



Developmental Services Advocacy

Annual Report

July 1, 2015 through June 30, 2016

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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 3-Person Committee meetings reviewing 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 2016:

Table 1: Developmental Services Clients

District	Active DS Clients
1&2	2085
3	952
4	560
5	899
6&7	1397
8	551
Total	6444

REPORTABLE EVENTS

Reportable Events are events that happen or may happen to adults with intellectual disabilities or autism, and that have or may have an adverse impact upon their safety, welfare, rights or dignity. All individuals, agency staff, sub-contractors, and volunteers who provide services that are licensed, funded, or regulated in whole or in part by DHHS are required to submit Reportable Events to the Department. Allegations of abuse, neglect, or exploitation are referred to Adult Protective Services. Allegations of rights violations are referred to DRM. If another agency is more suited to respond, DRM may refer the Reportable Event to the regional OADS supervisor, Adult Protective Services, or Licensing for investigation.

After appropriate follow up, DRM may pursue legal, administrative and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of individuals with intellectual disabilities or autism. DRM may refuse to take action on any complaint that it considers to be trivial, to be moot or to lack merit, or for which there is clearly another remedy available.

SAMPLE REPORTABLE EVENTS

DRM Addresses Array of Serious Rights Violations for Client

DRM received several reportable events alleging rights violations regarding a woman with an intellectual disability. The DRM advocate met with the woman, her staff, the guardian and the executive director of the agency and found out that the woman's rights were being violated in many ways; staff were restricting her right to her property; using the soda that she purchased as a reward for good behavior; restricting what clothes she could wear; refusing to let her keep her property in her room; making her clean up her feces and urine when she was incontinent and using planned restraints - all without any intrusive plans in place. The advocate also discovered that there were over 30 pages of plans that the agency was using and they were all outdated or unapproved. These plans were also wrought with disrespectful language and were not person centered. The advocate educated the entire home staff and their supervisors about rights and reportable event procedures. Because of the advocacy of the DRM, the woman's plans were discontinued and all of her rights were restored for the first time in her adult life.

DRM Investigates Use of Restraints

DRM received a reportable event alleging that an adult male with an intellectual disability was restrained in a face down position using a physical intervention technique that the service provider did not have approval to use. This event prompted DRM attorney to do a thorough review of the reported restraints performed by the client's service provider. Finding a pattern of inappropriate restraints, the attorney opened a separate project to investigate restraints and filed a systemic complaint against the service provider with the state citing this report and other reports from multiple other clients. The state referred the event to Adult Protective Services (APS) for further investigation. After investigation, APS substantiated the

service provider for physical abuse and directed them to submit behavioral plans with the use of this restraint to the oversight and review committee for approval.

DRM Investigation of Reportable Events Leads to Termination of Staffer

DRM received a reportable event regarding a woman with an intellectual disability who was taken by staff to a bowling alley, but was not allowed to bowl, forcing her to sit and watch staff bowl. DRM also learned of an instance where a staff member had left the client unattended in order to use their personal car to make cell phone calls. DRM discussed both reportable events with the service provider, who said that the staff member would be terminated. DRM also spoke to the guardian of the individual, as the individual was non-verbal, and received confirmation from the guardian that the matter had been satisfactorily resolved in the individual's favor.

INDIVIDUAL CASE DATA

Table 2.1: Overview

Number of Individuals Served During Period (Cases)	535
Number of Cases Closed During Period	569
Individuals Still Being Served at the End of the Period	244
Number of Service Requests Opened During Period	704

Table 2.2: Problem Areas/Complaints of Cases Closed During the Reporting Period

Abuse	17
Access to Administrative and Judicial Proceedings	1
Architectural Accessibility	2
Assistive Technology	1
Coercion	1

Disapproval of a Severely Intrusive Plan	2
Employment	1
Government Benefits and Services	8
Guardianship/Conservatorship	47
Healthcare	16
Home and Community-Based Services	411
Housing	12
Implementing a Disapproved Severely Intrusive Plan	5
Neglect	14
Privacy Rights	16
Right to Personal Property	2
Right to Receive Mail	1
Right to Visitors	3
Rights Violation	1
Transportation	5
Voting	3
Total	569

Table 2.3: Reasons for Closing Cases

Appeals Were Unsuccessful	0
Case Lacked Legal Merit	21
Individual Withdrew Complaint	28
Individual's Issue Not Favorably Resolved	10
Issues Resolved Partially or Completely in the Individual's Favor	480
Other Representation Obtained	10
Other Appropriate Entity Investigating	3
Services Not Needed Due to Death, Relocation, Etc.	12

Withdrew Because Individual Would Not Cooperate	5
Total	569

Intervention Strategies

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. DRM intervention strategies are defined as:

- **Advocacy Assistance** includes advice and counseling which can include informing the client of his or her rights, coaching the client in self-advocacy, reviewing information, counseling on possible actions and/or assisting the client in preparing letters or documents.
- **Limited Action** includes taking direct action on behalf of a client including communications by letter, telephone or other means to a third party, preparation of a simple legal document, or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- **Administrative Remedy** is any non-judicial complaint resolution process.
- **Negotiation** is a problem solving process in which two or more people discuss their differences and attempt to reach a joint decision.
- **Mediation/Alternative Dispute Resolution** includes any process for settling a contested matter outside of the formal judicial process.
- **Litigation** is any lawsuit or other use of the courts to determine a legal question or matter.

