Maine

Department of Health and Human Services
SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

FY 2023
PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS
Short Title: 2023 PAIMI Progress Report

Funding Opportuntity Announcement (FOA)
No. SM-17-F2

Catalog of Federal Domestic Assistance (CFDA)
No.: 93-138

A. PAIMI Program Information

General Information

1. P &A Identification

Name of state or jurisdiction	Maine
Name of P&A systems	Disability Rights Maine
Unique Entity ID	GJEPWTMKF5A3

2. Main Office

Agency Name of Main Office	Disability Rights Maine
Mailing Address of Main Office	160 Captiol St. Suite #4
City	Augusta
Zip Code	04330
Phone Number of Main Office	2076262774
Toll Free Number	8004521948
Email address	advocate@drme.org
Website address	www.drme.org
TTY phone number	2076262774
County of Main Office	Kennebec

3. Other Offices (if any)

Agency Name of Other Office	
Mailing Address (Each Statellite Office)	
City	
Zip Code	
County of Each Satellite Office (Location)	

4. Executive Director/Chief Executive Officer Contact Information

Name	Kimberly Moody
Mailing Address	Disability Rights Maine, 160 Captiol St. Suite #4
City	Augusta
Zip Code	04330
Phone Number & Extension	2076262774
E-mail Address	kim@drme.org

5. PPR Preparer Contact Information

Name	Mark Joyce
Title	Managing Attorney
Phone Number & Extension	2076262774
Email Address	mjoyce@drme.org

6. Governing Board President/Chair Name

Name	Andrew R. Sarapas, Esq.
Mailing Address	18 Pleasant Street Suite 214
City	Brunswick
Zip Code	04011
County of Residence	ME
Email Address	andy@sarpas.law
Current Term Started	9/30/2023 12:00:00 AM
Current Term Expires	9/30/2024 12:00:00 AM

7. PAIMI Advisory Council President/Chair Name

Name	April Kerr
Mailing Address	P.O. Box 244
City	Farmington
Zip Code	04938
County of Residence	ME
Email Address	aprillkerr2020@gmail.com
Current Term Started	4/15/2022 12:00:00 AM
Current Term Expires	4/15/2024 12:00:00 AM

8. Name Of P&A Chief Financial Officer/Accountant

Name	Shannon Crocker
Title	Chief Financial Officer
Phone Number/Extension	207-626-2774
Email Address	scrocker@drme.org

9. Governor's Liaison

Name	Sarah Squirrell
Official Title	Director Office of Behavioral Health
Mailing Address	State House Station, #11
City	Augusta
Zip Code	04333
County of Residence	Kennebec
Phone Number/Extension	
Email Address	Sarah.Squirrell@maine.gov

10. Commissioner/Director of the State Mental Health Agency

Name	Sarah Squirrell
Mailing Address	SAMHS State House Station #11
City	Augusta
Zip Code	04333
Phone Number/Extension	207-592-6406
Email Address	Sarah.Squirrell@maine.gov

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Footnotes:

A. PAIMI Program Information

Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff

		Governing Board	Advisory Council	Program Staff
Ethnicity				
	Hispanic/Latino	0	0	0
	Non-Hispanic/Latino	10	12	9
	Ethnicity Unknown	0	0	0
Race				
	American Indian/Alaskan Native	0	0	0
	Asian	0	0	0
	Black/African American	0	0	0
	Native Hawaiian/Pacific Islander	0	0	0
	White	10	12	9
	Two or more races	0	0	0
	Some other race	0	0	0
	Race Unknown	0	0	0
Gender				
	Female	5	11	3
	Male	5	1	6
	Transgender (Trans Woman)	0	0	0
	Transgender (Trans Man)	0	0	0
	Two-Spirit (if Client is AIAN)	0	0	0
	Gender Non-Conforming	0	0	0
	Other (if use a different term)	0	0	0
	Prefer not to say	0	0	0
Sexual Orientation				

	Lesbian or gay	0	0	0
	Straight (not lesbian or gay)	0	0	0
	Bisexual	0	0	0
	Other (if use a different term)	0	0	0
	Prefer not to say	0	0	0

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Footnotes:

A. PAIMI Program Information

Governing Board Information

Governing Board (GB) Type and Number of Members Included in Governing Board Information

Governing Board	Minimum # of Members	Maximum # of Members
Private, non-profit with multi-member	10	15
State-operated with governing board	0	0
State-operated with no governing board	0	0

Governing Board Information

In the following table, please provide the requested information for the GB members

	Number
Total seats available	15
Total members serving as of 9/30/2023	10
Total vacancies on 9/30/2023	5
Term of appointment (number of years)	4
Term maximum	2
Meeting Frequency	5
Number of meetings held this fiscal year (2023)	5
Percentage of members present at meetings during the 2023	88 %

Governing Board Composition

The governing board shall be composed of members who broadly represent or are knowledgable about the needs of clients served by the P&A System (count each GB member only once)

	Number
Number of individuals with mental illness who are recipients/former recipients (R/FR) of mental health services or have been eligible for services.	3
Number of family members of individuals with mental illness who are (R/FR) of mental health services, guardians, advocates or authorized representatives or other persons who broadly represent or are knowledgeable about the needs of clients served by the P&A system	7
Total	**10**

Footnotes:

A. PAIMI Program Information

Executive Director

Intial Appointment Date	12/10/1996 (mm/dd/yyyy)
Recent performance evaluation completed	08/24/2023 (mm/dd/yyyy)
Date of previous performance evaluation	12/15/2022 (mm/dd/yyyy)

Agency has written policy and procedures to guide the ED's evaluation process? Yes ○ No ◉

Input on ED's performance evaluation obtained from the following (check all that apply)	
All agency employees/staff	Yes ○ No ◉
Senior managers	Yes ○ No ◉
All board directors	Yes ◉ No ○
All PAIMI Advisory Council members	Yes ○ No ◉
Stakeholders	Yes ○ No ◉
Consumers	Yes ○ No ◉
Family members of consumers	Yes ○ No ◉
State mental health providers	Yes ○ No ◉
Private mental health providers	Yes ○ No ◉
Other	Yes ○ No ◉

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Footnotes:

A. PAIMI Program Information

Number of Mental Health Professionals On the Advisory Council

Professional Category	Number On Advisory Council
Social Worker	0
Psychologist	1
Psychiatric Nurse	0
Psychiatrist	0
Psychiatric Nurse Practitioner	0
Peer Support Specialist	1
Other (Identify the Professional in the Footnotes)	1
Total	**3**

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Footnotes:

A Peer Support Specialist employed by a mental health provider.

A. PAIMI Program Information

PAIMI Advisory Council (PAC)/Assigned Staff

PAIMI Advisory Council (PAC)	
Sits on the governing board?*	(•) Yes ( ) No
Appointment Date	01/27/2022
Other PAC member(s) sit on the governing board?	( ) Yes (•) No
If yes, number serving	0

** If no please explain in Footnotes*

Assigned PAIMI Staff

	Attorneys					Advocates				
	#	Full-time	Part-time	Male	Female	#	Full-time	Part-time	Male	Female
Ethnicity										
Hispanic/Latino (of any race)	0	0	0	0	0	0	0	0	0	0
Non-Hispanic/Latino	6	1	5	6	0	3	0	3	2	1
Race										
American Indian/Alaska Native	0	0	0	0	0	0	0	0	0	0
Asian	0	0	0	0	0	0	0	0	0	0
Black/African American	0	0	0	0	0	0	0	0	0	0
Native Hawaiian/Pacific Islander	0	0	0	0	0	0	0	0	0	0
White	6	1	5	6	0	3	0	3	2	1
Two or more races	0	0	0	0	0	0	0	0	0	0
Some other race	0	0	0	0	0	0	0	0	0	0
Race Unknown	0	0	0	0	0	0	0	0	0	0

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Footnotes:

B. Demographics - Interventions on Behalf of PAIMI Individuals

Population Information

Age of PAIMI-eligible Individuals Served

Age	Number
0-2	0
3-5	3
6-10	18
11-22	49
23-64	169
65+	17
Prefer not to say	0
Total	**256**

Gender and Sexual Orientation of PAIMI-eligible Individuals Served

Gender	Number
Female	126
Male	127
Transgender (Trans Woman)	0
Transgender (Trans Man)	0
Two-Spirit (if Client is AIAN)	0
Gender Non-Conforming	3
Other (if use a different term)	0
Prefer not to say	0
Total	**256**

Sexual Orientation	Number
Lesbian or Gay	0

Straight (not lesbian or gay)	0
Bisexual	0
Other (if use a different term)	0
Prefer not to say	256
Total	**256**

Ethnicity and Race of Individuals Served

Ethnicity	Number	PAIMI %	State %
Hispanic/Latino (of any race)	7	2.73	2.00
Non-Hispanic/Latino	204	79.69	98.00
Ethnicity Unknown	45	17.58	0.00
Total	**256**		

Race	Number	PAIMI %	State %
American Indian/Alaska Native	3	1.17	0.70
Asian	1	0.39	1.40
Black/African American	15	5.86	1.80
Native Hawaiian/Other Pacific Islander	0	0.00	0.00
White	200	78.13	94.20
Two or more races	9	3.52	1.90
Some other race	0	0.00	0.00
Race unknown	28	10.93	0.00
Total	**256**		

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Footnotes:

B. Demographics - Interventions on Behalf of PAIMI Individuals

PAIMI-Eligible Individuals served with PAIMI Program Funds

Count individual once per fiscal year (FY). Multiple counts not permitted for lines 1-2.

		Enter Number
1. Number of PAIMI-eligible individuals continued to be served with PAIMI program funds, including any program income resulting from legal actions supported by PAIMI program funds as of October 1, from the previous FY into the reporting year.		55
2. Number of new PAIMI-eligible individuals served during the reporting year.		201
3. Total number of PAIMI-eligible individuals served during this FY (Add lines 1 and 2).		256
4. Individuals with more than one (1) intervention opened/closed during the reporting year.		31
5. Individuals with a co-occurring mental illness and Intellectual and Developmental Disability (IDD).		9
6. Total number of PAIMI-eligible individuals who requested program related advocacy services during the reporting year, but were not served within 30-days of initial contact due to:		
	a. insufficient PAIMI Program resources.	0
	b. non-priority areas.	0
7. Individuals served as of September 30 and will be carried over to next reporting year (This should equal ≤ item 3 above).		63

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Footnotes:

B. Demographics - Interventions on Behalf of PAIMI Individuals

Living Arrangements of PAIMI-eligible Individuals at Intake

Living Arrangements	Number
Community Residential Home for Children/Youth up to age 18 Yrs.	6
Community Residential Home for Adults	35
Non-Medical Community-Based Residential Facility for Children/Youth	0
Foster Care	0
Nursing homes, including skilled nursing facilities	3
Intermediate care facilities	0
Public and Private general hospitals including Emergency Rooms	13
Public Institutional living arrangement	0
Private Institutional living arrangement	0
Psychiatric Hospitals (Public or Private)	
a. Public/State	47
b. Private	27
Jails	3
State Prison	2
Federal Detention Center	0
Federal Prison	0
Veterans' administration hospital/Clinic	0
Other Federal Facility	0
Homeless	21
Independent (in the community & PAIMI-eligible)	51
Parental or Other Family Home & PAIMI-eligible	48
Unknown	0
Total	256

Footnotes:

C. Complaints/Problems of PAIMI Individuals

Areas of Alleged Abuse

Number of complaints/problems – Make every effort to report within the following categories:

Areas of Alleged Abuse	Outcomes											Number from Closed Cases Only
	A	B	C	D	E	F	G	H	I	J	K	Total
a. Inappropriate or excessive medication	0	0	0	0	0	0	0	0	0	0	0	0
b. Inappropriate or excessive restraint and seclusion	1	0	3	2	0	0	0	0	0	0	0	6
c. Involuntary medication	1	0	4	0	0	0	0	0	0	0	0	5
d. Involuntary Electric Convulsive Therapy (ECT)	0	0	0	0	0	0	0	0	0	0	0	0
e. Involuntary aversive behavioral therapy	0	0	0	0	0	0	0	0	0	0	0	0
f. Involuntary sterilization	0	0	1	0	0	0	0	0	0	0	0	1
g. Physical assault	0	0	0	0	0	0	0	0	0	0	0	0
h. Sexual assault	0	0	1	0	0	0	0	0	0	0	0	1
i. Threats of retaliation or verbal abuse by facility staff	0	0	0	0	0	0	0	0	0	0	0	0
j. Coercion	0	0	0	0	0	0	0	0	0	0	0	0
k. Financial exploitation	0	0	1	0	0	0	0	0	0	0	0	1
l. Suspicious death	0	0	0	0	0	0	0	0	0	0	0	0
m. Other *Specify types of complaints. Please describe below. [This number should be less than 1% of the total number of total complaints.]*	0	0	0	0	0	0	0	0	0	0	0	0

Abuse Complaints Disposition	
For total closed cases listed in Table C.1., provide the number of abuse complaints/problems for each disposition category.	
A. Number of complaints/problems determined after investigation not to have merit	2

B. Number of complaints/problems withdrawn or terminated by client	0
C. Number of complaints/problems resolved in the client's favor	10
D. Number of complaints/problems not resolved in the client's favor	2
E. Other Indicators of success or outcomes that resulted from P&A involvement	0
F. Other Representation found	0
G. Services not needed due to client death or relocation	0
H. P&A withdrew due to conflict of interest or other reasons	0
I. Lost Contact	0
J. Outcome Unknown	0
K. Lack of Resources	0
Total number of Abuse complaints/problem addressed from closed cases	**14**

At least 1 case required.

Case of Alleged Abuse

A 13-year-old boy, who was an inpatient at a psychiatric hospital, reported bruising following a restraint. DRM's investigation revealed that the Centers for Medicare and Medicaid Services (CMS) had previously examined the case, contacted the boy's mother, and informed her that they found no evidence of abuse or neglect. While DRM's determination aligned with CMS on this aspect, the investigation also uncovered a critical gap in the documentation of medical assessments related to the restraint process. Recognizing the significance of this finding, DRM effectively communicated with the hospital, prompting them to implement corrective measures.

Case of Alleged Abuse

A 38-year-old man, previously identified by a qualified Maine mental health professional as having a significant mental illness or emotional impairment, reached out to DRM from the Maine State Prison. He found himself in solitary confinement and believed that certain aspects of his confinement were worsened by his disability, necessitating accommodation from the prison. In response, DRM promptly provided assistance by obtaining records from the prison and his treating providers. Despite the absence of supporting evidence for a reasonable accommodation request, the client was unaware that the prison had designated staff to handle such requests from prisoners. DRM supplied crucial information about this specific contact within the state department of corrections to the client for future reference.

Case of Alleged Abuse

A 47-year-old man, an involuntary patient at a psychiatric hospital, was subject to an order permitting the involuntary administration of psychotropic medications. Despite the client proactively communicating his allergy to the hospital, they lacked supporting documentation for this allergy and intended to administer the medication. In response, DRM swiftly obtained the comprehensive allergy list from the patient's prior medical records at a state facility. Armed with this crucial information, DRM promptly contacted the hospital's medical staff. Recognizing the potential threat to the client's health, the hospital immediately abandoned any plans to administer that specific medication.

Case of Alleged Abuse

A 36-year-old woman, previously identified by a qualified Maine mental health professional as having a significant mental illness or emotional impairment, was an inpatient at a psychiatric hospital, sharing a room with another patient. This situation caused her significant distress and was adversely affecting her treatment. Initially, the hospital did not agree to the client's request

for a single room. DRM advocated for the move, highlighting the detrimental impact on the client's treatment in the double room. After DRM's intervention, the hospital agreed to the request, and the client was subsequently moved to a single room.

Case of Alleged Abuse

A 43-year-old woman, an involuntary patient at a psychiatric hospital, claimed that she had sustained bruising due to being placed in restraints. DRM conducted an investigation into the incident but was unable to substantiate the allegations. However, during the course of the investigation, DRM discovered that the hospital had placed the client in seclusion without corresponding documentation in her chart, as required by federal regulations. The lack of documentation made it difficult to assess the circumstances regarding compliance. The hospital acknowledged this error, took steps to ensure that their policies aligned with regulations, and provided additional education to staff on this issue.

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Footnotes:

C. Complaints/Problems of PAIMI Individuals

Areas of Alleged Neglect

Number of complaints/problems	Outcomes											Number from closed cases only
	A	B	C	D	E	F	G	H	I	J	K	TOTAL
a. Failure to provide necessary or appropriate medical (other than psychiatric) treatment.	0	1	2	0	0	0	0	0	0	0	1	4
b. Failure to provide necessary or appropriate mental health treatment, including access to prescribed medication	0	1	8	0	0	0	0	0	1	0	0	10
c. Failure to provide necessary or appropriate personal care and safety	0	1	0	1	0	0	0	0	0	0	0	2
d. Failure to provide appropriate discharge planning or release from a residential care or treatment facility	0	0	11	2	1	0	0	0	0	0	0	14
e. Mental health diagnostic or other evaluation (does not include treatment)	0	1	0	0	0	0	0	0	0	0	0	1
f. Medical (non-mental health related) diagnostic physical examination	0	0	0	0	0	0	0	0	0	0	0	0
g. Other *[Describe and make every effort to report within the above categories].*	1	1	4	0	0	0	0	0	0	0	0	6
1. Admission to residential care or treatment facility [5] 2. Person safety issues (unsecured access to facility, resident rooms, patient abuse) [1]												

Neglect Complaints Disposition

For total closed cases listed in Table C.3., provide the numbers of neglect complaints or problem areas for each disposition category.	
A. Number of complaints/problems determined after investigation not to have merit	1
B. Number of complaints/problems withdrawn or terminated by client	5
C. Number of complaints/problems resolved in the client's favor	25
D. Number of complaints/problems not resolved in the client's favor	3
E. Other Indicators of success or outcomes that resulted from P&A involvement	1
F. Other Representation found	0
G. Services not needed due to client death or relocation	0
H. P&A withdrew due to conflict of interest or other reasons	0
I. Lost Contact	1
J. Outcome Unknown	0

K. Lack of Resources	1
Total	**37**

Case of Alleged Neglect

A 33-year-old man was an involuntary patient on a psychiatric unit of a general hospital. He had recently been treated for nerve damage in his arm and needed to have a follow-up appointment scheduled, and time was of the essence. The psychiatric unit, not being focused on his physical health, had not taken steps to ensure that he would be able to make and access this appointment notwithstanding his involuntary status. DRM met this man during an outreach visit to this unit and immediately met with the nursing director. The director then ensured that this appointment would be made and the client be able to access it, even if he was still involuntarily committed.

Case of Alleged Neglect

A 39-year-old woman was an inpatient on a psychiatric unit of a general hospital. She had been at this hospital for weeks and was ready for discharge, but the hospital was having difficulty with certain state administrative barriers regarding her ability to access a mental health group home where the client wanted to be discharged. DRM participated in a series of meetings with the client, client's family, hospital staff, and state officials to address these barriers. The barriers were addressed, and the client was able to discharge from the hospital to the mental health group home in the community.

Case of Alleged Neglect

A 35-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was in a county jail. The man faced obstacles in accessing community mental health services upon his discharge, including difficulties in accessing state services designed for this purpose. DRM contacted the state representative responsible for this jail and ensured the removal of these barriers, ensuring that the man would have crucial mental health services available to him upon transitioning back into the community.

Case of Alleged Neglect

A 36-year-old woman, an involuntary patient at a psychiatric hospital whose first language was Russian, was unable to use the hospital grievance process regarding complaints surrounding her care, including treatment planning issues, because the grievance procedure was in English. DRM spoke with hospital administration, who immediately modified the process to ensure that she could use the grievance process in Russian.

Case of Alleged Neglect

A 64-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was residing in a mental health group home. The group home aimed to discharge him without an adequate discharge plan, and the client, desiring to leave but not become homeless, sought assistance. The client had an ACT team, which believed that discharging him without a plan designed to prevent homelessness would be unsafe. DRM participated in a series of meetings with the group home managers and his ACT team to ensure the development of an adequate discharge plan, preventing homelessness. The client successfully located a different placement in another group home of his preference and made a successful move.

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Footnotes:

C. Complaints/Problems of PAIMI Individuals

Areas of Alleged Rights Violations

Number of Complaints/Problems	Outcomes											Number from Closed Cases only
	A	B	C	D	E	F	G	H	I	J	K	TOTAL
a. Failure to provide individualized written treatment or service plan	1	0	0	0	0	0	0	0	0	0	0	1
b. Failure to provide written discharge plan including a description of mental health services needed upon discharged from such program or facility	1	1	1	0	0	0	1	0	0	0	0	4
c. Failure to allow ongoing participation, in a manner appropriate to such person's capabilities, in the planning of mental health services to be provided such person (including the right to participate in the development and periodic revision of the plan)	4	2	10	2	0	0	0	0	0	0	0	18
d. The right to refuse treatment	0	0	0	0	0	0	0	0	0	0	0	0
e. The right to refuse to take prescribed medications	0	0	0	0	0	0	0	0	0	0	0	0
f. The denial of financial benefits/entitlements (e.g., SSI, SSDI, Insurance)	0	0	2	0	0	0	0	0	0	0	0	2
g. Guardianship/Conservator problems	2	0	6	0	0	1	1	0	0	0	0	10
h. The denial of rights protection information or legal assistance, including adequate and appropriate representation during commitment hearings	0	0	3	0	0	0	0	0	0	0	0	3
i. The denial of privacy rights (e.g., congregation, telephone calls, receiving mail)	0	1	10	0	0	0	0	0	0	0	0	11
j. The denial of recreational opportunities (e.g., grounds access, television, and smoking)	0	0	4	0	0	0	0	0	0	0	0	4
k. The denial of visitors	0	0	3	0	0	0	0	0	0	0	0	3
l. The denial of access to or correction of records	0	0	4	0	0	0	0	0	0	0	0	4
m. Breach of confidentiality of records (e.g., failure to obtain consent before disclosure)	0	0	2	0	0	0	0	0	1	0	0	3
n. Failure to obtain informed consent	0	1	0	0	0	0	0	0	0	0	0	1
o. Advance directives issues	0	0	1	0	0	0	0	0	0	0	0	1
p. The denial of parental/family rights	0	0	0	0	0	0	0	0	0	0	0	0
q. Housing Discrimination	1	1	16	0	0	0	0	0	4	0	0	22
r. The denial of access to administrative or judicial process	1	0	11	0	0	0	0	0	0	0	0	12
s. Failure to provide educational services in the least restricted environment for PAIMI-eligible individuals	0	2	9	1	0	0	0	0	6	2	0	20
t. The denial of access to community-based rehabilitation services and/or treatment	2	2	19	0	0	0	0	0	0	0	0	23

u. The denial of access to transportation	0	0	2	0	0	0	0	0	2	0	0	4
v. Employment Discrimination	2	2	3	0	0	0	0	0	0	0	0	7
w. The denial of access to personal possessions	0	0	0	0	0	0	0	0	0	0	0	0
x. Failure to comply with commitment regulations	0	0	0	0	0	0	0	0	0	0	0	0
y. Failure to comply with commitment time frames	0	0	0	0	0	0	0	0	0	0	0	0
z. Other *[Please make every effort to report within the above categories].*	0	1	21	2	0	0	0	0	1	0	0	25

Rights Violations Disposition

For closed cases listed in this Table, provide the number of rights complaints or problem areas for each disposition category.	
A. Number of complaints/problems determined after investigation not to have merit	14
B. Number of complaints/problems withdrawn or terminated by client	13
C. Number of complaints/problems resolved in the client's favor	127
D. Number of complaints/problems not resolved in the client's favor	5
E. Other Indicators of success or outcomes that resulted from P&A involvement	0
F. Other Representation found	1
G. Services not needed due to client death or relocation	2
H. P&A withdrew due to conflict of interest or other reasons	0
I. Lost Contact	14
J. Outcome Unknown	2
K. Lack of Resources	0
Total number of Rights Violation complaints/problems addressed from closed cases	**178**

Cases of Alleged Rights Violations

A 43-year-old woman, an involuntary patient at a psychiatric hospital, received notice from the mental health staff at the supported apartment she resided in that she was no longer allowed to return home. They had already packed all her belongings in boxes and instructed her to find a storage unit. DRM promptly contacted the mental health agency, apprising them of the client's due process rights and warning of legal action if such a drastic course of action were pursued. In response to DRM's intervention, the mental health agency relented, unpacked her belongings, and after the client received treatment, she was able to discharge back to her home.

Cases of Alleged Rights Violations

A 60-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was homeless and residing in an outdoor storage unit. Eligible for mental health crisis services, she reached out to her local crisis

agency, which advised her to go to an emergency room for an assessment due to their inability to see her in person within a reasonable timeframe. Despite her lack of transportation, they suggested this course of action. DRM contacted the crisis agency, urging them to meet the client in person. However, the agency only offered to conduct a ZOOM assessment, overlooking the client's living conditions in a storage shed with no electricity and a dying cell phone battery. The client managed to participate in the ZOOM assessment and was eventually transported to a crisis stabilization unit. On a systemic level, DRM contacted state officials overseeing the program, who assured DRM that this was not the level of service expected from their crisis contracted providers and would be educating that provider on its responsibilities.

Cases of Alleged Rights Violations

A 57-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was an inmate at the state prison and receiving treatment at the mental health unit. Formerly residing in a mental health group home, he was informed that the group home intended to dispose of his possessions that he couldn't take with him to prison. These possessions were crucial for his reintegration into the community upon release. Despite having funds for a storage facility, both the group home and prison staff claimed it was the other party's responsibility to assist. DRM intervened to prevent the immediate potential disposal of all his belongings and collaborated with the group home and prison staff to find a solution. The client successfully obtained a storage unit, and his belongings were moved there for safekeeping.

Cases of Alleged Rights Violations

A 46-year-old woman, an involuntary patient at a psychiatric hospital, expressed her prayers in the common hallways. The hospital informed her that she was not allowed to pray in the hallways and was prohibited from contacting her church. DRM met with hospital staff, who acknowledged that the client had the right to contact her church and that she was under no restrictions. The hallway restriction was not due to the act of praying but rather because the sound levels were disturbing other patients who had lodged complaints. The hospital offered a meditation room where the client could pray as loudly as she wished, or she could pray in her room if the noise levels did not disturb others. DRM provided the client with this information and assured her to reach out if there were any future issues.

Cases of Alleged Rights Violations

A 27-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, resided in a very rural part of the state and received psychiatric medications through an agency affiliated with a large provider. However, this provider was nearly a 3-hour drive from her location. The agency terminated her as a client because she had not obtained a necessary face-to-face assessment from this larger provider. Without her medications, the risk of her returning to the hospital was high. DRM contacted the larger provider agency, providing them with education about their obligations to clients residing in more rural locations. The provider agreed and reinstated the client’s medication services.

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Footnotes:

C. Complaints/Problems of PAIMI Individuals

Reasons for Closing Individual Advocacy Case Files

	Number
1. Client's objective was partially or fully met.	166
2. Case or investigation lacked merit.	19
3. Case withdrawn or terminated by the client.	26
4. Issue favorably resolved.	0
5. Issue not favorably resolved.	8
6. Other success or outcomes due to P&A involvement (i.e., provided self-advocacy assistance)	0
7. Other representation found.	2
8. Services not needed due to client's death or relocation.	2
9. P&A withdrew due to conflict of interest or other reasons (i.e., client would not cooperate).	6
10. Appeal(s) unsuccessful.	0
11. Other appropriate entity investigating.	0
12. Lost Contact.	0
13. Lack of Resources.	0
Total	**229**

At least 1 case required.

Case of Closing an Individual Advocacy Case File

OBJECTIVE MET: A 54-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, received notification from the Medicaid Transportation provider that his access to rides for medical appointments would be suspended due to purportedly missing three scheduled pickups. DRM filed an internal complaint with the transportation provider on his behalf, contesting the accuracy of the claims. Following an investigation, his complaint was substantiated, and as a result, his access to this crucial transportation service was not suspended.

Case of Closing an Individual Advocacy Case File

CASE WITHDRAWN: A 40-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, had lost her community mental health services and faced administrative hurdles in regaining access to these services. DRM assisted the client in securing an in-person appointment with a provider for the required paperwork and assessments to reinstate her services. DRM accompanied the client to the appointment. However, while in the waiting room, the client decided she no longer wished to access this service and terminated her request with DRM.

Case of Closing an Individual Advocacy Case File

ISSUE FAVORABLY RESOLVED: A 34-year-old man, an involuntary patient at a psychiatric hospital, was relocated due to ongoing construction in his unit. During the move, his Book of Mormon was not transferred with him, and the hospital refused to retrieve it, citing the construction activities. DRM assisted the client in filing a grievance against the hospital for violating his rights to religious freedom. The following day, the hospital provided the client with the Book of Mormon.

Case of Closing an Individual Advocacy Case File

INVESTIGATION LACKED MERIT: During a monitoring visit, DRM met with a 34-year-old man who was involuntarily hospitalized and alleged that he was harmed during a restraint. DRM conducted an onsite investigation, including accessing and reviewing the patient's records, but found no evidence to support the allegation.

Case of Closing an Individual Advocacy Case File

ISSUE NOT FAVORABLY RESOLVED: A 60-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, alleged that her Assertive Community Treatment (ACT) team providers were not delivering services in accordance with regulatory standards. DRM represented the client at an administrative grievance hearing addressing this issue. Unfortunately, the hearing officer ruled in favor of the ACT team, determining that the services provided met the required standards

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Footnotes:

C. Complaints/Problems of PAIMI Individuals

Intervention Strategies

The totals reported for the Abuse, Neglect, and Rights Violations Outcomes in this table **should be** the same as the totals reported in the Areas of Alleged Abuse, Areas of Alleged Neglect, and Areas of Alleged Rights Violations tables.

Outcomes												
Abuse	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**Total**
1. Self Advocacy Assistance	1	0	3	0	0	0	0	0	0	0	0	4
2. Limited Advocacy	1	0	2	1	0	0	0	0	0	0	0	4
3. Administrative Remedies	0	0	0	0	0	0	0	0	0	0	0	0
4. Litigation	0	0	0	0	0	0	0	0	0	0	0	0
5. Abuse/Neglect Investigations	0	0	0	0	0	0	0	0	0	0	0	0
6. Mediation	0	0	0	0	0	0	0	0	0	0	0	0
7. Negotiation	0	0	5	1	0	0	0	0	0	0	0	6
Total	**2**	**0**	**10**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**14**
Neglect	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	
1. Self Advocacy Assistance	1	1	5	0	0	0	0	0	1	0	0	8
2. Limited Advocacy	0	0	13	3	0	1	0	0	0	0	1	18
3. Administrative Remedies	0	1	0	0	0	0	0	0	0	0	0	1
4. Litigation	0	0	1	0	0	0	0	0	0	0	0	1
5. Abuse/Neglect Investigations	0	0	0	0	0	0	0	0	0	0	0	0
6. Mediation	0	0	0	0	0	0	0	0	0	0	0	0
7. Negotiation	0	3	6	0	0	0	0	0	0	0	0	9
Total	**1**	**5**	**25**	**3**	**0**	**1**	**0**	**0**	**1**	**0**	**1**	**37**
Rights Violations	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	
1. Self Advocacy Assistance	7	8	38	1	0	1	1	0	12	2	0	70
2. Limited Advocacy	6	1	41	2	0	0	0	0	2	0	0	52
3. Administrative Remedies	0	0	4	2	0	0	0	0	0	0	0	6

4. Litigation	0	0	3	0	0	0	0	0	0	0	0	3
5. Abuse/Neglect Investigations	0	0	0	0	0	0	0	0	0	0	0	0
6. Mediation	1	2	1	0	0	0	1	0	0	0	0	5
7. Negotiation	0	2	40	0	0	0	0	0	0	0	0	42
Total	**14**	**13**	**127**	**5**	**0**	**1**	**2**	**0**	**14**	**2**	**0**	**178**

At least 1 case required.

