her family member. The family member returned the client's property and understands that the client has a right to participate in community and social activities of her choice.

**CASES**

**Cases by Problem Area**

Abuse	22
Employment	3
Government Benefits and Services	3
Guardianship/Conservatorship	40
Healthcare	13
Home and Community Based Services	368
Housing	5
Neglect	21
Privacy Rights	14
Public Accommodations	1
Rights Violation	4
Transportation	9
Voting	2
<b>Total</b>	<b>505</b>



### Cases by Geographic Location

District 1: York	33
District 2: Cumberland	52
District 3: Androscoggin, Oxford, Franklin	93
District 4: Lincoln, Knox, Waldo, Sagadahoc	35
District 5: Somerset, Kennebec	55
District 6: Piscataquis, Penobscot	154
District 7: Washington, Hancock	18
District 8: Aroostook	65
<b>Total</b>	<b>505</b>

### Reasons for Closing Cases

Case Lacked Legal Merit	17
Individual Withdrew Complaint	37
Individual's Issue Not Favorably Resolved	11
Investigation Completed	1
Issues Resolved Partially or Completely in the Individual's Favor	418
Other Appropriate Entity Investigating	1
Other Representation Obtained	4
Services Not Needed Due to Death, Relocation, Etc.	7
Withdrew because individual would not cooperate	9
<b>Total</b>	<b>505</b>

DRM offers clients a full range of legal advocacy intervention strategies from personalized information and referral to full litigation. At each level of intervention, DRM empowers and supports individuals to speak up for him or herself.

### Intervention Strategies for Closed Cases

Administrative Remedies	2
-------------------------	---

Limited Advocacy	256
Mediation/Alternative Dispute Resolution	4
Negotiation	10
Self-Advocacy Assistance	233
<b>Total</b>	<b>505</b>

## INDIVIDUALS SERVED: DEMOGRAPHICS

### Age

18 to 25	89
26 to 64	235
65 and Over	22
<b>Total</b>	<b>346</b>

### Gender

Female	165
Male	181
<b>Total</b>	<b>346</b>

### Race

American Indian / Alaskan Native	3
Black / African American	1
Race Unknown	139
Two or more races	1
White	202
<b>Total</b>	<b>346</b>

### Ethnicity

Ethnicity Unknown	197
Hispanic / Latino	1
Not Hispanic / Latino	148
<b>Total</b>	<b>346</b>

## Living Arrangement

Adult Community Residential Home	221
Community Residential Home for Children/Youth	6
Homeless	1
Independent Housing	48
Intermediate Care Facilities	6
Non-Medical Community-Based Residential Facility for Children/Youth	1
Parental/Guardian or Other Family Home	56
Private Institutional Living Arrangement/Setting	3
Psychiatric Wards (Public or Private)	2
Public and Private General Hospitals	1
Public State Operated Institutional Living Arrangement/Setting	1
<b>Total</b>	<b>346</b>

## SAMPLE INDIVIDUAL CASES

### Abuse, Neglect & Other Rights Violations

#### Agency Returns Property and Privacy to Client after DRM Intervenes

DRM was contacted by a young woman living in a waiver home who felt her rights to privacy and accessing her property were being violated. The advocate at DRM met with the woman and her staff, including the home supervisor, and talked to them about the woman's rights; it was discovered that the home was preventing the woman from having privacy in her room and was taking some of her property away as punishment. As a result of DRM's advocacy, the woman has privacy for the first time in her life and her property is not being taken away as punishment. The agency has also received DRM rights training and they are reporting more reportable events out of better awareness and understanding of the statutory requirements.

#### DRM Intervenes in Matter of Client's Rights, Dignity, and Property

DRM received a reportable event that a staff person at a day program wouldn't allow a woman with an intellectual disability access to her property and was mean and disrespectful to her. The advocate at DRM talked to the woman, her staff and the executive director of the agency about the woman's rights, including her right to her property and the right to dignity and respect. The agency agreed that the woman's rights were violated and the staff apologized to the woman and agreed to respect her rights and the rights of everyone else attending the day program. The staff involved in the reportable event, as well other day program staff, attended a DRM rights training.