Table 2.4: Intervention Strategies for Closed Cases

Administrative Remedies	87
Individual Investigation	39
Legal Remedy/Litigation	3

Limited Advocacy	202
Mediation/Alternative Dispute Resolution	1
Negotiation	16
Self-Advocacy Assistance	127
Short-Term Assistance	52
Technical Assistance	42
Total	569

INDIVIDUALS SERVED: DEMOGRAPHICS

Table 3.1: Age

18 to 25	154
26 to 64	347
65 and over	34
Total	535

Table 3.2: Gender

Male	268
Female	267
Unknown	0
Total	535

Table 3.3: Race

American Indian/Alaskan Native	4
Black/African American	1
Race Unknown	86
Two or More Races	2

White	442
Total	535

Table 3.4: Ethnicity

Ethnicity Unknown	188
Hispanic/Latino	1
Not Hispanic/Latino	346
Total	535

Table 3.5: Living Arrangement

Adult Community Residential Home	329
Community Residential Home for Children/Youth	6
Homeless	3
Independent Housing	72
Intermediate Care Facilities	13
Non-Medical Community-Based Residential Facility for Children/Youth	0
Nursing Home	1
Parental/Guardian or Other Family Home	99
Private Institutional Living Arrangement/Setting	4
Public and Private General Hospitals	2
Public State Operated Institutional Living Arrangement/Setting	1
Unknown/Information Not Provided	5
Total	535

Table 3.6: Geographic Location

District 1 (York)	50
District 2 (Cumberland)	72
District 3 (Androscoggin, Oxford, Franklin)	104

District 4 (Lincoln, Knox, Waldo, Sagadahoc)	38
District 5 (Somerset, Kennebec)	63
District 6 (Piscataquis, Penobscot)	119
District 7 (Washington, Hancock)	24
District 8 (Aroostook)	65
No District Reported	0
Total	535

SAMPLE INDIVIDUAL CASES

Abuse, Neglect & Other Rights Violations

DRM Blocks Punitive Behavior Plan

DRM was contacted by a woman with an intellectual disability reporting that her rights were being violated as staff was implementing a behavior plan that punished the woman for bad behavior. The behavior plan had disrespectful language and unrealistic expectations. The advocate at DRM met with the woman's guardian/case manager and her staff about the woman's rights and asked them to change the behavior plan. Because of the advocate's intervention the woman now has a behavior plan that is respectful and not punitive in nature.

DRM Blocks Punishment Interventions Regarding Money, Community Access

DRM received a reportable event that a woman with an intellectual disability's rights were being violated when her staff at day program took her money away from her and prevented her from going out into the community because the woman's guardian wanted to punish her for "bad" behavior. The advocate at DRM talked to the woman, the guardian and her staff about the woman's rights and everyone agreed that the woman will keep the money that she brings to program and will go out into the community with everyone else; she will not be punished for "bad" behavior.

DRM Blocks Rights Violations

DRM received a reportable event that the rights of a woman with an intellectual disability were violated as staff was restricting her access to food, taking away her property and searching her belongings without her permission. The advocate at DRM talked to the agency staff about the woman's rights and they agreed that staff will not restrict her property or search her belongings. They also agreed to stop taking away her property.

DRM Enforces Right to Communication, Access to Community

DRM received a reportable event alleging the right to communication of a young man with an intellectual disability was being restricted by agency staff. The advocate contacted the agency plan coordinator and requested a copy of the client's current person centered plan. The plan restricted the client use of the telephone, social activity, access to the community, and placed restrictions on preferred activities in response to aggressive behavior by the client. There is not an approved severely intrusive plan in place for this client. DRM indicated that these restrictions should be removed from the client's person centered plan. The restrictions/rights violations were removed and the agency created a positive support plan to address behavioral concerns.

DRM Vindicates Right to Vote for 3 Individuals with DD

After 3 individuals with intellectual disabilities were denied the right to vote, staff at the provider agency serving these individuals contacted DRM. The first resident was initially blocked from voting by a female town employee when he tried to vote with assistance from staff. The town employee said staff could not assist the voter in any way. The town employee attempted to assist the individual and declared he could not vote. Two additional residents came with staff to vote, and the same town employee said staff could not help either voter. The town employee said only she could help these voters, and she would not let them vote if she could not understand them or if they could not understand her. The second and third voters filled out absentee ballots, before leaving, and handed them to the town employee, who accepted them physically, but appeared to toss them aside. The town employee offered, "This isn't going to work" as the only reason for refusing the right to vote. When voters the second and third voters were leaving, the town employee asked loudly, so that everyone could hear, "Are you bringing more of these people?" DRM attorneys met with witnesses, several staff from the residence; met with the three voters; reviewed records, including guardianship orders to verify that their right to vote was not restricted. DRM intervened with the town, and one year after the denial of the vote to the clients, staff at the residence brought the clients to vote on Election Day. Staff reported to DRM that the clients were welcomed into the town hall and they successfully voted, with the assistance from staff.

DRM Obtains Treatment, Discharge Services

DRM successfully advocated for a comprehensive discharge plan from a local emergency department on behalf of a young man with autism. The client successfully transitioned back to Maine following an extended out of state residential treatment placement for more than two years. Although his transition went well, he had a significant increase in self-injurious behavior and was transferred to a local emergency department. Initially the

emergency department wanted to discharge the client to a psychiatric hospital or to his home. Neither of these options was appropriate, therefore the advocate worked with the client's case manager and parents to coordinate a meeting with hospital staff. The advocate participated in this meeting and was effective in advocating for his continued stay to continue exploring potential medical causes to his increased behavior. Following this meeting the hospital worked with the client's team to identify medical issues and provide treatment. During his stay, his home service provider terminated services as they believed they were unable to maintain his safety in a community setting. The hospital continued to serve the client while a new service provider was identified and ready to transition the client back to his home. He was in the emergency department for a total of five weeks and numerous medical issues were identified and treated, including severe constipation. Due to DRM's intervention the client received appropriate medical treatment and an appropriate discharge plan back to his home in the community.

