

MAINE STATE LEGISLATURE

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Annual Report

2024



DEDICATION

Disability Rights Maine is honored to dedicate the 2024 Annual Report to Acacia Bernice Marquis, who passed away on September 7, 2024. Twelve years ago, DRM shared Acacia's story as the cover story of that year's annual report. When Acacia was in high school, MaineCare tried to reduce her nursing hours, putting her at risk of institutionalization. Acacia's mom, an unwavering advocate, called DRM for help. Staci Converse, the Director of DRM's Developmental Disability Program, represented Acacia at a DHHS hearing and won, which allowed Acacia to continue living in her home.

Acacia thrived as an active member of the Scarborough community, where she lived since 2001. Her favorite place was Kettle Cove. She lived a full and adventurous life and brought joy to everyone she met.

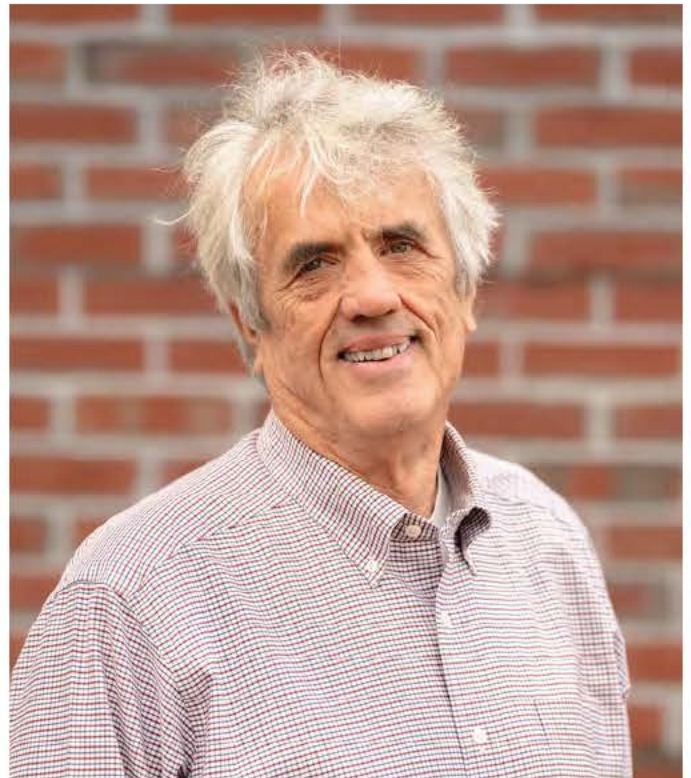


Photo courtesy of Julie Marquis.

THANK YOU

DRM also wishes to recognize and thank Peter Rice, who retired at the end of 2024. During his decades long career at DRM, Peter represented more than 3,500 individuals in more than 4,800 cases. His work transformed access to home and community-based services, removed caps on nursing care hours, and improved accessibility statewide. Through his steadfast commitment to disability justice and legal prowess, Peter improved the lives of countless individuals.

As DRM's Legal Director for more than 20 years, Peter served as a mentor to dozens of advocates and attorneys. In recent years, Peter dedicated most of his time to providing legal support to DRM's Deaf Services team. Thank you, Peter!



LETTER FROM THE ED

Dear Friends and Colleagues:

I am pleased to share Disability Rights Maine's 2024 Annual Report. This report highlights a mere snapshot of the enormous amount of impactful advocacy work undertaken by the DRM staff over the past year.

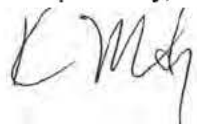
When I think about the present state of disability rights, I try to focus on the positive; on the many achievements we have realized over the past 40 years. One of the most exciting innovations coming from the disability civil rights movement is the advent of alternatives to full guardianship. Twenty-five years ago, when we first began talking about eliminating adult guardianship, it truly was an impossible goal because adults with labels of intellectual and developmental disabilities were routinely placed under full guardianship without much thought by the courts or the families or the service system. Now, we frequently hear from families who use supported decision-making or other alternatives. People with disabilities in Maine are therefore much more able to make their own decisions about where they live and work, who they hang out with and what they do in their spare time.

