DISABILITY RIGHTS MAINE

Celebrating Diversity

2018 Annual Report

DRM programs

DD Advocacy serves individuals with intellectual and developmental disabilities who have experienced abuse, neglect, exploitation or who have been discriminated against based on their disability. The Protection & Advocacy for Developmental Disabilities (PADD) program serves both children and adults with DD diagnoses, while the Developmental Services Advocacy (DSA) program provides legally based advocacy to adults with intellectual disabilities or autism who receive, or are eligible to receive, Developmental Services through the State of Maine.

MH Advocacy serves individuals who have a diagnosis or label of serious mental illness, with priority given to persons residing in facilities. In addition to the Protection & Advocacy for Individuals with Mental Illness (PAIMI) program, DRM also provides advocacy services to residents of Acadia Hospital and Riverview and Dorothea Dix Psychiatric Centers.

PAIR: Protection and Advocacy for Individual Rights serves individuals who have a disability and who are not eligible for either the PADD or PAIMI programs. PAIR focuses on civil rights violations under the Americans with Disabilities Act (ADA).

PAAT: Protection and Advocacy for Assistive Technology serves individuals who have a disability and who need assistance in obtaining assistive technology devices or equipment in order to live more independently, work, attend school, or meet medical needs.

Social Security Advocacy serves individuals with disabilities who receive Social Security Disability Income (SSDI) or Supplemental Security Income (SSI) and who want to work, return to work, or are working and need assistance with respect to benefits. DRM also monitors, investigates and reviews representative payees to prevent and detect financial exploitation or misuse of an individual's benefits. DRM may advocate on behalf of beneficiaries to ensure that their needs are being met.

PATBI: Protection and Advocacy for Traumatic Brain Injury serves individuals who have a brain injury and who have experienced a rights violation or discrimination.

PAVA: Protection and Advocacy for Voting Access works to increase access to voting and represents individuals who have been denied the right to vote.

Children's Advocacy serves children with disabilities who are denied access to appropriate and inclusive educational services; have been subjected to restraint and seclusion in school; are seeking assistance with obtaining appropriate home and community services; and who are in a hospital or residential facility and have experienced abuse, neglect or violations of their basic rights.

Deaf Services provides advocacy and technology to individuals who are Deaf, late-deafened, hard of hearing and Deaf-Blind. Individual programs include Civil Rights Advocacy, Communication Technology & Outreach, Peer Support Group (PSG), Visual Gestural Communication (VGC), and the Telecommunication Equipment Program (TEP).

a message from the ed

Dear Friends and Colleagues,

I am pleased to present Disability Rights Maine's 2018 Annual Report.

Our work is fueled by our collective passion for justice. We do not want to merely protect people from being discriminated against or having their civil and human rights violated. We want to be part of a Maine that embraces disability as a natural part of the human experience. Although we are not there yet, as a society, DRM continues to push for people with disabilities to be active and equal participants in all of our social and professional communities.

Children with disabilities need educational experiences that encourage their unique potential, and they need access to a robust array of services that help keep them successful in their homes and in their local schools.

Adults with disabilities need higher education, employment, barrier-free access to, and inclusion in, all of our communities. Adults with disabilities or labels of disability have the same dreams as adults who have not experienced "disability."

People with disabilities are often in restrictive settings – hospitalized, institutionalized, secluded, restrained. Although these kinds of restrictive "solutions" may have served society over the years by creating a separate place for people who are different, these isolating systems do all of us a disservice. And they don't work.

Restrictions on people's rights and liberties do not make people stronger, more productive, more creative, or more independent. And putting whole groups of people in segregated settings silences them and makes them invisible. Is there any other group in our society that is similarly prohibited from taking part in decisions about the design and implementation of services that are funded exclusively for them? It doesn't make sense, and it is a world that we can – and must – change.

People with disabilities are an untapped resource. Disability Rights Maine will continue the fight to ensure that the unique and varied skills of people with disabilities are maximized by ensuring that they are at every decision-making table, every job, every fun event in our communities, on boards, and in positions of power to steer policy in the direction that they themselves advocate.

Despite the pushback, DRM's promise to Mainers with disabilities is to continue this important work through individual advocacy, legal representation and public policy reform.

Thank you all for your support in this movement.