DRM Intervenes on Denial of Community Access as Punishment

DRM was contacted by a blind woman with an intellectual disability whose rights were being violated because she had a community support plan in place that prevented her from going out into the community unless her chores were completed. The advocate met with the woman, her case manager and the agency that provides community support and talked to them about the woman's rights. Because of the intervention of the advocate the plan was eliminated and replaced with a plan that was respectful and did not include any consequences.

Due Process

Client Discharged from Services after Going to Emergency Department

A young man, who received Sec. 21 Waiver services, was taken to the emergency room from his group home and when he was ready for discharge from the hospital, the provider refused to allow him back. DRM contacted the agency and informed them that by evicting the client without going through the appropriate process, it was violating the fair housing act and Maine eviction laws. Ultimately, the client secured a new placement and moved to a new home. DRM continues to work on resolving the systemic issue of services providers evicting and discharging clients without following the legal process.

Guardians Unsuccessfully Seek to Bypass 3 Person Committee Process

DRM was served with a legal filing from the guardians of a woman with an intellectual disability who wanted to create a guardianship plan that would bypass the State's Severely Intrusive Planning process. The guardians asked a state probate court to declare that multiple rights restrictions and/or potential violations were, as a matter of law, not violations under the applicable state statute. The filing also asked the court to circumvent the applicable state regulations rather than applying them. Both DRM and DHHS, through the Attorney General's Office, opposed this guardianship plan on the grounds that (a) the applicable state statutory rights should be followed and respected; and (b) the applicable regulations should also be followed and respected. The court ruled in favor of DHHS and DRM on both arguments.

DHHS Pays Client's Transportation Costs after DRM Files Grievance

The guardian of an adult female with a developmental disability contacted DRM because the client's non-emergency transportation (NET) services to her community supports program had been terminated without cause or

notice. DRM contacted both the transportation provider and the Department of Health and Human Services (DHHS). The transportation provider stated that they were acting on DHHS' direction. DHHS identified that there was a policy disagreement between two divisions of DHHS with one division saying that NET services were inappropriate in the client's case while another division stated that they were appropriate based on the funding source of the client's community supports program. The client's services had been terminated while the two divisions resolved their disagreement. DRM filed a grievance based on the denial and the lack of notice. DRM requested that services be reinstated immediately pending a hearing. DHHS initially refused to reinstate services and then eventually agreed to provide the services until a hearing could be scheduled. Approximately a year passed with no hearing scheduled. DHHS again terminated the client's services on the same basis. DRM resent copies of the pending appeal and sent a letter demanding that services be reinstated. DHHS did not reinstate services, but contacted the guardian directly and offered to pay directly for the client's transportation. The guardian accepted this offer.

Employment

DRM Intervenes to Block Implementation of Major Rule Change

The mother of a young man with intellectual disabilities contacted DRM for assistance after learning that a MaineCare rule change might cause him to lose his job. The client lived in a group home and worked full-time in an office for \$12/hour. He had held the job successfully for over 16 years, even managing to work his way off of SSI income. However, the client continued to need MaineCare in order to pay for necessary home supports and care, which he could not afford on his own. The client paid roughly half of his work earnings to the State to contribute to the cost of his care. Due to a rule change, MaineCare notified the client that he would no longer be

allowed to keep any his work earnings. Instead, he would need to pay everything except for \$70 to the State. This change removed any incentive for individuals living in residential care to have a job, since they could not keep any of their earnings. Moreover, without any income to pay for transportation to work, the client would simply be unable to afford to keep working. A DRM advocate contacted the Office of Family Independence on behalf of the client and advocated for the rule change to be repealed, since it would cause the client and many others to lose their jobs immediately. The advocate also explained the negative consequences that the rule would have on the ability to pursue employment for all adults with disabilities living in residential care in the future. As a result of this advocacy, the Department agreed to halt implementation of the rule change immediately while redrafting the rule to help individuals keep their jobs. The client was able to keep half of his earnings as before, and successfully maintained his full-time job.

DRM Helps Client Get Work Supports Restored

DRM was contacted by an adult male with an intellectual disability seeking assistance acquiring work supports. DSA Attorney met with the client and explained the types of services which are available under MaineCare for work supports. During this review, DSA Attorney discovered that the client's MaineCare had been terminated from lack of documentation from the client's guardian. DSA assisted the client in contracting a case manager who was able to help the client re-establish his MaineCare and review the types of work supports he was eligible for.

DRM Obtains Transportation to Work for Client

The Shared Living Provider of a young man with an intellectual disability contacted DRM when his transportation services were terminated. Without transportation, he would be unable to get to work. A DRM advocate contacted the client's state guardian and the Employment Coordinator for the Office of Aging and Disability Services to discuss the reasons for the termination. The client's transportation services were ultimately reinstated,

and OADS representatives met with MaineCare Services to negotiate a permanent resolution to the issue of transportation terminations for waiver recipients living with Shared Living Providers.

Guardianship

Client Becomes His Own Guardian Due to DRM Representation

A man with an intellectual disability contacted DRM requesting assistance terminating his guardianship and conservatorship. DRM discovered that the probate court had processed the client's mother's request for temporary emergency guardianship/conservatorship without contacting the client. Then, instead of scheduling a hearing, the court issued an order for full guardianship and conservatorship. The client was never contacted by the court and had no knowledge of the order until he initially contacted DRM. DRM assisted the client in petitioning to terminate his guardianship/conservatorship. DSA made a motion to the court requesting that the court vacate the client's guardianship/conservatorship on the basis that he did not receive due process when the order was made. At hearing, the court requested that the parties consider a potential settlement. The client's current guardian agreed to terminate guardianship/conservatorship if the client agreed to put his money in a special needs trust. The client met with an attorney specializing in special needs trusts and the Executive Director of a pooled special needs trust to fully understand his options. The client agreed to put his money in a special needs trust and the guardian agreed to terminate guardianship/conservatorship. At hearing, both parties submitted the Settlement Agreement to the court. Pursuant to that agreement, the court terminated the client's guardianship. The client is now his own guardian and his own conservator. He earns his own money, has kept his benefits, and submits to the special needs trust when he needs additional funds for larger purchases.

