DRM 2022 Annual Report

# 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.

# a message from the ed

Dear Friends and Colleagues:

I am excited to share some of the great work undertaken by the staff of Disability Rights Maine by presenting our 2022 Annual Report. This year marked 45 years of DRM serving the people of Maine as the designated Protection and Advocacy organization.

While we still have lots to do, Maine is ahead of the nation in so many ways, in how we provide services to people with disabilities. Perhaps most importantly, the State of Maine does not operate any large institutions for people with labels of developmental and intellectual disabilities and we no longer have sheltered workshops that pay people with disabilities wages that were far below the minimum wage.

What we need to work on though, and what DRM will continue to fight for is keeping our children out of institutional settings, including hospital emergency departments, providing the services they need to thrive in their homes and communities and ensuring they have real and regular access to quality education.

For and with adults with disabilities, we need to continue the push for individualized community-based services that include offers of competitive integrated employment. We need to listen to what people with disabilities are telling us they want and figure out how to let that inform policy making, rather than continuing to allow others to make all of the decisions that affect and impact their lives. We need to ensure access to health care, we need to continue to improve the mental health system, we need to fight the systemic barriers that keep people in poverty and we must increase our accessible affordable housing.

At DRM, we advocates and lawyers need to continue to lift up the voices of the people we are here to serve.

I am proud to work at DRM among an amazing group of dedicated, passionate people, to advance justice and equality for Maine people with disabilities.

Thank you to our funders, partners, and supporters who make this work possible and to our clients, who push us every day to be the best we can be and to strive for a more inclusive and more accessible Maine.

Respectfully,

Kim Moody

Executive Director

# 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

Acadia Hospital

the Maine Civil Legal Services Fund Commission

the Maine Health Access Foundation

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

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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/donate

Available in alternative formats upon request

# Maine’s Children Cannot Wait Any Longer for the Promise of Olmstead to be Fulfilled

When the Americans with Disabilities Act passed in 1990, there was hope it would be the start of a new world. In this future, at last, individuals with disabilities would be entitled to the same goods and services afforded every other American. Nine years later, the landmark Supreme Court decision in *Olmstead* v. *L.C.* further cemented the right of people with disabilities to be free from forced institutionalization. And while the disability community has experienced marked improvement in access and rights over the last 33 years, the reality is that much work remains in Maine and across the United States to fulfill the promises of both the ADA and the *Olmstead* decision.

Children today have only ever lived in a world where these promises exist. Yet, we see that children and their families remain impacted by the pervasive discriminatory practice of isolation and segregation based on disability label. Notably, on the 23rd anniversary of *Olmstead*, the Department of Justice (DOJ) issued their letter of findings which confirmed that as a result of significant and ongoing deficiencies, Maine over institutionalizes children with disabilities. The findings came as a result of a comprehensive investigation by the DOJ following a 2019 complaint filed by DRM.

Many of the 2022 findings mirror the deficiencies noted in Maine’s December 2018 Children’s Behavioral Health Services assessment: children’s behavioral health services were not available when needed, or not available at all.

“Children with disabilities deserve the opportunity to live at home with the services they need and grow up in the community alongside their nondisabled peers,” said Assistant Attorney General Kristen Clarke of the Justice Department’s Civil Rights Division.”[[1]](#footnote-1)

DRM’s Legal Director, Atlee Reilly, accurately captured the real human cost as a result of these failures in a press release following the DOJ findings letter, “Despite years of notice, Maine has not yet come to terms with the scope of the problem it faces, the significant harm being done to a generation of youth and families, and the enormous future costs that will continue to mount unless the longstanding deficiencies in the children’s behavioral health system are addressed with the urgency required.”

The continued need to advocate for system’s change is a driving motivation for DRM’s Children’s Advocacy Team. In the past year, DRM represented numerous youth forced into institutionalization. “Max” is one of those children.

Max is a 12-year-old with autism who languished in his local emergency department for three weeks without a clear plan. His family struggled to understand the system to obtain necessary supports outside the hospital. DRM helped the parents learn and navigate Maine’s system and pushed Max’s team to develop a plan that allowed for his discharge home. Max returned home and was matched with a local agency that could provide services in his community and that could develop a comprehensive safety/crisis plan. During this time, Max was also isolated from his classmates and his school. But, with DRM support, his parents were able to advocate for increased time in school at his IEP meeting.