Respectfully,
Kim Moody
Executive Director

Disability Rights Maine is supported by funding from:

the Administration on Intellectual and Developmental Disabilities

the Center for Mental Health Services

the Rehabilitation Services Administration

the Social Security Administration

the Federal Communications Commission

the State of Maine

Acadia Hospital

the Maine Civil Legal Services Fund Commission

private donors

DRM would like to thank all the individuals, businesses and organizations whose generosity enables our work, and hope this report illustrates how vital your support is to the disability community.

To learn how you can aid the work of DRM, visit www.drme.org/support

To protect the confidentiality of our clients, pseudonyms have been used.

Available in alternative formats upon request

Cover Image: DRM staff attend Disability Pride Maine in Capitol Park, Summer 2018.

Standing Up

against the criminalization of mental illness and ensuring access to emergency medical services

As a result of visits to hospitals and correctional facilities during the spring of 2018, DRM discovered that individuals with "mental illness" were often denied critical emergency mental health care in local emergency departments. Some individuals who were suicidal or in mental health crisis, or both, were being turned away from these hospital emergency departments without receiving adequate medical screening or stabilization services.

Emergency departments should be critical resources for people experiencing a mental health crisis.

This is a practice referred to as "patient dumping".

Instead of receiving emergency treatment for their symptoms, some individuals were arrested and taken directly to the county jail where they continued to experience the same or worsening symptoms for which they initially sought assistance.

Emergency departments should be critical resources for people experiencing a mental health crisis. The mental health system cannot function unless service providers are willing to engage with individuals and not only because they are legally required to provide treatment.

DRM filed complaints under a federal law known as The Emergency Medical Treatment and Active Labor Act or "EMTALA". This law requires emergency departments to screen any such individual for an emergency medical condition, such as suicidality, and then stabilize the individual if an emergency medical condition is found, before discharging the individual. This

law is intended to ensure that hospitals do not turn away or discharge people who need emergency medical services, regardless of their ability to pay.

After investigations by state and federal regulators, two hospitals were found to be in violation of both EMTALA and certain other licensing regulations. As a result of these findings, both hospitals were required to submit corrective action plans in order to continue to participate in the Medicare program. Some of these corrective measures included:

- Creation of an Emergency Department Triage Nurses' Station in the waiting lobby area of the emergency department in which all areas of the lobby can be viewed by the Triage Nurse.
- Enhanced staff training requirements regarding EMTALA as part of all employee orientation and continuing education, including requirements to demonstrate proficiency of understanding after the trainings.
- A letter sent from the hospital presidents to all area law enforcement and emergency service providers stating the hospitals' commitment to serve all patients who present at the emergency department.
- Creating a designated work area within the emergency department to enable contracted crisis workers to complete documentation at the hospital soon after providing crisis assessments.

Both hospitals were required to submit corrective actions plans in order to continue to participate in the Medicare program.

- Instituting a policy where no one will be removed from the emergency department by law enforcement without first being offered care.

DRM will continue to forcefully advocate for the rights of individuals who need emergency mental health treatment at emergency departments. Our continued presence and monitoring of these facilities provides us with the opportunity to identify and address future violations, and verify compliance with applicable laws and ordinances, which will result in decreased barriers to getting the care people need.

Supporting Autonomy

Far too often, when a person with a disability reaches their 18th birthday, they are almost automatically placed under guardianship. In some instances, guardianship is pursued at the recommendation of educators, providers and other professionals. The result is that people with intellectual and developmental disabilities are often stripped of autonomy before adulthood ever begins. In Maine, 70% of adults who receive developmental services have guardians, the vast majority of which (67%) are full guardians. Maine far exceeds the national average of 35% of individuals under guardianship. Individuals placed under guardianship are denied the ability to make their own decisions, to experience true independence and to exert any control over their own lives.

DRM believes that people with disabilities, like everyone else, are the foremost experts on themselves and have the right to determine the course of their lives. Preparation for adulthood should begin early on, teaching youth with disabilities about making their own decisions through gradual and supported skill building. Guardianship should be used as a last resort, in favor of alternatives that promote self-determination and independence.

Cecile, who has an intellectual disability, was placed under state guardianship fourteen years ago after making a series of decisions that were considered unsafe. In the ensuing years, Cecile stabilized her life and returned to school, and wanted to explore ending her guardianship. Her state assigned guardian representative withheld support. A DRM attorney worked with Cecile and her team to create a supported decision-making (SDM) agreement and to identify clinical support. The attorney secured letters of support from most every person who worked with Cecile, including her teacher, case manager and home support staff. When Cecile was ready, the attorney filed the petition to terminate the guardianship. DRM represented her in court and ensured that supportive witnesses attended the hearing and could testify to Cecile's ability to conduct her own affairs. After a hearing, the

Supported Decision-Making

probate court agreed that Cecile was no longer "incapacitated" and terminated the guardianship. Due to her hard work and perseverance, Cecile achieved her decade-long goal of restoring her rights.

