



**Developmental Services Advocacy
Annual Report
July 1, 2013 through June 30, 2014**

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INTRODUCTION

The Disability Rights Center (DRC) 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. DRC’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.

DRC is proud of the vastly increased advocacy services that we have been able to provide since September 4, 2012 to Maine citizens with intellectual disabilities and autism. There are Developmental Services Advocates (DSA), funded by the Maine Department of Health and Human Services (DHHS), Office of Aging and Disability Services (OADS) in Caribou, Bangor, Lewiston, Augusta/Rockland, and Portland.

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 statewide.

DRC is delighted that long time advocate Katrina Ringrose is now providing ongoing training, supervision and support to our highly qualified DSA advocates and attorneys.

Data provided by the Department in September 2014 shows the following breakdown of individuals receiving Developmental Services in each area:

Developmental Services Clients		
District Office	Active	Inactive
1 & 2	1829	63
5	830	45
3	862	38
4	540	29
6 & 7	1249	46
8	532	45
Total	5,842	266

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, staff of agencies, subcontractors 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 DRC. If another agency is more suited to respond, DRC may refer the Reportable Event to the regional OADS supervisor, Adult Protective Services, or Licensing for investigation.

After appropriate follow up, DRC 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. DRC 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.

REPORTABLE EVENTS

Reportable Events Resolved during the period	450
Reportable Events referred to OADS, APS or Licensing during the Period	205
Total Reportable Events	655

INTERVENTION STRATEGIES

DRC offers clients a full range of legal advocacy intervention strategies from personalized information and referral to full litigation. At each level of intervention DRC empowers and supports individuals to speak up for themselves.

- 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.

Advocacy Assistance	271
Limited Action	63
Investigation/Monitoring	29
Administrative Remedy	47
Negotiation	39
Mediation/Alternative Dispute Resolution	0
Litigation	1
Total	450

SAMPLE REPORTABLE EVENTS

- 1.) DRC received two reportable events alleging ongoing rights violations of a 27-year-old female with an intellectual disability by her Shared Living Provider (SLP). The client had lived with her SLP since she was placed in foster care as a teenager. She was making plans with her team to live more independently in the community and the report alleged that her SLP attempted to influence her decision to move out because the shared living stipend was the sole income of the provider. Additionally the reportable events stated that the SLP slept all day and the client reported that she had little access to the community. The advocate provided the client with information about her rights and facilitated a team meeting to clearly develop a transition plan for the client to move out of her shared living home into an apartment. Following the meeting the client expressed to the advocate that she did not feel comfortable going back to the shared living home. The advocate was able to immediately work with the oversight agency to develop a plan for the client to leave the shared living home and move into a transitional placement while waiting for a subsidized apartment. The client reports relief and excitement with her new home.

- 2.) DRC received a reportable event alleging the verbal and physical abuse of a 50-year-old male with an intellectual disability. The report alleged that a direct support professional took away the client's food and threw it away, scolding him for not eating fast enough, and threatened that he could not have any food or snacks for the remainder of the day. The advocate conferred with Adult Protective Services (APS) and conducted an initial investigation. The advocate visited the client at his home and interviewed the service provider administrator, reporter of the incident and the client's guardian. Based on information obtained during the interviews the advocate referred the reportable event to APS for further investigation.
- 3.) DRC received a reportable event for a 44-year-old woman with an intellectual disability. The report alleged that she was transported in a vehicle equipped with a safety barrier between the front and back seat and a barrier over each vehicle window. The client had an approved behavior support plan at the time that included less restrictive interventions to support her when in the vehicle. The use of safety barriers was not included in the client's behavior support plan, nor was the use of safety barriers an emergency intervention as defined by the regulations. The implementation of a new severely intrusive intervention or use of a safety device without appropriate, documented approval by the planning team, guardian, doctor, and 3-person committee is not permitted. The service provider submitted the use of the barrier to the 3-person committee and it was later approved. In response to the reportable event, DRC recommended that the service provider host a mandatory rights training by DRC.
- 4.) DRC accepted the provider resolution to a reportable event alleging that a 46-year-old female with an intellectual disability was forced to go to bed as a means of discipline by her direct care staff. The service provider residential director conducted an internal investigation regarding the allegations and based on that investigation was unable to determine whether a rights violation occurred. The resolution included increased on-site supervision by an administrator and unscheduled "drop ins" by multiple directors, increased staff meetings to two each month for six months, and the staff person noted in the reportable event was counseled on appropriate communication, expectations and the legal rights of individuals supported.