Other achievements changing the lives of Mainers with disabilities include a significant reduction in the use of seclusion and restraint of people with psychiatric labels, the downsizing and closure of institutions, the elimination of paying people far less than minimum wage, the creative use of Medicaid waivers to improve the service system and to include people with brain injury, the robust monitoring of representative payees to prevent financial exploitation, and the increased access to the polls due to accessible voting sites. And many, many more people actually have keys to their own front doors and locks on their bedroom doors. We are changing the world.

And yet, I believe that disability rights advocates and attorneys are needed now more than ever to protect the rights that we have won. We must ensure that children with disabilities are educated with their peers; that abuse and neglect is discovered and stopped; that accommodations are provided so disabled people can work and get around in our communities; that home and community-based services are strong; that our people can live independently without risk of institutionalization; and that communication access is not an afterthought.

I am enormously grateful to work alongside a scrappy, smart and dedicated staff, who bring creative strategies to their work, which allow DRM to make a profound impact on the lives of the people we serve. Thank you to our Board of Directors, funders, partners, and supporters who make this work possible, and to our clients, whose steadfast commitment to disability rights drives our work forward.

Respectfully,



Executive Director



Board President Andy Sarapas and Executive Director Kim Moody at Disability Pride 2024.

Disability Rights Maine is supported by funding from:

the Administration on Disabilities

the Center for Mental Health Services

the Rehabilitation Services Administration

the Social Security Administration

the State of Maine

the Maine Civil Legal Services Fund Commission

the Maine Health Access Foundation

the U.S. Department of Justice Office on Violence Against Women

private donors

DRM would like to thank the individuals, businesses and organizations whose generosity enables our work.

To learn how you can aid the work of DRM, visit:

www.drme.org/get-involved/donate/

Available in alternative formats upon request.

THRIVETOGETHER MAINE

More than 90% of people with developmental disabilities experience sexual violence in their lifetime – a frighteningly high rate. When abuse happens, only a small fraction of survivors are able to access supportive resources and seek justice for what happened to them because of numerous barriers.

To combat those barriers in Maine, Disability Rights Maine sought and was awarded funding in 2022 through the U.S. Department of Justice, Office on Violence Against Women (OVW) Discretionary Grant Program. The three-year project, “Grants for Training and Services to End Violence and Abuse Against Individuals with Disabilities and Deaf People Program (Disability Grant Program)” is designed to facilitate local, systemic, and policy change through an intensive collaboration process.

The project is led by Sammy-Ellie MacKinnon, pictured.

ThriveTogether Maine is the resulting collaborative and is made up of representatives from DRM, Speaking Up For Us, Maine Coalition Against Sexual Assault, and Maine Association for Community Service Providers. The goal of the collaborative is to address the organizational capacity to support individuals who have experienced sexual violence and live with Developmental Disabilities (DD) and/or are Deaf and Hard of Hearing or use visual gestural communication (VGC).



After successfully executing the planning and development phase of this project in fiscal year 2023, ThriveTogether focused its work in fiscal year 2024 on developing and implementing a comprehensive needs assessment plan. After the plan was approved in the Spring of 2024, ThriveTogether Maine conducted 15 focus groups, nine individual interviews, and two online surveys, resulting in feedback from 186 individuals. Respondents included survivors, family members, sexual assault center staff, professionals serving adults with DD, and advocates.

The collaborative is now in the process of analyzing the results to develop a strategic plan and to implement solutions to combat the epidemic of violence experienced by individuals with disabilities. Early findings indicate that ongoing collaboration across diverse organizations, trauma-informed professional development opportunities, and accessible education about bodily autonomy will be critical to addressing barriers in both the disability service system and the sexual assault response system.

The mission of ThriveTogether Maine is to create a state where people with developmental disabilities can recognize and disclose sexual violence and where they experience a safe, knowledgeable, and affirming response by: centering the lived experiences of people with developmental disabilities, building deep relationships among disability and sexual violence victim service providers to provide holistic support for survivors, and challenging long-held norms and beliefs about people with disabilities and sexuality.

ThriveTogether Maine is supported by Grant No. 15JOVW-22-GK-00334-DISA awarded by the Office on Violence Against Women, U.S. Department of Justice. The opinions, findings, conclusions, and recommendations expressed in this publication/exhibition are those of the author(s) and do not necessarily reflect the views of the Department of Justice, Office on Violence Against Women.