### **DRM Helps Client Access Mall after 7 Year Ban**

The guardian of a man with intellectual disability and autism contacted DRM because the manager of a shopping mall refused the client access. He had been banned from the mall 7 years prior after he broke a display case in a public area of the mall. DRM obtained an opinion from the client's psychiatrist confirming that he did not pose a direct threat to himself or others. The client's caregivers confirmed that the client has been in the community every day for years with his 1:1 support, has done very well, enjoys being in the community, and did not pose a direct threat. The manager was hostile to allowing client to return and requested that client be required to meet with her, look her in the eye and communicate with her, and express remorse for the damage he caused years ago (and for which he had provided restitution). DRM attorney explained that due to client's disability, he has limitations in communication and requested that this practice and policy of the mall be waived for client. The mall manager refused and also said inappropriate, baseless things about client based on his disability. DRM wrote a letter requesting a reasonable modification and access, and informed mall manager that her continued refusal to allow access was a violation law, and the manager relented.

### **DRM Changes Providers' Practices about Appointments**

DRM received a report concerning a woman with an intellectual disability who is non-verbal and whose doctor's appointment was cancelled without notice by the provider. The guardian was not notified of the cancellation and felt the individual was being denied appropriate medical care. DRM discussed the right to medical care with the provider who stated that moving forward they would not cancel appointments without first rescheduling and receiving guardian approval. Individual's appointment was rescheduled with another medical provider and

she attended.

### **Home Staff No Longer Violating Rights of Woman with Intellectual Disability Due to DRM's Intervention**

DRM received a series of reports alleging the rights of a 21 year old woman were being violated by her home staff. DRM interviewed the client, who reported that her residential staff informed her she must speak to her uncle whether she wants to or not because she has a guardian. The client also reported her calls are monitored by staff, and she is required to have staff in the room with her when she meets with her doctor. DRM intervened with the DHHS Case Manager, Case Management Supervisor, Residential Manager, and guardian and met with the client's person centered planning team. During the meeting, participants reviewed client rights, behavioral plans, and guardianship. Because of DRM's intervention residential staff are no longer enforcing requirements that violate the client's rights.

### **Agency Policy Change Implemented Due to Intervention by DRM**

DRM received a report that a staff person working at the home of several men with both intellectual and physical disabilities had violated their rights by refusing them access to their television and wouldn't let one of the men sleep in his recliner and made him go to sleep in his room. The advocate at DRM talked with the executive director and staff of the agency about the rights of the men who live in the home and the staff person was ultimately terminated. The staff of the home also attended a DRM rights training and because of the advocacy of DRM, there was a new agency policy implemented.

## **Due Process**

### **Client Eligible for Services After DRM Appeals Denial**

The legal guardian of a 20 year old woman with diagnoses of Prader-Willi Syndrome and Intellectual Disability contacted DRM about the client suffering from a lack of services. The client had been denied eligibility for Developmental Services based on an incomplete functional assessment measuring the individual's perceived functionality in a controlled school setting. After identifying the error, the DRM attorney appealed the decision and advised the individual's legal guardian to have a comprehensive assessment completed by a qualified clinician.

After a new assessment was completed, the individual was found eligible for Section 21 Services.

### **Client Determined Eligible after DRM Obtains Evidence**

The guardian of a woman with a developmental disability contacted DRM after the state found that the ward was not eligible for developmental services. DRM determined that the client was denied services because the state failed to update their regulations to match new diagnostic criteria. DRM obtained a letter from the client's treating psychologist identifying this issue and incorporated it as part of an argument to the State to provide the client with services. The State then overturned its decision and found the client eligible for services.

### **Provider's Closure Leads to Community Placement with DRM Assistance**

DRM filed a formal grievance on behalf of our client with an intellectual disability after her guardian reported that the client's service provider was closing with no plan for transition of services. DRM advocated with the Office of Aging and Disability Services to continue providing services until an appropriate community placement could be found. DRM also met with local legislators and members of the community to educate them about developmental services and the effect of losing those services for individuals who receive them. DHHS agreed to provide interim services and assist affected individuals in transitioning to a new and appropriate service provider within their community.

### **Client with Autism Diagnosed After the Developmental Period Found Eligible for Developmental Services Because of DRM Advocacy**

DRM assisted a 52 year old man with autism and mental health disabilities in obtaining developmental services after the client was admitted to a psychiatric hospital. The client was not diagnosed with autism until later in life, after the developmental period. DRM appealed the developmental services denial and successfully advocated with DHHS for an alternative eligibility process. DHHS then approved the client for waiver services and cleared the path for him to be discharged from the hospital into an appropriate waiver home.

