



Developmental Services Advocacy

Annual Report

July 1, 2014 through June 30, 2015

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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 in September 2015 shows the following breakdown of individuals receiving Developmental Services in each area for fiscal year 2014:

Table 1: Developmental Services Clients

District	Active DS Clients
1&2	1,956
3	915
4	556
5	887
6&7	1,318
8	531
Total	6,163

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.

Table 2: Reportable Events

Reportable Events Resolved During the Period	409
Reportable Events referred to OADS, APS or Licensing During the Reporting Period	184
Total	593

SAMPLE REPORTABLE EVENTS

DRM Intervenes to Restore Right to Privacy for Client

DRM received a reportable event on behalf of a 39 year old woman. The report stated that the client could no longer have time alone in her apartment as a result of her having a friend over to visit during a non-approved time. This decision was made by her public guardian and service provider with no input from the client. The client was not in agreement with a restriction that was put into place after she exercised her right to have visitors at her home. The advocate met with the client and provided her with information about her rights and participated in a planning meeting at which time her alone time was restored.

DRM Enforces Client's Rights to Property, Freedom from Improper Restrictions

DRM received a reportable event alleging the rights of a woman with an intellectual disability were violated when staff removed her personal property, over her objections, at the request of her guardian. The advocate attended an individual support team meeting and informed the team and guardian that they could not remove a client's personal property unless it was an emergency and there was a risk of imminent danger to self or others. Even in that instance, the client's property must be returned when

the emergency is over. Agency staff indicated they had called the guardian for permission. The advocate reiterated to the team that the only way agency staff could remove an individual's personal property is in cases of emergency, or by a severely intrusive plan approved by the 3-Person Committee.

DRM Obtains Disciplinary Action and Training for Staff Person who Violated Rights

DRM received a reportable event alleging concerning a 22 year old man with an intellectual disability whose rights were violated when staff attempted to restrict his access to the community. This action was taken because the individual did not follow a suggested diet plan. The advocate contacted the agency's Executive Director to discuss this reportable event. The staff person in question was placed on 90-day probation, ordered to repeat the Rights portions of the Direct Support Professional Training, and required to attend a DHHS Rights and Behavioral Regulation Training. The advocate accepted the provider resolution.

DRM Blocks Effort to Punish Client by Withholding Property, Community Access

DRM received a reportable event that an adult with an intellectual disability was prevented from going out into the community as punishment for her behavior. She was also being prevented from having access to her property by agency staff. The advocate pushed for the client to have access to her property and for the agency to discontinue any language or action that prevents people from accessing the community as punishment at their facility.

Client's Right to Receive Unopened Mail Affirmed

DRM received two reportable events involving a 35 year old woman with an intellectual disability whose staff would read her mail and then inform the guardian of its contents, per the guardian's request. DRM contacted agency, which then followed up with staff regarding the individual's rights.

As a result, the supervisor held a subsequent rights training with staff. Staff now understand that the guardian cannot delegate their power to staff and also that a person's mail is not to be read at the direction of a guardian.

DRM Blocks Phone Monitoring

DRM received a reportable event that a man with an intellectual disability had his rights to use the phone and right to privacy violated by agency staff. The advocate spoke with the agency and it agreed to discontinue the violating actions. The agency also discontinued the monitoring of his phone calls and staff participated in a Rights Training provided by the DRM. The client now chooses where he uses the phone, when he uses the phone, and who he talks to.

Staff Member's Employment Terminated for Rights Violation

The rights of 28 year old woman with autism and an intellectual disability were violated after an agency staff redirected the individual back to bed after the staff person told the individual that it was too early to get up. The agency reported that the staff member was terminated. Other staff received verbal warnings about not reporting the rights restriction or stopping the rights restriction. DRM accepted the provider resolution.

Provider Refuses to Follow Guardian Request

DRM received a reportable event regarding a 30 year old man with an intellectual disability that detailed a situation in which a parent/guardian had requested that the individual's service provider withhold the individual's personal property (in this case, a portable music player). However, the service provider informed the guardian that this was impermissible on the grounds that taking the individual's personal property would constitute a rights violation. Because the service provider correctly identified the issue and correctly declined to take the property from the individual it served, the DRM Advocate accepted the provider resolution.