- 5.) DRC received several reportable events on behalf of a 53-year-old male with an intellectual disability. The reportable events stemmed from the client changing case management agencies and moving to another city. Two reportable events alleged that the new case management agency coerced the client into changing providers and two other reportable events alleged the prior case manager violated the client's rights by not providing self-directed services, by failing to provide information about his representative payee and his money and by making threats about guardianship. The advocate met with the client and provided him with information about his rights and services that he was eligible for through Developmental Services and the mental health system. The client made it very clear that he chose to change case management services and move to a different city because he was not happy with his prior services. The advocate reviewed documentation and interviewed the prior case manager and was unable to substantiate any rights violation. The client reports that he is very happy with his new case manager and new apartment.
- 6.) DRC received nine reportable events on behalf of a 23-year-old male with an intellectual disability. The client previously agreed to a plan that included the limited use of his electronics to common areas of the home and daily room and pocket searches. This was a moderately intrusive behavior plan as the client agreed to the interventions, per the regulations. However, for it to be a moderately intrusive plan, the individual must retain the power to discontinue it at any time and the service provider has to immediately stop implementing the interventions. The reportable events indicated that the service provider continued to implement the interventions against the client's wishes and believed they could do this as long as they filed a reportable event. The advocate met with the client at his home to provide information about his rights, participated in several planning meetings to clarify that the regulations do not permit the use of non-emergency interventions without an approved severely intrusive plan. After several discussions with senior management staff the agency agreed to stop implementing the plan.
- 7.) DRC received a reportable on behalf of a 37-year-old male with an intellectual disability who receives 24-hour support in an agency owned home. The report identified several ways the agency staff violated the client's rights. As a means of punishment, agency staff removed the client's personal property and restricted his chosen leisure activity, which is impermissible under Maine Law. The report states that the removal of

his personal property and restriction of his leisure activity occurred after he was calm, sitting on his bed crying. Further, the report is not clear as to what behavior constituted an emergency requiring the use of physical restraint. It states that he was restrained for swearing at staff and ripping his shirt. Neither of these behaviors rise to the level of an emergency as defined by the regulations. The advocate reviewed the client's written behavior support plan and identified that it included severely intrusive procedures that were largely punitive in nature and did not promote the learning of safer behaviors in place of dangerous behaviors as contemplated by the regulations. In response to the reportable event and review of the client's record DRC recommended that the agency convene a planning team meeting including a representative from DRC to review the client's Behavior Support Plan and make revisions necessary to ensure it conforms to the governing regulations. DRC advocate attended the client's meeting to review his behavior management plan and less restrictive interventions were incorporated. DRC provided a rights training to over 45 agency managers and met with all senior management to discuss service delivery that can lead to rights violations and how to ensure that clients are informed of their rights and empowered to speak up for themselves. DRC has received a copy of all behavior support plans for clients supported by the agency, has scheduled rights training for individuals supported by the agency and guardians, and will observe the rights training provided by the agency.

- 8.) DRC received a reportable event alleging that the rights of a 48-year-old man with an intellectual disability were violated when a staff person searched his fanny pack without his permission. The advocate met with the client, Residential Director, a staff person who witnessed the event and the staff person who allegedly searched the bag. Although the staff person who searched the client's bag stated that the client gave her permission to do so, the client was clear that he did not give her permission and told the advocate, "I asked her to stop and told her no". The staff person who witnessed the event states the client attempted to block the staff person's access to the bag and his hands were slapped away. This was a violation of the client's rights under 5605(6). The advocate recommended that the employee be disciplined according to the agencies Policy and Procedures and receive additional training in regards to clients rights.
- 9.) DRC received a reportable event alleging that the service provider of an adult female with an intellectual disability misplaced the client's property

when the client moved. The advocate contacted the service provider's residential manager who said he did not know the items were missing. After DRC sent the manager an email with a list of the missing items, the manager said that the service provider would reimburse the client for the missing items. DRC accepted the provider resolution and recommended that the service provider create a better inventory system.

- 10.) DRC received a reportable event alleging that the staff member of an adult female with an intellectual disability told the client that she could not use her cell phone. The advocate contacted the client who understands that she has a right to use her cell phone and told her staff that. The advocate then contacted the case manager who said that the client is receiving mental health services and not developmental services. The case manager said that the client stays on the phone for hours and the staff tries to help her understand appropriate versus inappropriate times to be on the phone. The staff's supervisor said that mental health services cannot be billed unless the staff is engaged with the client and that the staff let the client know that they cannot stay with her if she's spending that time on the phone. Clearly this indicated that the staff was no longer working with the client. The supervisor agreed to meet with the client and the staff to address this issue with the client.
- 11.) DRC received a reportable event on behalf of a 43-year-old man with an intellectual disability. The report alleged that the client's staff was following the direction of the client's guardian to not allow access to his cell phone due to a history of calling 911 without cause. The advocate investigated and informed the provider that they could not restrict access to the client's property even with the permission of the client's guardian in a non-emergency situation, without a severely intrusive plan in place that has been approved by a statutorily empowered Review Committee. The provider agreed to cease restricting the client's access to his property.
- 12.) DRC received a reportable event on behalf on a 20-year-old man with an intellectual disability. The report alleged that the client had been told by a member of his staff that he would not be allowed to visit his father if he did not stop telling inappropriate jokes. The advocate investigated and was told by the client that he had resolved the matter with his staff and he was not prevented from visiting his father. The staff member's supervisor reported that the staff member at issue would receive additional training on client rights to prevent a similar incident from occurring again.

13.) DRC received a reportable event on behalf of a 25-year-old man with an intellectual disability. The report alleged that following an incident in the community his staff called his mother/legal guardian who directed the staff not to take the client out to eat as planned due to his prior behavior. The staff complied with the guardian's directive even though the client was not an imminent risk to himself or others. This is a violation of his rights. DRC accepted the provider resolution that included education to the guardian about her inability to restrict or waive the client's rights and further education of staff at the home to ensure this would not occur in the future.

