

DRM NEWS

In Focus: Deaf Advocacy & Communication Access

MERYL TROOP, DEAF SERVICES DIRECTOR



Deaf advocacy services are alive and well in Maine. After the closure of the Maine Center on Deafness, DRM stepped up to ensure that crucial advocacy and communication access programs would continue to serve Maine citizens who are Deaf, hard of hearing, late Deafened, and dual sensory impaired.

The staff of MCD, while sad to see the Deaf community's own agency dissolve, are delighted to become part of the DRM family.

AN OVERVIEW OF THE DEAF ADVOCACY & COMMUNICATION ACCESS PROGRAM

- **Deaf Advocacy:** DRM provides individual and systemic legally-based civil rights advocacy.
- **Telecommunication Equipment Program (TEP):** DRM operates a program providing specialty telephone equipment to those with a barrier to using a traditional landline phone, or one hearing aid to those over 65 and low income.
- **National Deaf-Blind Equipment Distribution Program:** This project provides computers, screen readers and other technology for those with dual sensory impairments who have difficulty accessing the internet.
- **Hamilton Relay Program:** This program provides telephone relay services to callers who use specialized phones such as Captioned Telephones (CapTel).
- **Peer Support Group (PSG) and Visual Gestural Communication (VGC):** This project provides a psycho-social educational activity monthly in Bangor and Portland, for individuals with intellectual disabilities who use signs and/or gestures as part of their communication repertoire, as well as Visual Gestural Communication workshops throughout the state to help staff, families, and peers enhance communication with people who use this communication style.

DEAF ADVOCACY SUCCESSES AND UPDATES

- DRM provided support and tutoring in American Sign Language and other skills to two Deaf individuals who had immigrated here and needed assistance understanding safety signage, transportation systems, and some employment skills development.

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Supported Decision-Making Comes to Maine: DRM and Maine Coalition Win Grant to Promote Alternatives to Guardianship

The National Resource Center for Supported Decision-Making has awarded a grant to Maine's Supported Decision-Making Coalition. Supported Decision-Making (SDM) is a creative alternative to guardianship and offers a formal method of decision-making in which a person can designate trusted individuals to help him or her process information and work through decisions. SDM can offer people with disabilities an important alternative to guardianship, which otherwise can completely usurp a person's autonomy and civil rights.

The grant will fund a year-long outreach project to educate and provide resources to the community on SDM and the empowerment it offers people with disabilities. DRM, alongside 9 other community leaders, will be developing materials and training individuals, families, service providers, and court officials on SDM. The Coalition's website, supportmydecision.org, will offer recorded webinars, laws and policies on alternatives to guardianship, and stories from individuals sharing their own experiences with guardianship and Supported Decision-Making.

For more information about SDM and this project, contact Lydia Paquette at 800.452.1948, Ext. 210 or via email, lpaquette@drme.org.

(Deaf Advocacy, Continued from Page 1)

- DRM provided support to a young man who was Deaf, allowing him to perform his job better. He served as a panelist at the Department of Labor's Empowerment Summit and shared his success story.
- Camp Sign-A-Watha, the world's only camp for Deaf adults with intellectual disabilities, held a one day BBQ at Range Pond State Park with 55 attendees. American Sign Language and Visual Gestural Communication is used to keep everyone engaged, active and learning. Highlights included T-shirt tie dying and Fire Safety Gesture Bingo.

For more information about the Deaf Advocacy and Communication Access Programs at DRM, visit <http://drme.org/deaf-services>, or

Contact our Portland Office at:

- Tel: 207.797.7656 (Voice/TTY) / 207.766.7111 (VideoPhone)
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In-Depth: EPSDT

PETER RICE, LEGAL DIRECTOR

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit provides health coverage to children who are under age twenty-one and who receive Medicaid. EPSDT is designed to improve the health of low-income children by funding appropriate and necessary children's healthcare services. Every state is required to provide services under EPSDT and, since one in three U.S. children under age six are eligible for Medicaid, EPSDT is key to ensuring that they receive appropriate preventive health care services.

The goal of EPSDT is to ensure that children receive appropriate health care when and where they need it. Through this benefit, children's health problems should be addressed before they become advanced, and before treatment becomes more expensive. The characteristics of EPSDT can best be summarized by referring to the name of the program:

Early: Identify problems early, beginning in infancy;

Periodic: Check children's health at periodic intervals;

Screening: Do physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems;

Diagnosis: Perform diagnostic tests to follow up when a risk is identified, and;

Treatment: Treat the problems found.

What Does EPSDT Cover?

Each state has a Medicaid State Plan, which is an agreement between the state and the federal government that describes how the state will administer its Medicaid Program. Federal law requires that state Medicaid programs cover a comprehensive set of benefits and services for children, regardless of whether these services are provided under the State Plan and regardless of any restrictions that states may impose on coverage for adult services, as long as those services could be covered under the State Plan. Services must be medically necessary in order to "correct or ameliorate" a physical or mental illness or condition.

Services available under EPSDT include physician and hospital services, private duty nursing, personal care services, home health care, medical equipment and supplies, rehabilitative services, and vision, hearing, and dental services.