INDIVIDUAL CASE DATA

Table 3.1: Overview

Number of Individuals Served During Period (Cases)	422
Number of Cases Closed During Period	636
Individuals Still Being Served at the End of the Period	136
Number of Service Requests Opened During Period	557

Table 3.2: Problem Areas/Complaints of Cases Closed During the Reporting Period

Abuse	20
Access to Administrative and Judicial Proceedings	2
Assistive Technology	1
Education	1
Employment	3
Employment Discrimination	2
Financial Benefits	1
Government Benefits and Services	10
Guardianship/Conservatorship	35
Healthcare	17
Home and Community-Based Services	453
Housing	20
Neglect	23
Privacy Rights	37
Transportation	8
Unnecessary Institutionalization	2
Voting	1
Total	636

Table 3.3: Reasons for Closing Cases

Appeals Were Unsuccessful	1
Case Lacked Legal Merit	41
Individual Withdrew Complaint	28
Individual's Issue Not Favorably Resolved	14
Issues Resolved Partially or Completely in the Individual's Favor	503
Other Representation Obtained	32
Services Not Needed Due to Death, Relocation, Etc.	7
Withdrew Because Individual Would Not Cooperate	10
Total	636

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 3.4: Intervention Strategies for Closed Cases

Administrative Remedies	69
Advocacy Assistance	290
Legal Remedy/Litigation	8
Limited Action	238
Mediation/Alternative Dispute Resolution	2
Negotiation	29
Total	636

INDIVIDUALS SERVED: DEMOGRAPHICS

Table 4.1: Age

18 to 25	101
26 to 64	286
65 and over	35
Total	422

Table 4.2: Gender

Male	212
Female	210
Unknown	0
Total	422

Table 4.3: Race

American Indian/Alaskan Native	4
Black/African American	4
Race Unknown	17
Two or More Races	1
White	396
Total	422

Table 4.4: Ethnicity

Ethnicity Unknown	119
Hispanic/Latino	2
Not Hispanic/Latino	301
Total	422

Table 4.5: Living Arrangement

Adult Community Residential Home	388
Community Residential Home for Children/Youth	4
Foster Care	2
Homeless	3
Independent Housing	79
Intermediate Care Facilities	32
Non-Medical Community-Based Residential Facility for Children/Youth	1
Nursing Home	3
Parental/Guardian or Other Family Home	111
Private Institutional Living Arrangement/Setting	6
Public and Private General Hospitals	5
Unknown/Information Not Provided	2
Total	636

Table 4.6: Geographic Location

District 1 (York)	36
District 2 (Cumberland)	40
District 3 (Androscoggin, Oxford, Franklin)	135
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	30
District 5 (Somerset, Kennebec)	57
District 6 (Piscataquis, Penobscot)	240
District 7 (Washington, Hancock)	19
District 8 (Aroostook)	79
No District Reported	0
Total	636

SAMPLE INDIVIDUAL CASES

Abuse, Neglect & Other Rights Violations

DRM Conducts Statewide Monitoring Visits to Emergency Housing Homes in Response to Client Concerns

The grandmother and guardian of a 21 year old man with autism contacted DRM with concerns regarding emergency housing. The client was in emergency housing for over nine months. The guardian alleged that during this period, her grandson did not receive appropriate services, including personal care, community integration and assistance with obtaining permanent housing. The advocate provided the grandmother with information about the client's rights and the grievance process. The advocate also provided technical assistance in self-advocacy. The client moved to permanent housing and the grandmother was independently pursuing a grievance related to his care while in emergency housing. As a result of this case, DRM conducted statewide outreach and unannounced monitoring visits at emergency housing homes statewide. DRM will continue to monitor these issues.

DRM Intervenes in Personal Choice Violation, Provides Rights Training in Home

DRM received a reportable event alleging a violation of rights regarding a man with an intellectual disability whose staff prevented him from wearing a skirt to day program. The DRM Advocate met with the client at day his program to discuss the reportable event. The Program Director and residential staff also participated in this meeting. The client reported that his staff was concerned that he may be teased for wearing the skirt in the community; he agreed to take it off and put it in his bag until he arrived at the day program. Staff confirmed they were concerned the client may be teased and discussed it with him, but informed him it was his choice and he could choose to wear the skirt if he wanted. The client chose not to wear the skirt that day but did wear it for three consecutive days that week before putting it away. The DRM Advocate recommended all home staff receive client rights training. The Program Director agreed that this training would be beneficial for all staff involved.

DRM Intervenes to Obtain Appropriate Discharge Plan and Services

DRM successfully advocated for a 23 year old man with an intellectual disability to be appropriately discharged from an emergency department. The client was transferred from the county jail to the local emergency department for a psychiatric evaluation. Once the client was determined not to need inpatient care, he was going to be discharged to the streets. The advocate provided the client with information about his rights and negotiated an appropriate discharge plan with the hospital. The discharge plan included the hospital securing and paying for four nights at a local motel and support from the Developmental Services Crisis Team.

Rights Restored for 30 Year Old Man

DRM represented a 30 year old man with an intellectual disability after he contacted the DRM to help him advocate for the discontinuation of his severely intrusive plan. DRM successfully advocated, along with the client,

at the review of his plan in front of the review committee and achieved discontinuation. He had been under a plan that restricted his rights to property and privacy for multiple years.