INDIVIDUAL CASE DATA

Number of Individuals Served During Period	415
Number of Cases Closed During Period	507
Individuals Still Being Served at the End of the Period	97
Number of Cases Opened During Period	559

PROBLEM AREAS/COMPLAINTS

Abuse	83
Health Care	34
Housing	22
Neglect	12
Rights Violations	8
Transportation	15
Assistive Technology	1
Employment	2
Employment Discrimination	2
Financial Benefits	1
Government Benefits/Services	2
Guardianship/Conservatorship	27
Privacy Rights	15
Unnecessary Institutionalization	1
Home and Community Based Services	334
Total	559

REASONS FOR CLOSING SERVICE REQUESTS

Issues Resolved Partially or Completely in Client's Favor	274
Individual Withdrew Complaint	14
Appeals were Unsuccessful	6
Other	38
Did not require further legal intervention	175
Total	507

INTERVENTION STRATEGIES/CLOSED CASES

Advocacy Assistance	310
Limited Action	91
Investigation/Monitoring	5
Administrative Remedy	56
Negotiation	40
Mediation/Alternative Dispute Resolution	4
Litigation	1
Total	507

DEMOGRAPHIC INFORMATION FOR INDIVIDUALS SERVED

AGE

18 to 25	129
26 to 64	264
65 and over	22
Total	415

GENDER

Male	214
Female	200
Unknown	1
Total	415

RACE/ETHNICITY

Hispanic/ Latino	1
Non-Hispanic/Latino	281
Unknown	133
Total	415

LIVING ARRANGEMENTS

Community Residential Home	249
Foster Care	3
Homeless	3
Independent	52
Intermediate Care Facilities	16
Nursing Home	1
Parental or other Family Home	71
Private Institutional living arrangements	6
Psychiatric Wards (public or private)	1
Public and Private general hospitals	2
Public (state owned institutional living arrangements)	1
Info not provided	2
Other	8
Total	415

GEOGRAPHIC LOCATION

District 1 (York)	41
District 2 (Cumberland)	61
District 3 (Androscoggin, Oxford, Franklin)	86
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	26
District 5 (Somerset, Kennebec)	61
District 6 (Piscataquis, Penobscot)	78
District 7 (Washington, Hancock)	13
District 8 (Aroostook)	47
No District reported	2
Total	415

SAMPLE INDIVIDUAL CASES

Housing

- 1.) The Disability Rights Center was contacted by a 26-year-old woman with an intellectual disability requesting assistance in moving into a new apartment. The client reported that her case manager told her she couldn't move from her current home because the apartment she was interested in had men in the building which created a potentially dangerous situation. The advocate contacted the client and met with her to discuss why she wanted to move. The client informed the advocate her current apartment was cold and drafty, the landlord refused to fix the drafty door and did not clear the sidewalks of snow and ice which she believed was dangerous. The new apartment was in a nice area with a yard and she had been told she could grow a garden in the spring. It was closer to her day program and she could ride her bike to her boyfriend's house during independent time. The advocate intervened with both the case manager and the case management supervisor. The supervisor agreed that the apartment was appropriate and agreed with the client that she had a right to choose where she lived. A new state case manager was assigned and the client has since moved into her new home.
- 2.) The guardian of an adult male with an intellectual disability contacted DRC after the client had been told to move out of his residence with less than twenty-four hours' notice. The client did not want to move and the guardian thought that there should be better transition services in place before any move took place. DRC contacted the guardian and 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.
- 3.) An adult female with an intellectual disability contacted DRC after her home supports were terminated by the State. The client had previously received home supports in her apartment with a roommate. After a physical altercation, her roommate moved out. Shortly thereafter, the State terminated her funding for home supports due to a new regulation promulgated two months earlier which required clients to have a roommate before they could receive developmental services. The State

contacted the client's service provider and instructed them to move the client in with another person. The service provider could not find another person who wanted to live with the client. The State then instructed the client's case manager to find her a new place to live. At no time did the State notify the client that her home support had been terminated or that the State was instructing her planning team to move her. The client had filed a grievance with her case manager, but had not received a response. DSA Attorney assisted the client in forwarding her grievance to the State and demanding a response. The State refused to reinstate the client's services and to stay the termination of services pending the resolution of the grievance, as required by law and regulation. The service provider notified DSA Attorney that they would not continue serving without funding. DSA Attorney sent a letter to the State stating the client's due process right to have her services pending the resolution of the grievance. The State then reinstated her services without explanation. DSA Attorney appealed the State's determination to an administrative hearing on behalf of the client. The hearing officer determined that the client's rights were violated when the State did not send notice to the client that her home supports were terminated and recommended that her supports be reinstated. The State confirmed the hearing officer's decision and reinstated the client's services.

Abuse, Neglect and Other Rights Violations

- 4.) The guardian of an adult male with an intellectual disability and multiple physical disabilities contacted DRC because the guardian was concerned that the client was being unnecessarily and improperly restrained while living at a private non-medical institution (PNMI). A behavior plan, developed while the client was at the PNMI, involved the use of arm splints and a helmet in response to self-injurious behaviors and was not approved by the appropriate monitoring authorities. Advocate investigated and notified the guardian that there appeared to be no pattern of neglect. However, DRC did find significant problems with the behavioral plan, the tracking of the use of the devices, and the lack of approval process. DRC met with the PNMI management staff and provided two separate rights trainings for the PNMI staff. The PNMI agreed that their actions had constituted a rights violation and would no longer implement behavioral plans without proper planning and approval.