Case of Intervention

LITIGATION: A 53-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, faced a lawsuit for eviction from his subsidized housing provider. Being evicted would render him homeless. DRM filed a motion to dismiss the entire case, citing the housing provider's non-compliance with specific Fair Housing Act laws and regulations. Following the court hearing, a ruling was issued, dismissing the entire eviction action pending against the client. As a result, the client could continue living in his apartment.

Case of Intervention

NEGOTIATION: A 34-year-old woman, an involuntary patient at a psychiatric hospital, received a bill for over $2,000 from the ambulance company responsible for her involuntary transfer to the hospital. Maine law allows for individuals to be involuntarily transported to such hospitals by ambulance from various emergency departments throughout the state. The client did not have the financial means to cover the bill, and incurring debt would have jeopardized her ability to successfully transition back into her community. DRM engaged with hospital administration and state representatives overseeing these transfers, reminding them that state law requires the state to fund these transfers. The state agreed and covered the ambulance bill, providing much-needed relief to the client.

Case of Intervention

ADMINISTRATIVE REMEDIES: A 45-year-old woman under state guardianship, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, had been residing in a mental health group home for 8 years. During this time, the group home imposed severe restrictions on the woman, including prohibiting her from leaving the facility and accessing her community unsupervised. DRM filed an administrative grievance under state law against the facility for numerous violations of the client's rights. A settlement meeting took place at the facility with representatives from the state, the facility owner and his attorney, the guardian worker, and clinical staff. An agreement was reached to ensure the client received the necessary assessments to determine her needs, with the goal of moving to a supported apartment being included in her plan. Within 4 months of the meeting, the client had successfully transitioned to her own supported apartment.

Case of Intervention

LIMITED ADVOCACY: A 39-year-old man, a veteran previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was dealing with housing and financing issues and accessing other services without assistance. Having experienced previous psychiatric hospitalization, he was concerned about readmission. Unaware of a recently implemented special mental health case management program for veterans in the state, DRM contacted state officials for information on agencies providing this service in his area. DRM, in collaboration with the client, reached out to the agency and ensured that he received this crucial service, and the agency took him on as a client.

Case of Intervention

SELF-ADVOCACY: A 30-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, sought to establish an advance directive for mental health care as a precautionary measure to avoid involuntary hospitalization and potential guardianship. DRM provided her assistance to ensure that her completion of the directive met the requirements of the advance directive statute, which she could then provide to her various healthcare providers

Footnotes:

C. Complaints/Problems of PAIMI Individuals

Death Investigation Activities

A. The number of deaths reported to the P&A for investigation by the following entities:	
1. State	0
2. The Center for Medicaid & Medicare Services (Regional Offices). If zero means the P&A did not receive any death reports from CMS for investigation, please note this in the Footnotes.	0
3. Other Sources. Briefly list the source for each death reported in this category (e.g., newspaper, concerned citizen, relative, etc.). N/A	0
Total Number of deaths investigated	**0**

If the information requested in this section was not available please explain

B. All death investigations conducted involving PAIMI-eligible individuals related to the following:	
a. Number of deaths investigated involving incidents of seclusion (S).	0
b. Number of deaths investigated involving incidents of abuse (A).	0
c. Number of deaths investigated involving incidents of restraint (R).	0
d. Number of deaths investigated NOT related to incidents of S&R, (e.g., suicides.).	0
e. Death investigations with a finding of determination.	0
f. Provision in policy added or prevented as a result of a death investigation.	0
Total Number of deaths investigated [Sum of 9b 1-6]	**0**

C. Provide a brief summary example of an individual's death, P&A involvement, and outcome.
If you reported deaths in categories B.9.b., please provide the following information on one death from each category, as appropriate:

A brief summary of the circumstances about the death.

A brief description of P&A involvement in the death investigation.

A summary of the outcome(s) resulting from the P&A death investigation.

N/A

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Footnotes:

The P&A did not receive any death reports from CMS for investigation

C. Complaints/Problems of PAIMI Individuals

Number of Interventions on behalf of Groups of PAIMI Eligible Individuals - Individuals Impacted

Multiple counts not permitted for lines 1 –3 and 6.

What to Count	
1. Group cases/projects still open on October 1, 2022. (Carried over from prior FY (s))	33
2. New group cases/projects opened during the year.	50
3. Total group cases/projects worked on during the year (Add lines 1 & 2)	83
4. Total group cases/projects as of September 30, 2023. (Carry over to next FY)	5
5. Group cases/projects targeted at serving the following special populations:	
a. Ethnicity	0
b. Racial Minorities	0
c. Homeless	0
d. Veterans	0
e. Urban	0
f. Rural/Frontier	0
g. Older Adults/geriatric	0
6. Total # of individuals potentially impacted by line 3	100,000

Only the number of cases are needed for the last three columns, not the number of individuals

Intervention Types (See the Instructions for Guidance)	Potential # of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	On-going
Group Advocacy (non-Litigation)	20,000	11	0	5
Abuse and Neglect Investigations (non-death related)	0	0	0	0
Facility Monitoring Services	20,000	18	0	0
Community Based Monitoring Services	20,000	45	0	0
Court Ordered Monitoring	0	0	0	0
Systemic Litigation	20,000	0	1	0

Educating Policy Makers	20,000	3	0	0
Other Systemic Advocacy	0	0	0	0
Total	**100,000**	**77**	**1**	**5**

Case of Intervention on Behalf of a Group

CLASS ACTION LAWSUIT: DRM continues to serve as Class counsel in the Bates v. Glover case, a significant legal action involving institutional litigation. The case aimed to secure comprehensive relief for approximately 3,500 individuals, both current and former residents of AMHI/Riverview Psychiatric Center, as well as 15,000 other qualified individuals with mental illness. The case reached a settlement in 1990, and one crucial aspect of the agreement is that community members are entitled to receive community services as outlined in the settlement terms. As part of the settlement negotiations, Maine committed to implementing compliance targets in 14 critical service areas. These areas include the duration of stay in state psychiatric hospitals, the obligations of contracted providers to accept clients, and the provision of state-funded housing vouchers for individuals with psychiatric disabilities who are homeless or undergoing discharge from a psychiatric or correctional facility. As part of this agreement, the state contracts with DRM to monitor the implementation of some of these compliance measures Settlement Agreement as well as provide on the ground advocacy. DRM provides quarterly reports on the status of the mental health system and offers recommendations to both the state and the Court Master. The Court Master, a former chief justice of the Maine Supreme Court, is responsible for ensuring the effective execution of the Settlement Agreement. Regular meetings take place between the state, DRM, and the Court Master, occurring at least quarterly. These meetings serve as a platform for discussions on the progress and compliance with the terms of the settlement, fostering ongoing collaboration to uphold the rights and well-being of individuals with severe and persistent mental illness throughout the state.

Case of Intervention on Behalf of a Group

STATE AND PRIVATE PSYCHIATRIC FACILITY MONITORING ADULTS AND CHILDREN: DRM provides contract advocacy services to both of Maine's state psychiatric hospitals and one of Maine's largest private psychiatric hospitals. (This is reported in the "Accomplishments" section G of the PPR). There are also 7 more private psychiatric hospitals throughout the state. The total bed count in all of these hospitals is over 500. Four of these private hospitals also have children's units DRM continues to provide in person regular outreach and monitoring visits to one or more of these psychiatric hospitals each month.

Case of Intervention on Behalf of a Group

YOUTH CORRECTIONAL FACILITY MONITORING: Monitoring Long Creek Youth Development Center: The Long Creek Youth Development Center is Maine's only juvenile correctional facility in Maine. It is administered by the Maine Department of Corrections. DRM monitors this facility on a monthly basis, including meeting with youth who are detained and bringing concerns to the administration.

Case of Intervention on Behalf of a Group

ADULT COMMUNITY MOINTORING AND OUTREACH: The State of Maine currently contracts with DRM, as the P&A, to provide community outreach and advocacy services for individuals across the state who have been determined to have a significant mental illness or emotional impairment by a qualified Maine mental health professional, and are eligible to be so determined, or whose eligibility for the service they currently receive requires such a previous determination. This program is designed to reach people in the community by going to where they are at. The Adult Community Monitoring and Outreach program in Maine, conducted by DRM, serves individuals with significant mental health conditions by providing community outreach and advocacy services. The program is designed to reach individuals where they are in the community, offering support and addressing rights violations. Key aspects of the program include: 1. Community Outreach Visits: DRM has conducted over 200 separate outreach visits to various locations across the state, reaching more than 1000 people. These locations include mental health crisis units, group homes, homeless shelters, public libraries, peer recovery centers, clubhouses, homeless tent encampments, and mental health agencies. 2. Individual Advocacy: Advocates work to correct rights violations observed during outreach visits. This includes addressing any restrictions on the exercise of basic rights and assisting individuals during treatment team meetings. 3. Assistance with Accessing Services: The program focuses on helping eligible individuals navigate

the mental health system, especially when facing difficulties accessing services or being placed on waitlists. Advocates also offer support to individuals in inpatient psychiatric units who may encounter barriers to discharge due to a lack of community services. 4.Statewide Coverage: The program covers the entire state of Maine, which spans over 33,000 square miles. Advocates work across diverse settings to ensure that individuals with mental health conditions receive the support they need. This comprehensive outreach and advocacy initiative reflects DRM's commitment to addressing the unique needs of individuals with mental health conditions and ensuring their rights are upheld throughout the state.

Case of Intervention on Behalf of a Group

CHILDREN'S COMMUNITY MOINTORING AND OUTREACH: DRM provided monitoring and outreach to children's residential facilities throughout Maine. This included Crisis Residential Units and long-term residential centers that are operated by some of the largest providers of mental health services in Maine

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Footnotes:

Note to #5c. Most projects are not targeted to any specific group. They are targeted to PAIMI-eligible individuals. Projects will reach many members of the group this PPR reporting requirement lists.

C. Complaints/Problems of PAIMI Individuals

Performance Measures of P&A Activities

Outcomes	Number from Closed Cases Only
a) PAIMI-eligible individuals who access community-based mental health or health care services that resulted in community integration and independence or are better able to advocate to do so;	22
b) PAIMI-eligible individuals who access benefits or services or are better able to advocate to do so;	78
c) PAIMI-eligible individuals who live in a healthier, safer, improved, or more integrated settings or are better able to advocate to do so;	16
d) PAIMI-eligible individuals are able to stay in their own home or better able to advocate to do so;	8
e) PAIMI-eligible individuals who can secure or maintain employment and/or are not subject to workplace discrimination or are better able to advocate for to do so;	2
f) PAIMI-eligible individuals who receive appropriate educational services and supports and/or are not subject to discrimination in educational settings or are better able to advocate for those outcomes;	9
g) PAIMI-eligible individuals who go to school in safe and more humane conditions;	4
h) PAIMI-eligible children (individuals) who receive appropriate services in the most integrated settings;	3
i) PAIMI-eligible individuals who were not subject to discrimination in government benefits/services, housing, public accommodations, etc. or are better able to advocate for such outcomes;	0
j) PAIMI-eligible individuals who were not subject to abuse, neglect, or rights violations or are better able to advocate for to do so;	0
k) PAIMI-eligible individuals who can make their own decisions to the maximum extent feasible or are better able to advocate to do so;	0
l) PAIMI-eligible individuals who had their rights enforced, retained, restored and/or expanded or are better able to advocate for to do so; and	85
m) PAIMI-eligible individuals who were more able to participate in the voting process or are better able to advocate for to do so.	2

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Footnotes:

D. Non-Client Directed Advocacy Activities

Non-client Directed Advocacy Activities

1. Individual Information and Referral (I&R).	Total
Provide the number of PAIMI Program I&R services.	746

2. State Mental Health planning activities
1. DRM meets with the director of the Maine State Office of Child and Family Services (OCFS) and other staff to raise and discuss issues of concern and seek information from OCFS about the status of certain OCFS projects. These meetings are focused on ensuring that children with disabilities served by OCFS are served in the most integrated setting and receive appropriate services. 2. DRM sits on the Maine Juvenile Justice Advisory Group (JJAG). The mission of the Maine Juvenile Justice Advisory Group is to advise and make recommendations to state policy makers and to promote effective system level responses that further the goals of the Juvenile Justice and Delinquency Prevention Act. 3. DRM sits as a member of the MaineCare Advisory Committee. This is a stakeholder committee that advises the state's Medicaid agency regarding all aspects of the state's Medicaid program. 4. As class counsel DRM participates in monthly meetings with the Court Master regarding compliance with the consent decree and the mental health system in Maine. This monthly meeting is also attended by state mental health officials, including the Director of Maine's Substance Abuse and Mental Health agency. 5. DRM sits as a member of the Transportation Advisory Committee of MaineCare. This is a stakeholder committee that advises the state's Medicaid agency regarding its Non-Emergency Transportation Service that is funded and provided to MaineCare members. . 6. DRM meets quarterly with the Maine Department of Education. Both agencies share updates regarding personnel, initiatives, trends, concerns related to student with disabilities. DRM raised such concerns as the inappropriate use of abbreviated school days, the lack of appropriate positive behavior supports, the discriminatory conduct of private-public schools, the overuse of restraint and seclusion, and compensatory education for pandemic impacts on students' FAPE. These meetings provide a valuable dialogue. 7. DRM participated in the Active Transportation Plan, being developed by the Maine Department of Transportation which aims to focus on public transportation routes and improving access to those who don't have access to their own vehicles which includes a disproportionate number of individuals with disabilities. 8. DRM participates in quarterly meetings with the Maine Department of Corrections regarding issues of ADA compliance, including responding to the reasonable accommodation requests of prisoners with disabilities. 9. DRM continued to participate on the Commission for Disability Employment, a statutorily required committee for the State Workforce Board. This board focuses on systemic solutions to improve employment outcomes for people with disabilities. 11. DRM meets quarterly with staff from the Maine Bureau of Rehabilitation Services. These meetings focused on discussions of joint collaborations, including on Employment First and the Bureau's monitoring of contract compliance with service providers. 12. DRM monitored the bi-monthy meetings of the IDEA Part B State Advisory Panel in which the MDOE and other education-interested entities such as DOL, MPF, special education directors, and parents provide updates and raise concerns regarding the state of IDEA Part B in Maine 13. DRM was invited to join the Advisory Committee on the Maine Rules of Probate Procedure. This committee review and recommended changes to the rules of probate procedure, as well as to the forms used by probate courts. IDRM has raised numerous issues with rules and forms and their concerns about due process of individuals with disabilities, including mental illness 14. DRM meets bimonthly with Children's Residential Licensing and others in the Office of Child and Family Services to discuss monitoring updates, out of state placements, and any other topics or concerns that arise related to children's residential programs.

3. Education, Public Awareness Activities, and Events	
1. Number of public awareness activities or events.	339
2. Number of education/training activities undertaken.	208
3. Number (approximate) of persons trained in 2.	14,925

4. Technical Assistance	
Provide the number of PAIMI Program TA services.	151

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Footnotes:

E. Grievance Procedures

Grievance Procedures 42 CFR § 51.25 (a)(1)(2)

}

1. Do you have a systemic/program assurance grievance policy as mandated 42 CFR 51.25 (a)(2)?	(●) Yes ( ) No
If Yes please upload your organizations Grievance Policy using the attachment tab	
2. The number of grievances filed by PAIMI-eligible clients, including representatives or family member of such individuals receiving services during this fiscal year. Total	0
3. The number of grievances filed by prospective PAIMI-eligible clients (those who were not served due to limited PAIMI Program resources or because of non-priority issues). 42 CFR § 51.25 (a)(1)(2)	0
4. The number of grievances appealed to : a. The Governing Authority/Board b. The Executive Director	 0 0
Total 4.a & 4.b	0
5. The number of reports sent to the Governing Board and the Advisory Board. Total	1
6. Please IDENTIFY ALL INDIVIDUALS, by name & title, responsible for grievance reviews (maximum 5): Name:Kimberly Moody Title:Executive Director Name:Mark Joyce Title:PAIMI Director Name:Staci Converse Title:PADD Director Name:Atlee Riley Title:Legal Director	
7. What is the timetable (in days) used to ensure prompt notification of the grievance procedure process to clients, prospective clients or persons derided representation, and ensure prompt resolution? Total # of days	42
8. Were written responses sent to each grievant? *If no, explain below*	( ) Yes (●) No
Not Applicable No Grievances Filed	
9. Was client confidentiality protected? *If no, explain below*	( ) Yes (●) No
Not Applicable No Grievances Filed	

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Footnotes:

DISABILITY RIGHTS MAINE

GRIEVANCE PROCEDURE

WHO MAY FILE:

1. Clients of Disability Rights Maine of Maine (DRM).
   - Parents of a minor child may file on behalf of their child.
   - Guardians may file on behalf of their wards.
2. Applicants who believe they are eligible for DRM's services.

BASIS FOR GRIEVANCE:

Clients or applicants may submit a grievance:

1. if they have been refused representation by DRM;
2. if DRM has terminated representation; or
3. if they believe they are not being appropriately represented.

SUBMITTED IN WRITING OR IF UNABLE TO WRITE:

1. Clients and applicants should submit the grievance in writing.
2. If the client or applicant is unable to submit the grievance in writing, they may call DRM and the Executive Director will designate a staff person to assist the client or applicant by collecting the information as outlined in the next section. DRM will mail the draft grievance to the client or applicant for review and signature.

CONTENTS OF GRIEVANCE:

The grievance should include

1. a statement of what happened,
2. which agency staff were involved, and
3. as specifically as possible, what the client or applicant was dissatisfied with.

EXECUTIVE DIRECTOR'S DECISION:

Within fourteen (14) days of receiving the grievance, the Executive Director or designee, will investigate and reply to the client in writing. The written reply must include:

1. the agency's findings, and
2. if the grievance is substantiated, what the Executive Director will do to correct the problem.

160 Capitol Street, Suite 4, Augusta, ME 04330
207.626.2774 • 1.800.452.1948 • Fax: 207.621.1419 • drme.org

Appeal of Executive Director's Decision to Board; Appointment of Board Panel:

The client or applicant can appeal the Executive Director's decision to the Board of Directors. If the client or applicant chooses to appeal, the Executive Director will immediately forward the appeal to the President of the Board. Within seven (7) days, the President will appoint a panel of three Board members to review the appeal, and will appoint one of the panel members as Chairperson.

Review By Board Panel/Hearing (Optional):

The panel may review the appeal based on the written documents generated during the grievance, or, at its discretion, may hold a hearing to review the appeal. In either event, the Board members must make a decision in writing within twenty-one (21) days of their appointment to the panel.

If Hearing is Held:

If the panel chooses to hold a hearing, the Chairperson must immediately notify the client or applicant in writing. The notification must include the date, time, and location of the hearing, and what staff and Board members will be present. Hearings are informal, and the rules of evidence do not apply. The client or applicant has the right to representation by a person of his or her choosing, and the right to give testimony.

Panel Decision Final:

The decision of the panel is final.

F. Other Services & Activities

Public Comment

1. Does the P&A have procedures established for public comment?

a. (●) Yes, briefly describe how the notice is used to reach persons with mental health illness and their families.
All clients are sent satisfaction surveys upon the closure of their cases. The survey includes a general question soliciting suggestions for change. All callers are sent copies of our priorities. At all public presentations, training and monitoring visits to psychiatric hospitals and residential facilities we hand out copies of our brochures and solicit input and comment. We also have state funded advocates at the two state freestanding hospitals and one private free standing hospital. These advocates also distribute DRM materials

b. ( ) No, (if no, briefly explain, limit to 500 characters).

2. Were the notices provided to the following persons:

a. Individuals with mental illness in residential facilities? (●) Yes ( ) No

b. Family members and representatives of such individuals? (●) Yes ( ) No

c. Other individuals with disabilities? (●) Yes ( ) No

d. Brief explanation is required for each no answer in 2.a., b., or c.

3. Do the procedures provide for receipt of the comments in writing or in person?

3a. (●) Yes, attach a copy of the agency's Policies & Procedures pertaining to public comment.

3b. ( ) If no to 2 a, b, c., explain why the agency does not have such procedures in place

4. Was the public provided an opportunity for public comment. (●) Yes ( ) No

5. If you answered Yes to 4 briefly describe the activities used to obtain public comment.
DRM provides ongoing outreach to provide information to service providers and individuals throughout the state both in person and virtually. For example in person outreach has been conducted that spans a distance of over 300 miles reaching hundreds of people, with in webcasts and zoom training reaching hundreds more.

6. What formats and languages (as applicable) were used in materials to solicit public comment?
As noted above we use the web page which is accessible. Surveys sent to clients are sent in the format identified as needed at the time of the initial intake with the client. Interpreters are present at the general public events. We have a program that converts any written document to voice, which we use as needed. Our brochure and agency publications are available in alternative format upon request.

7. If you answered No to 4, briefly explain why the public was not provided an opportunity to comment.

8. List groups (e.g., states, consumer advocacy, service providers, professional organizations and others, including groups of current and former mental health consumers or family members of such individuals) with whom the PAIMI Program coordinated systems, activities and mechanisms. [42 CFR 51.21 (a) (D)]
SEE ATTACHED LIST OF COLLABORATORS

9. Briefly describe the outreach efforts/activities used to increase the number of ethnic and racial minority clients served or educated about the PAIMI program [this information will be evaluated by using the demographic/state profile information contained in the PAIMI application for the same FY]
DRM provides ongoing outreach to provide information to service providers and individuals throughout the state. DRM continues to have a staff position of Cultural Strategist and DRM participated in a brown bag lunch sponsored by the University of Maine School of Law Black Students Association, Maine Juvenile Law Society and the American Constitution Society entitled “Class, Race, Civil Rights and Mental Health. DRM had a table at an all-day fair sponsored hosted by Wabanaki Public Health & Wellness and Together Place Peer Run Recovery Center and participated in the Pleasant Point Tribal Health Fair.

10. Did the activities described in question 9 result in an increase of ethnic and/or minorities in the following categories?

a. Staff ( ) Yes (●) No

b. Advisory Council ( ) Yes (●) No

c. Governing Board ( ) Yes (●) No

d. Clients ( ) Yes (●) No

If you answer no to any item (10.a-d), please provide a brief explanation, such as 10.a, b., or c. – no vacancies.

There was no increase due to the activities listed in 10. Maine has a very small minority population

Footnotes:

DISABILITY RIGHTS MAINE

CLIENT RIGHTS STATEMENT

You have the right to be treated with courtesy and respect by Disability Rights Maine staff.

Rights of Callers We Do Not Represent

If we decide we are not able to provide you direct advocacy services, you have the right to:

- information and referrals
- a letter explaining our decision

Rights of Clients We Represent

Clients of Disability Rights Maine (DRM) have the right to:

- prompt and ethical representation.
- be involved in the decision about how DRM can best represent you.
- be informed of all activity in your case
- approve any action before it is taken
- a written explanation if DRM decides it can no longer represent you.

Confidentiality

- We keep all information about you confidential
- It will not be released without your written permission

There is one exception to this rule. Agencies that fund us have the right to review client files in order to make sure that DRM is meeting the requirements of its contract or grant. More than one agency funds DRM. Only the agency that funds our activity on your behalf would be able to look at your file. If you wish to know which agency is funding our activity on your behalf, please ask us.

Complaints

If you are not happy with how DRM has handled your call or your case:

- you should discuss this with the individual staff person involved,
- you may contact the staff person's supervisor,
- you may file a formal grievance with the Executive Director if the problem is not resolved.

Please ask for a copy of the Client Grievance Procedure for information on how to file a formal grievance.

PROGRAM PRIORITIES AND OBJECTIVES

STANDARD: Each year, the programs of DRM shall develop a statement of priorities and objectives, consistent with the mission of the agency and the federal mandates and with input from the public. The program priorities and policies specific to the PAIMI program shall be established annually by the governing authority, jointly with the PAIMI Advisory Council.

Compliance Measures:
The priorities must:

1. address the client population to be served and the advocacy strategies to be employed;

2. address the needs of persons not capable of requesting assistance due to the nature of their disability;

3. address the needs of persons in segregated settings and those at risk of abuse, neglect and exploitation;

4. address the role of the program in serving racial and ethnic minorities and other historically unserved and underserved groups.

5. be developed through a process reflecting input from the public, individuals with disabilities, groups of individuals with disabilities and other affected and interested individuals.

6. be specific short-term program goals and objectives, with measureable outcomes to implement established priorities.

7. In developing priorities, consideration shall be given to, at a minimum, case selection criteria, the availability of staff and monetary resources, and special problems and cultural barriers faced by individuals with mental illness who are multiply handicapped or who are members of racial or ethnic minorities in obtaining protection of their rights.

8. Systemic and legislative activities shall also be addressed in the development and implementation of program priorities.

9. Members of the public shall be given an opportunity, on an annual basis, to comment on the priorities established by, and the activities of, the P&A system.

10. Procedures for public comment will be provided in a format accessible to individuals with mental illness, including such individuals who are in residential facilities, to family members and representatives of such individuals and to other individuals with disabilities.

11. Procedures for public comment must provide for receipt of comments in writing or in person.

AARP
Acadia Hospital
ACLU of Maine
Aging & Disability Services (OADS)
Alpha One
Alzheimer's Association
American Council for the Blind of Maine
Area Agencies on Aging
Ascentria Care Alliance
Autism Society of Maine (ASM)
Brain Injury Association of America - Maine Chapter
Catholic Charities
Center for Community Inclusion & Disability Studies (CCIDS)
Citizens of Maine
City of Portland
Coalition Against Restraint & Seclusion
Community Living Association (CLA)
Consumer Council System of Maine
Consumers for Affordable Health Care (CAHC)
Creative Work Systems (CWS)
Dorothea Dix Psychiatric Center (DDPC)
G.E.A.R. Parent Network
GLEAM
Goodwill NNE
Hands & Voices Maine
Hard of Hearing & Late Deafened
Health Affiliates of Maine
Home Care Alliance of Maine
Home Care for Maine
Independence Association
KIDS Legal
Knox County Jail
Learning Disability Association of Maine (LDA)
Legal Services for the Elderly (LSE)
Long-Term Care Ombudsman Program
Maine Adaptive Sports & Recreation

Maine Alliance for Addiction Recovery
Maine Association for Community Service Providers (MACSP)
Maine Association of Mental Health Services
Maine Association of Peer Support & Recovery Centers (MPSRC)
Maine Association of the Deaf (MeAD)
Maine Behavioral Health
Maine Bar Association
Maine CareerCenters
Maine Children's Alliance
Maine CITE
Maine Coalition for Housing & Quality Services
Maine Council of Senior Citizens-ARA
Maine Developmental Disabilities Council (MDDC)
Maine Developmental Services Oversight & Advisory Board (MDSOAB)
Maine Disability Employment Initiative (DEI)
Maine Educational Center for the Deaf & Hard of Hearing (MECDHH)
Maine Equal Justice Partners (MEJP)
Maine Health Access Foundation (MeHAF)
Maine Health Care Association
Maine Housing Authority
Maine Human Rights Commission
Maine Juvenile Justice Advisory Committee
Maine Medical Association
Maine Medical Center Vocational Services / WIPA Program
Maine Parent Federation (MPF)
Maine Prisoner Re-Entry Network
Maine Registry of Interpreters for the Deaf (MeRID)
ME Attorney General's Office
ME Department of Corrections (DOC)
ME Department of Education (DOE)
ME DHHS - Office of Aging & Disability Services (OADS)
ME DHHS - Office of Behavioral Health (OBH)
ME DHHS - Office of Child & Family Services (OCFS)
ME DHHS - Office of MaineCare Services (OMS)
ME DOL - Commission for the Deaf, Hard of Hearing & Late Deafened
ME DOL - Division for the Blind
ME DOL - Division for the Deaf

ME DOL - Division for the Deaf, Hard of Hearing & Late Deafened
ME DOL - Division of Vocational Rehabilitation (VR)
ME Secretary of State's Office
Mobius, Inc.
National Association of the Deaf (NAD)
National Disability Rights Network (NDRN)
National Association Rights Protection Advocacay (NARPA)
New Ventures Maine
Opportunity Housing Inc.
Pine Tree Legal Assistance (PTLA)
Pine Tree Society
Pleasant Point Tribal Government
Portland Disability Advisory Committee
Private Bar
Riverview Psychiatric Center (RPC)
Southern Maine Workers' Center
Speaking Up for Us (SUFU)
Spring Harbor Hospital
Spurwink
State of Maine Judicial Branch
State of Maine Legislative Branch
State Rehabilitation Advisory Council (SRC)
The Iris Network
The Maine Hospital Association
The Progress Center
United Way
University of Maine (UMO)
University of Maine at Augusta (UMA)
University of Maine at Farmington (UMF)
University of Maine School of Law
University of New England (UNE)
University of Southern Maine (USM)
USM Interpreter Training Program
Wabanaki Public Health and Wellness
Western Maine Community Action, Inc.
Woodfords Family Services

F. Other Services & Activities

Impediments

External Impediments
Describe any problems with implementation of mandated PAIMI activities, including those activities required by Parts H and I of the Children's Heath Act of 2000 that pertain to requirements related to incidents involving seclusion and restraint and related deaths and serious injuries (e.g., access issues, delays in receiving records and documents, etc.).
As we have stated in years past, we simply do not have sufficient resources to adequately conduct all of the activities that we know are needed to protect individuals with mental illness and promote their rights. The lack of resources is related to funding. DRM is a minimum allotment state. In 2004 our PAIMI grant was $410,000. According to a U.S. inflation calculator for this grant to just keep up with inflation it would need to be $666,444.09. It is not close to that amount.
Internal Impediments
Describe any problems with implementation of mandated PAIMI activities, including any identified annual priorities and objectives (e.g., lack of sufficient resources, necessary expertise, etc.).
See above.