## **Guardianship**

### **DRM Assists Client in Becoming Own Guardian**

DRM received a request to meet with a 21 year old woman with an intellectual disability because her guardian refused to allow her to remain in her home. The advocate met with the client at her grandmother's home to discuss this situation and provided information regarding crisis services and guardianship technical assistance. As a result, the client's mother is no longer her guardian and the Office of Aging and Disability Adult Protective Services is assisting her with obtaining the appropriate documentation needed to become her own guardian. The client was placed in an OADS Crisis home and her case manager will assist her in finding a permanent home.

### **DRM Assists Client in Guardianship Matter**

A woman with an intellectual disability contacted DRM requesting assistance terminating her guardianship. DRM assisted the client in keeping a record of decision-making and in joining organizations and coalitions where her membership and advocacy would be recognized. During the course of assistance, the client's guardian died. DRM notified the client that this meant she was no longer under guardianship and explained that the client should continue to make responsible decisions and she would receive notice if anyone attempted to put her back under guardianship.

### **DRM Advises Client on Guardianship Concerns**

DRM was contacted by a young woman who had been under guardianship her entire life and wanted to try and become her own guardian. DRM attended many meetings and worked with her guardian to get a current psychological evaluation and help the woman identify skills to work toward removing her guardian. The woman is now getting a second psychological evaluation and will continue to identify and work on skills that she feels will be beneficial in seeking to have her guardianship removed.

### **DRM Provides Assistance in Guardianship Matter to Young Woman with Intellectual Disability**

DRM received a request to meet with a 23 year old woman with an intellectual disability to discuss guardianship and her rights. The advocate met with the client, discussed client rights and provided her with a copy of plain language rights. The client is interested in becoming her own guardian and DRM advised her on that process and next steps.

## **Person-Centered Planning**

### **DRM Enforces PCP Rights of Client**

DRM received a request to attend a client meeting to discuss recent medical concerns of a 40 year old female client with an intellectual disability. The PCP team requested the client not attend the meeting because she may become upset discussing her nutritional choices. The advocate informed the team she had a right to attend her meeting and the client was invited. The team met and the client agreed to make healthier choices in the New Year. A positive support plan will be introduced to support the client in following a healthier lifestyle. Client agreed to participate in the creation of the plan addressing her life goals.

### **DRM Assists Client in Advocating for Himself at PCP Meeting**

The case manager of a man with an intellectual disability asked DRM to attend a client's individual support team meeting. DRM met with the client beforehand and provided him with assistance during his meeting so the client could advocate for goals he wanted included in his person centered plan.

### **DRM Provides Information on the Rights of Woman with Intellectual Disability**

DRM received an invitation to attend the Personal Centered Planning meeting of a woman with an intellectual disability. DRM attended the meeting and informed the woman, and the attendees, of her rights, especially the right to access her community even if her housework or other voluntary chores aren't completed.

### **DRM Provides Guidance to Young Woman with Intellectual Disability**

DRM received a request to attend a person centered planning meeting for a 23 year old woman client with an intellectual disability. The advocate met with the client prior to the meeting to discuss her concerns about her home life, day program, employment, guardianship and living independently in the community. The client currently works fifteen hours a week in the community and continues to work towards becoming more independent. DRM assisted her in advocating for changes in her life.

## **Transportation**

### **Client's Transportation Services Successfully Reinstated after Cancellation**

DRM received a reportable event alleging that transportation services for a



41 year-old man with intellectual disability, who is partially deaf and partially blind, had been abruptly cancelled after the parent/legal guardian was unable to meet transport one day and the individual requested drop off at another location. DRM intervened with the transportation broker, the case manager, and the guardian. The transportation broker agreed to reinstate transportation after numerous teleconferences and after being provided with an alternate drop-off location and multiple alternate phone numbers in the event that the guardian should be late in the future. As a result, the individual was able to resume attending his program 5 days a week.

### **DRM Intervenes to Obtain Accommodation for Safety in Van for Client**

DRM was contacted by a 31 year old woman with cerebral palsy and an intellectual disability requesting assistance with obtaining an accommodation from her residential provider. The client informed the provider that the van currently in use had no safety gate to prevent her from driving off the back of the lift. The provider was insisting she back onto the lift rather than drive on due to the manufacture's operational requirements. The client requested assistance from her primary physician stating backing onto the lift caused extreme anxiety. The physician wrote a letter supporting the client's request. DRM met with the client, DHHS Case Manager, agency staff and attended a team meeting to discuss this issue. The residential agency was able to make the accommodation and provide a van with a lift/safety gate.

### **Client Does Not Lose Transportation Services Because of DRM**

The guardian of a woman with an intellectual disability contacted DRM after a non-emergency medical transportation provider denied the client services. The transportation provider stated that the client needed an escort when being transported. Because there was no escort available, the client was unable to be transported. DRM successfully advocated for the State to require that the transportation provider transport the client without an escort.