DRM Addresses Lack of Professional Monitoring of Behavior Plan

The public guardian representative of a 59 year old man with an intellectual disability requested DRM's assistance regarding the lack of appropriate oversight and monitoring of the client's severely intrusive behavior plan by the psychologist. The client resides in a group home and attends a community support program five times per week. The client had an approved severely intrusive plan that was implemented in both settings. However the home provider agency had a policy that limited psychological consultation meetings to the house administrator and prohibited participation by the public guardian representative and community support program. It was clear that each setting interpreted and implemented the severely intrusive plan differently. The advocate participated in a person centered planning meeting in an attempt to resolve the issue. The house manager was clear that although he agreed the client would benefit from consistent implementation of his plan and oversight in all settings would be beneficial there was nothing he could do because of the agency's policy. Therefore DRM filed a complaint pursuant to Maine law that asserted the agency policy violated the client's rights. DRM requested the agency review and amend their policy to ensure all settings that the plan was implemented received appropriate oversight and monitoring by the psychologist. The agency rejected the complaint at the first level, therefore DRM appealed to the second level. DRM received a favorable response at this level from the Director of the Office of Aging and Disability Services. However, the agency appealed the decision to the commissioner who overturned the Director's decision. Although DRM was unable to resolve the agency's policy issue, DRM was able to advocate for ongoing training in all settings and additional consultation to ensure his severely intrusive plan was implemented in a consistent manner.

Plan to Fine Client Discontinued

DRM participated as a non-voting member of a committee which reviewed the behavior plan of an adult man with an intellectual disability. The plan involved fining the client with his own money. The client reported he enjoyed the process of budgeting and understanding his money. After reviewing the records, the advocate discovered that the client had not been fined under the plan in a significant period of time. The advocate argued for the discontinuation of the plan. The service provider agreed to discontinue the plan and the review committee disapproved the plan for future use.

Positive Support Plan Developed

DRM attended the individual support team (IST) meeting of a woman with an intellectual disability. The agenda for the meeting was to develop a severely intrusive plan for the client. During the meeting, The advocate advocated against implementation of procedures against the client's will, including physical and mechanical restraints. The planning team agreed to remove the mechanical restraints from the plan and take more time developing more positive supports.

Client Swallows a Battery; Provider Does Not Transport to the ED

DRM received a telephone call from a 31 year old woman with an intellectual disability asking for assistance after she swallowed a battery. The individual communicated that staff was not taking her to the hospital because they did not believe her. The advocate worked to get the individual medical treatment, via a hospital emergency department, after speaking by telephone with service provider staff, the staff supervisor, and the individual's public guardian. Emergency department doctors determined that a battery was in fact ingested; that it had already passed through the individual's throat (removing the risk of choking); and that it was not leaking. Doctors monitored the battery via x-ray until it passed without harm to the individual.

DRM Advocates for Deaf Client with an Intellectual Disability to Receive Interpreting Services

A 52 year old Deaf woman with an intellectual disability contacted DRM, through her guardian, for help with accessing interpreting services at a local hospital. She was in the hospital for a procedure and it took an unreasonable amount of time for her to access an interpreter. In the immediate, the issue was resolved, but the guardian was concerned that it could happen again. Since it was systemic change that the guardian was interested in, DRM connected her with the state's Deaf advocacy organization.

With DRM's Assistance, Client Understands Rights and Choices

With the assistance of a family friend, a 51 year old man with an intellectual disability contacted DRM to express his desire to return to his family home and live with his mother. His case manager and his home supports service provider told him that it was not an option. The adult protective agency also indicated that it would not support a move back home due to past issues with his mother. DRM informed the individual and his supporters of his right to change his housing, his provider, and his case manager and the practical implications of such changes. DRM spoke with the case manager and she then put out a call for an in-home provider at his mother's house. The individual was able to move to his family home and have in-home supports.

Due Process

Client Appeals Denial of Developmental Services, Found Eligible

The guardian of a man with an intellectual disability contacted DRM after the client had been denied Developmental Services. The guardian had appealed the determination on behalf of the individual and requested DRM representation at the administrative hearing. The advocate discovered that the client had been denied because the State was requiring written documentation of disability prior to age 18. While the regulations required

that the disability must have “manifested during the developmental period”, they did not require written evidence of disability during the developmental period. Through no fault of his own, the client did not have any documentation prior to his 18th birthday. DRM represented the client at the hearing. The Hearing Officer issued a decision stating that the State had incorrectly applied the regulations and granting Developmental Services to the client.

DRM Prevails at Eligibility Hearing

A 57 year old man with an intellectual disability contacted DRM because he had been improperly denied Developmental Services. A review of the individual’s case showed that DHHS had committed numerous legal and factual errors in denying services, and that the individual met all enumerated legal and factual requirements to receive Developmental Services. DRM successfully represented the individual in administrative appeal, and the Hearing Officer’s recommendation in favor of DRM’s client, including all findings of fact, was accepted in full by the Office of the DHHS Commissioner.