DRM Intervenes to Block Guardianship

DRM advocate received a request from a community case manager to attend a client meeting for a woman with an intellectual disability to discuss guardianship. The client recently transitioned from children to adult services and is her own guardian. The meeting was attended by the client, her mother and community case manager. The client would like to remain her own guardian but relies heavily on her mother for assistance with medical and financial decisions. The advocate discussed the different types of guardianships and alternatives such as supported decision making. As a result, the client's mother chose not to pursue guardianship at this time.

DRM Involvement Thwarts Guardianship

A man with autism contacted DRM after Adult Protective Services (APS) opened an investigation to determine if the client needed a guardian. The client stated that after his mother left him, he became depressed and has difficulty eating. He also stated that he refused to sign a release for the State to review his medical records. He said for these reasons an APS investigation was opened. He stated he understood the concerns, however believed he is still more than capable of making decisions regarding his life. DRM attended a meeting with APS and advocated on behalf of the client. The APS worker stated that the client "needed to stop trying to tell [her] how to do [her] job." DRM mediated between the client and the APS imparting to APS the gravity of guardianship and the concerns the client had. Subsequently, APS notified the client that they closed his case and unsubstantiated the allegations against him.

Housing

DRM Successfully Works to Allow Client to Stay In Place

The guardian of a man with an intellectual disability contacted DRM, along with an executive of the individual's service provider, due to the "no one person development" policy of the DHHS. The individual was at risk of being forced to move because he had lost his housemate through no fault of his own. DRM worked with the guardian and the service provider to obtain authorization for a temporary exception to the policy. Shortly into the coordinated effort, the DHHS provided the desired exception, authorizing the executive to convert the billing codes until a housemate was located, at which time the code would revert back to the normal code under DHHS' normal policy. This allowed the individual to stay in his residence.

DRM Acts to Keep Client in His Home

The DHHS guardian of an older man with an intellectual disability was concerned after the individual, who was also blind, had received a denial of services letter from a state-contracted provider of services, under the "Two Person Rule," because the individual's housemate had passed away earlier in the year. The individual was at risk not only of losing his funding and services, but also at risk of being forced to move from his long-standing home. The DHHS guardian was concerned that the individual could not survive a move from his home. DRM filed an appeal. As DRM was preparing to assist the individual at the appeal, DHHS was able to successfully place a new individual as the replacement housemate and the client was not forced to leave.

DRM Intervenes to Block Disruption in Housing/Supports

The DRM advocate received a call from the brother/guardian of a man with an intellectual disability, prompted by their sudden receipt of a 30-day termination notice that was issued by the individual's service provider. The

brother/guardian was concerned that his brother would be summarily displaced before he could locate new housing for him. The DRM advocate negotiated with the CEO of the service provider and obtained a representation that the service provider would not displace the individual until he had secured a new residence with the help of his brother and his case manager. The service provider honored its representation and the individual remained in his residence until he eventually moved into a new residence with a new service provider. Because this resolved the matter, the case was closed.

DRM Works with DHHS to Avoid Client's Eviction

DRM received a reportable event concerning a man with an intellectual disability that described circumstances in which the individual risked almost immediate homelessness because his landlord was allegedly attempting to evict him without notice on the eve of a holiday weekend. DRM immediately contacted the individual and the individual's DHHS public guardian, and confirmed that all necessary steps were being taken to protect the individual from eviction over the holiday weekend. DRM remained available over the weekend to provide assistance if needed. As a result of the successful coordinated efforts, the individual was not evicted. Moreover, the individual was later able to relocate to a new residence where his housing rights were respected.

Person-Centered Planning Process

DRM Assists in PCP Meeting

DRM received a request from a young woman with autism and a neurological disorder to attend her person centered planning meeting to discuss guardianship. The advocate met with the client and her team. Discussed supported decision making, limited, full guardianship and advocated on the clients behalf for the least restrictive alternative. The client is currently her own guardian and would like to remain so. The

client’s grandparents fully support her decision and the client has retained an attorney to advise her. The client has elected to move out of her mother's home and will live with her grandmother while she attends college.

DRM Assists Client with Plan for Independence

DRM received an invitation to attend a person centered planning meeting for a young woman with an intellectual disability. The client asked that the advocate assist her in advocating for a new shared living home. The client lived at home with her family and her father was her shared living provider. The client informed the advocate that she loved her family but needed to be more independent and no longer wanted to live at home. The advocate attended several meetings and assisted the client in advocating for a new placement, respite, counseling and employment services. The client who is not under guardianship moved into her new home and reports she is very happy with her new found independence.

SEVERELY INTRUSIVE & SAFETY PLANS¹

Table 4.1: Severely Intrusive Plans by Geographic Location

Districts 1&2 (York, Cumberland)	30
District 3 (Androscoggin, Oxford, Franklin)	26
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	5
District 5 (Somerset, Kennebec)	11
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	20
District 8 (Aroostook)	4
Total	96

¹ Data Provided by the State of Maine, Department of Health & Human Services

Table 4.2: Safety Plans by Geographic Location

Districts 1&2 (York, Cumberland)	91
District 3 (Androscoggin, Oxford, Franklin)	52
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	10
District 5 (Somerset, Kennebec)	44
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	104
District 8 (Aroostook)	73
Total	374

As the data illustrates, major inconsistencies in the number of severely intrusive and safety plans across districts still exist. This issue continues to be explored by the Statewide 3-Person Committee.