YOUTH SELF-ADVOCACY

In 2023, DRM launched a new Youth Self-Advocacy Program (YSAP), which began robust programming in 2024. Shortly after programming began, young folks reported that they wanted to talk and learn about advocacy in their interpersonal relationships, be it with parents or other family members, friends, romantic partners, online connections, and beyond. In July 2024, Program Director Kate Turpen saw an opportunity to achieve two goals with one initiative when they were trained in Mad Hatter Wellness' Empowered Together curriculum. With this training, Kate could both respond to program participants request for information and provide high-quality, comprehensive sexual health instruction to fill a systemic gap in the current educational landscape. A sobering truth is that students in special education are not included in the health lessons their peers in general education receive. There is overwhelming stigma that people

with disabilities are uninterested or incapable of having passionate relationships with others, dating, or planning for a future family – the YSAP team found this couldn't be further from the truth.

In the fall, in partnership with trainers from Speaking Up For Us, Kate trained six self-advocates and one professional in the Empowered Together Curriculum. This train-the-trainer model was critical to increasing the YSAP's capacity to offer lessons in more locations. The Empowered Together curriculum is unique as it requires lessons be co-taught by a professional and an adult with a disability. Lesson topics include having crushes, dealing with rejection, a brief exploration of gender identity and sexual orientation, dating, reproductive body parts and pregnancy, consent, self-esteem, and body image. The training culminated in a 2-day facilitator training with the Executive Director of Mad Hatter Wellness, Katie Thune.



Upon completion of this training, the YSAP team partnered with Deering High School to implement lessons. The pre-survey given to students showed that approximately 16% disagreed that they were in charge of their bodies and nearly 20% did not think that both people needed to consent before sexual activity. After spending 10 weeks with the students, post-survey results showed that 100% of students reported they were in charge of their own bodies and knew everyone needed to consent. The pilot program was a clear success and DRM will be offering the programming at more locations in 2025.

"You taught me to understand and appreciate myself."
- YSAP Participant

COMMUNITY ENGAGEMENT

Collaborative Outreach

In response to the housing crisis, DRM engaged in outreach and advocacy for individuals with serious mental health disabilities affected by the dismantling of a tent encampment in a local city. Following the city's actions to clear the encampment—issuing no-trespass orders and removing tents and belongings—a private organization rapidly established a shelter for those displaced. DRM staff partnered with the new program to conduct an outreach visit, connecting directly with affected individuals and equipping them with the knowledge and resources needed to navigate the challenges of displacement and secure necessary services.

DRM staff also collaborated to conduct outreach in rural areas of Maine, including the St. John's Valley and Downeast Maine, which are historically underserved. Through this effort, DRM reached more than 300 disabled community members and provided self-advocacy tools and information about employment resources.

Deaf Services Employment Conference

Over 80 people attended DRM's Deaf & Hard of Hearing Conference on June 7, 2024. The keynote address was given by Dr. Amie Fornah-Sankoh, who in 2023 made history as the first Deaf Black woman to earn a STEM doctorate. She shared an empowering message of self-reliance, perseverance, and the importance of communication access and exposure. Dr. Sankoh also moderated a panel discussion of Deaf & Hard of Hearing individuals discussing their experiences in the workplace. The afternoon saw workshops on employment rights, apprenticeship programs in Maine, assistive technology in the workplace, and work impacts on benefits.



Election Access

An important part of DRM's work is ensuring that disabled people can vote privately and independently and are fully included in the electoral process. In 2024, DRM engaged in significant efforts to increase the disability vote in advance of the 2024 General Election.

Highlights included:

- Developing Maine's RevUp Coalition.
- Training more than 590 people with disabilities on the voting process and the importance of civic engagement.
- Training over 600 election officials in Maine on compliance with the Americans with Disabilities Act and the Help America Vote Act.
- Monitoring more than 210 polling places in all 16 Maine counties, collecting over 8,000 data points.