- 5.) DRC successfully advocated on behalf of a 19 year old male to receive his prescribed medication while temporarily incarcerated in county jail. The advocate received a report from the client's service provider that the county jail would not administer his medications. The advocate met with the client and administrators of the county jail to ensure his medications were administered that day. Due to DRC's advocacy the client received his prescribed medication.
- 6.) DRC was contacted by a DHHS case manager regarding a 64-year-old woman with an intellectual disability who was being subjected to a behavior modification program without proper approval or the case manager's knowledge. The plan required staff to monitor specific client behavior and assess that behavior to indicate whether or not the client met the requirements for a "special outing". The DRC advocate notified the case manager that this was a rights violation and required reporting, and subsequently four reportable events were filed. At the request of the client's guardian, the advocate attended a special meeting to discuss the use of the behavioral tracking/reward program. The agency agreed that using a behavioral tracking/reward plan that was not part of the client's approved Person Centered Plan or an approved severely intrusive plan was a violation of the clients rights, and the plan was discontinued. The agency executive director informed DRC that he would conduct a formal in-house investigation and the responsible employee would be disciplined according to agency policy and procedure. In follow-up, the DRC advocate conducted a comprehensive client rights training for all employees.
- 7.) DRC received a report from the guardian of a 48-year-old woman with developmental disabilities alleging inhumane treatment by her waiver home staff. Of particular concern was a reported incident where the client had been forced to sit on a toilet for four hours. The advocate met with the executive director, home supervisor and staff to investigate the allegation and ultimately concluded that staff members denied the client humane treatment and dignity and failed to report the incident in a manner consistent with the regulations. DRC recommended the requirement that all staff assigned to this home attend mandatory client rights training and mandatory reporting requirements training (including the requirement to file Reportable Events immediately after an incident has occurred), and that all identified staff involved in this series of events be disciplined in accordance with agency policy and procedures. The agency executive director confirmed that all staff were disciplined

accordingly or removed from service, and that comprehensive rights and reporting training had been scheduled.

- 8.) DRC successfully advocated against the development of a severely intrusive behavior plan for a 53-year-old male with an intellectual disability and dementia. The service provider proposed a behavior plan including the use of restraint in response to the client's increasing dementia symptoms. The advocate provided the team with information about the client's rights and the behavior/safety regulations. The advocate successfully advocated for less restrictive interventions and increased staff training.
- 9.) The case manager of a 30-year-old adult male with an intellectual disability reached out to DRC. The client was being held waiting bail at a county jail and there were allegations he was being harassed by fellow inmates including his food taken. The advocate worked with the jail, the case manager, Crisis Services, his community support program, and a pretrial program towards ensuring that the individual was being treated well while in jail and would be bailed out in a fair and timely fashion. As a result of our intervention, the case manager was able to secure a defense attorney, get him out on lowered bail, and get him returned to his independent home.

Guardianship

- 10.) A Maine Probate Court limited a client's guardianship and restored his right to make decisions about his life. The client, a man with a developmental disability who had been under full private guardianship for decades, contacted the DRC because his private guardian wanted to move him to another residence against his will. Subsequently, the State became involved and sought to remove his private guardian and sought the Court's appointment as his full guardian. At a day-long hearing the client's persuasive testimony about his decision making abilities won out over two medical experts who initially recommended guardianship. As a result, the Court entered an order removing his private guardians and appointing the State as the client's guardian for medical decisions only.
- 11.) DRC successfully negotiated the completion of a guardianship suitability study for the mother of a 37-year-old male with an intellectual disability. The client currently has a public guardian and has requested for many years that DHHS nominate his mother as guardian. His

mother was unable to petition the court without a PP 505. The client has many ongoing conflicts with his public guardian agent. The advocate provided the client with information about his rights, the guardianship process and supported him in meeting with the Department Program Administrator to address his concerns. A suitability study was completed and the Department provided his mother with a PP 505. Due to DRC's advocacy the client is currently working with his mother to petition the court for a change in guardianship.

Person Centered Planning Process

- 12.) DRC participated in the Person Centered Planning meeting for a 25-year-old male with an intellectual disability. The advocate met with the client prior to his meeting to review his concerns. The client stated that he does not attend his meetings because of the conflicts between his co-guardians. The advocate provided the client with information about his rights and the person centered planning process. The advocate attended the meeting and clarified the role of the advocate and need for his team to work with the client to schedule meetings that he is comfortable in attending. Due to DRC's advocacy the client's team is working with the client to ensure his planning is person centered.
- 13.) 21-year-old female with an intellectual disability requested the advocate attend her Person Centered Planning (PCP) meeting to clarify whether her guardian could dictate to her service providers the type of television shows she watched and the type of books and video games she purchased. The advocate met with the client prior to the meeting to answer questions about her rights and provide information about the guardianship process. Due to DRC's intervention the client reports that her service providers are not restricting her purchases or what she chooses to watch on the television based on her guardian's direction.
- 14.) DRC attended the PCP meeting of an adult female with an intellectual disability who wanted assistance advocating for more time by herself without supports. The planning team agreed that she should have more time to be independent and created an action plan to reflect the clients new opportunities for alone time. The client agreed to contact DRC if she had any questions or concerns in the future.
- 15.) Disability Rights Center received a call from a 33 year old man with an intellectual disability and mental illness who is also Deaf. Client

contacted DRC for assistance with a number of issues including problems with his Person Centered Plan. Client's PCP has not been driven by him - neither the goals nor the support plan to achieve them. Advocate met with client to review his plan and talk about things he wanted. Advocate attended two PCP meetings with client and supported him to advocate for himself. Together, the client and advocate pushed for new goals that were more self-directed. Advocate provided significant feedback regarding the pre-planning, the meeting process and the written plan. Improvements were made to the plan and the support provided to the client.