Walter contacted DRM seeking assistance with terminating his guardianship. Walter has an intellectual disability and was subject to a limited public guardianship, which allowed him to make his own medical decisions, but gave DHHS all other decision-making authority.

At a Person-Centered Planning meeting attended by DRM, Walter's guardian indicated agreement with terminating the guardianship. Walter's home supports and guardian attended the court hearing to support him and to tell the judge that they were in agreement with terminating the guardianship. The judge signed the order and congratulated Walter on no longer having a guardian. Walter, who had been subject to guardianship

for 20 years, was overjoyed that the guardianship was finally terminated.

Big Changes: In July 2019, Maine's Probate Code will require the consideration of Supported Decision-Making, prior to placing an individual under guardianship. In preparation for this change in Maine's law, DRM trained more than 950 community members and stakeholders, including: individuals with developmental disabilities; family members; probate judges and registers; DHHS personnel; and advocacy groups.

If it becomes effective on July 1, the Probate Code will require the parties to consider whether an individual's decision-making challenges can be addressed through SDM and/or other less restrictive alternatives. The petition for guardianship must state why the person's needs cannot be met through less restrictive alternatives. Individuals interested in learning more about supported decision-making can visit www.supportmydecision.org, where they can download a copy of DRM's SDM handbook.

At the time of printing, an amendment to the bill has been submitted, which basically makes it easier to obtain guardianship than under current law. DRM is fighting it.

Fighting for Fundamental Youth Rights:

Currently, students with disabilities across Maine are inappropriately removed from school. From unnecessary suspension and expulsion to abbreviated school days and tutoring placements, students are too often kept from the most basic promise of a full school day.

Outside of school, youth in Maine who need home and community based services are waiting for services, which leads to regression and being stuck in unnecessarily restrictive placements.

Maine youth have rights to basic access to school and services, and DRM represents students from all levels – pre-K through high school – who are denied a full school day. DRM works tirelessly to represent youth in pursuit of timely access to home and community based services and increased access to individualized treatment in all settings. By enforcing the rights of youth with disabilities to education and community based services, DRM hopes to give them the opportunity to learn and participate in society free from barriers and discrimination.

Grace, a 14 year old student with a mental health diagnosis, was facing expulsion from school, her parents contacted DRM. The school moved to expel Grace after she tried to gain access to a room where her younger sister was being restrained by at least four staff. DRM attended an IEP meeting with the family where the school erroneously concluded that Grace's behavior was not a manifestation of her disability.

Later, DRM represented Grace at an expulsion hearing where the district expelled her in violation of her rights. DRM filed a due process hearing to challenge the expulsion. After a four day hearing, the hearing officer issued a decision

DRM coordinated with our partner, Speaking Up for Us, and with provider agencies across the state to conduct voter education fairs for 200 individuals. These events promoted active participation in civic affairs, voter registration and informed activism by people with disabilities.

Access to School and Services

overturning the manifestation determination, ordered Grace's return to school, ordered all references to the expulsion removed from her record, and ordered compensatory education for the time of the improper removal.

Following the hearing, a global settlement was reached, which required compliance with the ruling, removed all references to the expulsion from Grace's record, and facilitated continued placement in a school setting where she previously experienced success. The settlement also included compensatory education and prevailing party attorneys' fees. Grace has excelled in her return to school and has promised to invite the DRM attorney to her graduation.

Luke was 13 years old when sent to the emergency department and his guardians contacted DRM to advocate for improved treatment so that he could return to his residential program. The advocate worked extensively with OCFS, the residential provider, the emergency department provider, the mobile crisis provider, and Luke's guardian to individualize his treatment plan. While he was in the emergency department, Luke's team met regularly and eventually he was able to return to his residential program.

DRM successfully advocated for a thorough review and revision of Luke's individualized treatment and crisis plans at the residential program. The advocate also made a referral to the MaineCare Complex Case Unit to provide Luke support in improving his care at the residential program.

Due to DRM's advocacy, Luke's treatment has improved, which has led to fewer unnecessary emergency room stays.