Employment

DRM Intervenes in Sub-Minimum Wage Violation Case

A 28 year old man with an intellectual disability and his guardian contacted DRM for assistance regarding his employment at an establishment paying sub-minimum wage. The client was concerned that he was not being compensated consistent with state and federal guidelines for the work he completed given his paystubs were confusing and lacked the hours he worked. The advocate provided the client with information about his rights and, after a review of his employment records, filed a wage and hour complaint with the Department of Labor on his behalf. The Department of Labor completed a review of the client’s employment record and issued a letter to the establishment ordering them to correctly indicate the hours worked per week on each employee’s paystub. Additionally, the advocate

participated in a planning meeting with the employer to advocate for additional support each week so that the client could understand his pay. The advocate also supported the client through the referral process to Vocational Rehab to further explore competitive community employment opportunities.

Client Retains Right to Work During VR Assessment Process

An adult man with an intellectual disability invited DRM to his Individual Support Team meeting. The client had been restrained more than three times in a two week period. The client reported that he was bored and wanted to work. He was working with Vocational Rehabilitation (VR) to assess his abilities and available employment opportunities. The client's service provider offered him employment, but the State denied the client's request for work supports until such a time as VR completed assessments. The DRM Advocate attended the meeting and talked to the team about the client's right to choice and opportunities for employment. The advocate contacted the State after the meeting for clarification of their rule regarding work supports and VR services. After review of the current statutes and regulations, the advocate could not locate any provision which excluded work supports while receiving VR services and provided this information to the client.

DRM Assists Client with Employment Complaint in Sub-Minimum Wage Setting

A 41 year old man with an intellectual disability and his guardian contacted DRM with concerns about how his supervisor was treating him. The client was employed in a sub-minimum wage enclave and reported that his supervisor was disrespectful and rude to him on several occasions. The advocate reviewed the client's employment records, provided him with information about his rights, participated in his Person-Centered Planning meeting, and provided him with information about alternative employment options, including career planning. The employer conducted an investigation into the client's allegations. The client was not in agreement

with its outcome and chose to give his notice and pursue alternative competitive employment options.

Guardianship

DRM Aids Client in Avoiding Guardianship

DRM provided a 22 year old woman with an intellectual disability with information about her rights, alternatives to guardianship, the grievance process, and potential services that she is eligible to receive. The client requested DRM assistance in response to a reportable event to ensure she remained her own guardian and was able to receive appropriate services to live in the community. The client fled from an abusive situation and was receiving emergency housing. Her case manager was attempting to convince the Department of Health and Human Services that she lacked capacity to make her own decisions. The advocate met with the client and participated in meetings to develop her Person-Centered Plan and secure appropriate services. In part due to DRM intervention, the client continues to remain her own guardian and she is in the process of moving into permanent housing.

Client Uses Supported Decision-Making with DRM Support

A woman with an intellectual disability contacted DRM with questions about guardianship and alternatives. The advocate attended the client's Individual Support Team meeting. The client explained that she felt like sometimes she made poor choices and she wished there was someone who would help her think through her decisions. She thought that she might want to have a guardian. During the meeting, DRM talked to the client about what guardianship was and the array of alternatives to guardianship that exist, including supported decision-making. When the client said she wanted to think about it more, DRM sent her a packet of information about guardianship and alternatives. When DRM met with the client again, she stated that she did not want someone to have the legal authority to force her to do something she didn't want to do, but she still wanted help with

making decisions. The advocate talked to the client about advance directives, powers of attorney, supported decision-making, and other alternatives. After considering all alternatives, the client decided she wanted to try supported decision-making. DRM drafted a supported decision-making contract for her to use. DRM checked in after a month and the client is now successfully using supported decision-making and no longer wants to have a guardian.

Client Freed From Guardianship and Conservatorship

A 26 year old man with an intellectual disability contacted DRM for help in terminating his guardianship and conservatorship. He had been under guardianship and conservatorship since he was 18 years old and has gained much independence in the past 8 years. DRM filed for termination of both the guardianship and conservatorship. Both were terminated and he has regained his legal personhood.

Despite Default Judgment, Judge Refuses to Terminate Guardianship without Doctor's Approval

A woman with an intellectual disability contacted DRM requesting assistance with terminating her guardianship. The advocate initially provided the client technical assistance with writing an informal letter to the court in which she requested that her guardianship be terminated. When the client received no response or acknowledgement to her letter after two months, DRM contacted the court and was told that there was a backlog on mail. The advocate requested that the clerk look for the client's letter. The clerk found the client's letter in a stack of unopened mail. The advocate requested that the court begin proceedings to terminate based on the letter. The clerk told the advocate that she could not begin proceedings without a formal petition. DRM sent motions for termination, hearing, and appointment of attorney to the court which were eventually granted. A visitor was appointed and met with the client. The advocate finalized service on a formal petition and nearly a year after the client sent the letter, the court issued a hearing date. The client's case manager