ADVOCACY IN ACTION

Mary Maintains Access to In-Home Supports to Avoid Institutionalization

DRM represented Mary, a woman with ALS who needed more home support hours than MaineCare policy allowed. DRM filed a request for an exception with DHHS, so that Mary could receive the support she needed in excess of the existing monetary cap. DRM argued that without the exception, Mary would be institutionalized which would violate the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Supreme Court's decision in *Olmstead*. DHHS agreed to the request and allowed the client to receive more hours. As the client's condition progressed, DRM made subsequent requests for more hours, and each time, the request was granted. Mary eventually passed away, but was able to live out her remaining days in her home with her family by her side and in accordance with her wishes.

DRM Helps Lorraine Avoid Loss of Dog

Lorraine was involuntarily hospitalized at a psychiatric facility and faced losing her dog of over eight years, which had been taken by police and brought to a local shelter during the events leading to her commitment. Being involuntarily committed for 30 days, she was unable to address the shelter's warning that state law allowed them to rehome or euthanize the dog within 10 days unless arrangements were made by her to pick up the dog within that time. Lorraine's bond with her dog was crucial to her mental health, and its loss would

likely jeopardize her ability to transition successfully back home, prolonging her hospitalization. DRM intervened, negotiating an extension with the shelter and helping the client secure resources to transport the dog to an external kennel during the time of the client's commitment. This allowed Lorraine to focus on her recovery and after her discharge, she was successfully reunited with her beloved dog.

Making Preschool Accessible to All

Beginning at age 3, children with an Individualized Education Program (IEP) have a right to a free appropriate public education. Over the last few years, DRM received dozens of calls from families whose preschool-age children were not receiving the education and services they were entitled to. Oliver was one of those children. Oliver, who is blind, loves to play with his toys, explore the outdoors with his mom, and listen to stories. As soon as he turned 3, he was ready to go to preschool and make new friends. Instead, he received no education or services for 16 months. Oliver's mom contacted DRM and as a result, he received compensatory education services and is now enrolled in his local kindergarten. Oliver's story, which parallels the situation for many young children across Maine, is why DRM continues to advocate for systemic improvements to improve access to quality early childhood education.



BY THE NUMBERS

DRM provided direct representation to **1198** clients in **1430** cases. DRM's equipment distribution programs served an additional **185** clients, while information and referral services were provided to **1705** individuals.

Client Age

4 and under
5 to 12
13 to 18
19 to 25
26 to 64
65 and over

7
97
81
178
714
121

Client Disability

Blindness/Visual Impairment 14
Brain Injury 39
Deafness/Hard of Hearing 68
Developmental Disability 679
Mental Illness 310
Physical Disability, Health Impairment, Chronic Illness 88



Clients by County

Androscoggin
Aroostook
Cumberland
Franklin
Hancock
Kennebec
Knox
Lincoln
Oxford
Penobscot
Piscataquis
Sagadahoc
Somerset
Waldo
Washington
York
Out-of-State

151
71
257
14
28
133
29
18
33
207
14
25
28
34
31
122
3

Case Problem Area

Abuse/Neglect & Other Rights Violations 249
Community Integration 657
Due Process 11
Education 155
Employment 83
Government Services & Public Accommodations 102
Guardianship 91
Housing 41
Vocational Rehabilitation 41