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Footnotes:

F. Other Services & Activities

Accomplishments/Recommendations/Training Needs

Accomplishments
For this fiscal year, briefly describe the most important accomplishment(s) that resulted from PAIMI Program activities. Provide copies of supporting documents, e.g., case law, news, articles, legislation, etc.
1. IN 2023 DRM ISSUED A REPORT ENTITLED I DON'T GET THE CARE I NEED": EQUITABLE ACCESS TO HEALTH CARE FOR MAINERS WITH DISABILITIES. This report was generated because it had become clear to DRM that Mainers with disabilities face stark inequalities as they navigate Maine's health care system. This report includes a report on the lack of access and inequality of access to care for individuals with disabilities, including mental illness. As part of its outreach activities DRM conducted a number of surveys with consumers willing to share their experiences with their access to care. Almost 70% of all respondents identified that they had a mental health condition. Attached is the final report that DRM issued which included findings and recommendations. 2. DISABILITY PRIDE DAY: DRM held its annual Disability Pride Day in Augusta on July 21, 2023. It is an annual event that DRM organizes where the entire community is invited to attend. This year's celebration brought almost 200 people to this outdoor event that featured informational booths from a wide variety of organizations. Music, face painting, games, and food and drinks were all part of the celebration . The event was captured and placed on DRM's YouTube channel as well as covered by a number of media outlet, including the major media television stations in Maine. The DRM YouTube link and links to the news stories are attached. 3. DRM'S PROVISION OF CONTRACT ADVOCACY SERVICES IN THREE PSYCHIATRIC FACILITIES. DRM provides advocacy service to 3 psychiatric hospitals through contracts with the state Department of Health and Human Services and a private free standing psychiatric hospital. The state contract supports the services of 1.6 full time employee (FTE) advocates at the southern facility and 1 FTE advocate at the northern facility. The private hospital contract supports the services of .6 FTE advocate. The state institutions do not admit anyone under the age of 18. The private hospital does admit children and adolescents. The southern state institution has 4 units housing civil and forensic patients. The northern state institution has 4 units housing civil and forensic patients. The private facility has two adult units and two pediatric units. DRM staff advocates spend a significant portion of each day on the units, meeting with patients and staff. During those meetings DRM advocates provide informal advocacy, referral to resources, and information about patient rights. In addition to the advocacy provided above, some problems require a more formal approach, such as filing a complaint or grievance. The advocates meet with the clinical directors and superintendents at the two state institutions and the director of quality of the private hospital on a periodic basis to report on, and request action regarding, specific issues. Below are a few of the areas that the advocates provide consistent and quality advocacy services to protect individual rights and effect change in the facilities. TRAINING At both of the state facilities the advocates conduct weekly groups for patients to provide instruction on self-advocacy skills, especially on how to make the most of one's treatment planning meetings, including advocating for additional resources for themselves. Additionally, the advocates provide information on rights and discuss issues facing the individuals in the hospital and the community. Further, the advocates at both hospitals look for training topics for hospital staff trainings when rights related issues come up. Through the groups and interactions with hospital staff at each of the facilities, advocates frequently identify systemic issues that are then presented to hospital administration. In some of those situations what occurs are hospital staff trainings that target specific rights related issues. Furthermore, all three hospitals specifically request that the advocates train new staff on patient rights. Examples of some of the types of trainings conducted are: • In both the private and state hospitals the advocates provide regular new employee orientation training for all incoming staff on patient rights. This is to ensure patient rights are at the forefront of new employee's minds coming into the facilities. • Training staff in one state hospital on the process of responding to a grievance pursuant to the state regulations. Advocates had identified that in certain situations the staff responsible for responding to grievances was not meeting the regulatory requirements in those responses. MONITORING Monitoring for rights related issues is an integral part of the advocates role in all three facilities. In both state institutions, and the private hospital, advocates monitor the weekly civil commitment hearings looking for issues of concern. The advocates in one state institution regularly attend hospital unit community meetings with patients to monitor for rights related issues. Further, the advocates in both state hospitals regularly attend morning round reports for each unit to monitor for rights related issues that come up in those staff only meetings. All hospital advocates also participate in treatment planning meetings for patients, in addition to a variety of other in-hospital meetings. In one of the state institutions, the advocates monitor in-hospital clinical review panels that make decisions about medication-over-objection. Further,

advocates in the other state hospital monitor treatment over objection hearings that occur in the context of civil commitment. The advocates in one state institution monitor the treatment of patients who have been transferred to an out-of-state facility. The advocates look for rights issues related to those out-of-state placements such as access to telephones and communication with attorneys. The advocates also monitor those patients to ensure transfer back to Maine remains part of their plans.

Some examples of issues discovered and addressed as a result of this monitoring are:

• A patient at one state hospital had a mail issue. He had ordered a book but unit staff said he could not have it. The advocate spoke with unit staff and the Superintendent. There was a misunderstanding of a new hospital-wide policy regarding ordering take out versus client's ordering items in the mail. The advocate was assured that client would get his book and that staff were educated on patient rights related to mail/packages.

• The advocates in one state hospital identified that basic rights issues were continuously coming up where both direct staff and patients were not aware of those rights. The advocates worked with the state hospital to create fact sheets that were available for both patients and staff on the units related to basic hospital rights.

• The advocate in the private hospital worked with the compliance department to ensure that the visitation policy of the hospital was following the state mental health regulations in relation to visitors.

• The advocate at one state hospital identified over time that it would be beneficial to monitor evening shifts in the hospital. The advocate had identified that certain patients were easier to meet with in the evening. Further, the advocate identified that as different staff were usually on the evening shift it allowed that advocate to monitor their treatment of patients. The advocate was able to assist some patients that they may have not otherwise helped with issues due to this difference in monitoring.

ADVOCATING FOR COMMUNITY RESOURCES

At the state institutions and private hospitals individuals can face barriers to discharge despite a determination that they are clinically ready for discharge. The staff advocates frequently are involved in negotiating solutions with community providers and the state mental health authority in order to effectuate appropriate discharges.

In both state institutions, the advocates attend a weekly discharge planning meeting with the social work departments and representatives from the Department of Health and Human Services. Many issues are discussed, including barriers to discharge facing individual clients. The advocates are a consistent voice in this meeting: promoting the rights of individuals and the mandate that individuals receive mental health treatment in the least restrictive setting. Many of the issues found in these meetings become individual cases; however, the advocates also refer individuals to other relevant legal resources, and simply amplify their voice in the planning process.

Some examples of issues the advocates have identified in discharge planning meetings Include:

• Identifying people who are deemed ready for discharge but do not want the hospital recommended placement and ensuring their voice is heard by their hospital treatment team.

• One specific issue involved a state hospital patient ready for discharge to a group home. An advocate intervened after hearing for three consecutive weeks the same status as prioritized, but yet not discharged. An acceptable explanation was forthcoming.

PROTECTING INDIVIDUAL RIGHTS THROUGH ADVOCACY

At both the state institution and the private hospital, the advocates are frequently involved in resolving some seemingly minor issues, which, if left unattended, can escalate. Advocates assist clients in making their voice heard on everything from environmental conditions to medical and medication issues to restrictions on basic rights. Additionally the advocates are continuously watching for issues regarding the use of seclusion and restraint.

Some examples of the issues addressed in the state institutions are:

• A state hospital patient reached out to the in-patient advocate prior to discharge. New sneakers ordered had not yet been received by the discharge date. Patient requested advocate to locate and arrange for sneakers be sent at address provided. The advocate immediately obtained status of sneakers. They were ordered with no follow up. The advocate requested follow up be pursued promptly and the item be mailed to the former patient. The advocate persisted with another follow up visit to ensure former patient received sneakers. Confirmation was received from the staff person that the sneakers were delivered.

• Talked with both staff and patient at a state hospital regarding a visitor who financially exploited the client during a visit. Provided staff with information regarding client's rights and spoke with client regarding her rights and options. Also reviewed notes/documentations to ensure the client's Representative Payee took proper precautions to cancel the client's debit card (which was stolen) and order a new one.

At the private institution a sampling of the issues addressed include:

• Working with the hospital team to apply for state funds so that a patient's car could not be sold by a towing company. It was his only asset, had value, and he was in danger of losing it due to it being towed when he was brought to the hospital. The funds were approved and his car was saved.

• Making sure an adolescent was able to make the request of her treatment team to have her sibling visit when her parents visited her. This request prompted a whole review of the hospital current practice as it turned out the unit practice was not in line with the regulations. The request was made to the individuals treatment team.

Recommendations

Please provide recommendations for activities and services to improve the PAIMI Program. Include a brief description of why such activities and services are needed. [42 U.S.C. 10824(a)(4)].

Se Impediments response.

Training Needs
Please identify any training and technical assistance requests. [42 U.S.C. 10825]

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Footnotes:

DISABILITY PRIDE MAINE DAY

WCSH NEWSCENTER MAINE (NBC AFFILIATE)

https://www.newscentermaine.com/article/news/community/fifth-annual-disability-pride-day-held-in-augusta-celebrates-accomplishments-and-diversity-inclusion-maine/97-f935ba2d-0cc4-461f-887b-9eb236dbadfc

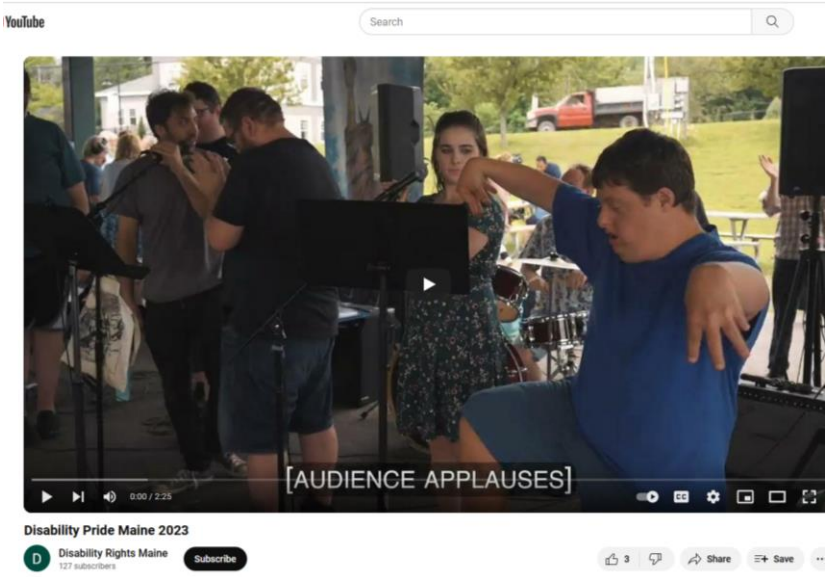
WABI NEWS (CBS AFFILIATE CENTRAL MAINE)

https://www.wabi.tv/2023/07/21/augusta-celebrates-disability-pride-month/

WGME NEWS (CBS AFFILIATE PORTALND METRO AREA)

https://wgme.com/news/local/mainers-mark-disability-pride-month-with-a-celebration

WFVX NEWS (FOX AFFILIATE BANGOR METRO AREA)



DRM Youtube Channel

https://www.youtube.com/watch?v=_lntDt5YRiQ

"I DON'T GET THE CARE I NEED":

EQUITABLE ACCESS TO HEALTH CARE FOR MAINERS WITH DISABILITIES

2023

DISABILITY RIGHTS MAINE

Acknowledgments

Disability Rights Maine (DRM) and JSI Research & Training Institute (JSI) would like to thank the hundreds of Maine residents with disabilities who participated in this assessment effort. Whether you responded to a survey, attended a focus group, or had a conversation with us—we are grateful that you entrusted us with your stories and experiences. We would also like to thank the Maine Health Access Foundation, whose funding and support made this project possible.

Last, but not least, we thank those who participated in this project's Steering Committee and Advisory Committee; your input and guidance were invaluable.

Steering Committee

Riley Albair
Jennifer Battis
Alan Cobo-Lewis
Lauren Michalakes
Kim Moody
Megan Salvin
Sara Squires
Meghan Ryan
Kevin Voyvodich

Advisory Committee

Nancy Cronin, Maine Developmental Disabilities Council
Maisy Cyr, Maine Family Planning
Sarah Gaffney, Brain Injury Association of America
Betsy Grass, AlphaOne
Jennie Kuhn, Health Equity Alliance
Simonne Maline, Consumer Council System of Maine
Terry Morrell, Maine Department of Labor
Jo Morrissey, Maine Shared Community Health Needs Assessment
Eileen O'Shea, Tufts University School of Medicine
Cheryl Peabody, Maine State Independent Living Council
Lane Simsarian, Disability Rights Maine
Monique Stairs, Speaking Up For Us
Jennifer Thompson, NAMI Maine
Carrie Woodcock, Maine Parent Federation

This report is available in alternate formats

Table of Contents

About Disability Rights Maine

Disability Rights Maine (DRM) is Maine's designated Protection and Advocacy (P&A) agency, a 501(c)3 organization authorized and mandated to protect and advocate for the rights of Maine people with disabilities. DRM's mission is to advance justice and equality by enforcing rights and expanding opportunities for people with disabilities in Maine.

DRM represents individuals whose rights have been violated or have faced discrimination based on their disability. Additionally, DRM offers training on rights and self-advocacy while actively advocating for reforms in public policies.

DRM believes that people with disabilities must:

- Be treated with respect and 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;
- Have equal access to the same opportunities afforded all people; and
- Fully participate in all aspects of society, including education, work, and community.

DRM is part of a nationwide network of disability rights organizations established by Congress to protect the rights of all individuals with disabilities.

Language Disclaimer

Language is a powerful tool that shapes meaning and understanding. This report uses person-first and identity-first language interchangeably to reflect the diverse ways the disability community identifies. Person-first language places the person before their disability. Identity-first language embraces disability as a fundamental aspect of one's identity and places identity first. For more information about combating ableism through language, we recommend the following:

- National Disability Rights Network: Communicating About People with Disabilities
- National Center on Disability and Journalism: Disability Language Style Guide
- Autistic Self-Advocacy Network: Identity-First Language

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Assessment Purpose

DRM has increasingly recognized the urgent need for advocacy to improve health care access and equity for people with disabilities. DRM has always handled cases that involve issues of health care access and equity, but, in recent years, cases have become more common and troubling. It has become clear to DRM that Mainers with disabilities face stark inequalities as they navigate Maine's health care system. Despite the lack of equity for people with disabilities in attaining the resources they need to achieve health and wellness, these issues are not rights violations that Protection and Advocacy agencies traditionally address. DRM knew they had to take action to shine a light on these dangerous problems.

> **The COVID-19 pandemic heightened the focus on inequities as people with disabilities grappled with challenges accessing testing, treatment, and vaccines. In certain instances, health care providers explicitly deprioritized them for life-saving care.**

In 2022, DRM 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. In doing this, one issue became glaringly apparent: there was a lack of data to characterize the issues that Mainers with disabilities face when seeking health care. DRM's Health Equity Work 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 in Maine.

While researchers have conducted numerous studies examining barriers and access issues from the provider's perspective, relatively few have focused on the direct experiences of people with disabilities and their encounters when navigating the health care system. DRM contracted with John Snow Inc. (JSI), a public health consulting and research organization, to lead this research project. The following report will hopefully result in meaningful change to improve access, choice, and health care quality for people with disabilities across Maine.

Background

People with disabilities are the largest minority group in the United States, with an estimated one in four adults (approximately 61 million) reporting a disability.[1] Disability crosses all age groups, gender identities, races, ethnicities, and social groups. Anyone, at any time, can join the ranks of disabled people, whether through an accident, illness, or the effects of aging.

Despite the common occurrence of disability, health disparities faced by individuals with disabilities remain highly prevalent and largely unaddressed. Socially disadvantaged populations experience preventable differences in the burden of disease, injury, violence, and opportunities to achieve optimal health, known as health disparities.[2]

Health disparities for people with disabilities are wide, varied, and impact all aspects of life. It is well-documented that, compared to those without disabilities, people with disabilities are:

- Significantly more likely to have unmet medical, dental, and prescription needs;[3]
- Three times more likely to have arthritis, diabetes, or a heart attack;[4]
- Five times more likely to report a stroke, chronic obstructive pulmonary disease, or depression;[4]
- Less likely to receive a pap smear or mammogram;[5] and
- More likely to have a lower life expectancy.[6]

People with disabilities are also more likely to be denied health care than people without disabilities, and face unique barriers and stigma when accessing health care. Women with disabilities are more likely to receive poor maternity care, experience severe pregnancy and birth-related complications, and are eleven times more likely to experience maternal death.[7,8,9,10] Additionally, people who are Deaf or hard of hearing are three times as likely to report being in fair or poor health compared to those who are not Deaf or hard of hearing.[11] Living in a rural area increases the barriers to accessing health care, and for people of color with disabilities, the disparities are even further compounded.[12,13]

Disabled people also encounter unique systemic and policy-level barriers that impact their health care. The rare inclusion of disability status in demographic data renders it nearly impossible to analyze disparities and outcomes for individuals with disabilities within federal, state, and local data sources. Inaccessible offices and medical equipment hinder the entry of people with disabilities into physical spaces to receive care, and health care providers callously deny procedures to disabled individuals when accessible medical or diagnostic equipment is unavailable. Limited provider training and awareness of disabilities results in a lack of clinical knowledge and comfort in treating such patients.

Stigma and bias also play a role. In a 2021 survey of 714 practicing physicians across the United States, 82% reported that people with significant disabilities have a worse quality of life than people without disabilities, and only 56% strongly agreed that they welcomed patients with disabilities into their practice. Only 41% of these physicians felt confident in their ability to provide the same quality of care to patients with a disability as they could to patients without a disability.[14]

Other complex, widespread, and long-standing social inequalities are inextricably linked to the health disparities experienced by disabled people. For example, people with disabilities have fewer years of education,[15] lower rates of employment,[15] higher rates of poverty,[15] more transportation barriers, lower rates of vehicle ownership,[16] and higher rates of housing insecurity.[17]

Inequities are compounded when other systems of oppression are layered upon disability. For example, women with disabilities experience more significant income, educational, and employment related disparities. Individuals who identify as both disabled and as part of the LGBTQIA+ community also face additional barriers that exacerbate structural disadvantages.

The onset of the COVID-19 pandemic amplified many of these issues. The exclusion of disability status from federal and state health care data collection efforts resulted in policymakers and researchers being unable to gather precise information about the effects of COVID-19 and the healthcare disparities experienced by individuals with disabilities. People with intellectual or developmental disabilities, often medically fragile or dependent on technology, faced a higher risk of being triaged out of COVID-19 treatment when hospital beds, supplies, and staff were scarce.[18] Crisis Standards of Care often targeted people with specific disabilities to be denied care during COVID-19 surges. People who lived in group homes, nursing homes, psychiatric facilities, and other institutions contracted COVID-19 and died from the virus in higher numbers, yet people with disabilities and chronic health conditions, including those in group homes, were not recognized as priority populations when vaccines were first made available.[19] Even in Maine, people with disabilities were not prioritized in vaccine distribution plans.[20] A 2021 report found that intellectual disability was the single strongest predictor for COVID-19 infection and the second strongest predictor for COVID-19 death.[21]

The need to act is clear. These disparities highlight the urgency of improving the health care system for people with disabilities and preventing a future pandemic response that repeats the same failures. Building a system that reduces barriers and disparities is possible. However, to do so, we must focus on achieving health equity.

Health equity is the principle that every person should have a fair and just opportunity to attain good health and well-being, regardless of race, ethnicity, socioeconomic status, disability, education, or geography.[22] Achieving health equity requires recognizing that some groups of people, including those with disabilities, face systemic and structural inequalities that result in unequal access to health care and reduced health outcomes. These realities compel us to act to identify and address these disparities through policies and practices. Maximizing individual health enables people with disabilities to lead independent and fulfilling lives.

> **DRM believes that the information gathered in this report is an essential step in identifying the barriers that disabled Mainers face in accessing health care, and offering solutions to improve access and quality of care.**

Approach & Methods

Overall Approach

This assessment utilized a mixed-methods approach that integrated quantitative and qualitative data to understand the leading barriers to care for Mainers with disabilities. The effort focused on compiling information through extensive community engagement activities, as described below.

Collection of Literature and Secondary Data

With the assistance of JSI, DRM collected relevant and timely research to characterize access to care and equity issues for people with disabilities in Maine and throughout the United States. Through this research, it became clear that the problems individuals face in Maine are common. However, our population faces distinct challenges because of the state's rural geography and older population.

The literature cited in this report includes articles in professional journals, reliable print sources (e.g., established newspapers), and statistical data from government websites and reports.

Health Care Access Survey

The Health Care Access Survey was developed jointly between DRM and JSI. It intended to gather information directly from Mainers with disabilities to better understand the barriers they face when seeking access to health care and interacting with providers.

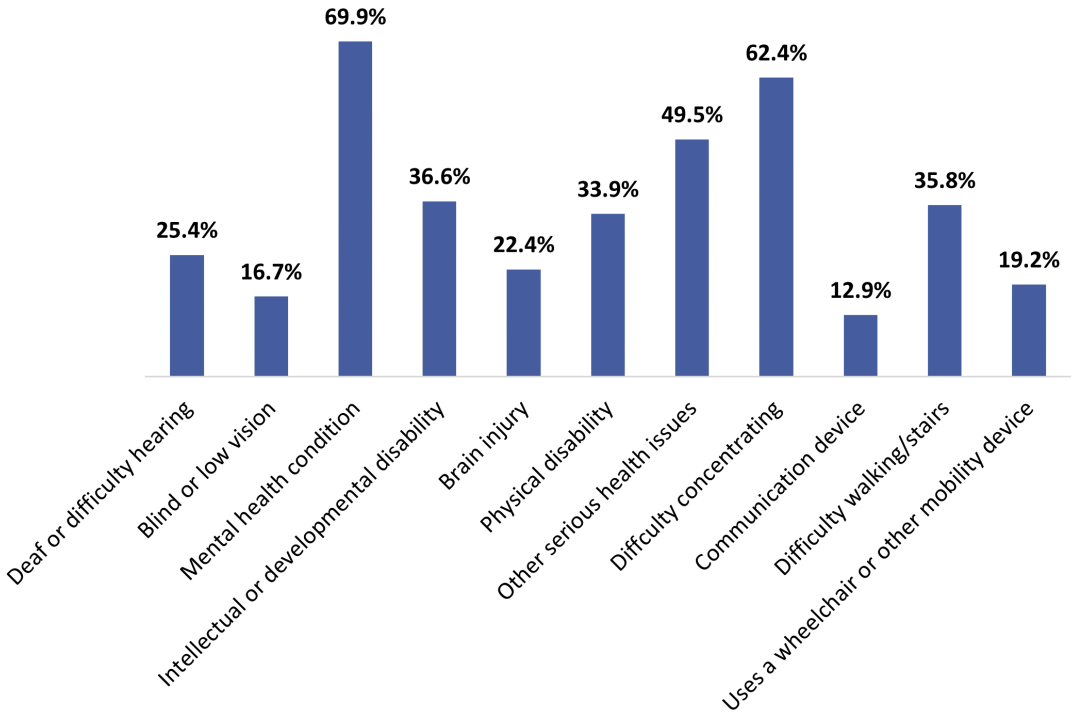
The survey was available in both web-based and paper formats. Two web-based versions were available: one in English and one in American Sign Language (ASL). The ASL version of the survey included accompanying videos for each question, with a Certified Deaf Interpreter signing questions and potential answers. Interpretation in other languages was available upon request. Though there were limited requests for direct assistance, DRM staff were available to assist individuals taking the survey.

The survey was launched in November 2022 and remained open until the new year. During the dissemination phase, DRM made significant efforts to distribute the survey throughout the state to reach a diverse range of respondents, considering factors such as their location, disability type, age, housing status, income, and life experience. Hundreds of organizations helped to distribute the survey to their clients, patients, residents, colleagues, and others. After data cleaning, the final survey count was 598 responses.

Survey results were organized based on various factors, such as the specific types of disability people had, their age, income, living situation, and their health insurance coverage.

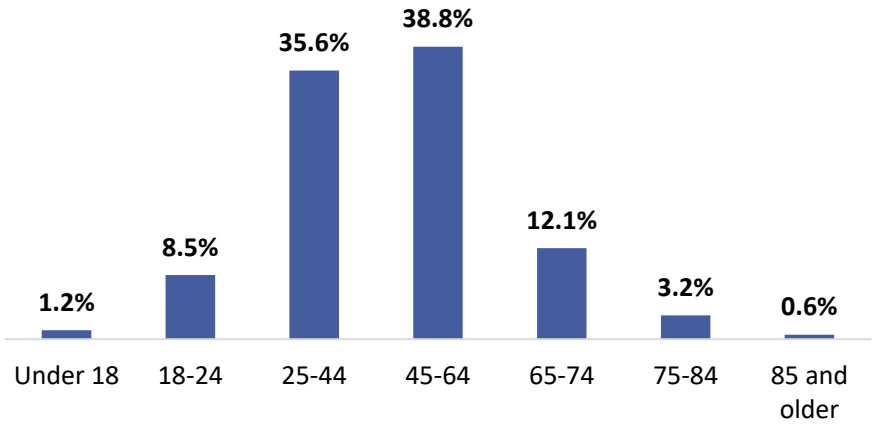
Survey respondents represented a diverse range of disabilities. Respondents could identify across multiple disability categories, in recognition of the multifaceted experiences and intersectionality across disability types.

Figure 1: Percent of Survey Respondents by Disability Type



Survey responses were highest among the 45-64 age cohort.

Figure 2: Percent of Survey Respondents by Age



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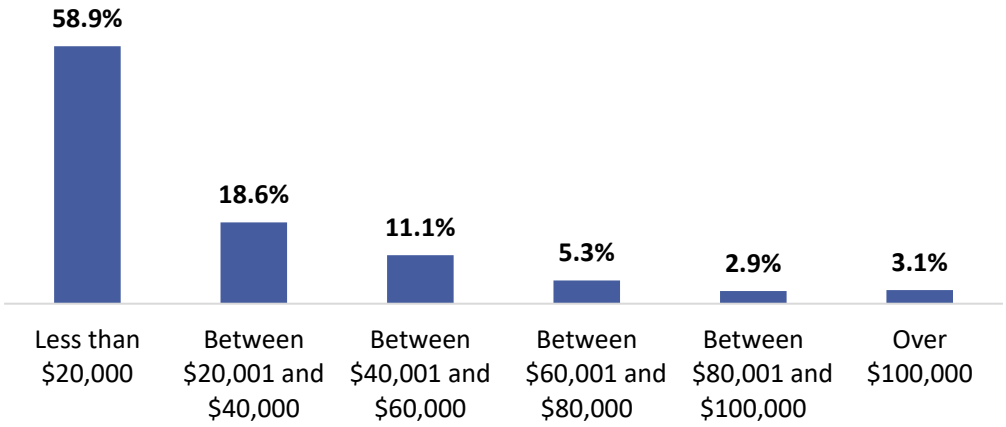
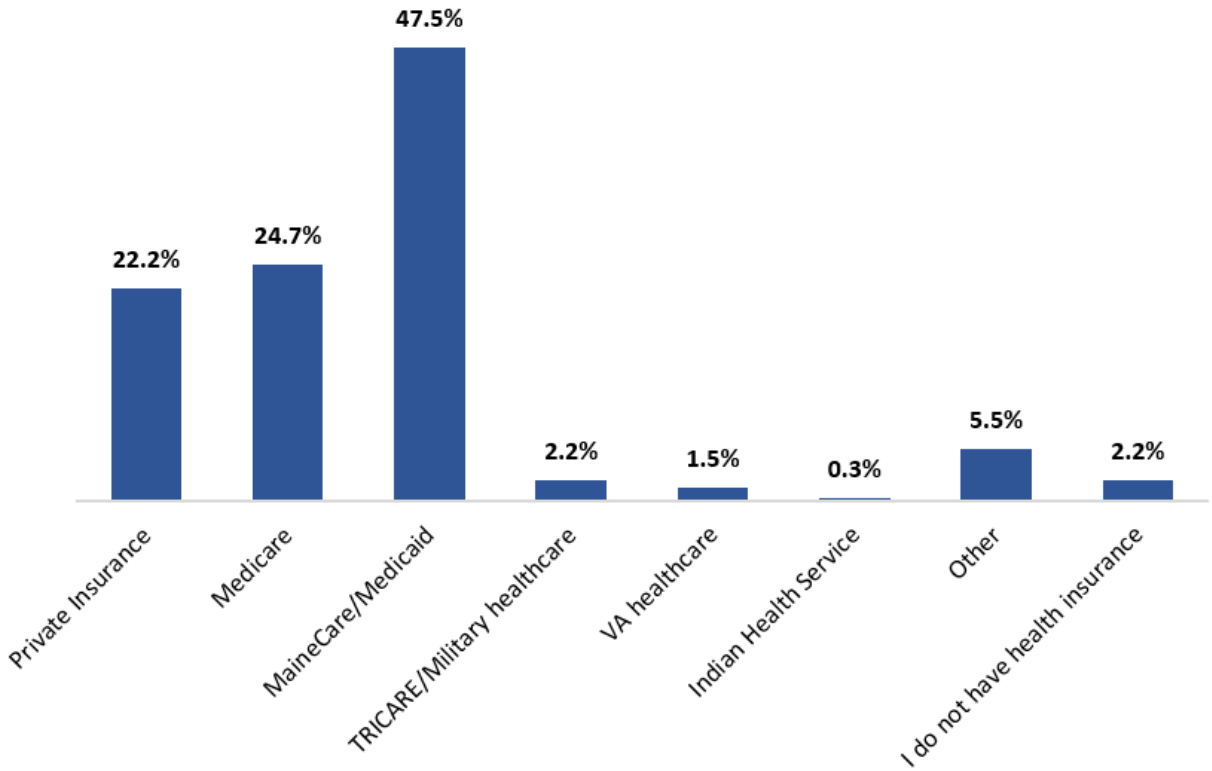
Nearly 60% of survey respondents reported that their annual income was less than $20,000.

Figure 3: Percent of Survey Respondents by Annual Income



Nearly half of the survey respondents (48%) were insured through Mainecare/Medicaid.

Figure 4: Percent of Survey Respondents by Type(s) of Health Insurance



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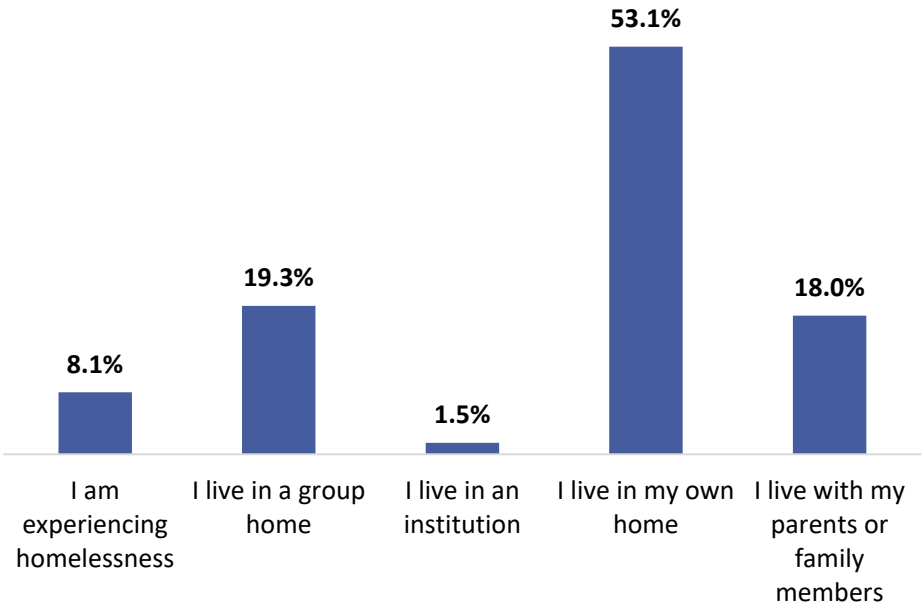
Most survey respondents (53%) reported living in their own homes.

Figure 5: Percent of Survey Respondents by Living Situation



Appendix A of this report contains the full survey text, a summary of results, and direct quotes from open ended responses.

Focus Groups and Open Forums

In addition to the survey, nine focus groups and two open forums were conducted as part of this assessment. Focus groups allowed for the collection of critical input from small groups based on disability type, with an emphasis on providing a forum for individuals to share their personal experiences. Open forums were marketed broadly and were available for anyone with a disability to attend. DRM organized focus groups in collaboration with community organizations, advocacy groups, and individuals who worked closely with the target cohorts. Focus groups were conducted virtually and in-person, depending on the communication needs of each group. A focus group guide is included in Appendix B. Key themes and quotes from focus groups and open forums are included throughout this report.