## **Housing**

### **DRM Assists Client in Maintaining Her Shared Living Home**

A 30 year old woman with an intellectual disability contacted DRM to prevent her public guardian from removing her from her shared living provider's home. DRM worked with all parties to negotiate an agreement whereby the shared

living provider would receive necessary professional training and client would remain at the home. Client later confirmed that she was happily living with her shared living provider.

**DRM Representation Means Gets Client More Time to Move**

DRM represented a 44 year old male with autism at a landlord-tenant Forcible Entry and Detainer ("FED") hearing and negotiated an agreement whereby the client was provided an extra four months to move.

**BEHAVIOR MANAGEMENT & SAFETY PLANS**

**Regional Review Team Meetings**

DRM advocates participated in all regional review team meetings as non-voting members of the review teams.

**Behavior Management Plans by Geographic Location**

Districts 1&2 (York, Cumberland)	55
District 3 (Androscoggin, Oxford, Franklin)	38
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	8
District 5 ( Somerset, Kennebec)	12
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	18
District 8 (Aroostook)	5
<b>Total</b>	<b>136</b>

**Safety Plans by Geographic Location**

Districts 1&2 (York, Cumberland)	119
District 3 (Androscoggin, Oxford, Franklin)	84
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	24
District 5 ( Somerset, Kennebec)	50

Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	96
District 8 (Aroostook)	68
<b>Total</b>	<b>441</b>

The behavior management review team is required by statute (34-B M.R.S.A §5605(13)(B)(2)) to review behavior management plans that are approved by the individual’s planning team and only used to correct behavior that is more harmful to the individual than the proposed intervention.

A behavior management plan is any intervention that limits the exercise of an individual’s rights for the purpose of addressing consistent dangerous or maladaptive behaviors. The use of these procedures is forbidden unless responding to an emergency or as a part of an approved behavior management plan. The systematic use of any behavioral intervention involving coercion is also forbidden unless it is part of an approved behavior management plan.

It is the responsibility of the regional behavior management review team to ensure that all possible steps are taken to protect the health, safety, and rights of the individual. The review team must then ensure that the plan is clear and comprehensible to all its users.

Additionally, the Department of Health and Human Services adopted regulations (14-197 C.M.R. Ch. 5 Sec 6) requiring behavior management review teams to review the use of safety devices as part of a Safety Plan. Safety devices are devices which reduce or inhibit a person’s movement in any way with a purpose of maintaining safety. A safety device must be designed and applied with concern for principles of good body alignment and circulation and allowance for change of position. The Committee must ensure that the plan is the least possible restriction consistent with maintaining safety and does not act as a substitute for a behavioral management plan.

DRM advocates fully participate in all regional review team meetings as one of the three persons, but they do so as a non-voting member.

As the non-voting member of each review team, the advocates raised concerns about compliance with due process, the justification for intrusive measures, and encouraged detailed and attainable discontinuation criteria. Consistently submitted plans are reduced to less intrusive means or discontinuation of the plan to altogether. The advocates also raised concerns with regard to numerous providers submitting safety plans which contained behavior management interventions. We encouraged data collection to capture accurate details surrounding all physical restraints and/or planned restrictions of rights. The advocates are also continuing to work with the other members of the regional review teams to develop consistent procedures to ensure timely and fair review of plans submitted.

## **SUMMARY OF SYSTEMIC ACTIVITIES**

### **Office of Inspector General Report**

In August of 2017 (after the end of the 2017 fiscal year) the Office of the Inspector General (OIG) issued its concerning Maine's critical incidents report. While the investigation was conducted, DRM had several meetings with OIG investigators and raised systemic concerns about Maine's critical incident and adult protective services system. Many of the issues identified in the report had been long-time concerns for DRM and we are hopeful the report can be a catalyst for systemic reform.

As the OIG report highlights, Maine needs to reform APS. APS needs to hire more investigators; to hold providers accountable for reporting suspected abuse, neglect, exploitation, and deaths; and to work with community providers and law enforcement to hold the individuals responsible accountable. DRM looks forward to working with the Department, people with disabilities, community service providers, law enforcement, and others on developing a system to address abuse, neglect, and exploitation within the system.