THE 3-PERSON COMMITTEE

Note: In April 2016, the regulations governing this process were repealed and replaced with new behavior regulations. While plans must still be reviewed by a committee of three, much of the nomenclature changed. For example, “three-person committees” under the new regulations are “review teams” and “severely intrusive plans” under the new regulations are “level 3, 4, and 5 plans”. Moreover, there are many substantive changes both to procedure and prohibitions, including a prohibition on prone restraints. During this transition phase, in order to protect the rights of individuals receiving services, DRM is working with DHHS, the OAB, and providers to ensure strict compliance with this new regulation. More detailed information this work is contained in the Systemic Work, Issues, and Problems section of this report.

The 3-Person Committee is required by statute (34-B M.R.S.A §5605(13)(B)(2)) to review severely intrusive behavior modification and

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 modification and 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 plan. The systematic use of any behavioral intervention involving coercion is forbidden unless it is part of an approved Severely Intrusive Plan.

The responsibility of the 3-Person Committee in reviewing Severely Intrusive Plans is to ensure that all possible steps to protect the health, safety, and rights of the individual are taken. The Committee 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 the 3-Person Committee 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 3-Person Committee meetings as one of the three persons, but they do so as a non-voting member.

DRM continues to strongly advocate for individual planning teams to consider reducing the intrusiveness of the plans while continuing to incorporate positive supports.

TRAINING ACTIVITIES

Rights of Individuals with Developmental Disabilities

DRM provides rights training to individuals with disabilities, family members, guardians, and service providers. Whenever possible, DRM co-trains with self advocates.

Table 5.1: Rights Training Attendees

Individuals with Disabilities and/or Family members	290
Developmental Services Providers	771
Total	1061

DSA Rights Training

DRM provided rights training to a total of 290 individuals receiving Developmental Services, family members, guardians, and 771 service providers statewide.

Sample trainings:

1. Consumer rights training for 15 consumers and 5 staff at day program in northern Maine.
2. Consumer rights training at day program in Presque Isle for 30 clients and 8 staff.
3. Consumer rights training at central Maine day program for 15 clients and 3 staff.
4. Rights training for 40 ICF staff in Houlton in response to a reportable event of a rights violation.

5. Consumer rights training at southern Maine day program in for 15 clients and 4 staff.
6. Rights training for 85 DSP/Managers/Directors and 5 consumers at Brewer Auditorium. Discussed Severely Intrusive Plans, Nutrition, Person Centered Plans.
7. Client rights training for 35 consumers, 2 guardians and 8 staff at program in central Maine. DRM provided copies of plain language rights regulations and answered questions about guardianship, severely intrusive plans, sterilization and social activity.
8. Behavior Regulation and Rights training in Houlton for 6 case managers, one guardian, 2 service providers and 3 DSP.
9. Rights training for 25 staff members at provider agency; answered questions about reportable events, guardianship, and severely intrusive plans.
10. Consumer Rights training at northern Maine provider agency for 30 consumers and 6 staff. Passed out business cards and talked about rights.
11. Rights Training for 10 Shared Living Providers at Day Program.
12. Client Rights Training in Bangor for 25 people.
13. Client Rights Training at mid-coast agency for 16 consumers and 5 Staff; discussed house rules, visitation, communication, severely intrusive plans, dignity and respect, and handed out copies of plain language rights.
14. Rights regulations training to DHHS in Augusta, to approximately 25 support staff.

Employment Rights Trainings for Individuals with Developmental Disabilities

DRM delivered two sessions of ADA Title I Employment Rights trainings to an agency providing employment support services to individuals with developmental disabilities in the Bangor area. The training was delivered to 20 attendees in total, including both employment support staff and people with disabilities. The trainings covered information on employment rights, antidiscrimination laws, and how and when to request reasonable accommodations.

Employment Training to SUFU

DRM attended a "Speaking Up for Us" Self-Advocacy Group meeting and trained 6 self-advocates and 2 support staff in employment rights for people with disabilities, including specific reasonable accommodation scenarios and options for individuals with developmental and intellectual disabilities. Information and materials on agency programs and services were distributed.

Alternatives to Guardianship

DRM provides training on alternatives to guardianship to individuals with disabilities, family members, guardians, and service providers.

Table 5.2: Guardianship Training Attendees

Individuals with Disabilities, Family Members and/or Guardians, Developmental Services Providers	726
Total	726

DSA Alternatives to Guardianship Training

To date, DRM has provided Alternatives to Guardianship/Supported Decision-Making trainings to 726 individuals receiving Developmental Services, family members, guardians and service providers. DRM is in the process of developing a new Supported Decision Making training.

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 alternatives.

OUTREACH ACTIVITIES

DSA Outreach

DRM's Developmental Services Advocacy program provided information through outreach to 1033 individuals receiving Developmental Services, their family members, guardians and 98 service providers statewide. DRM provided general information about DRM's services, rights, voting, and the grievance process. Outreach was provided to individuals in their homes as well as various community support programs. Additionally DRM reached participated in the MicMac Health Fair in Presque Isle and the Speaking Up for Us Conference. Outreach was conducted at various nursing homes, intermediate care facilities, community support programs, individual residences, and the Maine Parent Federation Transition Fair.

Table 6: Outreach Attendees

Individuals and Family Members with Disabilities	1033
Developmental Disability Providers	98
Total	1131

Sample outreach:

1. Outreach at 3 day programs in northern Maine, to approximately 40 people about rights, including PCP process and the right to invite the advocate, voting and the right to privacy.
2. Outreach at a PNMI in central Maine to 10 people about the role of the advocate and rights including the right to vote, their property and the planning process.
3. Outreach at southern Maine day program, to 25 people about rights, including voting, PCP process and inviting the advocate to meeting and the grievance process.
4. Outreach in Bangor to 10 people and 5 staff about DD services, DRM services, the role of the advocate and rights including the right to privacy, the right to property and the PCP process and inviting the advocate.
5. Outreach to day program to 20 people about the role of the advocate including the right to invite me to meetings, voting and the right to their property.