contacted DRM and told DRM that that the guardian did not intend on attending the hearing. When DRM contacted the guardian, the guardian confirmed that she would not be present. DRM contacted the court and requested that an Entry of Default be entered against the guardian, which it was. At the hearing, the judge asked the client to talk about her ability to make decisions. Even though no one was there to contest the termination, the judge issued an order stating that he could not terminate the guardianship without a recommendation from a physician or psychologist. DRM later submitted an affidavit from the client's therapist of three years advocating for the termination of the guardianship. The therapist's affidavit noted that the current guardianship was unnecessary and destructive, but the court still refused to terminate guardianship. The advocate contacted the client's primary care clinician and the overseeing physician signed the form, which DRM submitted to the court. Only after receiving this document did the court agree to terminate guardianship.

DRM Successfully Negotiates with DHHS to Terminate Limited Guardianship

DRM received a request for legal representation from a 39 year old woman with an intellectual disability. The individual had been her own guardian, but she had been placed under a limited medical guardianship approximately five years prior during a difficult period in her life. She had successfully ended this difficult period and thus wanted to end the medical guardianship. DRM successfully negotiated with DHHS to petition the probate court to terminate the guardianship. This was a distinct advantage for DRM's client, as usually DHHS agrees only to remain silent or take the position of "unopposed" while requiring the individual to petition the court him or herself. The court entered an order terminating the limited medical guardianship on the grounds that the client was no longer incapacitated.

Guardianship Terminated

A man with an intellectual disability had been put under guardianship and conservatorship without notice of the hearing or a court visitor to meet

with him. The advocate represented the client at a hearing and filed multiple motions challenging the guardianship. The client reached a settlement agreement with the guardian to terminate the guardianship and conservatorship, which the judge signed off on. Although allegations of financial exploitation remain, the client is now able to make his own decisions concerning all issues separate from his finances.

DRM Successfully Represents 46 Year Old Man to Become His Own Guardian

DRM represented a 46 year old man with an intellectual disability and as a result he is no longer under guardianship. He contacted DRM to help him through the process and represent him in court. After 29 years under guardianship, he was free and has chosen to share his story publicly to hopefully inspire others to pursue such independence.

DRM Heads Off Guardianship Inquiry

A 20 year old man with an intellectual disability contacted DRM because even though he is his own guardian, he was worried that the State or his grandmother might petition for guardianship. DRM sent materials to him, spoke to members of his team, spoke to the State, and attended meetings with his team, which included his grandmother, to discuss the issue of guardianship. The State withdrew their guardianship investigation as a result.

Housing

DRM Intervenes to Block Discharge from Program

DRM successfully negotiated an agreement on behalf of a 34 year old woman with an intellectual disability to remain in her home. Prior to DRM assistance, the agency provided written notice of their intent to discharge the client due to their ongoing conflicts with the guardian. DRM provided information to the guardian about the client's rights and the Developmental Services grievance process, participated in meetings to

address ongoing concerns, and represented the client at mediation. All issues were resolved during mediation and the agency withdrew their intent to discharge the client. As a result of DRM intervention, the client was not discharged and her services have vastly improved due to better communication between the agency and guardian.

Client Decides to Move after Reviewing Options

A 26 year old woman with autism contacted DRM because she was being harassed by the building management because of her disability. She wanted to know what her rights were and how DRM could help. There was ample evidence showing that the management was bothering her about numerous issues that did not appear to be lease violations. DRM presented her with options, including interceding on her behalf with the management, self-advocacy by affirming her rights within the lease or aiding her in breaking the lease based on the lease violations the management committed. The client decided to move out since there was only a few months remaining on the lease and she was exhausted. She submitted her notice.

DRM Assists Client in Obtaining Independent Housing and the Right to Live with Her Girlfriend

DRM advocated on behalf of a 32 year old woman with an intellectual disability under public guardianship who desired to live with her girlfriend. Prior to DRM assistance, the client lived in a supported apartment setting and desired to move into an independent apartment with her girlfriend. The advocate provided the client with information about her rights and the guardianship process. The advocate also participated in several meetings to negotiate additional overnight stays at her girlfriend's home. The guardian and other team members were concerned that the client was pressured to move with her girlfriend and potential domestic violence. During the course of representation the client chose to leave her supported apartment and move in with her girlfriend. To date, there have been no issues regarding domestic violence. The guardian is now supporting the

client to maintain an apartment with her girlfriend. Due in part to DRM's assistance, the client is now residing where she desires.

Client Avoids Eviction, Maintains Housing

The guardian of an adult man with an intellectual disability contacted DRM because the client had been told that he had to move out of his residence with less than twenty-four hours' notice. The client did not want to move and the guardian wanted better transition services before any move took place. DRM assisted the client in filing a grievance and contacted the service provider to ensure that the services stayed in place pending the resolution of the grievance. As part of the grievance, the service provider agreed to meet with the guardian to address her concerns. During the meeting, the service provider agreed that the client did not need to move. The case manager confirmed this resolution in writing following the meeting.