However, reform of APS alone will not keep people safe. The larger system of services for people with intellectual disabilities and autism also needs reform. People with disabilities are safest when they live and work in their communities; develop their own network of relationships; and are empowered to make their own choices. Although Pineland Center closed in 1996, DRM has found that some of the practices of the bygone intuition are still part of the system serving people with developmental disabilities. For some people, this means that restraints are an accepted practice of behavior management. Many people served by this system still lead isolated lives without connection to others unless they are paid to work with them. Some people are even denied access to the phone. Individuals with disabilities are safest when they know it is unacceptable for people to lay hands on them and they have access to trusted individuals who are not their service providers. Maine is at a critical turning point for reform to keep people safe must include eliminating outdated practices of the past and building a system that promotes autonomy, employment, true community connections, and independence. As detailed in our activities below, we continue to work to promote these reforms both in our individual case work and systemic advocacy.

### **Developmental Services Advocacy Outreach**

DRM's Developmental Services Advocacy Program provides ongoing outreach statewide to individuals receiving Developmental Services, their family members, guardians and service providers. DRM is continually striving to reach out to the community to provide information regarding the services we provide. 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. During these encounters, advocates will often get the opportunity to meet with not only their clients, but 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.

### **Developmental Services Advocacy Rights Training**

DSA 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. DSA participated in all quarterly, regional rights training in conjunction with the Department of Health and Human Services. Other trainings conducted

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. The team continues to identify strategies to reach more individuals receiving services.

### **Voting Rights Trainings**

DRM conducted statewide voter engagement and rights trainings targeting people with intellectual disabilities who have not been engaged previously.

Sample Voting trainings:

- a provider organization in Casco, serving people with developmental and intellectual disabilities; 25 participants;
- two provider organizations in northern Maine, serving people with developmental and intellectual disabilities; 40 participants
- the statewide conference of Speaking Up for Us, Maine's self-advocacy organization for people with intellectual disabilities; 200 participants.

### **Voting Fairs**

DRM conducted voting fairs statewide targeted to individuals with intellectual and developmental disabilities, and in conjunction with co-hosting provider organizations. Fairs presented participants with opportunity to register on site, learn about voting, candidates, and issues, meet candidates and party representatives, make buttons promoting activism, and try out the accessible voting system; 250 participants.

### **Disability Rights Training to Maine Voting Clerks**

DRM staff presented a training to 250 clerks representing towns and cities across Maine regarding voting rights, accessibility of services, and best practices in providing services to people with varying disabilities. Training highlighted DRM's intervention on behalf of three people with developmental disabilities and communication disabilities who were denied the right to vote.

### **Statewide Review Panel**

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") per a Memorandum of Understanding signed in January 2017. 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. The DSA Managing Attorney sits on the Panel as a non-voting member, and advocates for the least restrictive intervention, raising systemic concerns about the over usage of physical restraint in behavior management, the lack of due process, and the inconsistencies of BMP implementation by agencies. The DSA Managing Attorney has successfully argued for heightened scrutiny of many long-standing Plans that contain severely intrusive measures, and has encouraged uniform data collection of restraints and interventions carried out against individuals subject to these plans. The Panel is also developing best practices and procedures for the successful facilitation of Statewide Panel Meetings.

### **Statewide Regional Review Team Meetings**

DRM continues to facilitate meetings of all people sitting on Regional Review Teams (formerly "Three Person Committees", or "3PCs") that review Behavior Management Plans (formerly "Severely Intrusive Behavior Plans") and Safety Plans 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 identified areas of inconsistencies in plan implementation and has worked to correct these system-wide discrepancies. DRM successfully challenged the use of seatbelt locking restraints as safety devices, and they are now uniformly considered restraints pursuant to the oversight and monitoring requirements of a Behavior Management Plan (BMP). The group has also identified discrepancies in the implementation of the newly promulgated rules and discusses the continuing trainings led by OADS for providers around the state. The statewide regional review team is working to develop best practices and procedures for the successful facilitation of review team meetings.

### **Home and Community Based Services Stakeholder Group**

DRM participated in stakeholder group meetings regarding Maine's implementation of the Home and Community Based Services (HCBS) regulations. The focus of this stakeholder group was been feedback to DHHS's proposals for implementing the transition plan. In particular, the group has focused on fine-tuning the provider survey. DRM has raised concerns about the efficacy of relying largely on a provider survey. Instead, DRM advocated for site visits to providers as well as in-person surveys with individuals receiving services. DHHS ceased holding meetings, however, DRM continues to monitor progress on the State's implementation of this rule. In its regularly scheduled meeting with DRM, OADS leadership has indicated that they continue to await transition plan approval from the Centers for Medicaid and Medicare services. DRM has also monitored the status of these rules on the federal front. All indications are that these rules will go forward although full compliance with the rules was delayed.