Maine Psychological Association Presentation

DRM Executive Director and a Deputy Commissioner of Maine DHHS did a training for the Maine Psychological Association on what DRM can do for individuals with mental illness, intellectual disabilities and other cognitive disabilities, what the programs are in Maine that assist these individuals, what to look out for and how psychologists can help their clients access

services and supports. The ED used this training to talk about psychological assessments for education and services and what advocates are looking for to assist our clients. She also talked about Supported Decision Making as an alternative to guardianship. Out of that training, DRM got several calls from psychologists interested in assisting with and/or joining our Supported Decision Making Coalition.

SYSTEMIC WORK, ISSUES & PROBLEMS

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. Over 250 people participated. DRM sent press releases and reached out to local media, and obtained extensive coverage in television news and in print regarding the voting fairs. DRM staff members were interviewed by media outlets regarding voting as a means of civic engagement and community inclusion.

Supported Decision-Making Coalition

DRM applied for and was awarded this State Grant to provide information and outreach about Supported Decision-Making to the State of Maine. Supported Decision-Making was virtually unknown across populations and disciplines in Maine. For individuals experiencing difficulties in decision-making, guardianship was the only option offered to the families and services seeking to support their loved ones and clients. DRM founded and facilitates Maine's Supported Decision-Making Coalition, a partnership of

aging adults, individuals with disabilities, and agencies representing and supporting individuals with disabilities whose collective goal is to educate the public on and promote Supported Decision-Making as a legitimate and appropriate alternative to guardianship. As part of its membership, each partner agreed, at minimum, to attend and participate in Coalition meetings; to assist with distribution of Supported Decision-Making materials; promote Supported Decision-Making on their organization's website; and assist us in identifying adults and youth under or at risk of guardianship who would thrive under Supported Decision-Making. DRM provided outreach and training statewide for individuals, community members, and service providers. We participated in and provided training on Supported Decision-Making as part of major State initiatives such as the DOE's Transition Conference for youth transitioning into adulthood and at Maine's annual Brain Injury Conference and TASH's national conference.

DRM also prioritized developing training for clinicians and psychologists as these professions often produce the sole recommendation and evidence used at hearing to place individuals under guardianship. Within the grant year, we taped and produced an approximately seven minute video featuring six self-advocates speaking about their personal experiences with guardianship and Supported Decision-Making. The video is housed on our website and has been widely distributed and linked in training and presentations on Supported Decision-Making nationally. We have taped and are in the process of editing follow up videos which document individuals currently utilizing Supported Decision-Making.

DRM PADD Advisory Council

DRM continues to develop the membership and mission for its Developmental Disabilities Advisory Council (DDAC). The DDAC is intended to build partnerships in policy making, outreach and training activities, as well as to advise the PADD program on the development and

implementation of priorities and program activities. The council meets on a quarterly basis.

During the year, council membership significantly increased, as did council members' involvement in policy making. Council members partnered with others on the Supported Decision-Making Coalition, created a video about guardianship, and co-hosted a Supported Decision-Making luncheon for legislators. Members developed video scenarios for use in rights trainings and conducted rights trainings with DSA advocates. Members also helped DRM develop a voting rights training and planned for voters' fairs for the upcoming election season. Additionally, council members attended policy meetings, such as the Coalition for Housing and Quality Services, the Developmental Disabilities Council, and the Community Advisory Committee.

With DSA advocacy support, council members also commented directly about proposed regulations that affect their lives. Two council members testified at a regulatory hearing for the proposed Section 21 rules. Another council member provided written comments to proposed Section 21 waiver application and to the rules.

Developmental Disabilities Council

DRM continues to serve on the DD Council, working closely with our network partner to improve access, services, supports, education, and employment outcomes for individuals with developmental disabilities.

Center for Community Inclusion and Disability Services – Community Advisory Committee

DRM continues to participate in the CAC, to advise and collaborate with our sister agency, CCIDS, to promote opportunities for individuals with developmental disabilities to exercise self-determination, to be independent, to be productive, and to be integrated and included in all facets of community life

Comments to the New Behavior Regulations

DRM provided extensive comments to the proposed behavior regulations. In it, DRM noted that as written the regulations were confusing and some provisions were contradictory. The comments offered numerous editing suggestions to make the rules more clear and comprehensible and to strengthen the rights and protect the safety of individuals subjected to behavior plans. For example, DRM praised the regulatory prohibition on prone restraints and advocated for the Department to go further and prohibit all floor restraints and restraints that do not conform to nationally recognized physical intervention programs. Moreover, DRM advocated for more stringent oversight of any plans that limit community access through in-home stabilization.

The regulations were adopted in April and DRM continues to work with the Department and the Maine Developmental Oversight and Advisory Board in an effort to ensure strict compliance with the new regulatory requirements.

Statewide 3-Person Committee

DRM continues to coordinate an ongoing statewide group of all people serving on regional 3-person committees that review Severely Intrusive Behavior Plans and Safety Plans for individuals receiving Developmental Services. DRM works closely with the Maine Developmental Services Oversight and Advisory Board and the Department to hold these meetings every other month. Issues identified in these meetings include the need for strict adherence to the new behavior regulations, agencies' continued use of severely intrusive interventions without appropriate approval from the committee, and strategies to ensure agencies incorporate the use of positive supports.

The purpose of this group is to establish consistency and best practice for these reviews statewide, to discuss and get information and assistance for challenging cases and to refer cases and issues, as appropriate to the DRM.