DRM will stay vigilant in enforcing Maine youths' rights to access services in school, at home and in their communities by taking steps to address policies and practices that serve to limit access to programs and activities of youth with disabilities through systemic advocacy and participation in many stakeholder and coalition groups. Throughout the year, DRM trained hundreds of community members on the rights of youth and will continue to do so. DRM fights for an important goal: children in school all day, every day, with full access to the services to which they are entitled.

DRM provided training on Deaf culture, basic American Sign Language, and issues related to people who are hard of hearing or late deafened to 25 caseworkers and administrators of a homeless shelter.

Ensuring a Successful

For many youth, the transition to adulthood can be intimidating and scary. For youth with disabilities, this transition can be additionally difficult because they face the overuse of guardianship, learning to navigate the world of behavioral health services for adults and the challenges of a non-traditional educational path. Too often, young people and families find themselves approaching this transition with few resources and limited time to get needed services in place. As a result, youth frequently "fall off the cliff" between a highly structured childhood and an unexpectedly open-ended young adulthood.

DRM is committed to improving this transition process for youth on an individual and systemic basis. Preparation for adulthood should begin early on, by teaching youth with disabilities about making their own decisions through gradual and supported skill building. Guardianship should be viewed as an act of last resort, in favor of alternatives that promote self-determination and independence. Youth with disabilities are entitled to the same opportunities and experiences in life as their peers.

Lina's parents learned that her transcript identified her as a student with a disability and that her educational program differed from that of her peers, so they reached out to DRM for assistance. At one point during high school, when Lina experienced acute mental health needs, she was placed in a smaller learning environment. She always excelled academically and performed at or above grade level in challenging classes. Lina was assured that she would be given access to the same curriculum as her peers, but it was only after the year was over that she learned she would not receive general education credits. Instead, the special education classes would be designated on her transcript. Lina learned that her chosen college would not even accept those credits. The DRM attorney initially supported Lina and her parents in advocating for changes through the IEP process.

DRM collaborated with Maine's Office of Child & Family Services to train 450 professionals on the rights of children with disabilities regarding their mental health and educational services.

Transition to Adulthood

When this was unsuccessful, DRM filed for a due process hearing on Lina's behalf and raised claims under the ADA and Section 504. Prior to hearing, the two sides reached an agreement where the district agreed to give Lina an opportunity to meet several standards she was not exposed to in the special education class. Upon meeting these standards, she received credit for all of the general education classes on her transcript and the references to the special education classes were removed. The school district is now reviewing its policies and practices with regard to transcripts for students who receive special education support. Upon graduation, Lina hopes to begin training to become a special education teacher.

DRM provides extensive training throughout the state on the educational rights of children with disabilities. DRM works to ensure policies and practices at the state level support effective transition planning. We also educate youth, families and other stakeholders about the supports available in the transition to adulthood, and advocate for effective solutions to the gaps in that process.

A DRM attorney trained educators and service providers on best practices for bullying prevention and intervention, and offered insight into legal implications when students' rights are in conflict in schools. Training participants learned strategies for creating a "bullying-free" school environment and promoting positive and safe behaviors.

Making Waivers

Under MaineCare, there are five Home and Community Based Services waivers, which allow individuals who are otherwise eligible for nursing home level of care to instead receive services that enable them to live at home and in their communities, including Section 19, "Home and Community Benefits for the Elderly and Adults with Disabilities". The key to making these waivers successful lies with an individual's or an agency's ability to obtain adequate staffing.

Maine has a staffing crisis with respect to providing services to people with disabilities. This problem is magnified for people in rural areas and as a result, individuals often receive only a fraction of the care they are eligible for, or they go without critical services. In either instance, they face the possibility of being forced

to enter an institution – the very thing waivers are designed to avoid.

Some individuals are fortunate to have family members who can step in and provide some or all of the care, but they often do so without compensation. This means that these families may face economic hardship because of their limited ability to maintain employment outside of the home. Another barrier to receiving services is that Section 19 has a rule prohibiting staff from being paid for work in excess of 40 hours per week. Waiver recipients who are eligible to receive more than 40 hours per week of services, particularly those living in remote areas, and who are lucky enough to find one provider, are highly unlikely to find another.