### **Supported Decision-Making Pilot Project**

DRM partnered with a provider agency to complete a Pilot Project which aims 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. 4 individuals were identified, under full or limited guardianship, who receive developmental services and who would benefit from Supported Decision-Making. With the permission of the individual and their guardian, the individuals began a series of courses with the goal of learning to make decisions with support.

The DSA attorney helped with formulation of the project. An Advisory Committee was formed and met to provide input on the process, materials, and format of the classes. The Pilot Project classes began, focused on advocacy skills and learning to identify wants and desires. Some subareas of discussion revolved around understanding rights, learning how to subvert peer pressure, and different methods of expression.

The DSA attorney attended the graduation ceremony for the individuals who participated in the project. Each student presented to those in attendance a part of the project that resonated with them.

### **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. The DSA managing attorney in collaboration with self-advocate conducted a training at a transition fair for the blind and visually impaired, reaching both parents and students. The DSA team has collectively directly reached approximately 40 individuals with disabilities to introduce and train on the concept of SDM and offer information and guidance on restoration of rights.

### **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 210 professionals have been trained on Supported Decision Making.

The DSA managing attorney and self-advocate trained approximately 60 DHHS personnel from Districts 3, 4, and 5. Attendees included administrators, guardian representatives, case managers, and crisis workers from the Bangor, Lewiston, and Augusta areas, as well as approximately 120 people at the 2017 Community First Conference and approximately 15 administrators during a transition fair at the Center for the Blind and Visually Impaired. The DSA managing attorney trained 15 case managers at a shelter for youth experiencing homelessness and has 3 trainings scheduled over the next 3 months.

### **Alternatives to Guardianship Webinar**

DRM collaborated with Maine CITE, Maine's Assistive Technology Program, to produce a statewide web-based training on supported decision-making (SDM). This free event was offered to individuals with disabilities, guardians, family

members, service providers and anyone who was interested in learning about SDM. This training was also posted on DRM's website and made available for archived viewing. 79 people were trained.

### **Collaboration with the Office of Aging and Disability Services**

DRM has bi-monthly meetings with Office of Aging and Disability Services (OADS) leadership. These meetings provide a forum to discuss DRM systemic concerns, to receive updates on upcoming regulatory and policy changes, and to discuss cooperative efforts. During Fiscal Year 2017 topics discussed included: OADS' transition plan for the home and community based services rule implementation, behavior regulations, crisis services, non-emergency medical transportation, the brain injury waiver, reportable events, review teams, crisis services, and adult protective services.

### **STRIVE Training**

PSL Services/STRIVE asked DRM to provide training on special education law, procedural safeguards, and guardianship for individuals with disabilities and their support staff at STRIVE. End of Quarter Update: DRM attorney provided a training to STRIVE participants and supporters; 10 people in attendance; special education law, procedural safeguards, and guardianship/alternatives/supported decision making.

### **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.

Currently, the coalition has agreed to perform a number of "case studies" to determine the need, the obstacles, and the effectiveness of RJ-facilitated meetings in the DD community. These case studies are meant to encompass a

number of different situations in order to gather information in order to further development a concrete pilot project. 1 case study has been completed. The case study involved a consumer with DD and his agency and other residents of the program. The RJ session was very successful in that relationships were repaired and lines of communication and understand improved. The coalition is in the process of identifying at least 2 more case studies in a few areas that are considered fairly common in this field. The proposal for a pilot project is becoming more concrete, with an idea to possibly focus RJ principles on individuals in danger of being discharged by agencies in the hopes of salvaging long-term placements.

### **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 the use of restraints on individuals with developmental disabilities in residential settings. The project includes gathering data regarding information on how other states have worked toward this goal of eliminating 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 seeks to continue developing and identifying strategies and practices with state, local and community allies on how to collaborate to best serve disabled victims/survivors of human trafficking statewide through access to strategic and aggressive disability rights advocacy. DRM's Developmental Services Advocacy, PAIMI, and children's teams participated (approximately 30 staff) in a 1.5 hour long training on how to identify victims/survivors of human trafficking by attorney working on this issue throughout the state and received sample toolkits to develop materials on how DRM can identify victims/survivors moving forward. Six DRM staff including executive director, deputy director, managing attorneys and advocate attended NDRN annual conference and received training on this very crucial issue. Furthermore, project lead continued to establish contacts and network with state, local and community service providers.