Focus group cohorts

- Blind or low-vision
- Deaf or hard of hearing
- Individuals with a mental health diagnosis or label
- Youth
- Physical disabilities
- Brain injuries
- Individuals with a label or diagnosis of an intellectual or developmental disability
- People with dementia
- Family members and caregivers of people with disabilities

Stakeholder Interviews

The approach to conducting stakeholder interviews encompassed a deliberate effort to acknowledge the experience of historically marginalized populations. Acknowledging the substantial time needed to establish trust, DRM embarked on a mission to enhance relationships with immigrant, tribal, and other communities across Maine. This effort focused on engaging the organizations and individuals who work closely with these populations. Through five one-on-one stakeholder interviews, DRM sought to catalogue experiences and gain insights into the challenges encountered when seeking and accessing care. Furthermore, DRM recognizes the importance of addressing the specific barriers and considerations faced by individuals living with HIV/AIDS. By engaging in conversations with experts, DRM obtained contextual information that deepened their understanding of the health care landscape in Maine.

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Key Findings and Recommendations

This report has organized findings into five priority areas:

- Data Collection
- Provider Education
- Barriers to Care
- Communication
- Physical Spaces

Within each priority area are three sections. The first section contains background information drawn primarily from the literature. The second section focuses on key findings and highlights information from this assessment's efforts, including secondary data, focus groups, the Health Care Access Survey, and stakeholder interviews. The third section includes a table of recommendations and potential strategies to address issues within these priority areas. Appendix C provides a list of recommendations and strategies organized by the type of entity that would be responsible for implementation (e.g., policymakers, health care organizations, etc.).

Priority Area 1: Data Collection

Background

Unlike race, ethnicity, and age, disability status is not a standard demographic question, which creates a global lack of data on people with disabilities. The inadequate data contributes to an underrepresentation of disabilities in official statistics, causing policymakers to frequently disregard the needs of this population. Moreover, the lack of data poses challenges in identifying these needs, resulting in a scarcity of comprehensive programs and services to address them. This absence of data also makes it difficult to monitor progress or challenges over time. Given the substantial disparities in health care access, quality, and outcomes experienced by individuals with disabilities, it is imperative that data collection efforts capture their unique experiences and characteristics.

In the United States, many federal agencies track disability data, including the Department of Health and Human Services, the Social Security Administration, the Centers for Disease Control and Prevention, the Department of Justice, and the Department of Labor. The US Census Bureau also collects information on people with disabilities through various surveys. Though these efforts are essential, they are limited by gaps in specific tabulations, varying approaches to classifying disability types across agencies, and poor engagement with the population of people with disabilities. It is critical that future data collection efforts, at both the federal and state levels, involve people with disabilities in data collection processes to ensure inclusive samples and address historical disparities.[23]

The nature of disability is diverse and complex, and individuals experience disability uniquely. The absence of a standard definition of disability in data collection efforts can cause several problems. It can lead to inconsistent and incompatible data, underreporting of disability, limited understanding of the needs and experiences of people with disabilities, and inadequate policy reform and resource allocation. While it would not be possible to create a universal definition, disability status should be a standard demographic question, and should be asked in a way that makes data more comparable across data sets.

Additionally, many data collection efforts rely on individuals to self-report. Individuals may be reluctant to report their disability or diagnosis for fear of discrimination or disparate treatment.[24] A survey of over 3,500 adults in the United States working in "white collar" positions found that 30% have disabilities, but only 3% self-identify to their employer.[25] The "visibility" of a disability significantly impacts data collection efforts and an individual's experience in life, health care settings, education, and the workplace. In the same survey, 44% of respondents with a visible disability reported that they had experienced negative bias or discrimination at their companies, compared to 30% of those who defined their disability as invisible.[26]

When looking at the available data describing people with disabilities living in Maine, US Census Data for 2017-2021 shows that 16% of Maine's civilian non-institutionalized population (211,861 people) had one or more disabilities.[27] This proportion was higher than that of the United States, where an estimated

13% of residents had a disability. Piscataquis County, the least populated county in Maine, has the highest percentage of people with disabilities (26%). The following highest counties are Washington County (23%), Aroostook County (22%), and Somerset County (20%).[28]

The most common types of disabilities in Maine are:

- Ambulatory difficulties (7%);
- Cognitive difficulties (7%);
- Independent living difficulties (6%);
- Deaf or hard of hearing (5%);
- Self-care difficulties (3%);
- Vision difficulties (2%).[29]

It is important to note that the demographic data presented in this report pulls from the US Census Bureau's American Community Survey. Because of the survey design, estimates of disability characteristics draw from smaller sample sizes, which results in higher margins of error (the degree of uncertainty results may have). Higher margins of error mean that data is less reliable in smaller geographies (e.g., counties), especially when looking at data for subgroups (e.g., race and ethnicity).[30]

Key Findings

A scoping literature review found that the lack of representation of disabled people in public health data collection leads to a lack of understanding of their health needs and experiences. There are several challenges to collecting accurate and representative data on disability and health, including issues related to survey design, access to health care, and stigma and discrimination. Efforts to improve data collection and analysis on disability and health are necessary to address health disparities among people with disabilities.[31]

During the data collection process conducted as part of this project, it became apparent that there is a lack of data and data repositories available to accurately represent the total population of individuals with disabilities in Maine. For instance, the Maine Immunization Registry does not track disability status, resulting in a local example of data exclusion. This lack of data has made it challenging to monitor equity and access concerns related to the COVID-19 vaccine for people with disabilities, and actual vaccination rates remain unknown.

People with disabilities experience disparities in health behaviors, outcomes, and chronic disease risk factors. Individuals with disabilities were more likely than those without disabilities to have depression, smoke tobacco, have diabetes, and have heart disease.[32] Individuals with disabilities have a higher prevalence of chronic and secondary health conditions, higher rates of mental health conditions or labels, lower rates of engagement in preventive care, and experience more frequent barriers when accessing health care services. Additionally, research suggests that individuals with disabilities who belong to marginalized racial or gender groups experience compounded health disparities. Addressing

these disparities is crucial to achieving health equity and improving the overall health outcomes of people with disabilities.[33,34,35]

Recommendations

Recommendation	Potential Strategies
Make disability status a standard demographic indicator in data collection and surveillance efforts.	Establish rules and guidelines for all state-funded grants and surveillance efforts to include disability as a demographic indicator.
	Require self-reported disability status as part of standard demographic information collected in electronic health records.
	Tie state Medicaid and block grant funding to substantive evidence of health equity for people with disabilities.[36]
	Improve the quality of disability data through cross-agency collaboration on data collection/sharing to include standardized questions on disability.
Data on individuals with disabilities should be relevant, up-to-date, and accessible.	Establish a data dashboard that holds all state-wide data associated with health equity and disability in one place, similar to the Maine Statewide Epidemiological Outcomes Dashboard.[37]
	Develop annual reports that compile data from all statewide sources.
	Engage in feedback loops that prioritize community engagement in all steps of data collection, analysis, reporting, and dissemination processes.
Individuals with disabilities must be represented in public health surveillance efforts.	Ensure that individuals with disabilities are represented statewide and on state-level advisory councils to direct statewide guidance related to health care planning, health equity, and assessment processes.
	Advocate for better representation of people with disabilities in national surveillance efforts, such as the Behavioral Risk Factor Surveillance System (BRFSS) and the American Community Survey (ACS).
	Require that surveillance efforts engage individuals with disabilities residing in group homes or other institutional placements.

Priority Area 2: Provider Education

Background

This section will provide background, findings, and recommendations regarding the lack of clinical knowledge and cultural competency among health care providers. This issue significantly and adversely impacts the quality of care that disabled people receive.

Despite calls from the US Surgeon General, the World Health Organization, and the American Association of Medical Colleges for increased training on treating people disabilities, there are no specific requirements for US medical schools to teach about disabilities. Research has found that only half of US medical schools report having any disability awareness program as part of their curriculum.[38,39] A 2015 study stated that "every major report addressing the poor health of people with disabilities has called for improvements in the training of health care providers about adults with disabilities," highlighting the overwhelming need for provider training that focuses on improving care for people with disabilities.[40]

Through numerous studies, including this one, people with disabilities have reported experiences that illustrate the negative impacts of this lack of education and training. People with disabilities report that providers hold biases and are hyper-focused on their disabilities rather than the health concern they're being seen for. Disabled people also report that they have to educate providers about the basics of their disability.[41]

In health care, disability has traditionally been approached from the medical model perspective. This model views disability as a product of biology and a departure from a "normal" structure or functioning. This perspective assumes a need to "fix" or reduce the effects of disability on individual functioning, with a near-exclusive focus on deficits and negative impacts on the lives of people with disabilities. These assumptions lead to biases, stigma, and the belief that the lives of people with disabilities are lower in quality and, therefore, less valuable.[42] Alternatively, many people with disabilities prefer the social model, which recognizes that the most significant barriers that people with disabilities face are the environments and societies in which people live and interact.[43]

Without sufficient education and training on disabilities, providers lack both clinical knowledge about disabilities and the wide variety of ways people can experience or have their health impacted by their disability. The can cause immense harm. Misdiagnosis or delayed diagnosis of health issues can cause unnecessary suffering and worsen existing health problems.[44] Health care providers must take the time to educate themselves about disabilities and work to provide compassionate care to all of their patients. Lagu et al.'s 2022 study described instances where providers denied care or

> **Research has shown that for individuals with disabilities, interacting with health care providers who don't understand their disability can make them feel ignored, isolated, and even afraid to seek the care they need.**

discharged people with disabilities from their practices. As an example of an instance where providers deferred care for patients with disabilities, one primary care provider who participated said, "We talk to the caregiver or the patient or whatever, and just explain to them that it is very unlikely that they are going to develop cervical cancer." Study participants reported that they knew they could not outright deny someone care due to their disability, but would find reasons to justify why they were not the best person or best practice to provide care. Some providers who participated in the study reported telling patients that they needed more care than the practice could offer, or would tell prospective patients with disabilities that they were no longer accepting new patients.

> "I think the problem is that you cannot refuse them [patients] straight. We have to give [patients] an appointment. You have to come up with a solution that [tells the patient] that this is a small facility, we are not doing justice to you, it is better [that] you would be taken care of in a special facility."
> **– Lagu et al., 2022**

There is also a need for providers to develop greater cultural competency with disability. Culturally competent care involves being able to communicate effectively with people and being able to work with them in a way that is inclusive and respectful.[45] Though it is often discussed in the context of race, ethnicity, and religion, cultural competency is a crucially important factor in treating people with disabilities, as it is with all population groups that are at risk for stigmatization or face health disparities.[46] The results of Lagu et al.'s 2022 study supports this need. Physicians who participated in the study described a lack of clinical knowledge and negative attitudes towards people with disabilities, often mentioning they were scared they would hurt themselves or their patients when providing care.[47] Many of the study participants said that providing accommodations for people with disabilities was burdensome.

To create a health care environment that is culturally competent for people with disabilities, providers must learn how to communicate and interact comfortably with patients. It is also crucial for health care providers to understand and identify common biases and stigmas related to disability that can negatively impact patient care, such as the belief that people with disabilities cannot speak or make decisions for themselves, are asexual, or have a lower quality of life. Further, studies have shown that providers' biases and hesitance to care for people with disabilities perpetuate health care access and outcome disparities.[48]

The COVID-19 pandemic exacerbated existing health disparities experienced by people with disabilities, particularly those from historically marginalized communities. People with disabilities are more likely to have underlying health conditions, which put them at higher risk for severe illness or death from COVID-19. Additionally, many individuals with disabilities face barriers to accessing health care, including testing and vaccinations, due to inaccessible testing sites or lack of accommodations. There were also challenges faced by people with disabilities in accessing information about the pandemic. Many public health messages and resources were not accessible. Video materials were often not captioned, and materials were rarely provided in ASL.

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The lack of accessible information meant that people with disabilities may not have been able to fully understand the risks associated with the pandemic or how to protect themselves.[49,50,51]

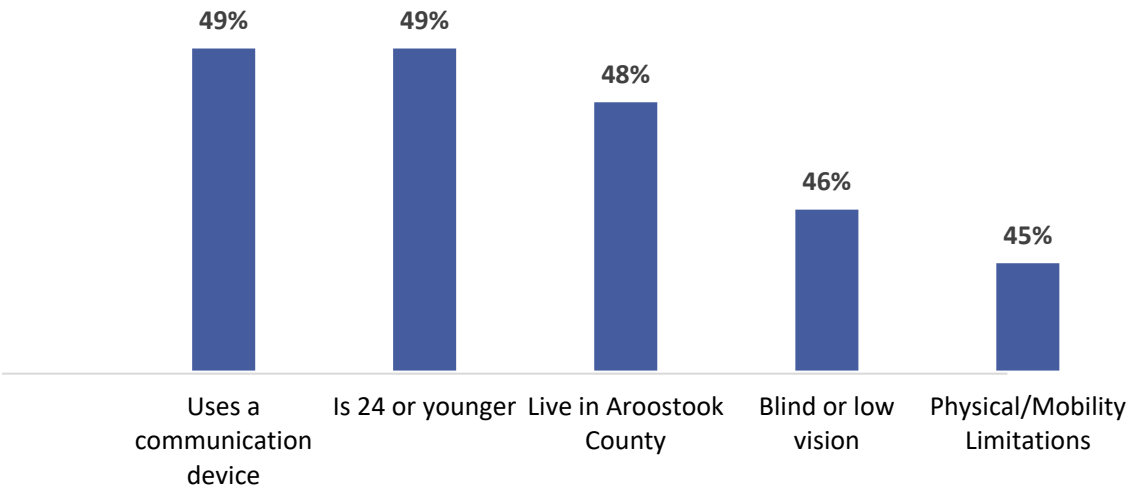
It is also crucial to highlight the significant incidence of trauma among individuals with disabilities, and the importance of utilizing a trauma-informed approach when providing treatment. Trauma—an experience or response that comes from an event, ongoing series of events, or circumstances that are physically or emotionally harmful or life-threatening to a person—can have lasting effects on mental, physical, social, and spiritual well-being and functioning.[52,53] The trauma-informed care approach recognizes that some individuals, including people with disabilities, are at a higher risk of experiencing trauma due to various factors, such as social isolation, discrimination, and power disparities in relationships. This approach also recognizes the need to fully integrate knowledge of trauma and its impacts into policies and practices. The primary objective of trauma-informed care is to promote a culture of trust and safety between the provider and patient, where the unique experiences and needs of the patient are acknowledged and respected.[54]

Key findings

Clinical Knowledge

Approximately 38% (n=203) of Health Care Access Survey respondents reported that they did not think doctors and medical staff were adequately trained and prepared to treat them in medical settings. Looking across survey results, percentages were highest among younger people, individuals in Aroostook County, and those with certain disability types or characteristics (Figure 6).

Figure 6: Percent of Survey Respondents Reporting They Did Not Think Medical Staff Were Properly Trained and Prepared to Treat Them



Participants in the focus groups and survey conveyed encounters that demonstrated how health care providers, particularly primary care practitioners, lacked clinical education and practical experience in treating those with disabilities. Participants acknowledged that this lack of education was often unintentional by providers, but nevertheless, expressed frustration with the providers' inadequate understanding of even the fundamental aspects of their care.

Participants in focus groups and the Health Care Access Survey expressed the need to continually educate their primary care providers about the specific nuances and details of their disabilities or chronic illnesses. Many participants reported encountering frequent provider turnover, resulting in the need for repetitive and ongoing education. One participant mentioned that their provider "barely knew more than what a basic Google search would tell them." Several individuals conveyed that the frequent turnover of physicians dissuaded them from attending their appointments. They experienced a sense of discouragement as soon as they started developing a level of comfort with a provider, only to have them depart, thereby necessitating the initiation of the process anew with a different provider.

A significant number of participants expressed the perception that providers held preconceived notions about their body or health condition solely based on their disability, even prior to meeting or conducting a thorough examination. While these assumptions were not meant to be malicious, they felt dismissive, and participants felt this was coming from a lack of understanding or awareness. Participants described situations where they felt "pigeonholed" based on their disability. Participants also said that getting an accurate diagnosis for their symptoms was often a long process.

The participants' comments in the focus groups and survey consistently highlighted instances where their doctors expressed a lack of knowledge about their medical condition or were unfamiliar with necessary treatments. People with disabilities often reported feeling like their providers were talking down to them and not listening.

> "The constant dismissal of my concerns as if I am not the one living in this body is incredibly frustrating. I want to be treated as at least somewhat of an expert on my experiences. I deserve to have my concern matched as well. If I'm worried about something and am met with a noncommittal response, that is stressful and disrespectful, in my opinion. I want to be treated as though I understand what is going on."
> **– Health Care Access Survey respondent**

Numerous participants in the focus groups highlighted instances where providers exhibited reluctance to engage in a collaborative relationship. They expressed concerns about providers not allocating sufficient time to listen to their needs and preferences, failing to present options, and disregarding their input in treatment decisions. Participants conveyed a sense that providers sought expedient solutions or answers, avoiding thorough investigation and inquiry into complex issues. Focus group participants felt providers treated patients like they were all the same. Similarly, survey respondents frequently stated they felt their providers were not reading their charts to understand what diagnoses, disabilities, or chronic health issues they had and that they overly relied on specialists for any discussion of chronic health conditions. One survey respondent expressed frustration with their primary care provider, saying, "My primary care provider not only had no idea of how to diagnose me,

but also had no idea of how to treat my symptoms. Now that I have a specialist, they don't even talk to me about my disease even though it is important in my regular care."

> "It would be really nice if more providers were required to have education on brain injuries and other disabilities. There are a lot of providers who know nothing about brain injuries. Some [providers] dismissiveness is not malicious. It's just that they do not know."
> **– Focus Group participant**

> "My PCP is good at listening, but they can't answer a lot of questions because I have very specialized needs related to my injury. I'm scared about having a serious event happen where I need care, and more generalist providers may not understand my very specific needs."
> **– Focus Group participant**

> "I have been through the gamut. I've experienced it all. Most places have no idea what to do when a Deaf person walks in. Some places are compassionate, and some places have no idea. They need so much education. If the shoe was on the other foot, imagine how they would feel, relying on lip reading or writing everything out - especially with medical terminology. For me as a mother, it's already a stressful dynamic there, with my son. A lot of providers don't understand disabilities in general. Of course, there are access issues being Deaf, but when you have added other disabilities, that lack of awareness on the part of the provider is really difficult. It's tenfold when you have additional disabilities."
> **– Focus Group participant**

Yet another concern raised repeatedly was that of health care providers not believing people with psychiatric labels or diagnoses. Individuals reported that providers often dismissed physical health issues and focused solely on their psychiatric label. Participants frequently mentioned that they felt that their mental health or substance use label was prioritized over any physical issues they were experiencing. One survey respondent summed up numerous participants' feelings when they stated, "The separation of body and mind treatments create worsening mental health and physical health problems."

Participants also reported that providers often made assumptions about their limitations and ability to comprehend information. For example, three focus group participants described experiences where their doctors did not provide information about their diagnoses, why they were prescribing certain medications, or what possible side effects of medication might be. One focus group participant mentioned feeling like a "guinea pig" regarding medication, not knowing how they would react to side effects. Participants often shared that they were recommending testing and treatment to their physicians.

One survey respondent stated the need for health care providers to have more education and experience working with historically marginalized populations, including people of color and immigrants, saying that this lack of understanding, "can lead to misdiagnosis because there is no knowledge of the important cultural practices (e.g., lack of eye contact is interpreted as a mental health condition or

there is little understanding of the way that non-white bodies grow and develop)." A conversation with an organization that addresses the needs of individuals living with HIV/AIDS further illuminated the need to address issues of cultural competency in health care, as culture plays a significant role in shaping individuals' beliefs, attitudes, and expressions of pain. An extensive body of research supports the belief that there are substantial disparities in health care access and outcomes by racial and ethnic groups.[55]

> "Health care in Maine is shaped by a culture steeped in white Puritanical patriarchy. It's very much a culture of "get outside, drink some water" and bootstraps. There's a constant barrier to getting care when providers lack even basic information, and worse, curiosity, about their client's condition(s). The cultural expectation here remains one of 'we don't talk about things that make folks uncomfortable.' And if you're not white, getting appropriate and compassionate and inquisitive care here must be like navigating hell. There is a dearth of trauma-informed care, and care is stingy and withholding to anyone lacking economic resources. Maine overall, from its lack of infrastructure, its inherent ruralness, and its aging architecture, is inaccessible to most of its aging and poor population."
> **– Health Care Access Survey respondent**

Cultural Competency

Approximately 27% (n=140) of the Health Care Access Survey respondents reported that health care providers do not respect them. When asked to elaborate on the reasons, 18% (n=105) said that providers do not consider their needs and experiences, and 16% (n=96) said they do not listen to or take their concerns seriously. The focus group attendees echoed the sentiments expressed by the survey participants. Many participants shared that in addition to a lack of knowledge on how to treat people with disabilities clinically, health care providers made little effort to comprehend their experiences. Participants suggested that providers engage more directly with people with disabilities to enhance their cultural competency and understanding.

> "The problem is not always about access to care – it's competent care."
> **– Focus Group participant**

Focus group participants frequently expressed the belief that health care providers, and the health care system as a whole, view people with disabilities as being less than a "whole person." Participants mentioned feeling like their providers were uncomfortable providing a complete examination and were

resistant to touching or moving their bodies. One survey respondent said that providers seem afraid of their disability and chronic health issues. Both survey and focus group participants also reported that health care providers often belittle or dismiss their concerns. The issue was particularly significant for individuals with mental health diagnoses or labels and individuals with intellectual or developmental diagnoses or labels, who said that health care providers used their diagnoses to disregard their concerns. Further, several participants raised concerns about the presence of fatphobia within the healthcare system, and described instances where providers perceived obesity as a moral failing rather than recognizing it as a medical condition.

> "As a fat person, I routinely feel like I have to convince doctors – of all kinds – that my pain is real and not always related to my weight."
> **– Focus Group participant**

> "They [providers] see me as an anxious patient, and they don't listen to me. It's the most irritating thing I've ever experienced. I have alopecia, and my hair falls out – they haven't been able to pinpoint why that is. It has taken three years of me advocating for support and not getting that support. I asked to see a specialist, and they said I couldn't. They blame everything on my mental health, and that I'm anxious."
> **– Focus Group participant**

Focus group participants expressed the need for more health care providers to adopt a trauma-informed care approach, particularly for people with disabilities. Recognizing and acknowledging that many people with disabilities have experienced discrimination and trauma from health care providers and other "trusted" individuals is crucial in providing culturally competent care. The desire for trauma-informed care and a demonstrated understanding of how post-traumatic stress disorder (PTSD) can affect people within a clinical setting was expressed repeatedly.

Additionally, multiple participants mention a need for gender-responsive and trans-competent health care. The importance of providing care that treats the whole person, including their many identities, cannot be understated.

To provide care using a trauma-informed approach, providers and administrators should ensure the following six principles, as defined by the Substance Abuse and Mental Health Services Administration (SAMHSA), are in place within their practice:

1. **Safety**: ensure that physical and psychological safety is a priority;

2. **Trustworthiness and Transparency**: provide transparency in the operations and decisions made at all levels of the organization or practice;

3. **Peer Support**: establish opportunities for individuals to connect with others who have a shared lived experience;

4. **Collaboration and Mutuality**: recognize the power imbalance between staff and patients or clients and provide meaningful opportunities to share power in the decision-making process;

5. **Empowerment, Voice, and Choice**: provide opportunities for patients to have a say in all levels of care;

6. **Cultural, Historical, and Gender Issues**: as a practice, recognize stereotypes and biases that have historically impacted the work, work towards addressing the biases, offer access to cultural- and gender-responsive care, and develop policies, processes, and procedures that address systemic and historical inequity.[56]

> "They [providers] do not understand or provide trauma-informed care. They make assumptions and generalizations that do not apply to me."
> **– Health Care Access Survey respondent**

> "I've faced such chronic shame that if I go to a medical professional and feel like they are shaming me in any way, I will not return. As a trans person, I have to find care that is trauma-informed and competent."
> **– Focus Group participant**

Recommendations

Recommendation	Potential Strategies
Ensure that individuals with disabilities are represented as decision-makers and subject matter experts in spaces where education and training curricula are established.	Establish guidance for hospital systems to include people with disabilities within their Diversity, Equity, and Inclusion efforts and patient and family advisory boards.
Train health care personnel to provide comprehensive and high-quality care to patients with all types of disabilities.	Implement licensing requirements that include ongoing provider education about providing care to individuals with disabilities.
	Embed requirements for direct service/practice experiences with individuals with disabilities in health care training and continuing education programs.
	Require that didactic education in health care fields include content on a range of disabling conditions and human responses.
	Continuing education on working with people with disabilities should be available and encouraged.
Increase the number of individuals with disabilities employed in health care settings.	Pilot programs that support individuals with disabilities to enter the healthcare workforce.
Improve the quality of care for people with disabilities.	Require that health care organizations provide disability specific training on an annual basis.
	Require that health care providers complete all routine aspects of care for people with disabilities (e.g., asking about mental health, substance use, and sexual health).
	Incorporate trauma-informed care approaches at all points of contact.

Priority Area 3: Structural and Systemic Barriers to Care

Background

Systemic barriers can make it difficult, or even impossible, for people with disabilities to access care. This section will discuss systemic barriers related to the costs of care and health insurance, the complex nature of the American health care system, and transportation.

People with disabilities often face economic disadvantages, due to discrimination in the workplace and other areas of life, that make it challenging to find and keep jobs. Policy failures have resulted in inadequate affordable housing and transportation options, difficulty accessing education and training, and health issues that may interfere with work.[57,58] In Maine, the unemployment rate for people with disabilities is 11%, more than double that of those without disabilities (4%). The median household income for people with disabilities is $36,000 compared to $62,000 for people without disabilities.

People with disabilities are nearly three times more likely to live in poverty than people without disabilities.[59] A contributing factor to this is the intersection between employment and health insurance. With lower employment, fewer people with disabilities can access employer-sponsored health plans. In addition, many people with disabilities require ongoing access to certain services necessary to live independently in the community, typically only available through MaineCare, Maine's version of the federal Medicaid program. MaineCare is a needs-based program with various income and asset limitations that impact eligibility. While MaineCare does offer the MaineCare for Working People with Disabilities, this too has income and asset limitations.[60] For people with disabilities who require MaineCare services to live independently and in their community, they must maintain eligibility for necessary services not offered through Medicare or private health insurance plans. This does not have to be the case. Maine could change the MaineCare for Workers with Disabilities option to encourage participation by more individuals. Better yet, insurance plans offered by Medicare and private insurers could be structured and designed to provide benefits that individuals with disabilities need to work and live independently.

The economic difficulties faced by people with disabilities are relevant because cost barriers to care are significant and can prevent people with disabilities from accessing the care they need. Approximately 27% of people with disabilities in the United States report not receiving needed medical care compared to 12% of people without disabilities.[61] People with disabilities may require more frequent medical visits, assistive devices, or home care services, resulting in higher out-of-pocket expenses. These costs can be especially burdensome for people with disabilities who may have limited income or rely on government benefits.[62]

People with disabilities face barriers to obtaining health insurance due to many factors. Beyond high out-of-pocket costs and co-pays, some health insurance plans may not provide adequate coverage for services necessary for people with disabilities, including durable medical equipment, assistive technology, or home modifications. This can result in high costs or individuals needing help accessing these services.[63] Insurance plans may also have limited networks of health care providers, which can

make it difficult for people with disabilities to find providers who are knowledgeable about their specific health needs.[64] Though Medicaid and Medicare are essential sources of health care coverage for people with disabilities, not all are eligible for these programs. Additionally, eligibility requirements and coverage limitations may make accessing the care they need difficult for some individuals.[65]

Many people with disabilities also face transportation barriers that prevent them from accessing care when and where they need it. For those without personal vehicles or the ability to drive, transportation costs can be a significant financial burden, especially for those who require specialized transportation services (e.g., wheelchair-accessible vans) or accommodations.[66] Many public transportation services, despite the A.D.A., are not always accessible to people with disabilities, such as buses or trains that do not have wheelchair ramps or lifts.[67] In rural locations, public transportation services may not be available or can be challenging to find.[68] Many health care facilities do not have enough accessible parking spaces for people with disabilities.[69] This can make it difficult for people with mobility impairments to reach the facility's entrance.

The fragmented health care system places an undue burden on patients to try and coordinate services across organizations and providers which is often the case for people with disabilities.

The American health care system is highly fragmented, which is felt acutely by many people with disabilities, who may require more complex health care services beyond traditional primary care. A fragmented health care system can have several negative consequences. For instance, people may receive care from multiple providers who need to be connected, leading to duplication of care, poor coordination of services, and increased costs. This can result in dangerous situations, such as doctors prescribing treatments that interact dangerously with other medications that a patient is taking.[70]

Key Findings

Cost and Insurance

Over half (57%, n=300) of survey respondents reported a time in the past five years when they needed health care but couldn't get it. Among these respondents, 21% (n=126) said care was too expensive, or insurance did not cover the service. Some participants lacked health insurance because the income restrictions for accessing MaineCare meant they made too much money, yet could not access private insurance through their employer or by purchasing it through CoverME.gov, Maine's health care marketplace.[71]

Focus group and survey respondents repeatedly identified a need for improved access to dental care, and a lack of oral health care providers that will accept MaineCare. According to the U.S. Department of Health and Human Services, more than 370,000 Mainers live in regions with dental provider shortages, and 15 of the state's 16 counties have a dentist shortage.[72] The number of participants who mentioned their inability to access oral health care due to a lack of availability or a refusal by dental providers to accept MaineCare was numerous, and spoke to the need for a better network of oral health care providers, particularly in rural areas of the state.

One focus group participant reported that when they finally found a dentist who accepted their insurance, they were still unable to be seen, and the office was booked for the foreseeable future.

Participants in both the survey and focus groups mentioned time and time again that they could not access medication or treatment because of insurance coverage. The high cost of prescription medications, regardless of whether they are covered by insurance, meant that participants could not accept or purchase their medicine. Another survey respondent stated they hesitated to use health care services because a simple visit could be too expensive. Survey participants felt disconnected from their health care providers, saying their providers did not know what it was like to be poor and needed to consider the financial implications of treatment options. Another participant reiterated this when they stated, "Providers don't think about the obstacles associated with being disabled and poor." One survey respondent shared their experience of receiving a diagnosis of Multiple Sclerosis while on private insurance and then having to switch to MaineCare, saying, "I felt care really changed for the worse after the switch. Many providers didn't seem to care about quality of life or have empathy for diagnoses". Another survey respondent shared their experience, saying MaineCare only covered their general care and immediate needs but did not support treatments that would address the underlying problem or provide resources for long-term therapies.

> "I wish it was more affordable to all in this country, as many people, myself included, are hesitant to use these services as they cost so much, even for a simple visit to answer a question or get a DX (diagnosis)."
> **– Health Care Access Survey respondent**

> "It [the health care system] is extremely classist. The specialist I need to see - I have to pay 100% of the costs for the visit and medicine. These are Drs that keep me alive, not extra support specialists. And these are the only people in Maine who can treat me. If I didn't have money and good insurance from my well-off family, I would probably die. In my experience, Maine greatly lacks in diversity of doctors, quality of care, Dr knowledge, and accessible low-cost options."
> **– Health Care Access Survey respondent**

Participants highlighted various limitations on health services coverage, particularly concerning MaineCare (Medicaid) and the frequency at which certain services were covered. They expressed frustration that standard health insurance plans did not include dental, hearing, or vision services coverage. Participants also raised questions about the decision-making process employed by insurance providers, specifically regarding treatments, diagnostic tests, or services that fell outside the coverage provided by their plans. This desire for transparency and clarity reflected their concerns about how insurance coverage decisions influenced their health care options. The frustration surrounding providers being "out of network" was a recurring theme among focus groups and survey participants. Given the limited number of health care providers in Maine, finding providers who were accepting new patients and could offer timely appointments took time and effort. Consequently, many participants mentioned the need to travel out of state, often to Boston, to access specialized care, which created additional barriers.