That is why DRM sued the Department of Health and Human Services (DHHS) on behalf of Mae, a woman who was on the Section 19 waiver and was eligible to receive 86 hours of in-home care per week. Mae lived in a remote area of Maine and could not find more than one person to provide care, and therefore could not access all her services. In its suit, DRM claimed that DHHS violated the Americans with Disabilities Act, which requires that individuals receive services in the most integrated setting

In 2018, DRM conducted statewide rights trainings to over 850 people receiving developmental services, as well as to their family members, guardians and service providers.

Accessible to Everyone

appropriate and requires the state to modify its policies to prevent the needless institutionalization of people with disabilities. DRM claimed that the state needed to create an exception to the rule so that waiver recipients, such as Mae, could request an exception to the 40 hour rule, allowing their staff to be paid for all the hours they work.

After DRM sued, DHHS agreed to settle the case and created a process whereby those at risk of institutionalization could seek an exception to the 40 hour rule. Consistent with the settlement, DHHS amended the Section 19 waiver to include the criteria it will look for when deciding to grant the exception. DHHS will look at the availability of workers in the member's area; the number of hours needed above the cap; whether the member's condition is unique as compared to other Section 19 members; the length of time for which the exception is requested; and the agency's or member's efforts to find other workers. The Department's decision will be in writing and can be appealed.

During settlement negotiations, DHHS asked DRM to work with them in developing a process for seeking approval to modify any DHHS policy so as to prevent unnecessary institutionalization of people with disabilities. This policy can be found at: https://www.maine.gov/dhhs/civil-rights-compliance/ada-modification.shtml

This is a great example of how DRM can use strong individual cases to effect broader systemic change.

DRM hosts the ADA Coalition, a collaboration of persons with disabilities and partner agencies. The coalition works to identify and address access issues in the community, foster awareness of requirements and rights under the ADA and the Maine Human Rights Act and to encourage disability rights activism.

Protecting Access

Thousands of Mainers rely on MaineCare to access vital health care and community support services. For individuals with mental health diagnoses, MaineCare is necessary in order to access services such as case management and Daily Living Support Services (DLSS). The ability to receive these services can be critical to an individual's success in the community, and the loss of this support can have a detrimental effect on their lives.

DRM advocates for the rights of individuals to access the services and supports necessary in order to live, work and participate in their communities. For DRM's hospital-based advocates, this means ensuring patients have the opportunity to participate in their treatment planning and are connected with appropriate services upon discharge. When DRM believes an inappropriate denial or termination of services has occurred, staff may intervene in a number of ways, from providing assistance with the grievance process, to representation in an administrative hearing.

Jim, a 55 year old man with mental illness who received case management services, was informed that these services would be terminated due to an assessment that found he was not at risk for homelessness or criminal justice involvement. DRM filed an administrative appeal of the termination of services and later met with Jim and his therapist concerning the proposed termination of services. The therapist stated that case management was necessary for Jim to be able to work with his landlord and other providers in order to maintain his housing and avoid criminal justice involvement. DRM represented Jim at the hearing and upon reviewing the evidence presented, the MaineCare representative agreed that the termination was in error. Jim's services were reinstated that same day.

In 2018, DRM supported a group of activists and self-advocates who partnered with us on outreach and training activities to systemically address problems in the service system in Maine. Members testified at the legislature on changes to Maine's guardianship law and advocated for greater control over their lives and services.

to Services

George, a 67 year old man, was hospitalized in a state institution. While there, it was determined that George also had a neurocognitive disorder, which could impact his ability to care for himself. George and his family struggled with what this new diagnosis meant for his way of life after discharge, because throughout the hospitalization, George was adamant that he would continue to care for himself and others, as he had always done.

DRM's patient advocate worked with George and his family to understand his rights to return to his home and retain his decision-making authority. DRM ensured that George received a thorough evaluation of his skills, in his home, to provide his treatment team with a complete picture of the real-world abilities he had developed over a lifetime of maintaining his home and caring for family members. Because of this evaluation, George's treatment team changed its recommendation that he enter an assisted living facility and supported George's plan to return to his home and enjoy his quiet retirement.

These cases illustrate the advocacy available to individuals experiencing serious rights violations or facing a critical loss of services. In addition to its advocacy efforts, DRM staff undertake training and outreach activities in the hope that violations can be prevented from occurring in the first place.

In 2018, DRM conducted outreach to psychiatric hospitals, crisis and respite programs, and group living situations across Maine. Staff distributed voting rights materials and absentee voting flyers and assisted people in registering to vote. Advocates met with people at hospitals in Portland, Biddeford, Brunswick, Augusta, Rockport, and Bangor, and crisis and respite programs across the state, and reached over 350 people.