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Donations are tax deductible and gratefully accepted.

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The Sweet Smell of Freedom

STACI CONVERSE, MANAGING ATTORNEY



As a result of DRM's settlement of a class action lawsuit and the creation of the "Other Related Conditions" waiver, Jacob Van Meter and Eric Reeves were able to move out of their respective nursing homes and into their own apartments. Leaving behind what they called "prisons without bars", Jake and Eric, both young men with cerebral palsy, have embraced their independence and are thriving in their communities. In 2014 they received DRM's Helen M. Bailey Advocacy Award, and this year both were recognized by the Daughters of the American Revolution with the Excellence in Community Service Award.



Jake requires personal care assistance to live independently. After spending half his life in a nursing home, he was finally able to move into his own apartment at age 30. Since leaving the facility, Jake gets out into the community often, going to movies and concerts. He said the transition was not without challenges; he initially had a difficult time learning how to budget and how to deal with his fellow neighbors.

In May, Jake earned his Associate's Degree in Mental Health and Human Services from the University of Maine at Augusta. He considers this achievement, and leaving the nursing home, to (so far) be his greatest life accomplishments. In the next few years Jake hopes to complete his Bachelor's Degree and find a part-time job.

Like Jake, Eric spent many years living in a nursing facility and can recall, to the hour, when he left: 10am on November 18, 2013.

For him, one of the biggest challenges he faced was learning to make his own decisions after having been without freedom of choice for so long. Eric said that now he chooses what he eats and what his day will look like – those basic things that so many people take for granted.

He also enjoys more personal space than he'd known before. One of the results of moving from a shared room in a nursing home to his own apartment is that Eric has room to paint.



Despite being underestimated his whole life – including being told he wouldn't be able to pursue his education – Eric continues to make the most of his newfound freedoms. He earned a diploma from Bangor High School in 2014, and this year he is enrolled at the University of Maine and is working towards a degree in new media.

One University professor admitted to Eric that when she first interviewed him, she wondered what he would be able to do there.

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Meet the New Children's Advocates!

Disability Rights Maine is pleased to announce the expansion of our children's advocacy services through the addition of two statewide Children's Advocates. The Department of Health and Human Services, on behalf of the Office of Child and Family Services, has contracted with DRM for these positions. Veteran DRM advocate Katrina Ringrose, and recently-hired Julian Richter are excited to begin this work.

Katrina has worked as a non-attorney advocate with DRM for nine years. For much of this time she provided effective statewide advocacy to youth who were not receiving an appropriate education or in-patient or community treatment. In 2012, Katrina transitioned to DRM's newly-formed Developmental Service Advocacy (DSA) Program, which provides advocacy services to adults with Autism and Intellectual Disabilities. While Katrina will continue to oversee this program, she is also excited to return to advocacy efforts that focus on children.

A native of Canaan, Julian began his career in social work with youth in a variety of settings, including the former Goodwill-Hinckley School, Youth Alternatives (now The Opportunity Alliance), Sweetser Crisis and the Preble Street Teen Center. Julian received his J.D. from the University of Maine School of Law in May 2015 and in October, he was sworn in as a member of the Maine Bar.

In addition to individual representation, Katrina and Julian will be conducting outreach and monitoring of children's services in the community, hospitals, residential treatment facilities, and out-of-state placements.

(Freedom, Continued from Page 4)

Eric is restless: he's now working to raise funds to get a service dog to assist him and increase his independence. A dog could pick up things he drops and turn lights on and off.

In the end, Jake and Eric are leading voices advocating for independence and community inclusion for all people with disabilities. They want everyone to expand their horizons and, particularly for those in institutional settings, to explore their options for independent living. According to them, it means nothing less than "remaking your life."



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Join DRM's DD Advisory Council (DDAC) Today!

The DDAC is a group of volunteers with developmental disabilities that works with Disability Rights Maine to create systems change. DRM supports the Advisory Council's grass roots efforts to improve the State of Maine for individuals with developmental disabilities. The Advisory Council's work focuses on training others about their rights and advocacy opportunities, letting policymakers know their views, and guiding the advocacy work of DRM by providing input into DRM's program priorities.

The Advisory Council is always looking for volunteers! If you or someone you know would like to join, please contact Chris Chavis at 800.452.1948, Ext. 205 or via email, cchavis@drme.org.

(EPSDT, *Continued from Page 3*)

Services can also include case management (including targeted case management), incontinence supplies, organ transplants and any related services: a specially adapted car seat that is needed by a child because of a medical problem or condition and nutritional supplements. Other medical or remedial services may also be covered.

What are EPSDT's Screening Requirements?

EPSDT covers regular screening services (check-ups) for infants, children and adolescents. These screenings are designed to identify health and developmental issues as early as possible. Covered screening services include medical, mental health, vision, hearing and dental services.

States must provide or arrange for screening services both at established times and on an as-needed basis. When a screening examination indicates the need for further evaluation of a child's health, the child should be appropriately referred for diagnosis without delay.