This fiscal year, the statewide group meetings included discussion of the newly adopted behavior regulations, training on these new regulations, and the positive behavior support plans required. DRM has established a regular working partnership with DHHS and the Developmental Services Oversight and Advisory Board to work on improving documentation, process and integrity of the 3-person committee.

Excellence Committee

A DRM representative attends monthly meetings of the Excellence Committee, an open provider forum for discussions concerning current issues affecting developmental services, areas for improvement, information sharing and training opportunities.

DRM uses these meetings as an opportunity to collaborate with service providers and the community about better advocacy outreach and potential legal issues affecting clients.

Coalition for Housing and Quality Services

DRM participates on the Coalition for Housing and Quality Services with the Developmental Disabilities Council, DD Advisory Council Members, the Center for Community Inclusion, DHHS, parents of children with intellectual disabilities and autism, service providers, educators and many others.

DRM attends these meetings each month to hear concerns of family members and people receiving services and to provide information about issues affecting people with intellectual disabilities and autism. Coalition members have divergent viewpoints and DRM continually advocates for Coalition members to promote a system of personal supports that is person centered, and promotes choice, dignity, and efficiency.

This year DRM provided a well-received presentation on Supported Decision-Making to the Coalition.

Collaboration with the Office of Aging & Disability Services

DRM has bi-monthly meetings with leadership of the Office of Aging and Disability Services. These meetings provide a forum to discuss DRM systemic concerns, receive updates on upcoming regulatory and policy changes, and to discuss cooperative efforts.

Topics discussed included transportation, three-person committees, rights violations, the supports intensity scale, waiver services, the home and community based waiver transition plan, behavior regulations, the grievance process, crisis housing, adult protective services, supported decision-making, guardianship, restraints, staffing concerns, adult protective services, and reportable events.

Maine's Transition Plan for Home & Community-Based Waiver Services

The Federal Medicaid agency enacted new rules about how services are to be delivered to people with disabilities in the community. DRM served on the Department's provider advisory group in the development of the transition plan and advocated for surveying all individuals receiving services to determine compliance with the new requirements, rather than relying on providers to self-identify non-compliance. The Department ceased having advisory group meetings after it submitted a revised transition plan to the Centers for Medicare and Medicaid Services. DRM continues to advocate for a comprehensive transition plan for full compliance with the HCBS regulations.

Supports Intensity Scale

The Office of Aging and Disability Services proposed restructuring the delivery of developmental services using the Supports Intensity Scale (SIS).

The SIS is an assessment tool that measures an individual's need for support in different areas of his or her life. OADS had also proposed a new rate structure based on the SIS.

Throughout the year DRM staff have taken part in stakeholder meetings, raised concerns with OADS management, attended trainings, and participated in weekly calls concerning proposals for the implementation of the SIS and the associated changes to the rate model. DRM also submitted oral and written comments to the proposed Section 21 rules. DRM's comments focused on the need for due process protections and making sure that policy and financial decisions would support and encourage client independence. For example, DRM has continued to advocate against higher budgets for individuals living in group homes rather than in their own home or apartment.

Ultimately, the Department withdrew the rules implementing the SIS. DRM looks forward to working with the Department, individuals receiving services, family members, and other stakeholders on expected changes to the Section 21 program.

Money Follows the Person - Demonstration Project

DRM is a participant in this advisory/stakeholder group regarding Maine's implementation of the Money Follows the Person Demonstration Project. The focus has been the ongoing implementation of the MFP project. There were only two stakeholder meetings. DRM continues to monitor the implementation of this program that has supported many Mainers in moving out of nursing facilities and into the community.

Section 21 Home & Community-Based Services Waiver Changes

DRM provided written comments to the proposed changes to the Sections 21 & 29 Waivers contained in the OADS' renewal applications submitted to the Centers for Medicare and Medicaid Services. Some of the issues identified in the Section 21 Waiver renewal application were the need to:

remove the term mental retardation from the application, increase the number of waiver slots for individuals seeking to leave institutions, review the waitlist priority protocol, decrease the participant/staff ratio for individuals receiving community support services, ensure that individuals receiving remote support have the ability to turn it off, and pay at least minimum wage to individuals receiving work supports.

Lack of Qualified Professionals to Provide Behavioral Services

DRM has raised several concerns with behavioral services for people with developmental disabilities. One of these concerns was the significant lack of psychologists across the state who are qualified to review and approve Severely Intrusive Plans (SIPs).

In the newly promulgated behavior regulations, expand the types of qualified professionals who can monitor these plans to include Licensed Social Workers, Licensed Certified Professional Counselors and Board Certified Behavior Analysts. Despite this change, DRM continues to hear from service providers that they are having difficulty locating qualified professionals to develop and monitor these plans. DRM continues to urge the Department to recruit and train more qualified professionals to meet this need.

DRM has also been concerned about the ongoing monitoring and oversight of plans by psychologists. Monitoring typically occurred through monthly psychological consultations. The quality of these consultations to implementing staff varied significantly statewide. Some included staff from all locations where the plan was implemented while others did not. In some parts of the state the psychologist merely reviews the documentation of the use of severely intrusive interventions and has no direct contact with the implementing or with individuals. DRM raised these concerns with DHHS, both informally and formally, through grievances and regulatory comments.

The recently promulgated behavior regulations specifically require the presence of at least one representative from each agency responsible for the implementation of during these monthly clinical reviews with the qualified professional. Likewise, the regulations now mandate that the qualified profession meet with the individual at least twice a year.

Protecting the Rights of People under Guardianship

People with intellectual disabilities continue to face significant challenges with respect to guardianship. Parents of individuals with disabilities are still often counseled to pursue guardianship as a matter of course when their child turns 18. Individuals are routinely placed under full guardianship by judges who do not explore whether less restrictive alternatives are available and appropriate. Individuals facing guardianship are often not fully informed of their right to challenge the guardianship petition. Individuals and their families and supporters are not aware of the alternatives to full guardianship. There remains confusion in the community around some of the most basic rights of individuals under guardianship.