And while Max was able to be connected to the services he needed, we continue to see many situations where children are stuck in the emergency room, hospital, or in a residential setting. In these situations, the children are often working with a Children’s Behavioral Health Services (CBHS) Program Coordinator, who is unable to find appropriate community-based resources to meet the child’s needs. Beyond the lack of services, there is also a lack of responsibility, accountability, and process for follow-up if any resources are located. The roles of the Program Coordinator and others involved in the process is unclear. Many families have also shared that the process is frustrating and ineffective to resolving the issues or barriers to accessing appropriate services. DRM raised these concerns with leadership at CBHS and requested that these issues be addressed to ensure appropriate planning occurs for children in these situations. CBHS leadership stated these improvements are part of their strategic plan and that they are working with a consultant to develop standards and expectations for this process and expect this won’t occur until 2023.

The unfortunate reality is that in addition to Maine violating the ADA, Maine children with disabilities are also at greater risk of experiencing violence when forced into segregated settings, like emergency rooms, psychiatric hospitals, and other out of home placements, in order to access behavioral health services. Studies have shown that children with disabilities are 3 times more likely to be sexually abused; 3.8 times more likely to experience abuse or neglect; and 4 times more likely to be emotionally abused. DRM believes that ending segregation is integral to preventing the disproportionate violence experienced by people with disabilities.

Children in Maine need the services they were promised and to which they are entitled. We cannot wait any longer.

# Ending Guardianship

In 2022, DRM continued the fight to limit the overuse of guardianship in Maine. DRM attorneys and advocates assist individuals with limiting and terminating existing guardianships and help people avoid going under guardianship altogether. We work frequently with individuals subject to guardianship to make sure they understand their rights and are able to maximize their autonomy and self-determination.

These are the stories of two former clients, who spoke with Staff Attorney Megan Salvin, pictured below, about their guardianship termination experiences.

Part 1: Cindy’s story

The first time Cindy was told about adult guardianship was by a staff member in her high school at age 17. The staff member recommended that her mother start looking into obtaining guardianship over Cindy when she came of age due to Cindy’s developmental disability and microcephaly diagnosis. The conversation turned more serious when Cindy was 19. Her case manager at the time told Cindy’s mother that obtaining guardianship was the only way for her mother to help Cindy make medical decisions and to have the ability to speak with doctors on Cindy’s behalf. There was no mention of less restrictive alternatives to guardianship, such as Supported Decision-Making or a medical power of attorney. That same case manager even said that Cindy would “likely never be able to live independently.” When it came time for the hearing, not only was Cindy not told that she was allowed to object to the guardianship, but her team prevented her from even attending the hearing out of concern that she would be “too overwhelmed.”

A few years passed and Cindy started to consider terminating her guardianship. She had concerns that her guardian was no longer doing the right things, and that she was capable of making her own decisions. By then, Cindy had graduated from college, was employed, and lived independently. When Cindy was 23, her guardianship was suspended by the court because her guardian mismanaged Cindy’s funds and personal property. However, the guardianship was still technically in place. Years went by and Cindy received no update from the court on what was to happen with her suspended guardianship. In 2021, Cindy reached out to Disability Rights Maine seeking assistance with finally terminating her guardianship. Because Cindy essentially acted without a guardian for several years, everyone agreed that the guardianship should be terminated. However, even with such a strong case for full termination, it took almost 9 months for the case to make its way through the probate court and for the guardianship to be officially terminated.

For Cindy, being under guardianship was difficult. It took away her independence and also negatively impacted the relationship with her mother. Now that the guardianship is terminated, Cindy’s relationship with her mother is much better, and she even seeks her mother’s input and opinions when making decisions. But now, Cindy is the final decision-maker in her life. Cindy’s life without a guardian is much improved - she has better housing, the support staff she needs in the community, and she successfully lives alone in her own apartment! It is a happy fact that Cindy chose not to be limited by her former case manager’s low expectations and incorrect prediction that she would never live independently. Cindy’s advice for those interested in terminating their own guardianship is “If you run in to any difficulty, you should know that there is help out there! There is a way to bounce back, you can have a better life!”

Part 2: Rose’s Story

Rose was 17 when her parents started talking to her about adult guardianship. At the time, Rose was attending high school and had a diagnosed learning disability as well as mental health conditions. Her parents were very supportive of her, but also explained that when she turned 18 she would have a lot of responsibility on her hands, and neither she nor her parents believed she was ready to handle those responsibilities independently. Thus, Rose agreed to guardianship because she felt it was the only way that her parents could fully support her. At that time, there was no information available around lesser restrictive alternatives to guardianship for Rose or for her parents.