DRM Assists Client in Housing Emergency, Planning Process

DRM participated in a meeting at the request of a 56 year old woman with an intellectual disability. The client was experiencing a bed bug infestation and harassment by her neighbors. The advocate provided the client with information about her rights and landlord/tenant disclosures. The client expressed a desire to move and her team developed a plan to support her to do so. No further advocacy services needed.

Man with Intellectual Disability Remains in Apartment because of DRM

The guardian of a man with an intellectual disability contacted the DRM because the public housing authority where he lived sent a letter to the client asking him to move out and threatening to evict him if he didn't leave voluntarily. The housing authority indicated that the client was harassing other tenants. The client acknowledged that he had some social skill limitations and had been attempting to get supportive services in his home. DRM assisted the client in getting a new case manager, who in turn was able to obtain in home support services. The housing authority agreed to

allow client to remain with the additional supports. Two months after staff began working with the client, the parties held a meeting and housing authority management indicated that the reasonable accommodation had been successful and the client was no longer at risk of being asked to leave.

Person-Centered Planning Process

DRM Educates Client re PCP Process and Rights

DRM provided rights and guardianship information to a 33 year old woman with an intellectual disability. The client contacted DRM for assistance following a meeting where she did not believe her team was listening to her desire for paid employment and to change day programs. The advocate provided her with information about her rights, the Person-Centered Planning process, Developmental Services grievance process, and guardianship. The client later reported that issues were resolved and no further services were needed.

DRM Assists Homeless Client with Access to Services

The DRM advocate met with of a 19 year old woman with an intellectual disability and her guardian. The client requested this meeting because she was homeless and in crisis. The advocate provided the client with information about her rights and services she may be eligible to receive through adult Developmental Services including emergency housing and crisis services.

DRM Assists in Protecting Rights in Intrusive Behavior Planning Process

DRM participated in the planning meeting of a 30 year old man with autism. His team was in the process of developing a severely intrusive behavior plan. The advocate provided the client's team with information about his rights and answered questions about the behavior and safety device regulations.

Advocate Aids Client in Effort to Move, Pursue Employment Goals

DRM's presence was requested at special meeting for a woman with an intellectual disability. The case manager, guardian and case management supervisor met to discuss the client's wish to return back home to live with her family. The advocate attended the meeting and discussed client rights issues, employment, and community support. The team was in support of the client's decision to return home.

DRM Advocates for Removal of Improper "Reward" Plan

A man with an intellectual disability invited the advocate to a Person Centered Planning meeting. While at that meeting the advocate became aware that the man's rights were being violated. The client was being prevented from staying home unless he earned that right through good behavior. The client also had to earn the right to go out into the community. The advocate spoke with the facility, as well as with the case worker, and the "reward" program is no longer in place.

No Intrusive Plan Created Due to DRM Attendance at PCP Meeting

A 40 year old man with an intellectual disability requested DRM attend his Person Centered Planning meeting because his case manager had advised him that the team was considering a behavior plan that could impact his rights. At the meeting, DRM advocated for alternatives to pursuing the plan; the team was receptive. They will be working on greater communication between the service providers supporting the individual and no intrusive plan is being created at this time.

Advocate Assists in PCP, Addresses Housing Concern

DRM was contacted by a woman with an intellectual disability because she wanted an advocate to attend her Person Centered Planning meeting because she was going to be removed from her current home without her consent. The advocate attended the PCP meeting and as a direct result of DRM's efforts, the woman is staying in her shared living home. The

advocate also had the team remove criteria that would've been a precursor to removing the woman from that home in the future.

SEVERELY INTRUSIVE & SAFETY PLANS¹

Table 5.1: Severely Intrusive Plans by Geographic Location

Districts 1&2 (York, Cumberland)	30
District 3 (Androscoggin, Oxford, Franklin)	29
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	6
District 5 (Somerset, Kennebec)	12
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	13
District 8 (Aroostook)	5
Total	95

Table 5.2: Safety Plans by Geographic Location

Districts 1&2 (York, Cumberland)	86
District 3 (Androscoggin, Oxford, Franklin)	45
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	6
District 5 (Somerset, Kennebec)	29
Districts 6&7 (Piscataquis, Penobscot, Washington, Hancock)	101
District 8 (Aroostook)	81
Total	348

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.

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

THE 3-PERSON COMMITTEE

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 6.1: Rights Training Attendees

Individuals with Disabilities and/or Family members	315
Developmental Services Providers	803
Total	1,118

Alternatives to Guardianship

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

Table 6.2: Guardianship Training Attendees

Individuals with Disabilities, Family Members and/or Guardians	60
Developmental Services Providers	0
Total	60

OUTREACH ACTIVITIES

DRM advocates participated in the Statewide Speaking Up For Us (SUFU) conference held in Bangor and spoke to over 100 people with disabilities about DRM’s advocacy services.