- 16.) The guardian and brother of a 31 year old male with Autism contacted DRC for assistance with resolving his brother's unmet need for sensory items. Prior to DRC intervention the client had an unmet need for a sensory swing and vibrating mat for a sensory room in his home for over two years. The advocate provided the guardian with information about his brother's rights and participated in several Person Centered Planning (PCP) meetings. The advocate ensured that the need was appropriately identified in the PCP as unmet and that an interim plan was developed. Due to DRC's advocacy the case manager secured funding to purchase the items and the client now has a sensory room in his home.

Due Process

- 17.) The case manager for a 24-year-old woman with an intellectual disability reported that the client was scheduled to undergo a medical procedure that would result in her sterilization without the court order required by law for patients under guardianship. The advocate met with the client and individual members of her team to explain the law and the client's reproductive and due process rights. Due to the intervention of DRC, the client's procedure was cancelled and her team has agreed not to proceed until all legal procedures have been followed to ensure the client's informed consent.
- 18.) The guardian of an adult male with an intellectual disability contacted DRC because the ward had been denied developmental services. The guardian had appealed the determination on behalf of the client and requested representation for the client at the administrative hearing. DRC discovered that the client had been denied because the State was requiring written documentation of the disability prior to age 19.) The

regulations stated that the disability must have "manifested during the developmental period" and did not require evidence of the manifestation to be in written form and dated during the developmental period. Through no fault of his own, the client did not have any documentation prior to his 18th birthday. DRC represented the client at the hearing and advocated for the client to receive the services. The Hearing Officer issued a decision stating that the State had incorrectly applied the regulations and granted developmental services to the client.

SEVERELY INTRUSIVE AND SAFETY PLANS

SEVERELY INTRUSIVE PLANS BY GEOGRAPHIC LOCATION

(Data provided by DHHS)

District 1&2 (York, Cumberland)	41
District 3 (Androscoggin, Oxford, Franklin)	47
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	6
District 5 (Somerset, Kennebec)	11
District 6&7 (Piscataquis, Penobscot, Washington, Hancock)	10
District 8 (Aroostook)	14
Statewide Total	129

SAFETY PLANS BY GEOGRAPHIC LOCATION

District 1&2 (York, Cumberland)	88
District 3 (Androscoggin, Oxford, Franklin)	108
District 4 (Lincoln, Knox, Waldo, Sagadahoc)	12
District 5 (Somerset, Kennebec)	56
District 6&7 (Piscataquis, Penobscot, Washington, Hancock)	110
District 8 (Aroostook)	89
Statewide Total	463

The data reveals that there are major inconsistencies in the number of severely intrusive and safety plans across districts. DRC compared these numbers to the population of people receiving Developmental Services in each district and this alone does not seem to clarify the inconsistencies. This issue continues to be explored by the Statewide 3-person committee.

DESCRIPTION OF 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 more harmful to the person than the 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 the plan takes all possible steps to protect the health, safety, and rights of the individual. 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.

DSA advocates fully participate in all 3-Person Committee meetings as one of the three persons but as a non-voting member. DRC recognized the inherent conflict in the statute when we were serving as an equal voting member of the 3-Person Committees while also contracted to provide legally based advocacy services to all clients. The statute was changed to modify DRC's role. DRC now acts as the client advocate at all 3-Person Committee meetings.

DRC continues to strongly advocate for individual planning teams to consider reducing the intrusiveness of the plans while continuing to incorporate positive supports. DRC has identified rights violations, such as restriction of telephone use or access to personal property, and advocated against their use.

TRAINING ACTIVITIES

Rights of Individuals with Developmental Disabilities

Number of Trainings Presented by Staff	52
Number of Individuals Who Attended These Trainings	
Individuals with Disabilities and/or Family members	137
Developmental Services Providers	1071

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

Alternative to Guardianship

Number of Trainings Presented by Staff	5
Number of Individuals Who Attended These Trainings	
Individuals and/or Family Members with Disabilities	61
Developmental Services Providers	33

DRC provides training on alternatives to guardianship to individuals with disabilities, family members, guardians, and service providers. During this reporting period, DRC presented a workshop on Guardianship and Alternatives at the annual Speaking Up for Us Conference.

OUTREACH ACTIVITIES

Number of Individuals Who Attended Outreach Events	
Individuals and Family Members with Disabilities	455
Developmental Disability Providers	368

DRC also reached over 400 people at the Autism Fair and 100 people at Maine's Speaking Up for Us conference. Outreach included collaboration with Speaking Up For Us (SUFU), community support programs, community case managers, regional OADS staff, and the Maine Developmental Services Oversight and Advisory Board.