Rose was very fortunate to have supportive guardians who involved her in every step of decision-making. They provided support around money management and medical decision-making, ensuring that she always understood exactly what was going on, and they never cut her out of any decisions. When reflecting on her guardianship, Rose explains that while she was technically under guardianship, her parents allowed her to be the final decision-maker, and she essentially acted without a guardian for almost 10 years. Around 2018, Rose began considering terminating her guardianship. When she discussed it with her parents, they fully supported her decision.

Even though everyone agreed termination was appropriate, when asked to describe the termination process in one word, Rose couldn’t help but yell “frustrating!” Like many, Rose felt that even filling out and filing the paperwork for guardianship termination was time-consuming and annoying. Rose reached out to Disability Rights Maine for assistance, but even with additional support from an attorney, it took almost 10 months to complete the process.

Now that Rose is free from guardianship, she is happy to be independent while still asking her parents for advice when needed, just like most people do.

Today, Rose is planning to go back to school to pursue a degree in childhood development. She is also on her 2nd term on the Board of Directors for Speaking Up For Us, Maine’s statewide self-advocacy organization. Rose’s advice for those interested in terminating their adult guardianship is “The process can be frustrating, but it is worth it and if you stick to it, it will pay off. Don’t back down!”

Because of DRM, adults under guardianship have the right to retain their own lawyer.

The 2019 changes to Maine’s Probate Code ensured that adults under guardianship retain the right to vote and the right to marry unless the court orders otherwise. However, it was not clear if an adult under guardianship had the right to retain their own counsel to challenge the guardianship.

A person under guardianship does not have the legal authority to sign a contract on their own behalf. Therefore, if an adult under guardianship wanted help from an attorney to terminate their guardianship, technically the attorney would have to seek the guardian’s permission to do so, a clearly backwards process.

DRM conceived of a piece of legislation (LD 1774), which explicitly retains the right of individuals under guardianship to privately consult with, and retain, attorneys and advocates without interference from their guardians. In March 2022, the bill was signed into law by Governor Mills. Now, adults under guardianship are free to seek out assistance with guardianship matters, and can sign their own retainers to do so.

# Mental Health Advocacy

At DRM, we have a team of advocates who work with individuals with psychiatric labels. These advocates are the watch dogs for individuals receiving mental health services in our state. Our team is made up of both community-based and hospital-based advocates. For all our advocates, no two days are alike.

Community-Based Advocates

Our community advocates meet people where they are. This can be at a crisis unit, group home, or encampment, or as became increasingly important this past year - hotels serving as emergency shelters. By being available in these spaces, we are able to connect with people who might not otherwise call our office.

A typical day for one of our community-based advocates might include connecting an individual, like “Daniel” to services. Daniel had tried unsuccessfully for months to be connected with mental health services to ensure successful completion of the terms of his probation. Within a week of DRM’s involvement in the matter, Daniel was connected to the services he needed and satisfied his probation requirements.

Other days, our advocates focus their work on concerns about rights violations. “Molly” connected with one of our advocates during outreach at her group home. Molly shared concerns about restrictions on her access to the telephone and mail. With the assistance of the advocate, Molly’s restrictions were removed from her treatment plan and her access to independent communication was restored.

Hospital-Based Advocates

Our hospital-based advocates are embedded inside Maine’s psychiatric institutions. Just like for our advocates in the community, no day is the same. One morning might begin with an individual client meeting, followed by a rights training. Another day might start with an advocate observing a commitment hearing, then being present on the units, where the advocate might be approached by an individual with concerns over their rights or treatment. At weekly discharge planning meetings, advocates ensure that all efforts are being made for timely discharges to the least restrictive and appropriate settings.

The advocates also address policies and practices that violate client rights or other laws. Often, we use regular meetings with the hospital superintendent to try and resolve issues informally. Through these methods, our staff resolved concerns regarding HIPAA, treatment planning, and the grievance process.

# Communication Access

It started with a simple question. A Deaf senior citizen called DRM and wanted to know who could help him fill out an Advance Directive form. The forms weren’t hard to find, but they were in English. He couldn’t understand them. His first language is American Sign Language (ASL).

Then, another call came in with the same question. Then more. In the midst of the COVID-19 pandemic, people were feeling anxious to be prepared. Deaf older adults wanted to make sure their end-of-life wishes were respected. But, hardly any had an Advance Directive in place. And it seemed impossible to do.