DRM also provided information to over 250 people at the Micmac Health Fair in Aroostook County.

DRM advocates conducted unannounced site visits at all ESM emergency housing facilities across the state. These visits were in response to numerous rights violation reportable events, as well as reports from individuals and family members regarding the lack of community access and personal care at these facilities.

Table 7: Outreach Attendees

Individuals and Family Members with Disabilities	536
Developmental Disability Providers	182
Total	718

SYSTEMIC WORK, SYSTEMIC ISSUES & SYSTEMIC PROBLEMS

DRM PADD Advisory Council

DRM has formed a Developmental Disabilities Advisory Council to build partnerships in policymaking, to partner in outreach and training activities and advise the Developmental Disabilities team on the development and implementation of priorities and program activities. Fifteen individuals from across Maine participated in the first meeting, which took place on March 17, 2015. The group elected Jack Jackson to be Chair of the Advisory Council and formed two sub-committees. Eric McVay serves as Chair of the Policy Making Sub-committee, while Randall Woodbury was elected Chair

of the Outreach and Training Sub-committee. Eric was also selected to be the Advisory Council's Representative to the DRM Board of Directors. The full council has assisted DRM's Developmental Services Advocacy program with reviewing and revising its rights training. This, presented by both a person with a disability and a DRM representative, provided to people who receive developmental services. The council developed various scenarios related to specific rights and decided to produce videos to accompany the training. DRM staff and the council collaborated and developed five rights scenario videos about dignity, respect, privacy, property, and the Person-Centered Planning process. Several councilmembers also participated in a Supported Decision-Making testimonial that will be debuted at the first meeting of the Supported Decision-Making Coalition in July. The council and DRM staff members continue to identify more people to fully partner with in outreach and training. Additionally Eric McVay is working to develop a strategy to provide training to the council and others statewide to ensure full and active participation in educating policymakers during the next legislative session.

Employment First Maine

DRM continues to serve as the lead partner responsible for coordinating the activities of the Employment First Maine coalition. In collaboration with OADS, SAMHS, the Maine Department of Labor, the Maine Department of Education, and allies and activists, DRM staff members serve on the executive committee of EFM and on work groups related to capacity building, policy, and transition.

DRM has helped the coalition coordinate its work regarding phasing out subminimum wage in Maine and, in that capacity, educated people with disabilities and policy makers regarding this outdated policy and advocated for its replacement with opportunities to pursue integrated, community based and competitive employment for fair wages. The phase out continues to be a focus of coalition work. People with developmental disabilities are disproportionately negatively affected by unfair sub-

minimum wage provisions, and DRM continues to make policy change and enforcement of existing regulatory wage requirements a priority.

Statewide 3-Person Committee

In an effort to bring consistency to the interpretation of the governing regulations and review of these plans, DRM coordinates a statewide group of all people serving on regional 3-Person Committees.

DRM works closely with the Maine Developmental Services Oversight and Advisory Board (MDSOAB) and the Department to hold these meetings every other month. The purpose of these meetings 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 DRM and the MDSOAB.

This year the statewide group has discussed issues related to food restrictions as a behavioral intervention, agency policies that restrict individuals' rights in response to an alleged crisis, discontinuation criteria and positive behavior supports. Representatives from Port Resources provided training to the statewide group about positive behavioral supports and offered specific resources for the group to consider. The group has continued to discuss the need for consistent interpretation of the 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. To date, the Department has not promulgated the proposed behavior regulations and this is an ongoing discussion and concern of the statewide 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.

At the request of the Excellence Committee DRM provided a grievance and appeals training for committee members. The training was held at OHI in Brewer and was attended by approximately 35 committee members from across the state. The training was well received and DRM plans to present this training in Augusta in October for individuals who receive services and their family members.

Housing Coalition

DRM participates on the Coalition for Housing and Quality Services with the Developmental Disabilities Council, Speaking Up For Us, DHHS, parents of children with intellectual disabilities and autism, service providers, educators and many others. The Coalition works to create a system of quality housing and personal supports that is person and family centered, and promotes choice, dignity, and efficiency. This group is helping to make policy changes in the service delivery system and promoting self-determination so that people receiving services and their families have more control over housing and the services they receive.

DRM participates in these meetings each month to hear concerns of family members and people receiving services and to provide guidance and information about issues affecting people with intellectual disabilities and autism.

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, and reportable events.

Training for Hospitals

DRM met with a northern Maine provider agency management in response to continued concerns with services provided to individuals with intellectual disabilities and autism at the medical hospital. DRM consulted with other P&A agencies to gather information about how this issue is being dealt with across the country. Developmental service provider agencies continue to develop and use special care plans to alert hospital staff of an individual's disabilities and assist them in tailoring services specific to their needs when they access health care services at the hospital.