Meeting Children's Needs in the

Children with disabilities have the right to be in the least restrictive environment (LRE) – to have access to the same opportunities and resources as their peers without disabilities. This is true both in school and where they live, and it leads to the best outcomes for youth and families. Too often, however, children with disabilities are denied that right by being placed in and then overstaying in highly restrictive settings such as special purpose private schools and institutions (hospitals, residential programs, jail, etc.). This makes it challenging for youth to have experiences that are developmentally necessary and appropriate.

DRM believes that when children with disabilities can engage with and contribute to their communities, we all benefit. This means applying our efforts to ensure that kids are served in the least restrictive appropriate environment. This looks different for each individual, and should be uniquely tailored to each child's needs and strengths, but the ideal is for children with disabilities to attend public school in an integrated setting and to receive any treatment they may need while living at home in the community. When a child needs to access a higher level of care or restriction, time spent in a segregated setting should be limited to what is necessary, and the transition back to a less restrictive setting should occur as soon as possible.

Sam, a 17 year old with autism and a mental health diagnosis, was at a juvenile correctional facility, having come from a residential mental health treatment program. Sam had trouble at several programs due to aggressive behaviors. DRM worked with Sam's team to transition her from the correctional facility back to a treatment-focused setting. DRM pushed for a different and more individualized treatment setting. Eventually, Sam was placed at a small, individualized treatment program tailored to her needs; avoiding commitment to the correctional facility.

In 2018, DRM conducted monthly monitoring visits to Long Creek Youth Development Center, Maine's juvenile corrections facility, to meet with youth and discuss their rights concerns, and to address concerns with the administration.

Least Restrictive Environment

Fred, a 15 year old student with autism who did not have an educational program. Fred spent a number of years in segregated and alternative settings and these were not working for him. He was motivated to return to the public high school and, with the appropriate supports put in place (including services from the district's behavioral specialist), he was able to successfully return. Although Fred is still primarily in a special education setting, he is increasingly participating in activities at the high school and accessing the general education curriculum. A few months after Fred's return, the school was able to successfully fade some of the intensive supports.

Advocating for a child can change the course of their life. But, to make the greatest impact possible, DRM works with numerous stakeholders to push for broader access to the least restrictive settings. On the education side, DRM collaborates with a coalition of advocates to identify trends of children with disabilities being pushed out of integrated settings and to design interventions that can be applied across the board. On the treatment side, DRM engages with the Department of Health and Human Services to address the extensive wait lists for home and community based services for children. This process resulted in an assessment of the Children's Behavioral Health Services (CBHS) system, which provides a blueprint for moving forward to ensure children can receive the services to which they are entitled, in the least restrictive settings.

DRM's efforts to promote access to the least restrictive setting remains a cornerstone of our advocacy for children. Building on recent reports and growing public awareness due to press coverage, DRM will continue working with fellow stakeholders, as well as maintaining a dialogue with the state and local districts, to ensure that children receive their educational services in the most integrated settings possible.

DRM looks forward to the implementation of the Children's Behavioral Health Services system assessment, hoping and pushing for improvement in access to and quality of home and community based services so that fewer children will be in residential placements, hospitals, jail, or out of state.

DRM meets with and provides rights education monthly to children and adolescents at psychiatric hospitals in southern and central Maine. In 2018, advocates helped youth file grievances regarding their care and met informally with staff to try to resolve concerns and help young people have a voice in their treatment.

Communication Access

The failure of individuals, businesses and government to adequately address communication needs results in barriers for Mainers who are Deaf, hard of hearing, late deafened, and deaf-blind. These barriers prevent individuals from receiving quality healthcare, obtaining or advancing in employment, progressing in school, or accessing public safety and emergency response services. Unfortunately, this is a common occurrence.

Communication is a universal need. At school or work, in the doctor's office, in our relationships with family and friends – we rely on communication in order to interact with the world around us. Without it, we are cut off and shut out, unable to express our needs or engage with others. Knowing this, DRM works to remove barriers to communication access and enforce the civil rights of Deaf, hard of hearing, late-deafened and deaf-blind Mainers through advocacy, legal assistance, technology, and training.