Typically, Advance Directives are seen as fairly simple and straightforward documents. But the ‘simple’ questions on the forms lack context and explanation. And the topic could not be more important. Deaf Mainers needed assistance. They needed to know what the forms meant, yes. But they also had questions about what end of life care options looked like. And there was no information in ASL on the topic anywhere.

DRM reached out to St. Joseph’s Hospital in Bangor, and hatched a plan to hold a workshop on Advance Directives hosted by the Maine Deaf Senior Citizens group. Sr. Barbara Theresa, a Utilization Review Manager, happily volunteered as trainer. As a long-time nurse with a background in hospital case management, hospice and palliative care, Sr. Barbara Theresa had assisted many people in completing Advance Directives.

And so, on a sunny day in June, about 40 Deaf seniors gathered in the cafeteria at the Maine Educational Center for the Deaf & Hard of Hearing and watched intently as Sr. Barbara Theresa, with the assistance of an ASL interpreter, explained the purpose of an Advance Directive, and the situations where it might be used. You have rights in end of life care, she emphasized. You can choose what it looks like, and what happens to you. She emphasized the need to evaluate personal beliefs and feelings. And she noted the importance of having conversations now with family, so that they are aware. Audience members peppered her with questions, and she worked through each answer. For the audience, a to-do list began to take shape. Think. Discuss. Choose. Complete. File.

After the training ended, Deaf seniors lingered and chatted. The topic might not be easy, but there was comfort in sharing it together, as a community. Organizing an event like this is a key part of the communication access work of the DRM Deaf Services Team.

# Health Equity

Good health is of utmost importance to all people - including people with disabilities. It’s key to maximizing our ability to live, learn, work, and earn. People with disabilities experience significant health disparities as compared to people without disabilities. Although disability is common, health disparities among this population remain largely unaddressed.

People with disabilities are more likely to be denied health care than people without disabilities, and face unique barriers and stigma when accessing health care. Many public health and research efforts remain focused on prevention and treatment of disability, rather than maximizing the health of people with disabilities.

DRM and P&As nationally have increasingly recognized the urgent need for advocacy on health care access and equity for people with disabilities. Historically, DRM has handled a high proportion of cases and calls involving access to health care. These cases have illuminated the stark inequalities faced by Mainers with disabilities as they navigate our health care system, often leaving resources for attaining health and wellness out of reach. The onset of the COVID-19 pandemic in 2020 brought those inequalities into sharper focus, as individuals struggled to obtain equitable access to testing, treatment, and vaccines.

In 2022, DRM’s Access Team formed a Health Equity work group to identify systemic approaches to removing barriers and improving access to health care for people with disabilities across Maine. But, one issue became immediately and glaringly apparent: there was a lack of available health data on Mainers with disabilities, or the issues they faced when seeking care.

DRM’s Health Equity group sought and received funding from the Maine Health Access Foundation to conduct a project to gather data and produce a report on barriers to health care for people with disabilities. DRM contracted with John Snow Inc., a public health consulting group, to lead this Health Equity & Disability research project. DRM and JSI analyzed existing data, surveyed individuals with disabilities about access to health care, and conducted 11 focus groups across the state. DRM formed a Steering Committee and Advisory Committee, representing a cross-disability group of people with disabilities and partner organizations, to provide input on the project. In addition, DRM hired a Health Equity Project Coordinator, to coordinate and lead DRM’s work on this and other Health Equity projects over the next year.

These research and data collection efforts will culminate in a report, presenting information, analysis, and recommendations to improve access to the health care system and health equity for people with disabilities. The resulting report will assist DRM in advocating for meaningful change to increase access, choice, and quality health care for people with disabilities across Maine.

# Global Perspectives on Disability

Last fall, DRM hosted a fellow from El Salvador through the Community Solutions Program (CSP), which is sponsored by the U.S. Department of State. The fellow, Irene Rivera, came to DRM with a passion to learn more about employment opportunities, services, and supports for people with disabilities in the U.S., so she could work towards improving the employment outcomes for people with disabilities in her home country. Irene’s own interest in this work came from her experience as a teacher and a strong desire to see expanded opportunities for young people with disabilities.

Through the course of her fellowship, Irene assisted DRM staff in conducting a series of 39 interviews with diverse stakeholders to assess the current status of Maine’s Employment First Act, which was enacted in 2013. Following these interviews, Irene worked with DRM to present on the trends identified through our interviews. While key successes were noted – including the elimination of subminimum wage – our interviews demonstrated that 10 years later, people with disabilities are still not offered employment as a first and preferred service and we have not implemented Employment First in our state.