DRM continues to provide individual advocacy assistance as requested and has offered to provide training to the hospital specific to "Understanding and Supporting Client's with Disabilities in a Hospital Setting". The focus of the training was assisting individuals with disabilities in crisis, guardianship issues, rights and communication. DRM will continue to provide this training as requested.

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. As part of this effort, the Department of Health and Human Services is required to create a plan that demonstrates how it will ensure compliance with these rules. The transition plan had to be submitted to the Federal Medicaid agency by March 17, 2015. DRM served on the Department's provider advisory group in the development of the transition plan. The provider group met twice and DRM raised concerns during these meetings related to the lack of client

representation on the group and limited time frame the Department created to seek public input. DRM also provided written comments to the Draft Transition Plan.

Supports Intensity Scale

The Office of Aging and Disability Services is 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 has 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 written comments to the draft Section 21 waiver renewal application. DRM's comments have 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.

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

Among the problems with behavioral services for people with developmental disabilities is the fact there continues to be a significant lack of psychologists across the state that are qualified to review and approve Severely Intrusive Plans (SIPs). In fact, only a few are involved with this process and provide the oversight and consultation required under the regulations.

Psychologists must agree to the ongoing oversight of the plan through monitoring its effectiveness. The monitoring typically occurs through monthly psychological consultations. The quality of these consultations to implementing staff varies significantly statewide. Some include staff from all locations where the plan is implemented while others do 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 staff on a monthly basis.

DRM continues to advocate for regulatory changes to address these issues. The proposed regulations expand the ability of drafting and monitoring plans to Licensed Social Workers, Licensed Certified Professional Counselors and Board Certified Behavior Analysts which would widen the pool of qualified professionals. OADS took the positive step of including these changes in amendments to the Section 21 Waiver but still needs to move forward with the rule making process for the proposed changes to the behavior regulations. DRM will advocate for OADS to immediately begin the work of training and providing assistance to this wider pool of credentialed professionals.

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 2015 Olmstead Plan update, 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 which is counter to the state's policies and practices.

This dual role continues to be one of long-term concern by DRM over the possible conflict in advocating for the clients wishes while at the same time protecting the public fiscally. In our last report, we addressed the stakeholder group which included OADS employees which stated to the 2012 legislature "The Department is committed to separating the case

management function from the public guardianship function. However, the timetable for accomplishing this goal is dependent upon the specifics of anticipated, but not yet announced, Departmental reorganization.”

It has now been over three years since the reorganization and there has been no mention from the Department regarding separation of these two roles. We continue 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. Until that time, DRM will also continue to represent individuals who do not have access to a case manager who represents their interests due to public guardianship.

Guardianship Reform

DRM continues to explore all avenues for systemic guardianship reform by representing individuals to contest or terminate guardianship and by educating the public and policy makers about alternatives to guardianship.

In June of this year, DRM was awarded a grant from the National Resource Center for Supported Decision-Making to fund a project to provide outreach to families and individuals on Supported Decision-Making as an alternative to guardianship. Maine law currently requires that all least restrictive alternatives are considered before guardianship. Much like the planning team process, Supported Decision-Making allows supporters to provide assistance to individuals in learning to use and apply the decision-making process. It allows individuals the ability to remain self-determined and autonomous while giving them the tools and the support they need to make informed decisions. Along with fifteen other community partners, DRM has formed a Supported Decision-Making Coalition whose website will launch by January 2016. The website will include information about Supported Decision-Making, guardianship and alternatives to guardianship, and individual testimonials of people affected by guardianship.

DRM has also provided comments to the Probate and Trust Law Advisory Commission on their recommendation to the legislature that Maine adopt the Uniform Probate Code with amendments. Included in those comments is the inclusion of Supported Decision-Making as an alternative to guardianship and the requirement of court-appointed attorneys be provided to individuals in all cases where guardianship is being considered.

As DRM moves forward, we will be looking for more collaborators, including psychologists, probate judges, lawyers, visitors, the Department of Health and Human Services, the Attorney General's office and other organizations.

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.

DRM recently 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 which were prohibited by the service provider's certification. In particular, we focused our review on the use of floor restraints, both supine and prone. After confirming that these restraints were not taught as part of the formalized behavioral intervention program, DRM filed complaints with the Department addressing the specific incidents and the systemic use of floor restraints. We continue to urge the Department to adopt standards which

would clarify that the use of restraints outside of nationally tested training is prohibited and specifically address the use of floor restraints.

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.

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 rights and do not receive sufficient notice when their services are reduced or terminated. DRM often finds significant deficiencies in notices, which can lead to the further violation of individuals' due process rights. DRM successfully advocated, in meetings with OADS management and in formal comments, for a clear appeal process for individuals whose services may be reduced as a result of the soon-to-be implemented Supports Intensity Scale. DRM attorneys also have raised individual concerns with notice in MaineCare appeals and developmental services grievances.