Financial Summary

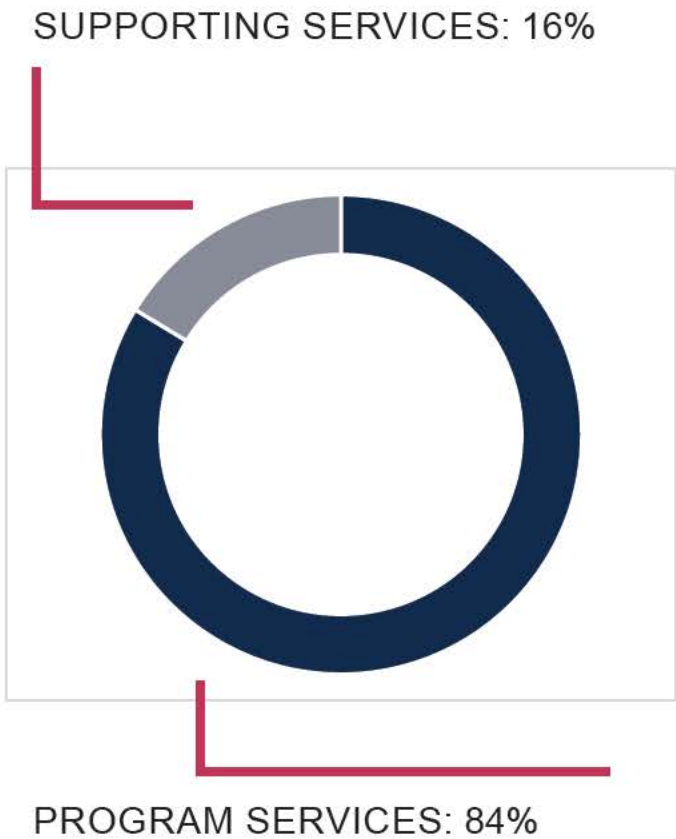
Year Ending September 30, 2024

REVENUE AND SUPPORT

Federal Grants	\$2,022,606
State Grants	\$1,876,964
Fee for Service	\$333,175
Contributions	\$36,443
Other Revenues	\$90,909
Other Grants	\$205,459
TOTAL REVENUE	\$4,565,556

EXPENSES

PADD	\$389,403
PAIMI	\$407,890
PAIR	\$165,661
PAAT	\$44,560
PABSS	\$135,548
PABRP	\$102,400
PATBI	\$34,080
PAVA	\$161,398
Client Assistance Program	\$97,415
Educational Advocacy	\$130,279
Psychiatric Center Advocacy	\$398,580
Maine Civil Legal Services	\$70,363
Acadia	\$22,605
Developmental Services Advocacy	\$605,581
Deaf Advocacy + Communication Access Program	\$549,794
OVW Disability Grant	\$132,445
Innovation Program	\$284,998
Health Access	\$85,905
Voting Access	\$6,747
Supporting Services	\$744,510
TOTAL EXPENSES	\$4,570,162



DRM PROGRAMS

Disability Rights Maine (DRM) is Maine's Protection & Advocacy agency for people with disabilities. This means we represent people whose rights have been violated or who have been discriminated against based on their disability. We also provide training on rights and self-advocacy and we advocate for public policy reform.

DD Advocacy provides legally based advocacy to individuals with intellectual and developmental disabilities who have experienced abuse, neglect, exploitation or who have been discriminated against based on their disability. In addition to the federal Protection and Advocacy program for individuals with diagnoses of developmental disabilities, DRM receives State of Maine funding to advocate for adults with labels of intellectual disability and autism.

MH Advocacy serves individuals who have a diagnosis or label of serious mental illness. DRM provides these services statewide to individuals in the community and in institutions through federal and State funds.

Protection and Advocacy for Voting Access (PAVA) is a federal program that allows DRM

to represent individuals who have been denied the right to vote and to increase access to the polls for people with disabilities.

Protection and Advocacy for Individual Rights (PAIR) 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).

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.

Brain Injury Advocacy provides legally based advocacy for people who have a brain injury and who have experienced a rights violation or discrimination.

Protection and Advocacy for Assistive Technology (PAAT) assists individuals with disabilities in obtaining assistive technology devices or equipment in order to

live more independently, work, attend school, or meet medical needs.

Children's Advocacy State funds allow DRM to serve 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; or who are in a hospital or residential facility and have experienced abuse, neglect or violations of their basic rights.

Deaf Services provides legally based advocacy to individuals who are Deaf, late-deafened, hard of hearing and Deaf-Blind; provides technology to improve communication access; provides peer support to Maine citizens who also have developmental disabilities; and provides outreach statewide to ensure that people know about communication options and access.

Client Assistance Program (CAP) is a federally funded program that provides information, assistance and advocacy to people with disabilities receiving services under the Rehabilitation Act.

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Mission

Disability Rights Maine advances justice and equality by enforcing rights and expanding opportunities for people with disabilities in Maine.

Vision

People with disabilities must not be stigmatized, undervalued, institutionalized or excluded. Disability Rights Maine envisions a just world, without barriers, where all disabled people have power and autonomy. In this world, disabled people have full and equitable access to education, jobs, resources and community.

Values

DRM Board and staff believe that the disability rights movement is inseparable from the human rights movement for racial, economic and gender equity. We renew our commitment to eradicate ableism, racism, sexism and bigotry, and to dismantle institutional and structural disadvantage.

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www.drme.org