States are Responsible for Ensuring Access to EPSDT

States have the responsibility to ensure that all eligible children (and their families) are informed of both the availability of screening services, and that a formal request for an EPSDT screening service is not required. States have an affirmative duty to conduct outreach efforts to inform parents and caregivers about EPSDT services and the importance of preventive care and early detection of health and mental health conditions in children. States also have an obligation to provide transportation and scheduling assistance when requested. Transportation can include covering the costs of an ambulance, taxi, bus, or other carrier. It can also include reimbursement for mileage.

Information about EPSDT benefits and services must be provided in a format that can be easily understood, using clear and nontechnical language to ensure that individuals, who may not read or speak English, understand what services are available. This can mean translating written materials or providing oral interpretation if the child's family has difficulty reading or understanding English.

Where Can I Get More Information?

Maine has nearly 150,000 children who are eligible for EPSDT. If you would like more information, you may contact Disability Rights Maine or Beth Pearce, EPSDT Coordinator for the Maine Department of Health and Human Services, at 207.624.4006.

Jacque's Story

LYDIA PAQUETTE, STAFF ATTORNEY



Fifteen days after Jacqueline Darling's 18th birthday, her mother petitioned for, and was granted, temporary guardianship over her. Jacque was not told about the petition or the hearing until after guardianship was granted. There was a second hearing scheduled, but again she did not receive notice or know about the hearing until after full guardianship was granted. For the next six years, Jacque was not legally able to make another decision concerning her life.

When Jacque contacted DRM for assistance, she was living in an independent apartment with a roommate and receiving limited services to assist her with skill-building. Her mother was not actively engaged in her life anymore. Because of the guardianship order, however, Jacque was still unable to sign anything on her own behalf.

Maine law states that a request to terminate guardianship may be made by informal letter to the court. When Jacque contacted DRM for assistance terminating her guardianship, an attorney helped her to write a letter to the court explaining that she did not need the guardianship any longer. After not hearing anything from the court for two months, Jacque contacted DRM again.

With the help of the DRM attorney , Jacque discovered that the court had not looked at her letter and did not intend to start proceedings to terminate guardianship without a formal petition. Meanwhile, Jacque's lease was coming to a close. She had the resources and the support to find a new apartment, but her mother refused to sign a new lease. Since she was still under guardianship, Jacque had no choice except to move home. The house was not large enough to accommodate her, so she and her therapy dog slept in the living room. Additionally, Jacque's mother reduced her support services in order to limit the number of people in the house at any one time.

DRM agreed to represent Jacque and filed repeated motions to the court. Finally, nearly a year after Jacque first sent a letter to the court, a hearing date was scheduled. An entry of default had already been filed against her mother for her open refusal to attend the hearing. Jacque went to court expecting to have her life back and was surprised when the judge denied her request. Even though no one was present to argue against the termination, the judge said he could not go forward without a form completed by a physician or psychologist.

Jacque was not seeing a psychologist, so she sent an affidavit to the judge from her psycho-therapist who stated that she saw no clinical justification for continued guardianship. Still, the judge denied her request. Only after her primary care provider's office completed the form did the judge agree to terminate her guardianship.

Three days before her 24th birthday, and for the first time in six years, Jacqueline Darling was legally declared a free person again. She plans on finding her own apartment, securing a good job, and enjoying a life shaped and decided by no one but herself.

**Disability Rights Maine seeks public comment on our Program Priorities throughout the year.
To submit a comment, please send an e-mail to advocate@drme.org.**

Disability Rights Maine is on a Mission to Educate People About Their Rights

ADAM WILSON, STAFF ATTORNEY



Every day, DRM works to enforce the rights of Maine citizens with disabilities. Whether in probate court, representing a person with an intellectual disability seeking to challenge their guardianship, or at the Maine Human Rights Commission, advocating for someone facing disability discrimination in the workplace, DRM is working in partnership with our clients to assert their rights. DRM is walking the halls of psychiatric hospitals in Maine, fighting to make sure that people receiving care are free from abuse and neglect and that their rights are respected, and representing children with disabilities and their families to obtain appropriate and inclusive educational opportunities for them.

But a crucial part of DRM's mission – apart from providing advocacy representation – is educating people with disabilities (and their allies and supporters) about their fundamental rights and how to enforce them. DRM is convinced that society can change and respect for rights can become a part of our culture, but that it will only happen if empowered people insist that it happen. Educating people of all varying life experiences of disability is core to that mission of empowerment.

This year, DRM's Developmental Services Advocacy team conducted outreach and training activities to people with disabilities, their family members, guardians and service providers. Topics covered included information about DRM's advocacy services, an overview of rights, and the grievance process. Nearly 400 individuals were trained, and 68 provider organizations were reached.

Recent DRM Training Topics Include:

Alternatives to Guardianship • Employment Rights • Housing Rights & Reasonable Accommodations
Special Education • Social Security Work Incentives • Voting Rights

DRM welcomes the opportunity to train people with disabilities and their supporters, their allies on rights and how to promote them. Our staff has broad expertise in legal rights across all disability categories and wants to share that information. Through the sharing of this important knowledge, we empower more people to become self-advocates, and change the world in the process. For more information on rights and training opportunities, please call our office at 800.452.1948.

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