> "In terms of finding occupational therapists, it's been a nightmare to find one that takes my insurance. They really need to find some really good people to do all of these services up here in Aroostook County. I'm not giving up, but it's been a nightmare to find [providers that take] my insurance. People should try to take as many insurances as they can - there are many people who need help, and they need treatment."
> **– Focus Group participant**

> "Insurance doesn't cover a lot. I haven't had glasses for a long time – it's so hard to find a place that will take MaineCare for doing actual vision tests."
> **– Focus Group participant**

Navigation

In addition to facing obstacles related to health insurance and costs, individuals encountered many problems navigating the health care system that hindered their access to health care. Of those who reported being unable to receive care in the past five years, 27% (n=159) cited long wait times as the primary barrier. Survey and focus group participants also highlighted the difficulty of navigating a complex healthcare system without sufficient support and needing more case managers and supportive services. As focus groups and survey participants noted, insurance does not always cover case management. This challenge is particularly significant for people with disabilities who may need to manage care across multiple specialists, making assistance with navigating care systems essential. For people experiencing homelessness, the additional barriers of a lack of a stable address, phone or internet access, and transportation mean it is exponentially more difficult to access care or coordinate care.

Participants shared their experiences of providers failing to communicate effectively across different care types and organizations, leading to exacerbated medical issues and delays in critical care. They highlighted instances where providers lacked coordination, resulting in fragmented care and a lack of continuity. Survey respondents expressed their awareness that, as patients, they often bore the responsibility of sharing new information with their doctors or following up on necessary actions after appointments with specialists. This lack of communication between providers led to different health care professionals holding varying opinions or treatment ideas without effectively sharing them, leaving the patient as the sole source of information. Moreover, participants mentioned instances where providers promised referrals but failed to follow through unless prompted by the patient. These experiences underscored the need for improved communication and a stronger sense of continuity of care among health care providers.

Additionally, participants felt providers need to be more knowledgeable about the different services and alternative options available within a local area, region, or even statewide. Some survey respondents said they did not know where to go for help. A survey respondent noted that the "availability of resources (i.e., reimbursement for rides to appointments) is information that all services providers have and should be relayed as a matter of course whenever a provider sees a patient." Similarly, participants in the Blind and Low Vision and Brain Injury focus groups expressed a desire to have been connected to

support groups or services that could have been beneficial when they experienced their injuries or received their diagnoses.

> "The delays are hard. It takes so long to get in to see someone right now. For my son, he lives in a group home. And then, with the turnover in his Direct Support staff, there will be all these mistakes. Like, my son will miss his specialist appointment. They were supposed to bring him, but with the turnover, someone doesn't tell someone else, and they don't bring him. They were supposed to bring him. And we waited six months for that appointment! So then he has to just start over and wait all over again."
> **– Focus group participant**

Transportation

According to the Health Care Access Survey, 11% (n=68) of respondents reported being unable to access health care in the last five years due to transportation issues. This barrier was even more pronounced among individuals with visual impairments, with 24% (n=24) reporting transportation as a barrier. In focus groups, many participants who lacked personal vehicles or could not drive expressed similar concerns, citing the scarcity of affordable and accessible public transportation options. In many areas of the state, particularly rural northern and western Maine, there is no public transportation, including taxi or ride-share services. A 2016 study of transportation barriers for chronically ill older adults in Bangor and the surrounding Penobscot County area found that 67% of patients wanted or needed public transportation services to get to care. In the same study, 80% of schedulers and social workers in medical offices reported difficulties in assisting patients who required transportation, and 40% said that appointment cancellations due to lack of transportation occurred at least once per week in their facility.[73]

> "If you do not drive, you are unable to access health care."
> **–Health Care Access Survey respondent**

Multiple survey respondents reinforced the importance of transportation to accessing health care. There are transportation options for individuals insured through MaineCare (Medicare), though there are requirements that may prohibit its use. Typically, the service can only be used for non-emergent MaineCare-covered appointments and requires a request to be submitted at least two business days before the appointment.[74] In August 2013, Maine underwent a significant transformation of its MaineCare transportation program to align with federal Medicaid regulations. This overhaul transitioned from utilizing local nonprofits to organize and provide transportation services to a broker-based model involving ride coordination in eight designated regions. However, this change introduced logistical challenges, leading to many patients reporting missed rides, consequently impacting their ability to attend crucial appointments.[75]

> "[There are] lots of public transportation problems for disabled people. It's not right. They don't understand that if you don't get the care you need, it could be serious."
> **– Focus Group participant**

Recommendations

Recommendations	Potential Strategies
Increase opportunities to access funding, resources, and technical assistance to better care for people with disabilities.	Expand efforts that identify Health Professional Shortage Areas (HPSAs) to include urgent care, specialty care, and home health services, which would allow centers to expand specialized services.
	Designate people with disabilities as a medically underserved population through the Health Resources and Service Administration (HRSA) to increase opportunities to access funding and technical assistance support at federally qualified health centers through a Governor's Designation.[76]
Provide navigation and supportive services to people with disabilities and their families/caregivers.	Nurture peer navigation and support programs that pair individuals with disabilities with peers who have expertise and experience successfully navigating the health system.
	Explore opportunities to offer or expand case management and care coordination services for individuals with disabilities with both public and private insurance plans.
	Advocate for supportive services for parents and caregivers of children with disabilities.
	Incentivize partnerships between health care providers and community-based organizations to address common barriers to care (e.g., transportation barriers).
Explore mechanisms to improve timelier access to care.	Expand after-hours and weekend care at primary care practices, including federally qualified health centers.
	Use telehealth technologies, such as virtual visits and remote consultations, to deliver health care services to patients in remote or underserved areas to reduce travel time and costs, and enhance access to care for individuals with limited mobility or transportation options.
	Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.

Priority Area 4: Communication

Background

Communication issues between health care providers and people with disabilities affect the quality of care received by people with disabilities and may lead to adverse health outcomes. Research shows that people with disabilities are more likely to report communication difficulties with health care providers than those without disabilities (28% vs.10%).[77]

Health care providers may have limited time to communicate with patients, leading to rushed conversations or a lack of clarity in the information provided.[78] The average primary care visit is 18 minutes long in the United States.[79] One study found that the average talk time between patients and physicians during appointments was only 5 minutes each.[80] Although this is a challenge facing all patients in our current health care system, it has particular equity implications for people with disabilities. For people who communicate differently, need more time for comprehension, utilize communication devices or require an interpreter, or have complex medical needs, the short time allotted for examination, questions, and discussion is even more limiting on their care.

Providers often use complex medical terminology that may be difficult for people with disabilities to understand.[81] Studies show that medical terminology also poses specific challenges for Deaf individuals who use American Sign Language and are at high risk for low reading levels, health terminology recognition, and health literacy.[82,83] Providers must speak in terms that allow individuals to understand diagnoses, treatment options and plans, directions, and medical advice.

People with disabilities also report difficulties obtaining accommodations from health care providers that would improve communication, such as captioning discussions, sign language interpreters, visual aids, and other communication aids and services. Providers that do not have education, training, or experience about the ways to communicate with individuals with disabilities may overlook the need for communication accommodations, such as the use of assistive devices, communication boards, captions, or interpreters.

Providers may also make incorrect assumptions about the patient's abilities and default to communicating with others in the room (such as family, caregivers, or support staff) rather than the patient directly. Many individuals with disabilities report that providers infantilize them by speaking to others in the room instead of speaking with them.

Key Findings

Approximately 44% (n=231) of survey respondents reported that it was challenging to communicate with their health care providers. When asked to provide additional context about their experiences, 20% (n=121) of individuals who reported difficulties said that providers did not listen to them or believe them, 13% (n=80) said providers did not speak directly to them, and 7% (n=40) said they were not

provided the accommodations they needed to communicate (e.g., interpreters, captions, or other aids or services). Focus group and survey participants expanded on these experiences, saying they felt their health care providers:

- Do not believe them;
- Dismiss their concerns;
- Do not include them in the decision-making process;
- Do not think they are capable of making decisions;
- Talk to their family members, guardian, companion, or staff member who are with them, rather than directly to them;
- Say things in the exam room and then do not follow up;
- Do not explain things well or use terminology they don't understand;
- Do not take the time to ensure understanding;
- Lack empathy and/or;
- Focus on their laptops rather than making eye contact.

Over a fifth (21%, n=103) of Health Care Access Survey respondents said doctors and staff do not listen carefully to their concerns and symptoms. Many reported on the rushed nature of health care appointments and the impacts this has on their ability to express concerns, ask questions, and discuss options for treatment and services:

22% (n=105)

of survey respondents said doctors and staff do not explain what they think about their condition

22% (n=105)

of survey respondents said doctors and staff do not answer all of their questions

23% (n=121)

of survey respondents said health care providers do not involve them in decisions about their health care

Participants described times when they felt their health care providers made assumptions about what they could do or comprehend. One participant said, "Providers make hasty assumptions about me in all directions. I am extremely intellectually capable but have trouble with auditory processing and emotional regulation, so sometimes it takes a while for me to understand things when people assume I should get things quicker. Alternatively, people see "autism" and assume I am intellectually disabled, which I am not. I am always over- or under-estimated.

Just speak to me directly, and I'll let you know where I am at and what I need!"

> "I would like people to take more time to talk to me. Doctors sometimes talk to the person with me instead of directly to me."
> **–Focus Group participant**

Other survey and focus group participants described similar experiences where providers spoke to them in patronizing tones. Alternatively, participants reported that providers use "doctor talk" and do not take the time to clarify specific medical terminology or explain things thoroughly.

Participants in focus groups and Health Care Access Survey respondents also reported that communication issues could occur at every point and throughout the process – from scheduling, arrival, and check-in to appointments, services, and follow-up. For example, some individuals reported that pre-appointment forms and questionnaires are dense, difficult to understand, or inaccessible formats they cannot complete. For people who are blind or have low vision, this could mean online patient portals that are not screen-reader friendly or paper forms that are not provided ahead of time, meaning the patient needs assistance to complete the form in the waiting room before their appointment.

> "They (providers) often treat me in an infantilizing way. They sometimes are unable or unwilling to assist with paperwork that they hand me at the office."
> **–Health Care Access Survey respondent**

> "What's hard for me when making an appointment is going through all of the automated stuff - trying to figure out the insurance stuff and the paperwork. I don't know what that means because I struggle with steps due to my autism. It's really hard - the way they word certain stuff. What is easier for me is when I have my mom or someone with me to explain what they mean. I feel like they should word things in a simpler way. People like me who have a harder time understanding these types of words could better understand what I need to do and what I need to sign."
> **–Focus group participant**

Individuals who are Deaf or hard of hearing face especially significant barriers in communicating effectively with their health care providers. Focus group and survey participants who are deaf and hard of hearing expressed that health care providers often overlook or ignore their need for communication accommodations, making it difficult to understand their health care and navigate the health system. Participants described providers needing to be more receptive to using captioning or sign language interpreter services, needing to be made aware of how to obtain such services for appointments, or stating they could not provide them. Participants reported that they felt the need to explain how to communicate with providers continuously and perceived that the providers did not retain information. Many providers assume that lip reading is universal or innate, while only a small subset of individuals can communicate this way (with limited accuracy). Participants also shared that during COVID-19, most providers did not wear or supply transparent masks, which further hampered communication by eliminating the ability to read facial expressions and mouth movements, both essential in American

Sign Language (ASL). Communication before and after appointments was also a concern. One focus group participant shared that when he needed to discuss urgent test results with a provider, the office had no way of communicating these results to him except by phone call, which he could not hear; the provider shared the results with his spouse instead, and he was unable to ask questions.

Deaf focus group participants who used American Sign Language described many concerns and barriers related to the need for interpreter services. Participants reported experiencing delays in their care because many health care facilities needed more, or minimal, ability to provide in-person sign language interpreters for urgent or last-minute needs. One survey participant stated that health care providers and their staff needed training on how to work with interpreters, saying that providers talk to the interpreter instead of the patient.

The number of issues reported with Video Remote Interpreting (VRI) services, in particular, was high. VRI provides an ASL interpreter pulled on-demand from a virtual pool of interpreters nationwide. Individuals reported experiencing frequent malfunctions of the VRI service and equipment that prevented effective communication. Individuals also reported frustrations with the "random" nature of VRI. Participants described trying to navigate communication through VRI interpreters who were not from Maine and, therefore, unfamiliar with regional signs, or inexperienced interpreters that they struggled to understand in high-stakes situations. Many survey and focus group participants described cases where the VRI was delivered on small devices like phones or tablets, which were difficult to see, or where the system kept freezing, making it difficult or impossible to communicate back and forth with health care providers. Participants also described feeling anxiety and stress when providers presented them with VRI, particularly when an on-site interpreter had been requested well in advance.

> “Most places want you to use VRI and it’s a problem. I don’t want VRI. They say, ‘I don’t care.’ That response - it’s so upsetting. Medical care, medical events, it’s important. Like, if I have a heart attack, I could die. That’s scary. They should have it set up so that I can get the interpreting services I need the way I know I need it. VRI is very hard – you need to be able to see it, you need to have it set up right, and staff need to know how to use it. But it doesn’t always happen right, and you are left there stuck.”
> **–Focus Group participant**

> "On-site interpreters make communication faster. If I have the same interpreter or two for a five-day hospital stay, they have the context. They can just interpret the questions being asked by the doctor, interpret my answers. Simple. If it's a VRI interpreter, the communication takes forever. The interpreter is random, someone different each time. They have to ask so many questions of me, of the doctor, to understand the context, what has happened already, what conversation they are jumping into, the terms being used—the schema. Our prior knowledge of the situation – our communication relies on that. The doctor has it, and I have it. But the interpreter needs to have it too. And the VRI interpreters don't."
> **– Focus Group participant**

Regarding preferred communication methods, the sentiment expressed by one focus group participant resonated with others: "I don't know if I've ever been asked by a provider's office what is the best way [to communicate]." This remark highlighted a shared experience where individuals felt their communication preferences were not acknowledged or respected by health care providers. A survey participant shared an incident where their audiologist did not utilize a clear mask during their interaction despite being aware of the participant's reliance on lip-reading. This lack of accommodation reflected a misconception among providers that speaking alone was sufficient for clear communication, disregarding the specific needs of individuals who required visual cues. In addition, several focus group participants expressed the added challenge of background noise impeding their ability to understand their health care providers. Whether it was background music, conversations between others, white noise machines, or other noise sources, these external factors further burdened their communication experience with health care professionals.

> "I'm a very easy-going person, and I know my providers well enough that I can lip-read. I use text-to-speech, but sometimes it's not perfect because I can swear like a sailor. But it does help at some points. The thing is that certain providers [differ]. It's interesting for an audiologist [to wear] a mask - a solid mask. Why? It's just like - use that common sense. So my experience has been mixed. And some providers who don't provide sign language and interpreters on behalf of a client could be doing more."
> **–Focus Group participant**

One survey respondent did express hope for the future, saying, "I am encouraged that the younger physicians seem to "get it" more quickly, and many – even specialists – often have better communication skills than one might expect."

Recommendations

Recommendations	Potential Strategies
Equip health care personnel with the necessary knowledge and tools to interact positively with patients with disabilities.	Require that all health care personnel, from administrative staff to physicians, receive formal training on effective methods for communicating with patients with disabilities.
	Conduct training on legal obligations providers have when interacting with patients with disabilities.
	Develop provider educational materials (e.g., guides, toolkits, checklists) that providers and staff can use to ensure accessibility during appointments.
Individuals with disabilities must be represented in decision-making bodies to ensure that communication needs are addressed sufficiently.	Require that hospital Patient Advisory Councils include people with disabilities to solicit and encourage improvements related to effective communication and patient access.
Inform individuals with disabilities of the rights afforded to them.	Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available to them.
Communication devices and technologies should always be working and available for use.	Examine the accessibility of health care technologies (e.g., kiosks, patient portals, telephone systems, video conferencing, websites) prior to implementation.

	Ensure that health care facilities have contracts for on-site and video interpreters in place before a request for interpreters is received.
	Develop and implement state-level guidelines for using ASL Video Remote Interpreting in medical settings.
All communications (e.g., forms, questionnaires, educational materials, instructions) should be accessible, easy to complete, and representative of people with disabilities.	Offer patients the opportunity to fill out all forms (electronically or in hard copy) prior to their appointment.
	Require that all materials distributed to patients during the visit are audited for accessibility.
	Ensure that all online data and information are provided in formats that can be interpreted by screen readers.
	Ensure the facility and providers have the ability to offer large-print versions of all printed materials (font size 18 pt or larger).
	Include images of people with disabilities in all educational and promotional materials.
Consider communication needs and privacy concerns when interacting with patients in health care facilities.	Implement more discrete communication strategies that do not rely on hearing a person's name called (e.g., distributing pagers instead of calling names in a waiting room).
	In places where masking is required and implemented, ensure all staff has easy access to clear masks and communicate that patients can ask for staff to wear them.
	Schedule longer appointments for patients with disabilities to accommodate diverse communication needs, styles, cognition levels, and use of interpreters/communication devices.
	Explore opportunities to be more flexible in allowing for longer patient visits.

Priority Area 5: Physical Spaces

Background

Physical barriers in health care settings can make it difficult or impossible for people with disabilities to access health care services or receive appropriate care. The Americans With Disabilities Act was signed into law in 1990, over 30 years ago, providing the minimum requirements that employers, government agencies, services, public facilities, transportation, and telecommunications must provide to ensure accessibility for people with disabilities.[84] While this legislation was a significant step forward for people with disabilities, inaccessible buildings and building features are still a common problem.[85] There are also gaps regarding mandatory standards for accessible medical and diagnostic equipment. In 2010, the Patient Protection and Affordable Care Act (ACA) added an amendment to Section 510 of the Rehabilitation Act where accessibility standards for medical diagnostic equipment were developed.[86]

Health care facilities are often not designed to accommodate people with physical disabilities, such as those who use wheelchairs. For example, inaccessible entrances, narrow doorways, stairs without handrails, and lack of accessible restrooms can impede people's ability to navigate the facility safely.[87] People struggle to access care in these spaces. A study published in the Journal of Rural Health found that people with disabilities in rural areas have limited access to health care facilities that are equipped to accommodate their needs, which suggests that inaccessible medical equipment may be more prevalent in rural areas due to the lack of resources and infrastructure and more limited options available in these regions.[88] The 2022 research study by Lagu et al. found that all physicians participating had physical barriers to providing health care, including inaccessible buildings and equipment (such as height-adjustable exam tables).[89] Some physicians even reported sending their patients to supermarkets, grain elevators, zoos, and cattle processing plants to obtain a weight when they did not have an accessible scale.[90]

Inaccessible medical equipment can delay the diagnosis of disease and treatment and affect the quality of care provided. Health care equipment is not designed to accommodate people with disabilities, such as adjustable examination tables, weight scales, and imaging machines. For example, some imaging machines may require patients to remain still for extended periods, which can be challenging for people with mobility impairments.[91] A study published in the Journal of General Internal Medicine found that more than half of primary care clinics surveyed in the United States did not have accessible weight scales, which can hinder the monitoring of critical health conditions such as obesity and diabetes.[92] Research has also shown that people with disabilities are less likely to receive diagnostic medical examinations due to inaccessible medical equipment. For example, reported cervical cancer screening rates for women with disabilities ranged from 60-80%, compared to 80% screening rates for women without disabilities. The percentage of women with disabilities between 50 and 74 years of age who had a mammogram was between 61% to 68%, compared with 74% of women of the same age without disabilities.[93]

A 2013 study evaluated health care administrators' knowledge of accessible equipment available for medical practices. Less than half knew accessible equipment existed, and only a fourth could describe the equipment. Less than half of the study participants reported ever purchasing equipment, and only a third said that the number of patients with disabilities could justify the cost of such equipment.[94]

Finally, many health care facilities are not designed to accommodate individuals with sensory issues, and specific facility types, such as emergency rooms and dental offices, can be unpredictable and overstimulating. Exposure to these environments can have physical and psychological effects that trigger adverse reactions.[95]

Key Findings

Nearly a fifth (18%, n=93) of Health Care Access Survey respondents reported that the spaces they receive care do not feel accessible or safe. The highest percentage of individuals reporting that spaces were not accessible or safe were those with physical disabilities or mobility issues, those who use communication devices, and individuals with intellectual or developmental diagnoses or labels (21%).

Focus group participants and Health Care Access Survey respondents shared numerous experiences detailing the difficulties they faced, including:

- Not enough designated accessible parking spots or even street parking only;
- Narrow or tiny hallways that did not allow enough space for wheelchairs, rollators, or walkers;
- No automatic door openers or inaccessible handles on doors too heavy to open;
- No elevators within the building;
- Inaccessible chairs in waiting rooms and exam rooms;
- A lack of accessible equipment or tools in the exam rooms, such as height-adjustable exam tables;
- Atmospheres that were triggering or overwhelming with too much noise or bright lights;
- Background noise that made it hard to understand people talking, such as music, other people talking, and white noise machines;
- A lack of appropriate placement for pediatric psychiatric patients in emergency room settings;
- Bathrooms that were not large enough to accommodate power wheelchairs and have soap and paper towel dispensers that are out of reach to someone using a wheelchair.

Several respondents shared difficulties in gaining entry into the facilities where they were to receive care and navigating the space:

> "ADA [Americans with Disabilities Act] scrapes the bottom of the barrel. Doors are always too narrow, getting through is hard; there are too many chairs to park a wheelchair. There are no spaces to park in the waiting room. There's an awkward dance with people. This includes parking lots and maintenance of pathways which aren't safe or accessible. Exam rooms are usually too small to move my chair around."
> **–Focus Group participant**

Participants also described experiences where they were explicitly told by health care providers that they could not receive the diagnostic treatments for which they were scheduled.

> "Another issue sometimes is getting up onto tables. It's not easy for somebody in a wheelchair to get up on a table- it takes three people to get me up onto a table. That is one reason why one time I didn't have a full bone scan because they couldn't get me up on the table to have the bone scan. Those tables are very difficult. I've been having to bring my sliding board with me lately to get from the chair to the table. Those tables can be hard to get up to. When my mom started coming with me, she could help me get up onto the table - one time, they only did a bone scan on my wrist because they couldn't get me up. One time they had to x-ray me in my chair."
> **–Focus Group participant**

Focus group participants and Health Care Access Survey respondents also reported that some physical spaces do not protect the privacy of their names and personal information.

> "The front desk staff who assist with filling out forms want to do it in the waiting area surrounded by other patients who can easily hear the whole thing."
> **–Health Care Access Survey respondent**

> "Sometimes [I have to meet] with doctors in the hallway where there's no privacy; the doctors just want to speak quickly, like they have no time, and just get the meeting done in the hallway instead of taking the time to properly meet."
> **–Focus Group participant**

Recommendations

Recommendations	Potential Strategies
Create, implement, and improve mechanisms for notifying providers and staff of patient accommodations and needs.	Embed questions about accommodation needs at first contact (scheduling, registration, triage, etc.)
	Proactively communicate with patients ahead of health care visits to assess potential accessibility needs and accommodations for individuals with disabilities.
	Clearly and prominently identify patient accommodation needs in Electronic Health Records.
	Enable Electronic Health Record pop-up notifications at log-in, advising of accommodation needs (including whether an interpreter is needed), and that require an action such as clicking an acknowledgment button to dismiss the pop-up.
	Provide regular reports to administrative staff and providers that identify upcoming patient appointments where accommodations or accessible equipment is needed.
Equip all health care organizations with tools, assistive devices, medical equipment, and personnel that allow for	Ensure that an on-site "Access Coordinator" is appointed and available at all times. This person should be on-the-ground and responsible for

universal access to all recommended screening and diagnostic tests and treatments.	providing immediate assistance to staff to locate and implement communication aids and services, schedule interpreters, and assist/troubleshoot issues.
Create accessibility guidelines that go beyond the basic minimum requirements and provide additional access whenever the needs of the population go beyond those minimum standards.	Require that healthcare organizations routinely assess and report on the accessibility of their building (e.g., parking lots, waiting areas, exam rooms).
	Increase the number of accessible parking spaces at health care facilities, rather than meeting ADA minimum requirements.[96]
	Increase availability of accessible medical equipment (e.g., height adjustable examination tables, accessible mammography equipment, accessible weight scales, and lift equipment).[97]
Ensure that patients are fully aware of the accessibility-related services available to them.	Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available.

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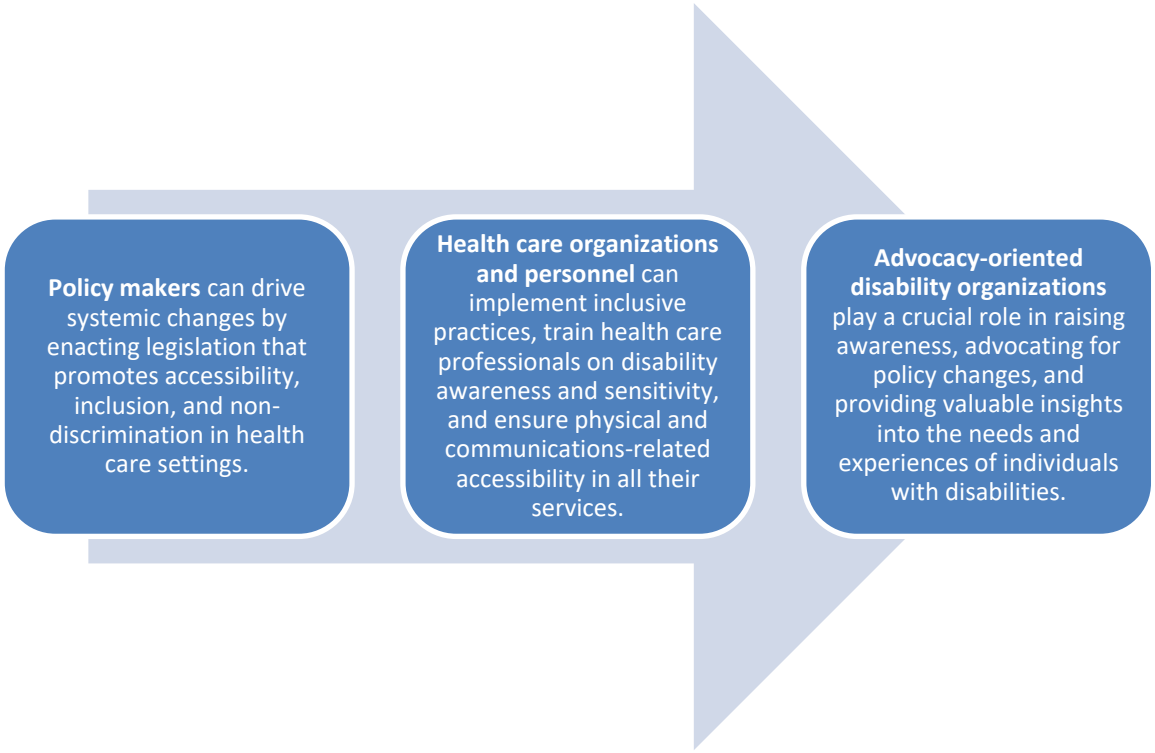
Conclusion

As highlighted throughout this report, the first of its kind in Maine, individuals with disabilities face significant barriers when seeking health care services, often resulting in disparities and inequities in their health outcomes. The challenges surrounding equitable access to health care for individuals with disabilities are intricate and multifaceted, demanding sustained dedication and collaborative endeavors from diverse stakeholders.

We recognize that transforming existing structures and practices requires careful planning, coordination, and consideration of diverse perspectives. However, the situation's urgency demands swift action to ensure that individuals with disabilities can access quality health care on an equal footing. While policy changes may take time, there are ample opportunities for organizations, policymakers, advocates, and health care organizations to collaborate and make meaningful strides toward improving equitable access to care for people with disabilities. By fostering partnerships and working together, different entities have specific opportunities to identify and address the challenges faced by Mainers with disabilities.



Collaboration between advocacy-oriented disability organizations and other groups can result in the development of innovative programs and services tailored to the unique needs of people with disabilities. DRM hopes that the insights presented in this report will serve as a valuable resource to establish new partnerships or reinforce existing ones with clinical and community-based organizations. These collaborations are essential for effectively addressing the recommendations and exploring potential strategies outlined in the report. By leveraging the expertise and resources of various stakeholders, we can create a collective force that drives positive change and dismantles the systems

force that drives positive change and dismantles the systems that hinder health equity and access for people with disabilities.

Through collaboration, persistence, and a shared commitment to social justice, we can foster a health care system that treats all individuals with the respect, dignity, and equitable care they deserve. While the road ahead may be challenging, the potential to create lasting change is within our grasp. Let us seize this opportunity to work together and build a society that ensures equitable access to health care for all, regardless of ability.

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APPENDIX A

1. HEALTH CARE ACCESS SURVEY
2. SURVEY FINDINGS
3. DIRECT QUOTES FROM OPEN RESPONSES

Health Care Access and Equity for Individuals with Disabilities in Maine

Survey for Individuals with Disabilities in Maine

Page exit logic: Skip / Disqualify Logic
IF: #1 Question "**Do you live in Maine?**" is one of the following answers ("NO") **THEN:** Disqualify and display:
We appreciate your interest in this survey, however, it is intended only for individuals with a disability(ies) in the state of Maine. If you have questions, please contact Jennifer Battis at jbattis@drme.org or (207)626-2774

1. **Do you live in Maine?** *

- YES
- NO

Page entry logic:
This page will show when: #1 Question "**Do you live in Maine?**" is one of the following answers ("YES")

2. **Are you deaf or do you have difficulty hearing?** *

- YES
- NO

3. **Are you blind, have low-vision, or have serious difficulty seeing even when wearing glasses?** *

- YES
- NO

4. **Do you have a mental health condition or been given one of these labels? This may include anxiety, depression, post-traumatic stress disorder (PTSD), bipolar disorder, schizoaffective disorder, substance use disorder or other conditions.** *

- YES
- NO

5. **Do you have a developmental disability or been given one of these labels? This may include Intellectual Disability, Down Syndrome, Autism, Cerebral Palsy or others.** *

- YES
- NO

6. **Do you have a brain injury or related condition? This may include brain tumor, stroke, impacts from loss of oxygen to the brain, traumatic brain injury, or others.** *

- YES
- NO

7. **Do you have a physical or mobility disability? This may include spinal cord injury, cerebral palsy, limb or body structure disabilities, muscular dystrophy, multiple sclerosis, or other conditions.** *

- YES
- NO

8. **Do you have any other serious health problem or condition expected to last for six months or more? This may include auto-immune disorders, cancer, digestive disorders, diabetes, epilepsy, long-term disease or illness, or others.** *

- YES
- NO

9. **Do you have difficulty, concentrating, remembering, or making decisions?** *

- YES
- NO

10. **Do you use a communication device or communicate alternatively? This may include letter or word boards, eye gaze, gesturing, text to speech apps, and others.** *

- YES
- NO

11. **Do you have serious difficulty walking, climbing stairs, using your hands or fingers, or doing other physical activities?** *

- YES
- NO

12. **Do you use a wheelchair or other device for mobility?**
*

- YES
- NO

Experiences with Health Care Providers

LOGIC Show/hide trigger exists.