Arthur, a Deaf man with severe anxiety and PTSD, contacted DRM for help after struggling to gain communication access to medical care at his local hospital. During primary care visits and trips to the emergency department, the hospital did not schedule American Sign Language interpreters. Instead, they tried to use a remote interpreter on a tablet screen when Arthur arrived. The technology often failed, and hospital staff struggled to use it to communicate effectively with Arthur. He left his appointments unsure of whether he understood the doctor, and scared about how the communication difficulties were impacting his care. DRM contacted the hospital on Arthur's behalf to advocate for improvements. As a result, the hospital agreed to ensure that Arthur's communication needs were documented in his patient record. The hospital also agreed to contract with a local interpreting agency for on-site ASL interpreting services in the future.

Noah lost his ability to speak as a result of a surgical procedure. While he was able to hear over a traditional telephone, he could no longer communicate back.

DRM coordinates quarterly meetings of the Deaf Rights Group to provide a forum for sharing systemic concerns and accomplishments of the Deaf community in Maine. These discussions are open to all and provide guidance to DRM about priority issues facing the Deaf community.

is a Civil Right

DRM's Telecommunications Equipment Program helped Noah to obtain a Hearing Carry Over phone so that he could communicate independently with family and medical providers again. The Hearing Carry Over phone allowed Noah to listen to callers and respond by typing. In addition to the phone, Noah was provided with installation and training help. Learning to use the new telephone was a wonderful experience for Noah and his family, as they had not been able to communicate over the phone for a long time.

While working with clients on an individual basis is important and can help lead to broader change, it is inherently reactive. DRM also proactively seeks opportunities to break down barriers and provide education. Deaf awareness education and training was provided to five nursing homes that serve Deaf residents. DRM also checked for the presence of videophones for signing residents. This training has also been given to police and first responders throughout Maine, to create better interactions between first responders and the Deaf and hard of hearing community.

Looking to the future, DRM intends to continue this vital individual and systemic advocacy, while seeking broader initiatives such as discounted internet services for videophone users so they don't have additional economic barriers to achieve the same basic level of communication and fruitful business partnerships.

After the Deaf Community raised concerns, DRM intervened with Portland Jetport administration and developed a plan to implement closed captioning on all monitors, videophones in two locations, upgrade of flight information displays and public announcement systems to allow for visual access, and text boarding information at airline gates.

Promoting Recovery for People with Brain Injuries

DRM works in partnership with Mainers recovering from brain injuries to help them obtain the services, rehabilitation and access to society to which they have a right.

Individuals with a Traumatic Brain Injury (TBI) have an array of advocacy needs including challenges with employment, accessing needed supports and assistive technology, and obtaining appropriate rehabilitation services. Often these individuals, including returning veterans, are forced to remain in restrictive institutional settings far longer than necessary without the intervention of DRM.

DRM promotes the rights of people with brain injuries through advocacy, education, and outreach, and through systemic work with coalition partners.

Carl, a man with a brain injury, had DRM intervene to block his transfer out of state, after his group home provider attempted to discharge him to a hospital emergency department without pursuing lesser restrictive appropriate options. DRM filed for an administrative hearing, blocking his discharge, and entered into negotiations around appropriate services for him. DRM's intervention allowed Carl to locate an in-state option to meet his needs.

Credit: Kay Inoue, local photographer

Jane, a woman with a brain injury residing in a nursing facility, came to our attention when DRM received a report of neglect. She had expressed an interest in leaving and obtaining supportive services in the community, but the home failed to assist her. DRM intervened with the director of the facility and obtained an assessment and a discharge planning schedule for Jane, and she was discharged to a supported apartment in the community.

Phil, a 63 year old man with a brain injury, had DRM intervene on his behalf after receiving reports of financial neglect and rights violations. DRM obtained a full accounting of Phil's special needs trust assets to share with him, and arranged for him to meet with a representative of the bank to understand how to access his funds independently. His guardian and payee provided an updated accounting of his assets and revised his care plan to reflect his wishes.

Representative Payee Review Program

In August 2018, DRM launched its newest program – Protection and Advocacy for Beneficiaries with Representative Payees. The program is a collaboration with the Social Security Administration (SSA), and focuses on providing oversight and monitoring of representative payees in Maine.

A representative payee is a person or organization who receives Social Security payments on another person's behalf. This person is assigned by Social Security and helps the beneficiary manage their benefits. Unfortunately, there have been instances of representative payees who have stolen or misused funds, exploited, neglected, and even abused the people who they were supposed to be helping.