In response, DRM has attempted to address these concerns individually in case work, PCP meetings, and 3-Person Committee reviews of Severely Intrusive Plans. Systemically, we have also attempted to address these concerns through trainings and advocating for policy change. We are currently available for trainings in the community for families, individuals, and service providers. We are also in the process of developing a training event for legal professionals on the guardianship process for Continuing Legal Education credit.

Public Guardians as Case Managers

According to the 2016 Olmstead Plan Roadmap, the state continues to cite to case managers as acting as neutral facilitators in the planning and

coordinating of services directed by the individual. However, state case managers remain in conflicting roles when they are tasked with both supporting the individual in directing their services and acting as public guardian against the expressed wishes of the individual. This role is particularly difficult when the individual is seeking support in a position that is counter to the state's policies and practices. DRM continues to advocate and urge the Department to change its policies so that all individuals under state guardianship have access to an independent, community case manager.

Physical Restraints

Individuals receiving Developmental Services continue to be treated differently in that they are subject to restraints which are outside of nationally recognized and formalized behavioral intervention programs (such as the Mandt System).

The current regulations and statutes require that restraints be reported within one business day to the Department. Further, that improper or unauthorized use of a restraint on adults with intellectual disabilities or autism is considered abuse. While these restraints are generally reported, they are often reported without detail or review.

Last year, DRM conducted a targeted review of restraints reported to the Department and found that an overwhelming number of individuals receiving services were subjected to types of physical restraints that were prohibited by the service provider's certification. In particular, we focused our review on the use of floor restraints, both supine and prone.

The newly adopted behavior regulations prohibit the use of prone restraints. We continue to urge the Department to adopt standards, which also prohibit the use of supine restraints, and restraints outside of nationally tested training

Housing

Finding and maintaining affordable and accessible housing remains a barrier in increasing independence for people with developmental disabilities. The waitlists for subsidized housing are multiple years long, leaving individuals with limited options for housing independent of services. People receiving developmental services are often forced into emergency housing or overly restrictive supported housing because they have no other place to go.

Though there are options for individuals eligible for waiver services, such as agency support homes and shared living, there is no guarantee that the individual will be able to remain in those placements. When service providers own the house that the person rents from, they are tied to that provider and subject to that provider's discretion. Though tenancy and services may not be terminated without appropriate notice and enforcement, DRM has observed a disturbing trend of providers leaving individuals at hospitals and refusing to allow them to return to their homes.

Efforts to separate housing from services needs to continue as do the efforts to educate providers as to their client's housing rights. DRM conducts and is available for trainings, which address tenancy and the rights of individuals receiving developmental services. We will continue to provide these trainings and further outreach to address this overwhelming problem. Additionally, we continue to promote the use of leases, also a requirement of the Federal Home and Community Based Settings regulations.

Also gravely concerning is the Section 21 Home and Community-Based Waiver regulations which promote the eviction of individuals based on their ability to find and maintain a roommate. The regulations currently require that individuals living in apartments owned by service providers have a roommate in order to receive home support services. Additionally,

providers are now required to give notice to individuals that they must leave the residence when the Department stops their services in accordance with this rule.

The Department regulations do not include exceptions for individuals who require 24/7 support, but cannot live with a roommate for medical reasons. Further, the Department has not acted on or recognized that individuals who cannot medically live with another person are entitled to reasonable modifications of the current rule. We continue to represent individuals who are effectively denied support services when they are unable to live with another person due to their disability and educate the Department and community about rights under the Americans with Disabilities Act.

Notices to Reduce and/or Terminate Services

Many people are still not aware of their appeal and grievance rights. Frequently, individuals do not receive sufficient notice when their services are reduced or terminated. Similarly, case managers do not understand the grievance process and Department officials do not follow adhere to the timeframes outlined in regulation. DRM has raised these concerns with OADS. DRM attorneys also have raised individual concerns with notice and failure to follow required procedures in MaineCare appeals and developmental services grievances.

Inability to Access Services Waiver Services

Several factors limit individuals' ability to access services for which they are eligible to receive.

Despite additional funding for the Section 21 waiver and additional offers made, there continues to be a sizeable waiting list of individuals waiting for a funded opening in this program.

Increasingly, even those individuals who receive offers of Section 21 waiver offers continue to wait for services because no service provider responds to

their request for services. Even those individuals, who are able to locate a willing provider, wait a significant amount of time for providers to hire and train staff.

Although there is no official waiting list for Section 29 waiver services, people who apply for these services tell us they wait for up to nine months after their application is complete to get a funded offer from DHHS for this program. Like individuals with Section 21 waiver offers, individuals who have Section 29 waiver offers often find no provider willing and able to provide services or wait significant amounts of time to find a provider and for that provider to hire and train staff.

To make matters worse, by regulation, if an individual does not access services within six months of receiving a funded offer, they forfeit their offer and have to reapply for waiver services. DRM has successfully advocated on behalf of clients to retain their waiver slot when they were unable to access services due to the lack of a willing and able service provider and advocate that the Department change its regulations to reflect this change.

While not unique to these programs, the lack of competitive wages and benefits for direct support professionals (DSPs) is creating a significant crisis for these programs. In addition to the increased waiting time for these services, individuals receiving services express dissatisfaction with high staffing turn over and frequently do not receive all of the services they need and have been found eligible to receive. Individuals receiving services, the Department, service providers, advocates, DSPs, and other stakeholders need to come together to develop creative solutions to this problem. Possible reforms could include salary floors; the increased use of technology to supplement the work of DSPs; and increasing access to self-directed options, which reduce administrative overhead and increase individual's independence.