13. **Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.**

- YES
- NO

LOGIC Hidden unless: #13 Question "**Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.**" is one of the following answers ("YES")

14. **Does your doctor and staff listen carefully to your concerns and symptoms?**

- YES
- NO

LOGIC Hidden unless: #13 Question "**Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.**" is one of the following answers ("YES")

15. **Does your doctor and staff examine you the way you think you should be examined?**

- YES
- NO

LOGIC Hidden unless: #13 Question "**Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.**" is one of the following answers ("YES")

16. **Does your doctor and staff explain to you what they thought about your health or medical condition?**

- YES
- NO

LOGIC Hidden unless: #13 Question "**Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.**" is one of the following answers ("YES")

17. **Does your doctor and staff answer all of your questions?**

- YES
- NO

LOGIC Hidden unless: #13 Question "**Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.**" is one of the following answers ("YES")

18. **Think about your most recent primary care visit. Did your doctor ask you about the following? Check all that apply.**

- ☐ Getting screenings for cancers. This might include screenings for cervical, breast, colon, or prostate cancer (age and gender appropriate).
- ☐ Making sure you are up-to-date in vaccinations. This includes your Flu and COVID-19 vaccinations.
- ☐ Your exercise habits or weight control.
- ☐ Tobacco use.
- ☐ Alcohol and other drug use.
- ☐ Sexual practices.
- ☐ Safety risks such as guns, seatbelt use, and helmets.
- ☐ Whether your mood is okay or if you feel sad or anxious? Does your doctor ask you if you have ever thought about hurting yourself?

LOGIC Show/hide trigger exists.

19. **In the past year, have you gone to an Emergency Room?**

- ○ YES
- ○ NO

LOGIC Hidden unless: #19 Question "**In the past year, have you gone to an Emergency Room?**" is one of the following answers ("YES")

20. **Why did you go to the Emergency Room? Check all that apply.**

- [ ] I do not have a primary care provider.
- [ ] My primary care provider told me to go to the Emergency Room.
- [ ] I was not able to see my primary care provider.
- [ ] It felt like it could not wait.
- [ ] Other - Write In (Required)

*

LOGIC Hidden unless: #19 Question "**In the past year, have you gone to an Emergency Room?**" is one of the following answers ("YES")

21. **In the Emergency Room, did the doctors and nurses listen carefully to your concerns and symptoms?**

- ○ YES
- ○ NO

LOGIC Hidden unless: #19 Question "**In the past year, have you gone to an Emergency Room?**" is one of the following answers ("YES")

22. **In the Emergency Room, did the doctors and nurses examine you the way you think you should be examined?**

- ○ YES
- ○ NO

LOGIC Hidden unless: #19 Question "**In the past year, have you gone to an Emergency Room?**" is one of the following answers ("YES")

23. **In the Emergency Room, did the doctors and nurses explain to you what they thought about your health or medical condition?**

- YES
- NO

LOGIC Hidden unless: #19 Question "**In the past year, have you gone to an Emergency Room?**" is one of the following answers ("YES")

24. **In the Emergency Room, did the doctor and nurses answer all of your questions?**

- YES
- NO

LOGIC Show/hide trigger exists.

25. **Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.**

- YES
- NO

LOGIC Hidden unless: #25 Question "**Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.**" is one of the following answers ("YES")

26. **What type of care were you not able to access? Choose all that apply.**

- [ ] Primary care
- [ ] Oral/dental health care
- [ ] Mental/behavioral health care
- [ ] Substance use care
- [ ] Emergency care
- [ ] Urgent care
- [ ] Home health care/Personal care services
- [ ] Other - Write In (Required)

*

LOGIC Hidden unless: #25 Question "**Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.**" is one of the following answers ("YES")

27. **For the times you were not able to access care, what was the reason? Check all that apply. Was there a time in the past five years where you needed to see a health care provider, but you were not able? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.**

- [ ] The wait was too long.
- [ ] I had no way to get there.
- [ ] It was too expensive or my insurance did not cover it.
- [ ] The provider hung up on me or did not call me back.
- [ ] The provider did not provide the accomodations I needed (e.g., ASL interpretation, accessible medical equipment, allowing me to bring a support person).
- [ ] The provider did not feel able to meet my needs.
- [ ] I did not know how to find a provider.
- [ ] Other - Write In (Required)

*

LOGIC Show/hide trigger exists.

28. **Are health care providers properly trained and prepared to treat you?**

- ○ YES
- ○ NO

LOGIC Hidden unless: #28 Question "**Are health care providers properly trained and prepared to treat you?**" is one of the following answers ("NO")

29. **What makes you feel that way?**

30. **Do health care providers involve you in decisions about your healthcare?**

- YES
- NO

LOGIC Show/hide trigger exists.

31. **Is it difficult to communicate with your health care providers?**

- YES
- NO

LOGIC Hidden unless: #31 Question "**Is it difficult to communicate with your health care providers?**" is one of the following answers ("YES")

32. **What experiences have you had? Choose all that apply.**

- [ ] They do not know how to communicate with me.
- [ ] They do not provide accommodations that I need (e.g., captions, interpreters).
- [ ] They do not speak directly to me.
- [ ] They do not listen to me or believe me.
- [ ] They do not make sure I understand.
- [ ] Other - Write In (Required)

*

LOGIC Show/hide trigger exists.

33. **Do health care providers respect you?**

- ○ YES
- ○ NO

LOGIC Hidden unless: #33 Question "**Do health care providers respect you?**" is one of the following answers ("NO")

34. **What experiences have you had? Check all that apply.**

- [ ] Providers do not listen to me or do not take my concerns seriously.
- [ ] Providers talk to the people with me and not to me directly.
- [ ] Providers do not consider my needs and experiences.
- [ ] Providers are rude or hostile to me.
- [ ] Other - Write In (Required)

*

LOGIC Show/hide trigger exists.

35.

Think about the spaces where you receive care. For example, cliniciansor doctors' offices, waiting rooms, hospital rooms, and other places. Are these spaces accessible and do they feel safe?

- YES
- NO

LOGIC Hidden unless: #35 Question "
Think about the spaces where you receive care. For example, cliniciansor doctors' offices, waiting rooms, hospital rooms, and other places. Are these spaces accessible and do they feel safe?

" is one of the following answers ("NO")

36. **What makes the spaces inaccessible or feel unsafe? Choose all that apply.**

- [ ] Parking lot does not have appropriate parking.
- [ ] I cannot get into the building.
- [ ] Staff are not trained to handle my body in a safe way.
- [ ] The medical equipment is inaccessible. For example, there are no height-adjustable table, no accessible scale, no accessible MRI or mammogram, or something else.
- [ ] The staff were not trauma informed.
- [ ] Other - Write In (Required)

*

37. **How do you typically get health information? Check all that apply.**

- [ ] Friends and/or family.
- [ ] Medical providers.
- [ ] Residential or group home support staff.
- [ ] Television or internet (e.g., television news, social media, WebMD, Mayo Clinic website).
- [ ] I do not have access to health information.
- [ ] Other - Write In (Required)

*

Health Care Experiences

LOGIC Show/hide trigger exists.

38. **Have you received primary care services sometime in the past 5 years?**

- ○ YES
- ○ NO

LOGIC Hidden unless: #38 Question "**Have you received primary care services sometime in the past 5 years?**" is one of the following answers ("YES")

39. **How did you feel about the quality of the primary care services that you received, on a scale of very unhappy to very happy.**

○ Very unhappy ○ Unhappy ○ Neutral ○ Happy ○ Very happy

LOGIC Show/hide trigger exists.

40.

Have you received mental/behavioral health care services sometime in the past five years?

- YES
- NO

LOGIC Hidden unless: #40 Question "**Have you received mental/behavioral health care services sometime in the past five years?**" is one of the following answers ("YES")

41. **How did you feel about the quality of the mental/behavioral health services that you received, on a scale of very unhappy to very happy.**

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

42. **Have you received oral/dental health services sometime in the past 5 years?**

- YES
- NO

LOGIC Hidden unless: #42 Question "**Have you received oral/dental health services sometime in the past 5 years?**" is one of the following answers ("YES")

43. **How did you feel about the quality of the oral health/dental care services that you received, on a scale of very unhappy to very happy.**

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

44. **Have you received emergency care services sometime within the past 5 years?**

- YES
- NO

LOGIC Hidden unless: #44 Question "**Have you received emergency care services sometime within the past 5 years?**" is one of the following answers ("YES")

45. **How did you feel about the quality of the emergency care services that you received, on a scale of very unhappy to very happy.**

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

46. **Have you received home health care services sometime in the past 5 years?**

- YES
- NO

LOGIC Hidden unless: #46 Question "**Have you received home health care services sometime in the past 5 years?**" is one of the following answers ("YES")

47. **How did you feel about the quality of the home health care services that you received, on a scale of very unhappy to very happy.**

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

48. **Have you received specialty care services sometime in the past 5 years? For example - occupational therapy, physical therapy, audiology, or something else.**

- YES
- NO

LOGIC Hidden unless: #48 Question "**Have you received specialty care services sometime in the past 5 years? For example - occupational therapy, physical therapy, audiology, or something else.**" is one of the following answers ("YES")

49. **How did you feel about the quality of the specialty care services that you received, on a scale of very unhappy to very happy.**

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

50. **Is there anything else you would like to share about your experiences with the health care system?**

Demographics

51. **What is your age?**

- Under 18
- 18-24
- 25-44
- 45-64
- 65-74
- 75-84
- 85 and older
- I prefer not to answer

52.

Which of these groups best represents your race? Choose all that apply. You will have space to enter ethnicity in the next question.

- Asian
- Native Hawaiian or Other Pacific Islander
- Black/African-American
- White
- American Indian/Alaska Native
- I prefer not to answer
- I prefer to self describe

*

53. **What is your ethnicity?**

54. **Do you identify as Hispanic/Latino(a)?**

- ○ YES
- ○ NO
- ○ I prefer not to answer

55. **What is your primary language?**

56. **What type(s) of health insurance do you have? Check all that apply.**

- ☐ Private insurance (for example, insurance provided through current employer or union, or purchased directly from an insurance company)
- ☐ Medicare
- ☐ MaineCare/Medicaid
- ☐ TRICARE or other military healthcare
- ☐ VA (enrolled for VA health care)
- ☐ Indian Health Service
- ☐ Other health insurance/health coverage plan: *
- ☐ I do not have health insurance
- ☐ I prefer not to answer

57. **What best describes your current housing situation?**

- I live in my own home.
- I live with my parents or family members.
- I live in a group home.
- I live in an institution.
- I am experiencing homelessness.
- I prefer not to answer

58. **What best describes your current gender identity?**

- Genderqueer or gender non-conforming
- Man
- Transgender man
- Transgender woman
- Woman
- I prefer to self describe
- I prefer not to answer

59. **What best describes your sexual orientation?**

- Asexual
- Bisexual
- Gay or lesbian
- Straight/heterosexual
- I prefer to self describe
- I prefer not to answer

60. **What was your total income last year, before taxes?**

- Less than $20,000
- Between $20,001 and $40,000
- Between $40,001 and $60,000
- Between $60,001 to $80,000
- Between $80,001 to $100,000
- Over $100,000
- I prefer not to answer

61. **What county do you live in?**

- Androscoggin
- Aroostook
- Cumberland
- Franklin
- Hancock
- Kennebec
- Knox
- Lincoln
- Oxford
- Penobscot
- Piscataquis
- Sagadahoc
- Somerset
- Waldo
- Washington
- York
- I don't know
- I prefer not to answer

Full Sample Frequencies		
Question	**N**	**%**
Do you have a health care provider that you see regularly?		
NO	52	9.68
YES	485	90.32
Does your doctor and staff listen carefully to your concerns and symptoms?		
NO	103	21.46
YES	377	78.54
Does your doctor and staff examine you the way you think you should be examined?		
NO	121	25.10
YES	361	74.90
Does your doctor and staff explain to you what they thought about your health or medical condition?		
NO	105	21.74
YES	378	78.26
Does your doctor and staff answer all of your questions?		
NO	105	21.78
YES	377	78.22
Think about your most recent primary care visit. Did your doctor ask you about the following? Check all that apply.		
Getting screenings for cancers	190	31.77
Making sure you are up-to-date in vaccinations	350	58.53
Your exercise habits or weight control	279	46.66
Tobacco use	249	41.64
Alcohol and other drug use	233	38.96
Sexual practices	114	19.06
Safety risks such as guns, seatbelt use, and helmets	107	17.89
Whether your mood is okay or if you feel sad or anxious? Does your doctor ask you if you have ever thought about hurting yourself?	282	47.16
In the past year, have you gone to an Emergency Room?		
NO	269	50.75
YES	261	49.25
Why did you go to the Emergency Room?		
I do not have a primary care provider	9	1.51
My primary care provider told me to go to the Emergency Room	58	9.70
I was not able to see my primary care provider	58	9.70
It felt like it could not wait	129	21.57
Other	69	11.54
In the Emergency Room, did the doctors and nurses listen carefully to your concerns and symptoms?		
NO	84	32.68
YES	173	67.32
In the Emergency Room, did the doctors and nurses examine you the way you think you should be examined?		
NO	89	34.63
YES	168	65.37

In the Emergency Room, did the doctors and nurses explain to you what they thought about your health or medical condition?		
NO	85	33.20
YES	171	66.80
In the Emergency Room, did the doctor and nurses answer all of your questions?		
NO	104	40.31
YES	154	59.69
Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.		
NO	231	43.50
YES	300	56.50
What type of care were you not able to access? Choose all that apply.		
Primary care	153	25.59
Oral/dental health care	154	25.75
Mental/behavioral health care	134	22.41
Substance use care	23	3.85
Emergency care	29	4.85
Urgent care	33	5.52
Home health care/Personal care services	39	6.52
Other	52	8.70
For the times you were not able to access care, what was the reason? Check all that apply.		
The wait was too long	159	26.59
I had no way to get there	68	11.37
It was too expensive or my insurance did not cover it	126	21.07
The provider hung up on me or did not call me back	52	8.70
The provider did not provide the accommodations I needed (e.g., ASL interpretation, accessible medical equipment, allowing me to bring a support person)	33	5.52
The provider did not feel able to meet my needs	54	9.03
I did not know how to find a provider	37	6.19
Other	42	7.02
Are health care providers properly trained and prepared to treat you?		
NO	203	38.09
YES	330	61.91
Do health care providers involve you in decisions about your healthcare?		
NO	121	22.79
YES	410	77.21
Is it difficult to communicate with your health care providers?		
NO	297	56.25
YES	231	43.75
What experiences have you had? Choose all that apply.		
They do not know how to communicate with me	89	14.88

They do not provide accommodations that I need (e.g., captions, interpreters)	40	6.69
They do not speak directly to me	80	13.38
They do not listen to me or believe me	121	20.23
They do not make sure I understand	82	13.71
Other	81	13.55
Do health care providers respect you?		
NO	140	26.77
YES	383	73.23
What experiences have you had? Check all that apply.		
Providers do not listen to me or do not take my concerns seriously.	96	16.05
Providers talk to the people with me and not to me directly	55	9.20
Providers do not consider my needs and experiences	105	17.56
Providers are rude or hostile to me	63	10.54
Other	28	4.68
Think about the spaces where you receive care. For example, clinicians or doctor's offices, waiting rooms, hospital rooms, and other places. Are these spaces accessible and do they feel safe?		
NO	93	17.71
YES	432	82.29
What makes the spaces inaccessible or feel unsafe? Choose all that apply.		
Parking lot does not have appropriate parking	23	3.85
I cannot get into the building	12	2.01
Staff are not trained to handle my body in a safe way	28	4.68
The medical equipment is inaccessible. For example, there are no height-adjustable table, no accessible scale, no accessible MRI or mammogram, or something else	13	2.17
The staff were not trauma informed	43	7.19
Other	47	7.86
How do you typically get health information? Check all that apply.		
Friends and/or family	246	41.14
Medical providers	392	65.55
Residential or group home support staff	99	16.56
Television or internet (e.g., television news, social media, WebMD, Mayo Clinic website)	250	41.81
I do not have access to health information	19	3.18
Other	67	11.20
Have you received primary care services sometime in the past 5 years?		
NO	17	3.23
YES	509	96.77
Have you received mental/behavioral health care services sometime in the past five years?		
NO	163	31.11
YES	361	68.89
Have you received oral/dental health services sometime in the past 5 years?		

NO	108	20.69
YES	414	79.31
Have you received emergency care services sometime within the past 5 years?		
NO	169	32.31
YES	354	67.69
Have you received home health care services sometime in the past 5 years?		
NO	405	77.29
YES	119	22.71
Have you received specialty care services sometime in the past 5 years? For example - occupational therapy, physical therapy, audiology, or something else.		
NO	245	46.76
YES	279	53.24

Provider Education and Cultural Competency

Open-ended responses to "Are providers properly trained and prepared to treat you? If no, what makes you feel that way?" All responses are presented as written, with identifying information redacted.

• Because they mixed up the chart and diagnosis and a Parent had to straighten it out
• I have significant gastro issues. My former NP and gastroenterologist failed to work with me to figure out I am dairy sensitive. I made my own appointment with a specialist, and she figured it out in one meeting. I suffered for 10 years. A gastroenterologist couldn't figure it out????
• Too little time and only want to deal with simple issues.
• Many providers did not understand my brain disorder.
• they keep changing and new ones come in who don't know what they are doing
• Often "basic" providers like PHPs are Jack of all trades, master of none. They rely on specialists that have literal years long waits in order to make decisions about critical health issues and rarely do more than a google search on a condition they aren't familiar with. It's extremely rare for them to update themselves on new research and information in their field.
• Current medical education programs do not include intellectual and developmental disabilities, including autism as part of the mandatory education academically, nor in their day today clinic experiences. Understanding that someone can have alternative methods of communication, or in fact, have an intellectual disability, and yet still deserve the same preventive healthcare, urgent, healthcare, and acute care that everyone else needs is essential. Secondly, it is important for providers and their entire staff to be able to build in the time to learn how to communicate with someone spend the time necessary for someone to process information to change communication, language, style, and comprehension levels when speaking with an individual. Third providers need to take into account that some people with ADD need a health partner whether that's a staff member a family member or a trusted friend the same way in the geriatric population someone brings a spouse an adult child, or a personal care assistant. An example is the primary care doctor and staff don't inquire about mental health issues that affect daily functioning and emotional status and ability to engage with other people other than offering an SSRI, which have been an effective a primary care provider is unable to make a reasonable referral to a psychiatrist is there a virtually none with experience an ID in the state of Maine.
• Because I feel like they don't believe me.
• They just don't care, why would they have to care, there's no whistle-blowers in Maine.
• Some of them are uncomfortable or not familiar with services
• Brain injury is largely invisible. Even with a service dog, I often have to remind practitioners about my disability and its effects.
• no way to help transfer out of wheelchair
• They don't seem to know a lot about brain injury and understand the before and after life of living with it
• Many doctors do not understand my condition and tell me so. Since I have an autonomic condition I need multiple specialists for related problems and conditons it becomes very

difficult when my specialists do not understand my primary condition (POTS) and thus do no give the best recommendations for whatever secondary issues I am seeing them for. I wind up reading a lot of research articles and lectures from medical conferences to inform my medical decisions and what testing/treatment I ask my doctor for. It makes me feel like I have to be my own doctor or medical case worker or what have you.
• Dr. Says one thing in the exam room and then doesn't ever follow up
• When I contacted my provider about ongoing pain and fatigue, she said it was simply from being a mom and dismissed all of my concerns when my blood work was normal.
• I have had some ongoing health concerns and I often have to suggest ideas re: dx , testing, & treatment
• I have a neurological condition that required me to go out of state to see the right kind of specialist that understands myoclonus.
• I had one doctor ask why I had morphine in my system (when I take codiene which gives a pos morphine)... I had to research this myself. Should a dr. know that?... Also, when I voiced my concerns, she said it was inappropriate.
• they speak as if i am a child
• Always seeing an FNP or PA when feel should be with an MD due to chronic conditions.
• They often talk about me to Guardian/Parent not to me. They also act like they are afraid to touch me in order to give me a real examination. Usually it it in and out in 15 minutes.
• Due to my MS and aging issues I am regularly sent home from ER with no support. A am a victim if hospital violence everytime I go to an ER and advocate for myself. I do not feel safe, heard or respected at the ER...leaving me trauma informed everytime pretty much.
• They make assumptions about what is going on with me without taking the time to ask. They do not have the time to check things out nor ask the right kinds of questions. They write notes in my health portal that are frequently inaccurate and these notes are then re-written by other doctors at shift change and this causes ineffective treatment. They often assume if you've been there before - that you are having the same issues when that is not always the case.... And a big one: If I go to the ER for a mental health emergency - they ignore and/or refuse to treat the physical issued including severe pain, infection symptoms, - like no reclining chairs with headrest or anyway to elevate legs, inappropriate hospital beds (no head and foot adjustments and very painful to sleep on beds, nor pain medication (that ARE prescribed by PCP and are listed). The separation of body and mind treatments create worsening mental health and physical health problems.
• has no clue what to do with deaf people
• I can't find a regular PCP so am seeing Drs at a Residency program. It's not adequate, integrated or comprehensive.
• Don't seem very educated on psych illnesses Also understanding of obesity is fat-phobic and moral failing view instead of medical view
• Can't answer questions
• I have a rare condition not well understood and treatment options are limited.
• Providers make incorrect assumptions about my disability and my capabilities. They often treat me in an infantilizing way. They sometimes are unable or unwilling to provide assistance with paperwork that they hand me at the office. When I bring my children to see their health care

providers, the providers assume that I am either not their parent or that I am unable to make decisions on my minor children's behalf because of my disability.
• I feel like they lack the knowledge on treating someone who is transgender and has mental illnesses. They dont seem to know when to differentiate mental health symptoms with physical symptoms that need to be looked into and not blamed on mental illness without looking into it.
• They don't understand autoimmune conditions and their complications well. I often have to explain them and teach them about certain things. Also, sometimes they push antibiotics for wound care instead of just treating a wound or sending you to a specialist.
• Lack of accessible communication tools, provider training and poor care
• The psychiatric system did not listen about who I was or my individual experiences. Kept giving medication, took over a year and a half for a proper diagnosis.
• Not enough physicians take mental hlth issues seriously. Was told to get a grip when I, due to PTSD, asked for someone else. Had double kidney infection, could not keep even H2O down and given incorrect oral meds to take. Was back in ER less than 8 hours later where I was admitted by a knowledgeable physician
• I was referred to a pulmonologist that had no clue what an 8th thoracic vertebrae was. My situation was a total cluster. The ER doctor just dismissed me (I had 2 breaks in my back, a deflated lung, a damaged diaphragm, and a sever traumatic head injury), plus I had to call an ambulance because I couldn't drive myself.
• My PCP doesn't really understand my condition, Paralytic Polio. However, on my own, I have found specialists who do understand, but wait times have been long.
• Their focus is on data entry for insurance coverage, prescribing drugs that cost $10K+ a year even with disability Medicare. And, most recently, reduced or nonexistent COVID mitigation practices such as masking. I am at high risk for severe disease and physical therapy practice was surprised when I left their crowded waiting room with no one wearing a mask.
• I love my pcp but he admits to not being an expert on multiple sclerosis. I have not been happy with the neurologists I have seen so I prefer to stick with my pcp.
• Half the time do not even take my vitals
• The support staff are always quick to make judgmental comments, are dismissive, and do not treat with dignity. My PCP tries but she is overworked and under supported in her rural office and all follow up care has to be done elsewhere which is exhausting. Most importantly, the lack of care shown by staff in taking serious Covid mitigations means I have had to delay care (one-way masking, inappropriate masking, no masking.) Additionally, our dental practice closed for six months in 2020 so we had to delay care because of that absolutely reasonable and necessary mitigation effort.
• They do not understand my triggers and don't take the time needed to understand my reactions.
• Helping me to format my thoughts and feelings in a constructive way that makes sense to them.
• A lot of rural doctors don't know how to manage patients with spinal cord injuries. Likely due to no experience.
• Many of my conditions aren't discussed at all in most medical schools, and many doctors recommend harmful "treatments" that have been disproven. I often find myself being the one explaining my medical conditions to doctors.

• Most know very little about the complex health problems I deal with daily
• It seems that only specialists these days have any intimate knowledge of any specific condition or idea. PCPs (or more likely, nurse practitioners) seem like they are only checking very basic things and missing the nuance that doctors understood in the past.
• PCP is great! The issue with almost every other is with providing an in-person ASL live interp
• They have limited knowledge of alternative options for all aspects of care. They are also prone to bringing in their own preconceived notions and assumptions of what is going on with us (the patient) prior to even meeting with us and examining us.
• He doesn't do a complete exam. I think it is because he is uncomfortable doing it with me.
• They spend their time looking at their laptop and rarely looking at or talking directly to me. The patient doctor relationship has vastly disintegrated.
• I do not feel heard. My concerns are brushed off or dismissed. I get told to go to a specialist who has a months long waiting list, they spend a few minutes with me, only looking at paperwork and say I should see a different specialist. I gave up when my Mainecare didn't get renewed after months of no resolution/diagnosis.
• Focus only when I present symptoms. I expect preventive care to happen as opposed to Wellness. Telehealth is useless.
• Many do not get training on interacting with autistic clients. As well as mental health and it is common to be treated as a "psych patient" the minute you have a mental health diagnosis in your chart. You then receive inadequate or no care. They also are not trained in how to help other conditions without defaulting to weight- which has been proven to rarely be a health factor in chronic conditions.
• Lack of knowledge by many providers of the ins and outside of brain injury.
• My child has autism and most medical providers we have encountered have limited knowledge on this disorder unless they specialize in the behavioral health field.
• Mental health care really does not exist. Not enough providers or support people or any medical people trained to help with mental health..very sad
• They don't seem to be willing to do what it takes physically to examine me.
• I was psychotic due to a misdiagnosis from major depressive disorder which was actually bipolar disorder. I was on the max dose of zoloft and put on prednisone because my primary care provider at the time didn't notice. The emergency room doctors laughed at me, mocked me, sent me home with no transportation and dead phone so I had a panic attack outside northern light's emergency room. I remember being heartbroken that I knew I was in danger and not even a hospital would help me. I could have ended my life. I had a nurse say "we have real emergencies to deal with. This is a free country you can go". I had a doctor tell me I was a waste of an emergency bed, and to keep "barking up trees" when I had an ovarian cyst rupture and was psychotic. He gave me sedatives that weren't need to shut me up. They let me go without ever having seen a psychiatrist. I tapered myself off medication incorrectly as I wasn't receiving the help I desperately needed. I have never felt like less of a human. It was disgusting display of humanity and I will never trust health care "Professionals" again.
• therapists are not equipped to deal with development disabilities and cognitive disabilities
• They know much less than I do about dinner if my illnesses. They dismiss or minimize the symptoms that I report. They chalk physical symptoms up to mental health issues and refuse to

address them except for a referral to mental health. They only treat one system/specialty and are not able to appropriately address the complex, multi system issues I have.
• They are not paralyzed like I am so they do not understand the pain or spasms I'm having. It's been 8 years and they still do not know the right treatment or why I continue to have out of control spasms. They can't help me and don't have answers.
• #1 this is NOT a 'feeling.' I have multiple rare conditions and long covid. They aren't even trained in long covid so I've been working on ensuring it. Maybe also because i was told that if I didn't start a treatment I would risk my life and I looked at teh provider knowing that if I did start the treatment I would risk my life and then was later backed up by providers educated in diseases and long covid.
• They only focus on their "specialties" they don't treat me as a whole person.
• patience and distance
• I have been mistreated in emergency rooms because I have a mental health diagnosis. My physical symptoms are often ignored, downplayed or belittled because I have a mental health diagnosis.
• It's gotten better but I feel they could still use more training when working with adults w/disabilities. Especailly about treating me like everyone elseand I'm an adult
• I feel rushed and too many patients crammed in one day. Don't always listen to me. Doctors don't talk to one antoher about treatment and disagree on treatement and leaves me confused
• They use "doctor" talk and I cna;t understand them. They talk to me like I was 2 years old and talked in "riddles".
• Sometimes may not completely understand about a specific disability and how to treat and talk to
• Could use more training and don't feel like the nurses and the doctors always talk to each other. I had health cnocners and couldn;t get in and I ended up having cancer!
• I don't have one
• They do not understand or provide trauma informed care. They make assumptions and generlizations that do not apply to me about my weight and mental health and don't believe me when I provide accurate information about my body like about A1C Levels, cholesterol , my diet, and lack of blood pressure issues.
• Need more training for trauma informed care - seem to just want to get you and get you out without really hearing concerns and trying to fix it
• I had a stroke and I have a benign brain tumor so I get MRIs every year. Usually I go to Augusta but one time I went to [redacted] and there were two girls who could not get the needle in my arm for the dye. The two girls were young and lack experience. So I told them to stop. When I talked to the doctor later, I asked if the MRI was good without the dy and they said yes, they still got a good MRI. I don't like [redacted], but it is a lot better than my experience in [redacted]. They usually give me warm blankets during the MRI and they did that in [redacted] too, but they wrapped me up like a burrito so I couldn't move. I did not like that either.
• Physically: It is standardly minimalistic, meaning that unless I appear to be dying, they often only provide the bare minimum care. Mentally: I'm treated with professional bias even though the vast majority of mental health issues can only be solved on a case by case basis.
• Need more training or such in empathy. Pay more attention to me, not my condition.