Under this program, DRM provides oversight and monitoring of representative payees. DRM conducts reviews of payees and their finances to ensure that they are following legal requirements and best practices. DRM also interviews beneficiaries as part of the review to make sure their needs are met. When necessary, DRM recommends corrective action and follow up by SSA. DRM's staff also provides outreach and education to payees, and connects beneficiaries to other services address unmet needs. The Rep. Payee Review Program works in partnership with DRM's other programs to identify and address payee-related concerns and issues and to get client referrals.

Ensuring Voter Access

DRM's intervention plays an important role in fulfilling the promise of the Help America Vote Act. DRM works in partnership with people with disabilities to ensure their full participation in the electoral process in Maine, including registering to vote and being accommodated in the voting process. DRM works collaboratively with election authorities to survey and adapt polling places for accessibility, selecting balloting equipment that is accessible to all voters, ensuring the accessibility of voter outreach materials, and training poll workers on disability rights and voting.

DRM intervened on behalf of three hospitalized individuals who requested assistance with absentee ballots but were denied help from the facility. These individuals were eligible for Maine's special circumstances provision in election law, but the hospital claimed administrative burden. DRM filed formal reasonable accommodation requests on behalf of all three, intervened with the hospital's attorney, and the hospital took steps to obtain and deliver ballots for all three before the close of the polls on Election Day.

our clients

DRM provided direct representation to 1345 clients for 1849 cases. Information and referral services were provided to an additional 2269 individuals.

Client Age

4 and under	13
5 to 12	130
13 to 18	173
19 to 25	176
26 to 64	758
65 and over	95

Client Disability

Blindness/Visual Impairment	9
Brain Injury	54
Deafness/Hard of Hearing	84
Developmental Disability	881
Mental Illness	258
Physical Disability, Health Impairment, Chronic Illness	59

Clients by County

Androscoggin	140
Aroostook	61
Cumberland	252
Franklin	25
Hancock	26
Kennebec	150
Knox	36
Lincoln	27
Oxford	68
Penobscot	208
Piscataquis	20
Sagadahoc	38
Somerset	83
Waldo	35
Washington	24
York	141
Out-of-State	11

Case Problem Area

Abuse/Neglect & Other Rights Violations	1088
Community Integration	285
Education	201
Employment	87
Government Services & Public Accommodations	130
Guardianship	42
Housing	14
Voting	2

financial summary

Year Ending September 30, 2018

REVENUE AND SUPPORT	
Federal Grants	$1,216,668
State Grants	$1,323,135
Contributions	$9,766
Other Revenue	$421,956
TOTAL REVENUE	$2,971,525

EXPENSES	
PADD	$320,916
PAIMI	$408,671
PAIR	$194,376
PAAT	$54,994
PABSS	$91,102
PATBI	$47,845
PAVA	$59,559
Rep. Payee	$9,939
EA	$127,552
Psychiatric Ctr Adv	$138,710
Maine Civil Legal Svs	$30,136
Acadia	$58,199
Developmental Svc Adv	$475,985
Deaf Advocacy + Comm Access Prog	$585,028
Supporting Services	$340,966
TOTAL EXPENSES	$2,943,978

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Sean Ociepka, Esq., Secretary
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Kathleen Shevenell
Tracy Silverman
Willie Tarr
Rachel Violette, Esq.
Sally Walsh

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Michelle Ames, Program Director
Caleb Baker, J.D.
Debra Bare-Rogers, Advocate
Gabrielle Bérubé Pierce, Esq.
Olivia Blom, Advocate
Nell Brimmer, Esq.
Foxfire Buck, Esq.
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Maureen Chick, Finance
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Jeffrey Skakalski, Esq.
Sara Squires, Public Policy Director
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Kevin Voyvodich, Esq.
Lauren Wille, Esq.

DISABILITY RIGHTS MAINE

our mission

Disability Rights Maine is a private non-profit organization, incorporated in Maine, governed by a volunteer Board of Directors and designated by the Governor of Maine to serve as Maine's independent advocacy agency for people with disabilities.

Our mission is to ensure autonomy, inclusion, equality, and access for people with disabilities in Maine.

DRM Board and staff believe that people with disabilities must:

Be free from abuse;

Control the decisions that affect their lives;

Receive the services and supports necessary to live independently;

Have the opportunity to work and contribute to society; and

Have equal access to the same opportunities afforded all other members of society.

Please consider donating to support us in this mission. Donations accepted at our website.

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