An example of the impact of DRC's outreach activities: The Advocate noticed while visiting several homes in Northern Maine that refrigerators, cupboards, and closets were locked at six different homes. This violation affected 20 different individual's receiving services. After several conversations with the

executive director, the issues were corrected. All 20 individuals now have the benefit of access to their fridges, cupboards, and closets.

SYSTEMIC WORK, SYSTEMIC ISSUES AND SYSTEMIC PROBLEMS

Collaboration with Speaking Up for Us of Maine

DRC counts on Speaking Up for Us (SUFU), Maine's self-advocacy network for people with developmental disabilities, to help us determine what our priorities should be by providing information about the everyday experiences and challenges for people receiving developmental services. DRC collaborates with self-advocates statewide through trainings, outreach, and empowering self-advocates at Person Centered Planning meetings. Advocates have met with SUFU advisors in their respective regions to discuss training opportunities and further collaboration opportunities. Advocates disseminate SUFU information to individuals and provider's through training and outreach.

Some of the things we did this year with SUFU include: developed and presented a training for self-advocates on the new person centered planning process, attended and provided a rights training at their statewide conference, and DRC participated in SUFU board meetings. Also throughout this year, various SUFU members participated in portions of our Developmental Services team meetings monthly.

Project Vote

People with developmental disabilities are often denied full participation in the election process.

To address this issue, DRC teamed up with SUFU to provide education and training to individuals with developmental disabilities to encourage their participation in the electoral process. DRC and SUFU were awarded a Project VOTE training grant from Self-Advocates Becoming Empowered (SABE). DRC and SUFU chose a team to participate in a webinar series to train the trainers. Under the grant, DRC and SUFU trainers were then required to hold one joint training prior to the 2014 election.

During the summer and fall of 2014, DRC and SUFU held joint trainings around the state, including in Houlton, Bangor, and Sanford. In total, SUFU and DRC trained 125 people, including 100 people with disabilities.

Although SUFU and the DRC have fulfilled their grant commitment to SABE, DRC will continue work with self-advocates offering this voting training on a statewide basis.

Employment First

People with developmental disabilities are often directed towards community support or day habilitation programs and often discouraged from pursuing competitive employment opportunities. Additionally there are approximately 170 people with developmental disabilities who currently work for sub-minimum wage.

DRC is proud that Maine has fully embraced employment as a first and preferred option for people with disabilities. DRC has been a core coalition member of Employment First Maine (EFM) from the outset and was instrumental in educating policy makers and gaining initial support for this project. To date over 25 organizations and activists with disabilities have met to develop policy goals and outline a roadmap for systems change in Maine. Main focus areas of the coalition involve capacity building in the service system, information and knowledge dissemination regarding benefits counseling and work incentives, transition and quality planning for school-age Mainers with disabilities, and cooperation with the business community and employers. EFM recently convened a statewide summit for 150 participants focusing on customization in employment.

The coalition is currently developing recommendations for policy change, including a phase out of subminimum wage at the state level, comprehensive overhaul of the service system with regard to funding employment in lieu of day programming, and implementation of effective transition and career planning across Maine schools.

Statewide 3-Person Committee

As previously mentioned there are over 129 severely intrusive behavior plans statewide. To bring consistency in the interpretation of the governing regulations and review of these plans DRC coordinates a statewide group of all people serving on regional 3-Person Committees.

DRC works closely with the Maine Developmental Services Oversight and Advisory Board (MOAB) 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 the DRC and the MOAB.

This year the group developed and published standards, guidance, forms, and processes for review and consideration of Severely Intrusive Plans and Safety Plans. Important issues discussed this year include: proposed changes to the Safety Device Regulations so that the Safety device regulations and the proposed behavior regulations can go to rulemaking together.

Excellence Committee

A DRC representative attends monthly meetings with the Excellence Committee. The Excellence Committee is an open provider forum for discussions concerning current issues affecting developmental services, areas for improvement, information sharing and trainings.

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

Housing Coalition

DRC 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, with choice, dignity, and efficiency. This group is helping to make policy changes in the service delivery system, promoting self-determination so that people receiving services and their families have more control over housing and the services they receive. DRC 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 Office of Aging and Disability Services

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

Topics discussed included: DRC collaboration with OADS adult protective services and Maine Care licensing, grievance training, clients in nursing facilities, the selection of a single assessing agency, amendments to home and community waiver programs, non-emergency medical transportation, dental services, the supports intensity scale, the brain injury waiver, crisis services, due process concerns, the grievance process, and upcoming rate setting.

Service Provider Interviews

People with developmental disabilities are often excluded from the process of interviewing and choosing their own service providers.

DRC worked with SUFU and others to distribute sample interviews for people to use when looking for a service provider. This sample interview is adaptable to an individual's needs when interviewing potential service providers for Home Support, Community Support or Community Case management.

This year, DRC facilitated the community case management interview being shared with 180 clients who were losing case management services and needed to find new a case management agency.