DRM continues to work with stakeholders to advance Employment First and to advocate for systems change to create sustained follow-through to improve employment outcomes for people with disabilities.

While Irene’s fellowship ended after the presentation, DRM’s relationship with Irene did not. In October 2022, DRM’s Communication Director, Julia Endicott, traveled to Washington, D.C. to finally meet Irene in person at the CSP Global Impact Summit. This summit brought together dozens of fellows from across the world with their U.S. host organizations, many of whom had only previously met in virtual spaces.

Although disability justice was not a specific theme of this program, it became a central topic throughout the course of many conversations during the summit. The diversity of backgrounds shaped robust dialogue and allowed for extensive cross-cultural exchange about what disability means across the world, what laws and policies exist to increase access and equity, and what commonalities exist regardless of what community you are from.

# Access Advocacy

DRM advocates for inclusion in town ski program

“Joseph” was looking forward to participating in a local ski program, offered by his town’s parks and recreation department. But, just weeks prior to the first scheduled trip, the parks and recreation department told Joseph’s family he could only participate in the ski program if a nurse aide rode on the bus, too. Joseph did not require the presence of a nurse aide.

In late November 2021, a DRM attorney drafted a letter requesting that the town permit Joseph to access all municipal programming without any additional requirements that do not apply for participants without disabilities. Still reluctant, the town responded through its attorney. DRM then arranged a meeting between all parties to mediate the situation. Joseph’s family was able to use the joint meeting to educate the town and reject the town’s imposition of barriers on his ability to participate in recreational programming. The town ultimately agreed to Joseph’s requests and permitted him to ride the bus with his peers—which he did without incident—all winter long. With the support of DRM, Joseph wielded his power and asserted his right to be treated equally to other youth in his community who do not have disabilities. Joseph reported that he had a great time on the slopes!

**our clients**

DRM provided direct representation to **1072** clients in **1280** cases. DRM’s equipment distribution programs served an additional **213** clients, while information and referral services were provided to **1671** individuals.

Client Age

4 and under 16

5 to 12 86

13 to 18 93

19 to 25 153

26 to 64 642

65 and over 82

Clients by County

Androscoggin 146

Aroostook 60

Cumberland 225

Franklin 18

Hancock 30

Kennebec 122

Knox 21

Lincoln 20

Oxford 40

Penobscot 166

Piscataquis 13

Sagadahoc 16

Somerset 42

Waldo 25

Washington 21

York 98

Out-of-State 9

Client Disability

Blindness/Visual Impairment 15

Brain Injury 38

Deafness/Hard of Hearing 73

Developmental Disability 679

Mental Illness 220

Physical Disability, Health   
Impairment, Chronic Illness 47

Case Problem Area

Abuse/Neglect & Other Rights   
 Violations 481

Community Integration 238

Due Process 18

Education 129

Employment 53

Government Services & Public   
 Accommodations 152

Guardianship 93

Housing 57

Vocational Rehabilitation 53

Voting 6

**financial summary**

Year Ending September 30, 2022

REVENUE AND SUPPORT

Federal Grants $1,757,043

State Grants $1,893,550

Contributions $82,866

Other Revenue $208,139

TOTAL REVENUE $3,941,598

EXPENSES

PADD $496,105

PAIMI $455,598

PAIR $120,406

PAAT $61,968

PABSS $76,120

PABRP $99,488

PATBI $23,238

PAVA $86,416

Client Assistance Program $163,017

EA $132,434

Psychiatric Ctr Adv $414,742

Maine Civil Legal Svs $86,604

Acadia $40,667

Developmental Svc Adv $603,431

Deaf Advocacy +   
  Comm Access Prog $610,342

Supporting Services $418,034

TOTAL EXPENSES $3,888,610

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Keenan Weischedel, Advocate

Lauren Wille, Esq., Managing Attorney



# mission

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

vision

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.

values

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.

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

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https://[www.facebook.com/DisabilityRightsMaine/#](http://www.facebook.com/DisabilityRightsMaine/)

https://[www.facebook.com/DRMDeafServices/](http://www.facebook.com/DRMDeafServices/)

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1. https://www.justice.gov/opa/pr/justice-department-finds-maine-violation-ada-over-institutionalization-children-disabilities [↑](#footnote-ref-1)