• I shouldn't have to explain how I feel.
• Asked to see doctors about physical stuff (like fast heartbeat; thought it was a heart attack) but was taken to a psych ward
• Don't explain things well
• Few of the rural pediatricians or dentists or MD's have experience working with Down Syndrome.
• I've had to instruct them how to do simple things like measure BP (I don't let them do it electronically) a lot of them can't take a manual BP
• I have chronic pain. They always blame/say its my Fibromyalgia. NO IT IS NOT!! I have spinal stenosis, degenerative bone disease etc. They never look into my charts The list goes on.
• I have chronic pain along with Fibromyalgia. What they dont look into are my spinal stenosis, degenerative bone disease. Sick and tired of them saying its your fibromyalgia all the time. When it is NOT just fibr
• It took seven years to find a doctor who would listen and look past lab results.
• It's not that I "feel that way," it's that they've told me that.
• Providers continually advised that best treatment was [redacted] but because wait was too long prescribed multiple pharmaceuticals with significant side effects and no impact on overall symptom burden. Providers said to take more medication and to "try harder" while waiting for BHH.
• I'm often dismissed due to perception of and assumptions based on mental health condition.
• They don't understand my disability
• When you have a mental health diagnosis in your chart your physical issues are often ignored. Also you are not treated well or with respect.
• I have a colostomy and hernia and chones and the doctors had to send me out of state for medical needs
• With all the issues I have had for 14 years. Not once have they been able to give me a good answer for why my body is trying to destroy itself. Whenever I have gone to the doctors for anything all I ever get is everything looks fine your blood work is normal. So I leave and have no answers once again. Frustrating now I don't see a doctor unless I am in really bad shape. Just not worth the time and co-pays sadly.
• Even their handicap accessible rooms do not have a way for you to be weighed. Because my arms are so spastic, they don't have a way to properly take my blood pressure without causing me to be bruised
• Thye dont' talk to me - just staff need go listen and understand me they try to get me to take meds that I don't want to take
• thye could do better and need more training
• we have a hard time understanding each other they don't call back and don't tell me things they don't always believe me my cas emanager stopped me from getting counseling
• more training
• need to learn more about me/disabilities learn how to communikcate with me better learn hoe to treat me better

- They are not trans competent, they discriminate based on my mental health conditions and memory issues
- I have had multiple medical professionals look me in the face and tell me they don't know how to help me. Doctors don't listen to me when I tell them I am dealing with a certain issue, they will try to diagnose me with something else.
- There's a lot of misinformation about my conditions out there and it does carry over into the medical/mental health field and they were not properly educated on my conditions, i was constantly having to correct them or explain things about my disorders that i would expect a healthcare provider to know already.
- They don't seem trauma informed or I needed a higher level of care then they were trained for.
- Disgusted with PCP
- They don'y understand PTSD and how it affects/effects people in a clinical setting.
- Don't tell me what is going on. Have a blood disease but no one will tell you what it is.
- Not the eye doctor
- Not my psychiatrist - not able to meet my needs
- When the doctor asked questions, they assumed the answers. They didn't try to get more information and rushed through it. They just "threw meds at the problem" and did not explore other options.
- big barrier is communication
- communicatin could be better
- somtimes they "skip a page" and I don't understand or they don't explain things, espeically new people. They don't always understand my communicatin needs. Need more training on getting to know people better & get people's info
- There isn't an ENT with the qualifications to help me.
- They don't talk with me they talk with everyone else about me.
- Sometimes I'm not taken seriously, since it's all "in my head," and often I'm told it's growing pains. I didn't realize I was being abused because nobody asked me about my home life except to say "things are good, right?"
- I feel like they don't listen to me or believe I am in pain
- I don't get the care I need.
- I feel as though most healthcare workers, especially in the age of covid are trying to get patients in and out as quickly as they can
- Not being listened to about my symptoms and concerns due to their biases.
- I'm answering all my questions for my PCP and not my specialists. My PCP not only had no idea of how to diagnose me but also no idea of how to treat my symptoms. Now that I have a specialist she doesn't even talk to me about my disease even though it's important in my regular care.
- I have had bad expirences with doctors' knowledge in queer health
- I feel like there are many situations where a healthcare provider is so wonderful to me, but there are so many more times that I have to explain so clearly what my needs are and just hope they're met.
- lack of practial knowledge in patient care

• Autism is a huge barrier in receiving care. For example I have anorexia and have left school twice for inpatient treatment. While I was there, both times, I was not accommodated, insurance cut me, and I ended up losing weight. I've reached a point where health providers' ignorance has actually worsened my state so I just try my best to eat and keep myself alive on my own. Similarly I have PTSD and health providers' lack of trauma-informed care is a barrier.
• Many professionals are not prepared for neurodivergent clients and often do not understand common autistic problems nor do many offer realistic changes for the poor. Often the provider will offer an idea that would help however they wouldn't help me understand what the cost or how I would fund it if insurance denied me.
• Many are not well equipped for neurodivergent clients and will oppose their care if the client challenges their authority and ethics (such as denying someone surgery for a clear issue bc of believing they may not have money, despite being bound by ethics to help all)
• My primary care is good. We have a long, established relationship. Other specialists you have to explain how to communicate to someone with hearing loss.
• I think they don't have a full understanding of the medications I take and their side effects. They don't have an understanding of the degree to which my mental health challenges impact my life or the resources to help. They assume other providers are meeting my needs.
• Providers change too often...when you finally get comfortable with a Dr..they leave and you have to start over with someone else..which makes you not want to go
• No idea how to be personal. Nurse had a business attitude - no patient interest. "Just get on a scale for weight." No nice greeing. New doctor is 35 years old, seems to have no idea about anxiety, etc. Non-personal attitude, no interest in my losing my past doctor. 1st meeting with new PCP was a real disgrace and embarrassment for me. Can't switch as no doctor is taking new patients.
• mental health makes most health providers treat me like trash
• Because of the assessment in the ED I didn't get the attention that I needed. I fired just about everybody at that facility, and found drs at another location. Just to be clear: I finally discovered (purely by chance) that I had a significant break in my back, head trauma/concussion, a deflated lung, damage to my diaphragm. All this was "discovered" piece meal and dismissed. I now have a new team at a different facility.
• I am still trying to fin provider who has experience with TBI's
• Most of them, especially my primary doctor at the moment, seem afraid of my disability and chronic health issues.
• they are now, but it took a while for them to understand me and for me to feel comfortable talking with them.
• Depends on where I go; lack of empathy; don't care about people's pain levels
• not well equipped to deal with mental health disabilities, especially PCP
• I have very rare diseases and tumors and a specialist in these areas are far and few between.
• Need education about deaf-blind people
• poor quality of case - feel like some of them don't care they hurt me and didn't care
• Need better positive bedside manner feel like a burden feel like I'm being rushed
• need to work with people in thier specific needs talk to my daughter more than me

• I feel they are prepared but I don't know when. I want them to tell me when.
• Providers do not believe or listen to me. They utilize restraint too quickly. They do not include me in planning.
• They only saw me quickly.
• could do better at taking the time for better communication
• not sure - just better
• sometimes they rush through
• I am feeling hurried because of the time peramiters.
• I feel like some of my providers are able to assist and willing to assist but ultimately they don't have enough experience working with individuals with spinal cord injuries
• need more understanding about my specific needs/treatments need to stop using languag/terms I don't understand
• I have inner knowledge
• Sometimes. They are so limited by the rules and guidelines of the State and others, that it is sometimes impossible for them to accomodate their patients with the help they need.
• It depends on what their specialty is buy my main doctor does not know mental health stuff that well so I keep my mental health matters for my mental health providers at Acadia. I wish them to coordinate, so I sign released for them to talk to each other about me.
• I feel like a lot of providers are there for a paycheck. They don't listen to what I need, they just kept pushing meds at me.
• Because of what I need. What I'm dealing with, the injuries I have sustained.
• The staf here at [redacted] isn't always agreeable and caring towards me in particular at all! I have Bipolar Disorder Type II which means I have a mostly depressive illness. My speech is rampant at times because of my disability too.
• [Redacted] views me as a woman who is bipolar.
• Some do not treat those with disabilities like they are valued equal to normal people. They do not look into options for scans to rule out things. They assume the patient will give them all the history, but forget that some clients cannot tell all, sense all, feel all that could be happening. Some have had conditions go unfound due to delay into looking deeper.
• Lack of understanding about mental illness and multiple sclerosis
• PCP didn't pursue medical treatment or exams for diabetes despite having a family history of diabetes and showing symptoms. It took going to the ER to get the exams done and to be diagnosed with diabetes
• [Redacted] said "I don't know what a pro-drug is, I just use my DSM-V for everything."
• CNAs, NPs, RNs, have communication barriers; push medications even if I don't want them. they prioritize medication over other preferences of treatment
• In Maine, health care providers do not have as much experience with communities of color, immigrants, and underrepresented minority groups. This can lead to misdiagnosis because there is no knowledge of important cultural practices (e.g. lack of eye contact in interpreted as a mental condition or there is little understanding of the way that non-white bodies grow and develop.

• -Knowledge base lacks when people rely too heavily on automation. Didn't know how to do manual blood pressure. - Passing knowledge from those medical professionals - who have been here for years down to the newbies, 15 minutes per patient may not be adequ
• They understand things like "diabetes" but don't understand my need to self harm and hating myself.
• My PCP can't weigh me. They don't have a wheelchair scale. The electric blood pressure cuff doesn't work well with my spasms. I've been seeing this doctor for 17 years. My specialist has a wheelchair scale. That's how I get weighed and they tell my PCP.
• Mostly yes, but missing empathy.
• My new PCP scrapped my skin in two places for skin cancer leaving me very scared. NOT for her to do, should send me to a specialist.
• For the most part, yes, although recent experiences made me feel uncomfortable.
• they don't understand that blindness doesn't automatically limit the ability to do certain things. Most don't even know how to do sighted guide. The front desk staff who assist with filling out forms want to do it in the waiting area surrounded by other patients who can easily hear the whole thing.
• They referral to a place without explaining what they provided and I ended up stuck with expenses that does not fit my expectation. I wish my referral person explain more of what they actually do in their practice.
• Ok, after first coronavirus shot with ASL, then I requested ASL for second shot, never happened, then again third one, no ASL, the nurse was not friendly. I was damn innocent. The nurse brought vrs with terrible Wi-Fi. Of course, I reported on vrs "ðŸ‘Ž".
• Today I am calm because the sunny weather.
• They were not efficient with the VRI provided
• No, I had to ask live ASL interpreter, but changed to VRI without my knowledge
• No one spends time in knowing me

Open-ended responses to "Do healthcare providers respect you? If no, what experiences have you had?" All responses are presented as written, with identifying information redacted.

• Not all providers disrespect me but older white male doctors certainly do it at a higher frequency
• Provider tried to provide parenting advice when I was very ill with COVID. I was the patient,not my child.
• Providers have made jokes about disability symptoms
• Not properly trained people in mental health care
• Emergency room providers made assumptions based on my mental health diagnosis and ignored my physical symptoms.
• Denied knee surgery because of weight. I expirenced a lack of understanding of trauma informed care including Assault by police officers who were called to the ER because I didn't give the nurses my keys. There was absolutely no aggression on my part and had communicated that I was experiencing trauma related dissociation for the reason for going to the ER.

• What Family Practice, have their patients, swab their own Vagina for a yeast infection, put the swab on a paper towel & not in a tube?? I sat in the room to see how long it would take for them to come and put the swab in the tube. I waited 5-7 minutes. And,left the room, as I was asked to after I swabbed my va jay jay. I am still quite disturbed by this.
• it was assumed that I was drug seeking when in fact I had a fractured neck! I had to go to two different doctors to get a diagnosis.
• I have had healthcare providers ignore my physical needs. I have had doctors mock me as well
• They have no idea what it's like to be disabled and poor, and can't seem to even fathom the obstacles I face
• didn't try hard to find problem
• Providers make hasty assumptions about me in all directions. I am extremely intellectually capable but have trouble with auditory processing and emotional regulation so sometimes it takes a while for me to understand things when people assume I should get things quicker. Alternatively people see "autism" and assume I am intellectually disabled, which I am not. I am always over- or under-estimated. Just speak to me directly and I'll let you know where I am at and what I need!
• some are better than others!

Open-ended responses to "Is there anything else you would like to share about your experiences with the healthcare system?" that relate to provider education and/or cultural competency. All responses are presented as written, with identifying information redacted.

• I have found that in the ED the providers see that I have received psychiatric care and I am treated much differently I think than others. They think physical complaints are related to mental illness.
• The constant dismissal of my concerns as if I am not the one living in this body is incredibly frustrating. I want to be treated as at least somewhat of an expert on my experiences. I deserve to have my concern matched as well, if I am very worried about something and am met with noncommittal response that's stressful and often disrespectful in my opinion. I want to be treated as though I understand what is going on.
• We need to have more accessible ready for deaf patients with no stress involved like in staff interpreter (s)at hospitals . Drs office, hospitals staff need trainings on deaf etc more often due to high volume of staff turnovers.
• [Redacted] Is very knowledgeable, patient, and responsive. I have a rare airway condition and he said we would find a way to treat my apnea, considering my: 1. Airway sensitivity 2. Violent night terrors
• Above questions are misleading. Very happy with current dental, fired last one. Some mental health professionals have been good some poor. Etc.My rankings do not necessarily refer to current, but any I have received over past 5 years.
• I sometimes feel like my issues are not getting addressed enough just because their test comes back negative. They do not try to peruse why then do I feel like this?? Instead I am made to feel like it is in my head until I ask them for something else. Then I feel like I am diagnosis searching Instead of just trying to figure out what is making me feel like this? Like now I am going to ask for allergy testing.

• While my current medical team is amazing, it took me years to find providers that wouldnt ignore my health problems and brush them off as mental health. I feel a lot of people with mental health problems get ignored by their medical team when it comes to physical illnesses and physical symptoms.
• Specialists need to take a more "whole body" approach and not just narrow in on their area. For instance the thyroid can effect other systems of the body and the endocrinologist needs to be able to focus on more than just the endocrine system when it effects more than that. But they tend to only go as far as their specialty area.
• No facility has a public toilet that is accessible to me! Even the hospitals. All I need is a modern version of an outhouse seat (a smooth wide hole in a board). This is what I use at home. See www.handicaptipsfordailylife.net
• Medical professionals MUST become more trauma informed and social workers must be available for us to talk with!!!
• I am grateful every day I went to [redacted]. They finally diagnosed me with catatonia as I turned 18. I suffered for a year and a half with the wrong diagnoses.
• Health care needs to be healthy care. Not enough providers or knowledgeable staff to be able to help. Stop cookie cutter medicine. Not all patients are the same. All health care Staff need to be trained for mental health care to better understand mental health issues in patients
• Mental health services are hard to access. Once I receive the services they are sometimes very helpful and sometimes not very helpful. I have an extremely hard time opening up to providers, partly because I'm not sure what the result of talking about "serious" issues like, for example, suicidal thoughts will be.
• The health care system treats mentally Ill adults like meaningless scum.
• I've had 6 heart attacks in my lifetime and no medical doctor that takes me seriously. No RX prescription medications were ever prescribed for the attacks and no medications prescribed for my chronic A-fib that I suffer from. Also, my penis and testicles were found inside my pelvic cavity during a routine ultra sound and still no referral to a surgeon who can surgically make my male reproductive normal (on the outside) like any normal man.
• I've been blessed to have competent providers who make me feel good and meet my needs. I feel like oral dental care is to expensive and hard to access if you do not have proper insurance.
• Doctors sometimes do not respect my questions and answer them impatiently without verifying that they actually answered the question I had. The tone is "I'm the expert so what I already said is relevant and if you are asking about something else, it is irrelevant/wasting my time."
• Organizing my care, scheduling appointments, following up with doctors about things they said they would do, and advocating for my needs with doctors takes a huge toll on my mental and physical health. It feels like a full time job, and it's very frustrating and stressful.
• They do not care about chronically ill and/or medically complex individuals. They want quick and easy answers.
• There is a large knowledge gap for brain injury- PCP or neurologists. I have experienced MULTIPLE providers that made unsafe medication recommendations, didn't return phone calls/emails, or simply said they couldn't help me.
• They feel that they do understand what they're going through.
• I am grateful every day I went to [redacted]. They finally diagnosed me with catatonia as I turned 18. I suffered for a year and a half with the wrong diagnoses.
• Was medically abused as a child repeatedly and avoided medical system for several years to avoid further harm. It took a lot of trial and error to find providers who would not perpetuate

harm and would actually listen to me. Particularly as a non-binary disabled person, this was doubly difficult to find inclusive practices. Additionally, weight stigma and anti-fat bias made it challenging to seek treatment for eating disorders, which were often exacerbated by medical providers. Several times medical providers affirmed disordered exercise and eating and penalized me when I stopped those behaviors.
• I am encouraged to take way too many medications. I am encouraged to undergo way too many tests and scans that ultimately do not change course of treatment. I am always secondary to the computer screen from check in to time with provider to check out.
• Healthcare in Maine is shaped by a culture steeped in white Puritanical patriarchy. It's very much a culture of "get outside, drink some water" and bootstraps. There's a constant barrier to getting care when providers lack even basic information, and worse, curiosity, about their client's condition(s). The cultural expectation here remains one of "we don't talk about things that make folks uncomfortable." And if you're not white, getting appropriate and compassionate and inquisitive care here must be like navigating hell. There is a dearth of trauma informed care and care is stingy and withholding to anyone lacking economic resources. Maine overall, from its lack of infrastructure, its inherent ruralness, and its aging architecture, is inaccessible to most of its aging and poor population. Maine, frankly, for all its "the way life should be", is hostile to anyone who doesn't embody the LL Bean model of health.
• A doctor insisting that they're 45min college lecture makes them more qualified than me, with 40 years of experience with a disease, is unacceptable. Decades of medical gaslighting/abuse had led to severe medical trauma. Even a simple PCP appt sends me into a tailspin due to the trauma and fear it will happen again.
• it is broken. There is no room for a doctor to spend an adequate amount of time with you due to the hierarchy in which they work. We as patients feel like a number, or even a fraction.
• I have had difficulty with providers both for physical an mental health needs not having knowledge about alternative therapies and when the do the do not know how I could access what they are suggesting unless I can pay for them out of my pocket which I am unable to afford. So , I have been forced into more invasive treatments for conditions such as ECT, injections, surgeries, and medications when alternative approaches have been proven to be more effective and less invasive. Such as bio- feedback, hormone therapy for a hormonal imbalance, massage therapy, acupuncture for pain management, and meditation classes. None of these things are accessible to the poor and these services are cheaper, preventative, and work better to support a sustainable wellness than more invasive options that are paid for by mainecare.
• Stop treating homeless people like sub-standard people. I didn't decide to be homeless.
• medications are hard to discuss or to scribe some pain or mental needs
• No. I hate doctors.
• Wish felt more care or love or supported by doctors, staff, guardians, and peers; wish I had more friends, to be safe.
• Not enough doctors; have to work with nurse practitioners. They are too by-the-book and don't listen to what works for you in the past.
• I would not recommend anyone go there becasue staff need more training!
• I don't like the fact that I have to fight so hard to get into a mental health hospital. I've been turned away several times and it's not right.
• Health care provdiers, in general, seem to have very little training on how to assist people who are blind...I'm often treated like anelderly person who has lost thier sight later in life rather than

someone who has lived with blindess for years. The few times I've been to the emergency room, my cane is folded up and since I don't look blind, i have to explain to all the different peole who come into the room that I am blind. This also happens when i have to undergo some type of testing.
• It is not safe to go to an emergency room by yourself. It is best to go with someone you trust and have them stay with you.
• If my health care provider didn't respect me, I would go somewhere else. I really like my PCP. They are right in my neighborhood, which is a great thing because I don't drive. They listen well as well. Mental health/med. management/some pharmeceutical stuff: not so good. My provider is far away so I need to rely on [redacted] to get there and back. At least one local pharmacy is so strict about when people with prescriptions for controlled substances can get them filled that I have had to go without medicine because of a lack of public transportation on Sundays.
• I think they are doing a good job.
• My health care provier is funny and gives lots of information
• No, I am happy with my doctor.
• I see a muscle doctor for my muscles and a pediatrist. I wish my muscle doctor did primary care! They are the best. I know when we were dealing with COVID, they should let my caregiver assist me. I had to speak with my PCP and he talked to [redacted] and they apologized and were good in the future, but I should not have had to do that. They should have known better in the first place.
• When I had mental health episode, I was brought to [redacted], where they didn't know me. I was kept in the emergency room and released either too early or simply monitored. I needed to go in-patient at [redacted]. I needed medications changed and observed. I finally went in-patient at [redacted] in the next couple of years. Had I been brought by [redacted] to the place sooner, as I said in my crisis plan, I would have had fewer hospital/emergency room visits.
• I am upset about the psych rooms in hospitals and the staff. They make you feel like an animal in a cage and hygiene doesn't seem important.
• [Redacted] does not see me in person. He does not ask enough questions. My PCP does not ask me if I'm eating, how I am getting my food.
• My doctor (PCP) in [redacted] is at [redacted]. He is neglected to gain access to speak directly to him personally about my brother's interests concerning me at this group home! Guardianship, he didn't want to grant to me! I don't need a payee either!
• I would like [redacted] to listen to my childhood trauma.
• We often see specialists that do not take the time to address ailments, often seeming to treat the person as if because they have a developmental disability they do not deserve all the time they should get. Like they are not equal in value of care. We have had ICU doctors reluctant to take all avenues to save a person because they implied it was not worth it. Regardless of the expected outcome, all avenues that are basic should at least be tried.
• All my professional doctors, therapists, and social workers have always been prompt, well prepared, and helpful to all my needs: mental, physical, and emotional. I appreciate Maine very much for all they have done for my mental health, physical health, and emotional health. Please give everyone my thanks. I have almost everything I need thanks to Maine.
• Receive MS diagnosis with good insurance then switched to MaineCare/MediCare. Feld care really changed for the worse after the switch. Many providers didnt' seem to care about quality of life or have empathy for diagnoses.

• I like when they interact w/ the patient to diagnosis. For diabetes they go over the weight and A1C. Never feels judged about diabetes.
• Entered ER they dismissed concerns of frontal lobe injury.
• My urologist is very easy to speak to and helpful but I find my primary care service providers to be less educated on my needs due to my disability
• I've noticed a difference in how I'm treated by docs and etc. since I've stopped talknig about any current or past mental health stuff, and since I've requested labels to be taken off records. I only go to PCP and gynocologist when I have to. I interact as little as possible with the "health" care system. And my (not recent) experience and experience from working in EDs, I've seen how a patient is treated differently depending on why the person is there (in the ED).
• I am treated with a lot of respect each time.
• Sept - went to primary care in fort kent; didn't feel safe sharing personal info, scared of being committed
• no empathy at er primary care is amazing therapist is amazing
• there could be improvement more trauma-informed staff @ group homes and doctor's offices
• don't feel like i am seeing the person who has the best knowledge about my condition
• Re: Q12 on paper version: The people at this group home bought a wheelchair for me but won't let me use it. Q29. I do not know how hold I am but not 61 years old Q38. Someone won't let me know my income I was "diagnosed" as a "paranoid schizophrenic" after a 6 weeek long drugging and gang rapes without having an exam. The "diagnosis" was called into [redacted] before I even arrived there. First time I was ever put in any psych hospital. This keeps happening to me everywhere I go from ME to Washington, D.C. and from Mass. to the State of Washington. Someone keeps badmouthing me.
• I've been advocating since I was 12 and am mid-40's. I don't have enough spoons and this survey is too long for spoonies who have limited energy. I'm surprised this was not considered.
• I have experienced many forms of care over the last 5 years but the lack of training and judgements people made about me in emergency rooms resulted in my physical issue being totally ignored while I had a focus being made towards a false belief I was suicidal because the pain I was experiencing made me teary. My physical pain not only was ignored by emergency room notes but the false belief I was suicidal notes followed me so when I sought care in the nexgt emergency room, again my physical issue was ignored and the focus was put on a mental health concern. I had to go to a 3rd emergency room who finally ran the correct test on me physically to discover the true issue I had that needed to be fixed. The events of those visits cost me over $7500.00 because I had no health insurance at the time. I am still paying because some admitting nurse made a false judgement based about me because my chart had a diagnosis of a mental health issue and I was teary upon arrival in pain from my stomach issue.
• fellowship, together, proper care, due care 100 percent
• I see a psychiatrist [redacted] for medication management for schizophrenia. He has help me a lot.
• Before finding our primary care doctor two years ago, most doctors were completely useless and actually make things worse.
• There needs to be alternative testing available for diagnosing Alzheimer's/Dimentia for people with developmental Disorder (Down Syndrome) and are non-verbal. The testing methods are impossible to complete for this population.
• I've been blessed with the best care I think I can get. I've been very happy with all my doctors, nurses, and all staff. I'm so grateful to have these people in my life. When my PCP moved from a

Primary care facility in my town even though I'm legally blind and have to get rides I chose to follow her even given I'm legally blind to a much further facility out than I am, and to be seen at a "clinic" because she listens completely to me and we discuss everything together. Dr. Amanda Powell is awesome! I would highly recommend her to anyone. I'm very grateful for her and her staff and would highly recommend her to anyone I know.
• [Redacted] did a horrendous job upon my entry with a physical issue. The nurse assumed I was having a mental health issue because I was crying and in pain. I was labeled suicidal despite never having been suicidal in my life. I did not get the care I needed
• I'm astonished by how good this system is sometimes, and then they throw me into a "play later" kind of situation. I need the demands that I need.
• I have had good experiences.
• Just wish they would be more educated in Autoimmune diseases and Tick borne illnesses
• I'm my own guardian and I don't bring stadd with me. Overall they listen to me and talk to me like an adult. After my day surgery staff sent a card that everyone signed - I felt appreicated.
• They could do better for sure, especailly working with people with disabilities
• My dentist hurt me and didn't seem to care
• they could do better and need more training
• I like them but needs improvement
• Most doctors are ableist, transphobic, homophobic, racist and/or saneist towards me and many people I know.
• Mental health professionals don't understand transgender identities. Multiple times I have been referred to as an it by doctors in the ER when I was in a mental health crisis.
• I am not one the best patients in the world but my primary care doctors and physical therapists have been a lot of help.most of my mental health care has been through [redacted], and the change over is just too much. I get very overwhelmed by the amount of times I have had to describe my life and what I have had to deal to a new person, it sets my mental health back even further. Most of the doctors at [redacted] are great, but I have felt a few doctors didn't care about what was going on. I felt neglected and had to wait a very long time to get help. I have had to tell a couple if they weren't going to help me then sign me out and give me the slip of paper that need for a taxi home. And twice in my life I have had a hospital doctor not give me the correct x-ray, or refused to give me telling me my ankle wasn't broken just sprained. My primary care dog was livid, and my ankle never healed correctly.
• I was turned away many times because of being transgender until I found the right doctor
• I am thankful and they put time and effort to help me. They are doing it for my best interest.
• They look out for the rich people. When they see me coming, it's all down hill.
• Very unhappy with health care system in Maine. I am treated differently because of my disability. I was kicked out of [redacted]. I feel no better after 22 years in Maine. They shouldn't discriminate because I am mentally and physically disabled.
• Have a lot of confidence in it.
• Although I was happy overall with the care I received, I feel my diagnosis of substance use disorder is still used as a label and I am viewed through that lens first rather than a person. It determines certain treatments offered. I've also seen the phrase "patient is an addict" on a medical/dental chart before. That bothers me and stuck with me.
• [Redacted] used racial comments at one of my appointments.

• As a fat person, I routinely feel like I have to convince doctors - of all kinds (dentists, etc) that my pain is real and not always related to my weight. And sometimes, doctors make assumptions about me because I have PTSD - also that I might be making things up or my pain isn't real. It's very frustrating and I have to advocate for myself every time I'm in a medical professional's office to be taken seriously.
• I am fat. I eat healthily, I do moderate exercise, yet anytime I complain about symptoms or speak about my concerns, health care providers advise me to lose weight.
• Have found very few providers who are even have baseline understanding of the difference in cognition between neurotypical and autistic clients.
• yearly wellness exam is poorly designed. no unclothed thorough exam, and no labs or tests prior to visit so results can be discussed. obviously designed to make money for insurance companies. also great need for urgent care clinics in rural areas to stop over use of E.R.s.
• I was diagnosed with Hashimoto disease and also was diagnosed with Sensory integration disfunction as a child which I have mostly grown out of but still have many autistic tendencies and was told I could definitely be autistic but my mom didn't want to get the studies fully done because we were doing just fine with me having sensory and didn't need to have full label for my few issues. I have just expressed I on on the spectrum since when I was diagnosed with Sensory it was part of the autism spectrum in the year 2001 and my doctor made sure to mention that to my mother. I don't obviously know for sure all of it but I just believe I am a high function person with autistic tendencies. This was the first big medical issue to happen to me I am of course okay and doing a lot better but trying to adjust and not knowing what was wrong and all the blood testing was definitely a very hard time for me. I do live in NH but I have been living at [redacted] since August of this year and so I have needed to get medical care in Maine it was very sufficient which is why I still felt that my feedback could still be beneficial for your research. Thank you for listening to my story and if you have any questions feel free to email me at [redacted].
• Super not trauma informed! Very trauma inducing! Especially emergency settings.
• My provider is trauma-informed, and I am very lucky in that. If they weren't, it would be much less accessible.
• My current primary care physician is amazing, she is respectful and kind and a good communicator. I feel comfortable with her. In the past however that was not the case. Before I saw her I saw a few other providers and some specialist who were pretty awful. One ignored my complaints about my hearing and said I had "teenaged selective hearing". Turns out I have hearing loss and needed hearing aids. I stopped seeing that doctor after that. The doctor I saw after her was aware of some trauma I had that made certain examinations difficult for me and was not as empathetic about it as I would have liked. She made me feel like I was making a poor choice choosing not to do certain screenings due to my PTSD and very recent trauma. (My current doctor is very different about that subject and has encouraged me not to do anything I feel would be damaging to me mental health wise and not to go through with procedures like that unless I feel ready to do so). The specialist who was awful I saw was for "womens health" and she just did not listen to me at all. She ignored everything I said and just made me feel uncomfortable. It felt like she didn't want to hear about my symptoms. I never saw her again and when I told my current primary (the good one) about her and the experience she apologized and asked if I wanted to be refered somewhere else. I ended up just choosing not to see anyone after that and tried to deal with the issue with just my primary and not a specialist since she was the only one I was comfortable with and actually listened to me. I feel very lucky

that my primary is so wonderful because outside of her I don't feel seen or cared for all that much.
• I'm almost 27 & have never been asked about getting a mammogram before. I've not asked myself because I'm scared
• I've had interactions with 2 different facilities, so the questions are a little difficult to answer. I can't say that I had any positive treatment at the 1st one; the 2nd one was so much better! I truly believe I'd be at a much better place had I been treated appropriately at the 1st ED. Instead I was dismissed and sent home. I'm still dealing with the aftermath.
• have had fine experiences

Structural and Systemic Barriers to Care

Open-ended responses to "Is there anything else you would like to share about your experiences with the healthcare system?" that relate to systemic barriers. All responses are presented as written, with identifying information redacted.

• Losing one's license due to a medical cause even though no accidents. Statutes are punitive.
• I think it is very important to expand sufficient health care programs for everyone, regardless of income, medical background, and/or other factors such as race, sex, religion, etc. It is very disappointing to see the domino effect of not providing safe and fair working conditions to providers (as well as other medical staff) while CEOs and hospital admin made record profits during the height of COVID. The cascading effect translates to tangible diminishment in care throughout Maine. Many providers have left or are leaving Maine (high provider turnover), medical professionals offer insufficient care due to disturbingly high patient-to-provider case loads that increase stress across the board, and then add how already marginalized groups receive a lesser quality of care on top of that.
• I think the health care system is severely lacking. Doctors do not look at you; you don't undress so they can check for skin tags, etc. I beieve thie current health care system is awful, and the primary reason is insurances. Years ago, I had a 45-minute appointment for my annual physical. No stone went unturned. Now, you are lucky to see a provider for 15 minutes. The communication is severely lacking. Doctors dismiss symptoms if they cannot explain it with a lob test.I feel like they just phone it in and don't really care about patients.
• Transportation is my biggest barrier, since I do not drive.
• Patient would not have been unable to navigate health care over the past five years (given multiple medical conditions and acquired intellectual disability resulting from a lifetime of epilepsy) without a family member in the capacity of family caregiver.
• My mother is my healthcare advocate. She works with my group home to make sure appointments are scheduled. She also goes with me to all of my appointments. Sometimes my [redacted] staff also attends.
• It is horrid! Doctors dont stay. Hospital is substandard...
• Had insurance purchased through Obamacare and was kicked out three times. They accused me having double insurances. While i was working part time with SSDI. They forced me to buy part B with SSA but it cost double than my Obamacare plans. Obamacare plans are far better than SSDI coverages. So i went without the insurance and no Doctors to see. Even have health problems or dental care that I needed badly.
• Finances limit my access to proper dental care. Finances limit my access to adequate eyeglasses. my glasses are about $900 cheapest at Walmart and much higher elsewhere. That is almost one months income.
• Psychiatric care, mental health therapy, dsp support staff, medical care (primary, neurology), dental care and eye care are all so separated. Lack of providers who are comfortable with patients who have IDD and mental illness is the main problem. Systems are not flexible for people who have difficulty communicating under pressure.
• I have access to private insurance and to a living wage so healthcare is at a baseline more accesible for me.
• There needs to be better options for dental, hearing and sight. It should be included in general health and covered by insurances and mainecare and medicare

• [Redacted] is the hardest to deal with if you have non geriatric conditions I was constantly told "idk all my other patients on this/wirh this are 90". While ageism is certainly a problem it seems that there is an inverse issue of younger disabled people getting subpar care. I had to transfer my speciality care to southern maine/out of state
• There are no dbt therapy in-person groups avaiable, theres only one intensive outpatient program accepting clients and the wait is long, also I've been waiting for a neuropschology evaluation for 2 years. Due to the trouble with not being able to access services, [redacted] couldn't hold my spot, and I am unable to get the help I need. So. I cannot work and be independent. :(
• I wish it was more affordable to all in this country as many people myself included are hesitant to use these services as they cost so much, even for a simple visit to answer a question or get a DX.
• these people need to be trauma informed and need to stop pushing treatments that make them money vs. helping people... also why does mainecare cover $200 inserts but not $15 eye drops? And why is the mainecare pharmacy so unwilling to help?
• Thank God for IPS and being a ME CIPSS navigating this broken for profit clinical healthcare system where lived experiences and ability to advocate for myself protects me to some degree when life "requires" an ER visit that never fails to leave me trauma informed pretty much everytime. Been to ER about 30 times in last 5 years I'm guessing
• I need help getting back on SSDI I couldn't do paperwork to stay on it and they stopped my benefits. I have no help or transportation and I am feeling hopeless because I have a hard time knowing how to get help.
• Difficulty in availability of appointments with my physician
• I have given up on the public health care system , and have switched to naturopath and homeopath , defitenly a chunk out of my pocket despite having insurance but private care is what works for me and not the big public system. For my PCP I fought for a year to get a live interpreter after a failed traumatic expiereince with a new provider (former one closed) then once i finally got a terp, they cancelled on my twice. I have. dropped them and will be finding a new private provider who gives a damn. My phoen will work for both naturopath and homeopath, but it does not work for my provider. Blood work and X rays are also very traumatic because you have to go through multiple people. So I switched to using a private lab ... .in and out easy... had that this morning, the person is used to me ONE person and not 9 , person new how to gesture and communicate with me and never spoke a word. :) . My family has a lot of medical and autoimmune issues , so I do fear that I will inherit one of these and be stuck with whatever I get and no access to the information I need for now, will stick with homeopath and naturapath who take the time to listen and explain, and also schedule me for extra time as needed. Looking forward to the new provider in january who also emailed me a lengthy email explaining how she does things :O) . Referrals from Physicans or dentist never happen
• It's hard to get prescriptions filled. Offices say they will do things like referrals but they don't.
• Case management is not covered by MaineCare Quimby. It def should be.
• Emergency room waits are too long. I was sick with cushions for six years and undiagnosed. I was in the emergency room once a month during those years and would be left very ill in a chair for up to 5 hours and then released my treatment there was horible. The wait time to get into see primary care is too long, and the wait to see a specialist can take months.
• Answers would be different if focused on assisting a client with obtaining healthcare.