Access to Adult Briefs

Pharmacies across the State switched to a lower-quality adult brief for MaineCare clients. They indicated that they were told by MaineCare that the former brief distributor no longer contracted with the State. Clients who used the new briefs had to frequently return home from the community to change. DRC contacted MaineCare and requested a copy of their list of contracted vendors for adult briefs. After reviewing the list, DRC determined that MaineCare had mistakenly interpreted an edit in the list as a cancellation by the vendor. DRC contacted MaineCare and alerted them of the mistake. MaineCare confirmed that a mistake had been made and agreed to provide prior authorization for the correct briefs to any pharmacy that requests it. DRC contacted pharmacies in Northern and Southern Maine to alert them of the

mistake. DRC also spoke at Office of Aging and Disability Services case management meetings to alert them of the miscommunication between MaineCare and durable medical equipment providers.

Training for Hospitals

As a result of a grievance filed by DRC on behalf of a client who received poor and improper treatment in the emergency department, DRC offered to provide training to the Emergency Department and other hospital staff. The training provided was developed in collaboration with and paid for by the hospital. The focus of the training was assisting clients with disabilities in crisis, guardianship issues, client rights and communication. As a result of the DRC intervention more than 60 staff members from all departments at the medical center received formal training on "Understanding and Supporting Client's with Disabilities in a Hospital Setting." The training was provided by three staff from DRC. The reviews were outstanding and the Director has requested the training be repeated for all physicians. The training has been requested by affiliated hospitals across the state and DRC will provide the training as requested.

Supports Intensity Scale

The Department of Health and Human Services is undertaking a massive restructure of the delivery of developmental services using the supports intensity scale (SIS). The SIS is an assessment tool that measures individuals' need for support in different areas of their lives.

Throughout the year DRC staff have attended stakeholder meetings concerning proposals for the implementation of the SIS and a new rate setting model. DRC also submitted written comments during the informal comment period. DRC's comments focused on the need for adequate due process protections and making sure policy and financial decisions would support and encourage client independence.

Section 21 Home and Community Based Waiver Changes

DRC provided comments and raised issues to the changes to Section 21 and 29. Some of the issues identified were; (1)the proposed rule stated that the member had sixty days to "accept waiver services" and that if the member fails to "accept the funded opening" they will be removed from the waitlist, (2) that the proposed 60 hour annual cap on Career Planning services is too low, (3)

that it does not make logical sense to limit the use of Employment Specialist Services to 10 hours monthly and deny Employment Specialist Services to individuals enrolled in high school. Some changes to the final rule were made as a result of DRC's comments

Transition

Individuals 18-21 years old face a dilemma. They are old enough to receive adult services but due to the long waiting lists, often opt to continue to receive children's services to which they are entitled. Even when appropriate transition plans are in place, the inevitable lack of adult services often leads to loss of skills, little community access, deterioration of employment, and reduced overall quality of life. Individuals who had been expecting to have a job and be part of the community are often faced with increased dependency and continued segregation.

Certainly much can be accomplished to make the transition from children's services to adult services for children within DHHS smoother and more effective. OADS promised to continue to improve coordination with the Department of Education (DOE) and school districts and to develop a Memorandum of Understanding with DOE. DRC strongly supports these efforts but questions whether they are sufficient.

This year DRC provided written comments to the 2014 Olmstead Roadmap for Change Update for Developmental Services developed by the office of Aging and Disability services and participates collaboratively in several transition reform committees.

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.

Further, not all psychologists have kept up to date with best practices and innovative positive behavioral supports. There are not enough psychologists familiar with this population or trained in dual diagnosis. Some psychologists are simply unwilling to support such intrusive measures, and there are insufficient reimbursement rates and unfamiliarity with Maine Care billing.

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.

DRC 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 now needs to move forward with the rule making process for the proposed changes to the behavior regulations. DRC 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 still face significant challenges with respect to guardianship. Guardians often act in the “best interest” of their ward rather than substituting their judgment for that of their ward. Parents of individuals with disabilities are still counseled to “take guardianship” 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.

Further, individuals petitioning to remove a guardian face unnecessary barriers created by Probate Courts. For example, DRC has witnessed some courts require petitioners to use court approved special forms when all the statute requires is a letter from an interested person. Individuals also have difficulty obtaining court-appointed attorneys even when they are aware of their right to representation and request it.

Providers, guardians and DHHS personnel lack knowledge about how guardianship impacts individuals and their rights. There is a substantial need for

advocacy and training about guardianship. DRC continually raises these issues at PCP meetings and 3-Person Committee reviews of Severely Intrusive Plans.

In 2011, the legislature amended 34-B M.R.S.A §5604(4) and in doing so clarified that individuals under guardianship retain certain rights when receiving services funded by the Department. The statute reads: “The rights and basic protections of a person with an intellectual disability or autism under section 5605 may not be restricted or waived by that person's guardian, except as permitted by rules adopted pursuant to this section.” This means that any restriction of an individual’s right by a service provider, even if requested by a guardian, is subjected to a process. The process may at times include the need for a Severely Intrusive Plan that includes oversight by a psychologist and approval by the 3-Person Committee.

Providers, guardians and DHHS personnel need to be aware of this clarification to Maine statute as basic rights are still being restricted by service providers at the request of guardians. DRC continues to educate service providers and guardians through trainings, participation in Person Centered Planning meetings, and advocacy efforts in 3-Person Committees.

Public Guardians as Case Managers

According to the 2014 Olmstead Plan update, state case managers act as neutral facilitators planning and coordinating services. That may be true for some people, but DRC is aware of instances where state case managers, who are also the individual’s guardian, have acted in ways that are seemingly not in the client’s best interests, but are supportive of the state and its policies and practices.

This dual role has been one of long-term concern by DRC over the possible conflict in advocating for the clients wishes while at the same time protecting the public fiscally. In 2011, the legislature convened a stakeholder group to develop a working plan for a program to transition public guardianship responsibilities for adults with developmental disabilities from the Department to an entity independent of that agency. This stakeholder group included OADS employees. The stakeholder report submitted to the legislature in January of 2012 stated: "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."

Although the Departmental reorganization occurred two years ago, the separation of these two roles has not. It is long overdue. 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.

Policy Changes and Practices Related to Guardianship

From the perspective of promoting the independence of clients who receive developmental services some of the policy changes over the past year have resulted in some positive effects and some have had negative consequences for our clients.

OADS employees were key members of Maine's Guardianship Alternatives Project, a five year grant-funded program. As a result of the project, in 2010, OADS published an excellent guide to understanding adult guardianship and alternatives. This publication is still relevant and used today. This guide and additional information about alternatives to guardianship are also found on OADS's website.

The Department now conducts a suitability study for each individual for whom they plan to seek guardianship. This provides a systematic way for the Department to look at whether or not an individual requires guardianship - a positive step.

There are also some negative consequences. OADS officials have indicated that OADS is no longer willing to serve as an individual's social security representative payee (rep payee) unless they are appointed the individual's full or financial guardian. This represents a shift in policy. Historically, the Department served as an individual's rep payee even when the individual wasn't under public guardianship. Moreover, this seems to contradict the Department's website and handbook on guardianship alternatives which touts rep payeeship as a less restrictive alternative to guardianship.

Also, until recently, if the Department and an individual under public guardianship agreed that the individual no longer needed a guardian or that the guardianship should be more limited, the Department would assist the individual in terminating or modifying the guardianship. OADS personnel have indicated that they no longer do this. This policy undermines OADS's vision to "promote individual dignity through giving respect, choice and support for all adults."

Guardianship Reform

DRC is exploring a number of avenues for systemic guardianship reform including: changing current probate court practices, changing current probate statutes, working with psychologists, and use of an alternative form of supported decision making.

This year DRC conducted outreach to the Maine Psychological Association in an effort to build new partnerships. We have also reached out to our sister organizations, the Developmental Disabilities Council and the Center for Community Inclusion and Disability Studies. DRC's reform team is ongoing and has begun conducting research into guardianship law around the country and alternative decision making models used in other countries.

As DRC 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.

Grievance Process

Individuals receiving Developmental Services are often unaware of the grievance process and how it works and as a result are not afforded the right to use the process to challenge decisions made about their services. This is a denial of due process. Additionally, people do not always get notice that they have the right to appeal decisions, and if they do get notice, the notice is complicated and difficult to understand.

Both State and private case managers are involved in the first step of the grievance process but are often unaware of their responsibilities. DRC is pleased that OADS has begun providing statewide training to case managers however more efforts must be taken to reach people receiving services and their family members.

Additionally the Department proposed significant changes to the grievance rules. DRC provided written comments and raised issues with the proposal including the absence of stakeholder input, the limitation of continuing services pending the resolution of the grievance, and increase in timeframes for the resolution of the grievance.

Housing

DRC has identified multiple concerns for protecting the housing rights of individuals receiving developmental services. Affordable and accessible housing for people with developmental disabilities remains a key issue.

When service providers own houses, people are often tied to those providers in order to receive services. Tenancy may not be terminated without the appropriate notice and judicial enforcement and yet it is frequently attempted. This applies whether or not the tenant is receiving home supports and/or the service provider owns the building. This is a due process right which is continually and systemically violated. Efforts to separate housing from services needs to continue as do the efforts to educate providers as to their client's housing rights.

While DRC recognizes that the Department provides support in residential options ranging from supported living, shared living, family centered support, group living, and non-waiver residential services the Department does not provide support to maintain consistent housing in the same residence.

For example, the Department no longer allows individuals with the Home and Community Based waiver to continue receiving services when they live alone. This is a substantial limitation on the person's choice of residence and leaves the person at the mercy of their roommate's status.

In addition, the Department passed new regulations which instruct service providers to give notice to persons that they must leave the residence when funding stops. For some, this creates a nomadic culture of persons moving from place to place in an attempt to find a stable roommate. For others who are medically or behaviorally incapable of living with someone else, this requirement can prevent them from having the ability to live safely in the community.

This year DRC has identified several providers that illegally "discharged" their clients. Through individual representation DRC has ensured that people with intellectual disabilities and autism are not illegally evicted from their homes. DRC plans to provide housing and tenancy rights training to people in the coming year.

Notices to reduce and/or terminate services

Many people are still not aware of their appeal rights and often do not receive proper due process protections unless they have an advocate assisting them. DRC often finds significant errors in notices that can easily lead to further violations of their due process rights. Sometimes people do not get proper notice of their appeal rights at all and when they do, often the notices are complicated and difficult to understand. This year DRC has been vigilant in raising and resolving these issues both informally with OADS management and formally in MaineCare appeals and developmental services grievances.