• I am currently struggling to find an appropriate medical care provider to treat my provisionally diagnosed ADHD. This has been causing me problems in other areas of my life.
• Chronically ill patients should not have to fight with insurance companies to get the care they need and deserve!
• I'm 53 yo female and my lived experience has been largely disregarded/ignored by most medical providers. Systems designed for efficiency and profits do not recognize the unique or specific experiences of disabled people.
• There was no box for what I didn't have access to, I am on a waitlist for mental health care neuro psychologist and general counseling.
• There are several barriers to receive care for my child, such as long wait lists, few providers available for section 28 services, case management, and play therapy, etc. The changes happening with CDS is affecting my child's ability to maintain services there. We needed to wait several months to get an appointment to get an autism diagnosis that delayed services for my son.
• Aetna Insurance - doesn't cover a lot of health services I need because it's out of range. Dental - I need more work on my teeth than just a cleaning and insurance won't cover so I have to pay out of pocket. I am very happy with dental services but insurance doesn't cover it. Pain Management through [redacted] - Won't take me because of my drug use in the past and my doctors referred me to them because there is nothing else they can do. :(
• A disabled caregiver is afforded no accommodation or leeway to help them care for their charges. Example: I, with a sleep disorder, cannot always get my mom with a brain injury up for day care. No attempt at accommodating me was made and I was treated as though asking was ludicrous on its face.
• Not enough home health care workers. It pays too little
• Insufficient providers in rural areas...
• need more access to quicker treatment options for substance use disorder and mental health challenges; need more access to quicker treatment for dental care; more options for cost effective dental and eye care, prescription costs
• Medicare directs our health
• My PCP is closing her office and it will take months to get set up with a new provider. There are limits on how many patients who have Medicare for insurance that providers will take. Ittook month to find the doctor who is closing and I was only with her for 6 months, and now need to seek new care.
• Access to specialists in rural communities
• I am not sure that I qualify for a handicap card for my car, but some days my MS makes a walk just exhausting. I would like to understand at what point will I qualify.
• I'm learning that Medicare Advantage plans do are not adequate if one has a chronic or disabling condition. For example: My [redacted] plan denied my new orthotics because I was out of network. There are also co-pays for every OT and PT service which do add up.
• Very confusing knowing what provider to see that my insurance will cover.
• It takes way too long to get an appopintment and especially if it is a specialty doctor - it takes months. Then there are different opinions of treatment, without talking to each other, Should be a care team approach
• Transportation is an S.O.B. My OT was great, but they closed and I had to go somehwere else and it was bad. Medication: I am legally blind and take a lot of medications. It's up to me to get my medications. I get them from [redacted] and they put it in a square, see-through

envelope which i like. It's been easier because I don't have to pick it up, they mail it to me. But every month I hae some left over so it concerns me that I might be getting more than I ned. Also, when they mail it, the Post Office or whoever is delivering it to me just leave it with the rest of the packages. They don't put it in my mailbox. They leave it with the packages in my apartment building's entry way. I don't want it just hanging around. It's a 9" round box and I don't want people to steal it. Can they do something else? I called the pharmacy this morning and they said they will label it so it says "put in mail box" so we will see if that changes anything. From my own brain injury from my stroke, I was paralyzed for 3 weeks until I had surgery. Now i have a lack of focus and concentrating can make me tired. I could use more support.
• I lost my MaineCare and food stamps. I find the lack of a primary/personal care worker has lead to a severe lack of willingness to provide me care. I can't even find out my own blood type, for example. I've been diagnosed with ADHD, ADD, OCD, ODD, Chronic or Reccuring Manic Depression and I haven't been able to get my meds for 12 years (since becoming an adult and homeless back in April 2010).
• Why is everything so expensive
• Insurance companies don't trust the PCP and won't approve the claim
• We have asked for referrals to mental health providers for anxiety. As her mom, I have contacted numerous providers who weren't taking new patients. The only person who had room in her practice , we will be seeing next week. This is a wait of over 5 years.
• Need more mental healthcare such as PET/CT Scans because of brain injury. Dentist drilled tooth but have not removed it and other wisdom teeth - it is a lot of pain aind scheduled way in the future
• Availablity of resources (i.e. reimbursement for rides to appointments) is information that should be information all services providers have and should be relayed as a matter of course whenever a provider sees a patient.
• I could not afford my prescriptions so I ended up in the hospital. I was also told I could not have a therapist or case manager when I moved to Maine 5 weeks ago. I had both and psychiatrist in New Hampshire where I am from.
• We are looking for a dentist.
• I don't have stable housing, which makes it hard to find providers. I am homeless, and sleep wherever I can find all over the state. Providers won't accept me if I don't live in their area.
• I blame the current medical system for my dissatisfaction with my primary care, as seeing more patients and making more money is seen as more important than providing quality care.
• Feel like I'm not treated the same as people with good insurance because I have MaineCare
• Providers don't accept MaineCare; can't get treatment. Providers treating me like a dollar sign. MaineCare only covers general care, but not necessarily specialty care or specialty referrals. No intensive outpatient programs or rehabs that accept MaineCare. Get mental health treatment for immediate needs, but no resources for long-term treatment. Psychiatrists treat people with substance use disorder different, as "med seeking' or like they have other motives. The State is doing nothing to address the underlying problem; just putting in solutions that look good at face value, but don't do anything. It's a vicious cycle
• I am lost within the mental health system. Before COVID, I was attended with a mental health system once a week. Now I am told that I have to wait 6 months and I feel so defeated. No one to guide me - give me medications. I am here in Maine - single - no family - senior citizen and I truly feel I am all alone. I am now at the Peer Support in [redacted] and have a place to

go isntead of going to a "bridge". Why is the mental health system so limited? It takes a "shooting" before any action is taken. So sad - so disappointing - so inadequate.
• The health care system is bureaucratic and broken. National and local rules on vaccination and masks have driven doctors, nurses and therapists away from their profession, leading to shortages of caregivers. Inefficient and confusing billing and reimbursement leds to patient stress and higher costs.
• Medication is very expensive
• I did not have a primary care provider prior to hospitalization @ [redacted]
• 2 year waitlist for dental services
• There is high turnover in my PCP office. This has resulted in staff not knowing me and this is a barrier to accessing my PCP.
• It tends to work for me. I have had trouble filling a prescription when I was out of state. When I have had a problem (prescriptions) it has been due to MaineCare.
• Sometimes hard to get services.
• It is hard to find healthcare in the Houlton area. My doctors are kind and polite. I have been working with home staff for a while.
• There isn;t currently a dentist in [redacted]. There isn't any public transportation in [redacted]- not even a taxi
• Dental care had long waits
• VA is useless for receiving help when you need it; access to their services is impossible. VA has a lot of people working from home. Hard to get through to a provider.
• Having a long waiting list for dental care really stinks. I have 3 broken teeth that need to be pulled and I am still waiting to be seen.
• While it doesn't impact me, there are many people with mental and physical health problems that are unable to access a provider due to long wait times or unavailability.
• It's broken. We need to move away from for-profit driven system of care to a system that actually wants people to be well!
• Yes, I have been in jail for 3 years awaiting trial. The jail has denied me health care and dental services even though my teeth were knocked out in jail. I almost lost both my legs (twice) too diabetes (necrotising fasciates) while in jail. The skin was gone from my legs! I was also with covid19 delta for 6 weeks and was told I needed to go to the hospital since I was coughing up blood and could barely breath, but the jail had no staff to take me and they left me to die! Expect a huge law suit!
• I feel stuck working a job that is difficult for me to maintain in order for my to have insurance/access to healthcare
• Excellent care; good systems. PCP's are overbooked. Especially in summer. Sometimes getting a ride is tricky.
• I haven't gotten in th the dentist and I don't feel they can accomodate my sensory needs. It can be hard to get an appt.w/my promary care and it is diffucult for me to wear a mask so I'm unable to go in person most of the time. Need better seating
• Very happy with my primary care but there were times I could not access health care in person, which was difficult for me. I also had issues with long wait times to ge my meds from the pharmacy and had insurance issues.
• The home health care system fails people on MaineCare or with disabilities. The home health care system is not coordinated with the health services offered while patient is within the public school system. A person with disabilities who needs SPEECH !!!! The school system is

offering one or two 30 minute session per week, when the person likely needs an hour daily â€" outside MaineCare services are not available outside of school hours. The local school system is hiring a speech therapist IN [redacted] to serve students in the school system in [redacted]

- Children with mental health conditions and their families are a neglected, underfunded and underserved component of health care. The 2020 pandemic caused irreversible trauma in children and their families who were already struggling with a mental health condition. The pandemic postponed appropriate, timely, care and interventions for children with mental health conditions. It provided no additional support for families and parents on how to best navigate this time without support and caused significant lag time in accessing the appropriate care. Public Schools have continued to have the same expectations for students during and after the pandemic. They have continued education as if these children have experienced no change or lack of social/emotional support and development as well as trying to make up for "lost time" by forcing their academic demands over social and emotional well-being in the classroom. Schools have not adequately supported their staff to be trained in social and emotional health as well as accommodating children who need alternative learning styles, settings or teachers. Educators have continued to see through a narrow scope in how they assess learning. They cannot think outside of the box to integrate different approaches to learning to engage all students. They lack the ability to engage and understand neuro atypical learners when the can't "see" the disability. The ER is not a place to hold a child and their family over and over again when the child continues to need and cannot access services that can PREVENT the ER visit in the first place. The wait time to see a Psychiatrist, therapist, HCT (Homecare team) and OT is totally unacceptable and dangerous. Any other chronic or acute illness requiring a 2 week long hospitalization would never make a patient wait months to get a home care support team. Accessing Mainecare and trying to communicate with DHHS is impossible. We speak English, have a college education and work in healthcare and it felt hopeless, confusing, frustrating and exhausting. Applying for Maine Care, accessing a case manager, finding a therapist, OT provider and psychiatrist for our 8 year old son was a full time job. Maintaining safety, keeping him engaged in a school curriculum (though very difficult due to the lack of school support, delayed IEP assessments and poor staffing), and accessing healthcare for him was not sustainable for a working parent. We had to transition to one income while still not having the services we needed for his mental heath for over 7 months. The only reason we received HCT was because his mother called DRM, and DHHS almost daily to access support. Police were in our home multiple times a week when our son was suicidal, dysregulated and unable to communicate his needs. While the police department became very familiar and fond of our son and family, they did not have the training to respond to his mental health needs. Our son was admitted to a mental health hospital during the week of Christmas last year for SI. Because of Covid we could not visit him. He was 7 years old and it was the first time he had ever been away from his family. When he came home he shared with us all the video games and iPad time he had in his room (unsupervised, without parent consent and with games that were violent and not age appropriate). He also explained the screen time was because of "not enough staff". He came home with sores all over his feet because of wearing shoes without socks and getting blisters, his skin was raw on his toes and he had a skin infection from poor skin care. He lost weight due to not having his dietary needs met. Although the hospitalization was to establish safety and initiate a medication regimen, we felt horrified as parents knowing the care he received was inadequate and the communication to his parents was negligent. He received care as of it was a glorified babysitter at [redacted]. Once we did receive HCT and a case manager 7

months after his hospitalization, we knew it would be the missing piece of the puzzle to support him and our family. The mental health needs of our child affect the entire family unit and our healthcare system does not support the needs of the family unit. HCT has been hard work and exhausting for our son and our family but it has provided us all with structure, behavior modification support, healthcare addressing real-time problems and needs in our family, a working relationship that is patient and family centered. Our mental health system for children needs more support. We need more staff, research based clinicians and training, trauma informed care, age appropriate treatment, better access to outpatient services, improved outreach to families and patients with new mental health and chronic diagnosis, increased awareness and funding for programs to support families like the GEAR parent network, increased education and training for schools, parents and caregivers of those with mental health conditions, emergency support services to families in crisis such as meals, and providing services in the home, reducing the barriers to accessing Maine care and communicating with DHHS to complete forms or inquiring with questions, increasing the ER response for children and keeping them in a safe, age appropriate unit.
• Long waits for BHH caused a significant and life threatening decline. When trying to access support continual messages of "more meds" and "try harder" pushed our son to suicidal behavior. It wasn't until a 30 day stay in the ER that we were finally able to get help. This has been traumatic for our entire family. We have lost income, experienced financial hardship, and our family will forever be changed by this horrific experience. Our son is recovering but there is no way to know what the long term impact will be on his life.
• I am in [redacted] and there are very few providers to choose from and most are too quick and don't listen to me. I haven't had a therapist for a long time because I am on the waiting list everywhere but no one wants to take me as a patient because of my disability.
• there is no availability of mental health counseling through mainecare. i have been on a [redacted] wait list for a year.
• I am not able to receive any health care due to my income exceed for MaineCare.
• [Redacted] needs more dentists - it's hard to get in to see one
• I find the quality and availability much worse in Central Maine then when I lived in the Portland area.
• There is not enough mental health providers in the state of Maine that are familiar with DID (Dissociative Identity Disorder) specifically, i have been desperately trying to find one that takes mainecare. There is just honestly a huge lack of mental health services in general that are accessible but for people with more complex disorders it is even harder to find help, a lot of therapists i have seen are not able to meet my needs or are unsure of how to treat me due to lack of experience treating my disorders.
• With Maine Care, I get lower quality of care than people with other insurances. I don't have many options. If I don't feel comfortable or trust a specialty doctor, I don't have a choice to go to another doctor because they are the only ones who take my insurance. The mental/behavioral health services are the worst. Especially with my insurance. No good quality provider takes Maine Care. They are in private practices or only take "real" insurance. I get the scraps. I need trauma therapy and no one takes my insurance. I've been on a years long waiting list for over a year, and got nowhere. I'm still waiting, twiddling my thumbs, needing it to get on with my life. My access to good quality health care services is cut short because of my insurance. It shouldn't be that way, but I feel discriminated against because of the insurance I have due to my being disabled.
• Triaged and waited 14-16 hours so I left.

• transportation psychiatrist - case manager - no help
• no transportation to get to certain health care such as physical therapy, cortizone shots...
• I moved to Maine from Vermont last year, and I feel like I'm in a healthcare desert when it comes to specialists.
• It is literally impossible to find dental care that takes mainecare. There is a one year wait, except they call and cancel and you wait another year. The [redacted] clinic is the only option and it's students experimenting on you with treatments you don't want to get to the treatments you need, one root canal took 5 meetings, 4 hours each, and 2 hours drive (1 hour each way) and I have so many cavities to fill back from 4 years ago that will need root canals eventually because no one will fix them. It's not my fault during pregnancy my calcium levels were so low, I had a difficult and dangerous pregnancy and a bunch of stuff happened including my teeth rotting. I haven't developed new cavities since then on X-rays. I can't afford a regular dentist but why should I have to lose my teeth? They should make regular dentists take mainecare or a certain amount of mainecare patients a year. I'm a high honors premed student, single mom to an autistic child, and I'm currently doing undergrad research myself. You shouldn't have to deserve healthcare but if you did I think I'd qualify. How am I going to do med school interviews missing teeth?
• I have been struggling to get the right care for my disabilities for over 15 years. I almost died multiple times from being denied care at [redacted] ER triage. However, it is [redacted] that has saved my life. In addition it has been very hard to get MaineCare or food stamps when I was homeless because I couldn't work due to mental illness.
• It has been impossible to find a dental care provider that takes Mainecare, because of this I have not had dental care in over 10 years, This includes the recent changes of the state helping more providers take mainecare- there are no providers available.
• The healthcare system is not designed for anyone with a long term illness or disability. It's only designed for quick checkups on healthy people. When you aren't an easy fix, you will be shamed and gaslit, and ignored. This is my experience going from abled to disabled. It is extremely classist, the specialist I need to see I have to pay 100% of the costs for the visit and medicine. These are Drs that keep me alive, not extra support specialists. And these are the only people in Maine who can treat me. If I didn't have money and good insurance from my well off family I would probably die. In my experience, Maine greatly lacks in diversity of drs, quality of care, Dr knowledge, and accessible low cost options.
• The access to dental care has been atrocious as nearly every dental facility I have search for will NOT accept Mainecare as an insurance provider. This has lead me to have a sever abscess for well over two years as a result of not being capable to pay out of pocket
• cost/lack of Mainecare coverage for services/lack of providers accepting Mainecare and limited provider availability make finding dental and mental health care extremely difficult. I was able to get counseling and psychiatric support through USM's counseling services, but now that I have graduated I will no longer have access.
• I spend a great deal of time navigating the health care system as a patient with a complex ultra-rare primary immune deficiency.

Communication

Open-ended responses to "Is it difficult to communicate with your provider?" All responses are presented as written, with identifying information redacted.

• Telemedicine via phone call with no caption service/audiologist wearing opaque mask and needing lip reading for verbal communication
• They do not take the time for me to process questions and offer a response. Because it takes a long time, theu keep changing the wuestions, causing anxiety, and I can't answer. They don't offer time for my health partner/companion
• I was under stress when video remote interpreting constantly frozen that caused me lost track of my thoughts and more stress for me.
• They do not make themselves available for communication
• Some doctors are blatantly sexists and will instantly go to anxiety that said I have learned how to deal with these providers to not get subpar healthcare but it requires more work.
• I have not had any doctors, on the list to get some help.
• They say I am difficult and inappropriate when I advocate for myself
• They only want info through their portal/online
• The do not touch me.
• They do not include me in decisions and send me home too often than not.
• inaccurate speech-to-text apps delay things. Using the Notes app on iPhone 11 since seems almost as good as $ apps.
• I need to read lips or ability to use my caution on my phone in there office space it does not always work. I was told by a specialist once when I told them I could not hear but read like well. He said well if you except me to remove my mask I'm not
• No timely answer to questions.
• Not enough support staff
• They don't want to hear about the individual when it comes to mental health care. They have a checklist response and don't listen to you as an individual. Some do but lost don't. Worse with mental health. to
• Don't listen and treated as infants
• History of eating disorders and doctors' internalized weight stigma frequently steamroll over my concerns about relapses and often make ED behaviors worse
• The solution for every symptom is yet another prescription, nothing else.
• They will not wear respirator masks while treating everyone, including high-risk individuals
• confirm what I had said.
• They do not let me make the full decision about my health needs but rather encourage alternate pieces of equipment.
• They belittle me for the symptoms I have and tell me it's all in my head
• They do not respond to phone calls, emails, etc.
• unavailable/too busy
• I have PTSD and it is difficult to advocate for myself, especially with brusque/dismissive doctors.
• They gaslight, they don't track my illnesses

• Jail did not provide access
• can't alk to doctor directly
• They patronize me and assume I am under educated speaking in small words. They also seem to conclude that all my problems have to do with my weight or mental health.
• They try to "railroad" me the majority of visits, portraying a "I know best" attitude with a lack of considering my personal experiences and varience
• They speak to my mother my guardian, as I have speech delay
• Trying to contact over the phone is impossible
• Clear masks should be mandatory. Since the pandemic, noone would get or wear one!
• Clear masks ARE a must for the HOH/Deaf!
• They use language that I dont understand and they do not explain it. They just don't listen to me.
• they don't return phone calls or emails
• I bring my mother in with me --I need her to help me understand and she is my guardian, but in the past they have said that they won't speak to her and make her leave.
• Make assumptions and judgements based on diagnosis
• Too many layers. you have to leave a message with a receptionist, the receptionist tells the medical assistant, the medical assistant tells the nurse, the nurse tells the doctor by the time the doctor gets the message, it's been interpreted differently than the original meaning
• I leave messages through the portal and they do not respond. They mix up medications and do not follow threw from one facility doctors to the others to know what is and isn't avalible
• They are busy
• They are usually very quick to dismiss whatever med you may mention to them to possibly try.
• can't always understand what they mean
• At [redacted] a doctor did not listen or believe me when I told him that though my shoulder blade was injured in a fall that I was concerned for my neck. So instead of x-raying my that has cervical disk disease, and has a crushed vertebrates, he x-rayed my shoulder blade instead. We had agreed before hand that my shoulder should be fine, and I just needed a sling for it.
• they make assumptions - jump to conclusions
• rushed
• They don't understand my condition
• I have experienced medical gaslighting for years with my chronic health conditions and mental health.
• They use checklists surveys and rattle off questions instead of understanding conversations
• They don't offer help that I ask for
• They don't seem to care - too young - I too old.
• I have aphasia
• They often believe in false claims by public health officials
• I can't get out of my head what's going on inside me
• It is hard to reach out
• Speech impediment
• Don't listen to personal experience; don't spend enough time with patients
• they do not understand the way I communicate

• rather tell staff
• gave me weightloss tips and diagnosed me with anorexia all in the same meeting. Told me she doesn't believe in bipolar disorder even though that is my diagnosis.
• I'm treated like a hypochondriac
• "If you can talk you can hear" Not true! In hospital they made decision to have surgery, didn't ask me. Because I can talk, they assume I can hear.
• not individualized care
• Sometimes my head gets tired when talking to my doctors
• do not include in decision making
• Not making sure I understand is a big one.
• the wait can be difficult
• i don't comprehend well.
• you can't get ahold of them
• Some treat patients as if they are too busy to treat them properly.
• they're overloaded with work and can't give enough time to me
• They sometimes make it extremely difficult to get in contact with them (i.e. long hold times, days before getting a call back, etc.)
• My mental health care is new
• They speak to staff
• sometimes they yell at me
• They speak to my staff
• don't care
• VRI sometimes freeze. Caused communication misunderstanding. I want to talk more.
• Doctors need to review patients charts and make sure what is then entered is accurate. Please use names. They are in the chart.
• I have communicated with my doctor via the patient portal about health needs that need to be explored more deeply and received a negative response. I also advocate for holistic care and continue to receive a negative response. The doctors are only worried about the symptoms and not the root cause of the issues.
• We need to have more accessible ready for deaf patients with no stress involved like in staff interpreter (s)at hospitals . Drs office, hospitals staff need trainings on deaf etc more often due to high volume of staff turnovers.
• It is frustrating to continually remind people about my audio processing issues and ask them to slow down or ask only one question at a time. However, I have been fortunate to be able to assemble a team of providers that are caring competent, and responsive. I am encouraged that the younger physicians seem to "get it" more quickly and many -even specialists- often have better communication skills than one might expect.
• I have TBI but look fine on the outside. Even when providers are told I cannot read and find a lot of communication hard to understand they don't seem to care and never follow up
• We have changed primary care doctors because of the lack of communication and feeling that needs were not being met. We were very clear with new primary care of what expectations were, and it was okay for the first two visits and then started going down hill. Now care is the same as before. No communication to me directly, and no physical examination or testing beyond bloodwork.

• most of difficulty is with making appointments or dealing with automated online stuff, and poor captions. Had to drive 5 hours each way to make first appointment with [redacted]. Once get face to face with a health person, they have been very accommodating and patient. Note that hearing went from severe to profound during this time. Difficulties have increased since hearing aids became mostly useless in past 6 months. cochlear implant not viable - did get tested for that during this time.
• I am happy with my current provider. About 4 years ago, I left a provider who continually "forgot" to speak slowly and clearly, facing me. I reminded them several times.. Then I changed medical offices.

Open-ended responses to "Do healthcare providers respect you? If no, what experiences have you had?" All responses are presented as written, with identifying information redacted.

• I HAD to have dirty work to contact nurse for ASL interpreter.
• [Redacted] just views me as a woman who is bipolar. I don't think [redacted] listens to my childhood traumas.
• Demeaning and condescending
• no empathy; just getting to the next person
• 85% of time they talk to the interpreter, not me.
• talk to me like a child
• talk down to me
• The people who run their offices are rude and don't even know the correct policies for what is being done right now with Covid, masking
• Talk to my family members, not me
• Some providers are great but others do bot make it comfortable to communicate and don't give my health partner/companion time to facilitate successful conversation
• I HAD to have dirty work to contact nurse for ASL interpreter.

Open-ended responses to "Is there anything else you would like to share about your experiences with the healthcare system?" that relate to communication. All responses are presented as written, with identifying information redacted.

• I would like to have 2 or 3 consistence interpreter for appointments. Not just random interpreter it does effect my progress of becoming healthier.
• Overall my experience with health care has been good. Sometimes it has been hard to get an appointment if Dr office is full. Really wish that hearing aid manufactures would bring back analog hearing aids ad the digital ones do not work as well for me.
• Nope interpreting for er Not like vri
• VRI shouldn't be used in ER, X-ray, etc. Sometimes VRI in doctor's office or ER freeze and I had no way to express more of my health issues, I prefer to express my words in ASL rather than writing notes. [Redacted] rescheduled my appointment because they forgot to request an interpreter. [Redacted] has contract with [redacted] interpreter agency. I was not happy with ASL interpreter (from [redacted] interpreter agency) who is not qualified. Same thing happened at [redacted] with same interpreter when my son was sick. This interpreter sometimes had difficult understanding what I said. I had to repeat.

• I can do zoom video
• The way nurses call paitents to the room is not accessable Should give out # and display them like they do at DMV
• I feel that there SHOULD provide ASL Medicare book annually. I know it's too much to ask, but deaf people deserve to understand PRETTY much!
• My family makes decisions for me and communicate with me after doctors office.
• problems with interpreters
• My provider and my sister does the communicating with medical provider, and share with me when is needed. Interpreter has always been provided, along with CDI as well.
• I do have communication issue with my health care provider, but they do provide appropriate service.
• I depend on lip reading to understand speech. When I went to the emergency room for COVID, the doctor and nurses noted my hearing loss and wore a clear shied in place of a face mask.
• I have learned more to advocate for needs and be open to share what I feel needs to be shared.
• Doctors need to learn to listen to patients because no one knows your body better than you. PCP treats me differently because of mental health diagnosis; they talk down to me, are condescending, and treat me like I don't know what I'm talking about
• I feel like I am treated better than people with MaineCare and that I have access to better providers than people with MaineCare. When in the ER, staff don't watch what they say around patients. While I was in the ER in [redacted], I was kept in the hall for hours and was not given a private room. People there for physical medical issues could have their cellphone, but because I was there for mental health, I was not allowed to have mine. While I was there, staff made the comment "Of course she's here for crisis. It's Halloween, what do you expect." I felt very offended and disrespected; like she wasn't taking me seriously.
• A patient with patience makes the best patient.
• MyChart is not private because staff can see it. PCP and psychiatrist appointments: staff attend and the person [patient] is ignored.
• Communication problems, but new girl is good
• Fight to get interpreter, long time waiting
• Lots of problems with audiologists, had to switch due to MaineCare Would be nice if they had people with expertise working with deaf people. Stop imposing VRI. Heard in community many problems with VRI. Need in-person interpreters. If use VRI, need better interpreters. New interpreters can't handle problems. In state of Maine, 95% of deaf people hate VRI. Story: I was living in NH taking care of my son. My mom was there. My son was hit by a pickup truck. We went to the hospital, he was screaming. There were no interpreters. I had no idea what was happening. Can you imagine that?! For example, if I help my dad go to the doctor, they won't get an interpreter for me.
• communnication skills could be better - speak "above me or below me" treat me better as a veteran
• I feel rushed, the wait time is ver long as well They don't listen and tell you what you want to hear to get you our
• Wants more personal care. Easier ways to communicate with providers and more consistency in care given.
• I am very outspoken to them

• The system seems to be too hurried and too busy. My doctor doesn't remember me (understandable considering the workload) but does not review my records before seeing me. Part of the visit is him getting up to speed. It is as if I have a new visit every time. And no communication betwee specialists and my doctor. He gets the reports but never, never reads them before seeing me.
• Masks have made communication access challenging.
• In speciality care services - I had one incredible doctor and many that were disrespectful - refusing to speak to me, ignoring my concerns. I was at the hospital getting tests done for a diagnosis and a doctor, insensitively, looked at me and said, "The good news is it's DEFINITELY not what you thought it was." Which ended up being untrue.
• Need more training with communication, especially specialty doctors like urologist. Need to take more time and carte. Some people have different pain tolerance than others
• They need help in understanding about "life inforamtion - need to get the whole picture of a person and review all of the inforamion. Sometimes I feel rushed
• I always have to make sure to request an ASL interpreter when I make an appointment. I can't make an assumption that they will automatically schedule one. I had to share my frustrations with one medical provider site as they were not prepared for communicating with me even though I clearly explained my communication needs when I made an appointment for COVID testing. When I scheduled a sleep study evaluation, a medical provider suggested VRI. I explained that it was not going to work due to the nature of the appointment and requested in-person interpreter. They did comply with my request. There were times where I had to educate the medical staff about using ASL interpreters. Also, it is very hard to be 6 feet away from the front desk trying to "check in" for an appointment - it is hard to see VRI when one is 6 feet away from the window.
• Frustrated with medical provider not aware of providing interpreter service, Video Relay Service is not reliable and keeps freezing.
• My Doctor is good keeping up to make sure that I had communication access, but there were several times where they forgot to schedule interpreters, so they resorted to using VRI which was not favorable.
• [Redacted] wanted to know why staff is asking him these questions and not the doctors.
• I do feel my healthcare provider can be pateint when I don't understand things
• I think the ER People at [redacted] need to be trained in patient rights. When I was seen in the ER last Monday, they prohibited me from calling my patient advocate. I think it adversely affected the quality of my care because the doctors didn't understand me and I didn't understand them. My advocate could have helped explain things.
• [Redacted] asked why there were so many questions that didn't make sense to her.

Physical Spaces

Open-ended responses to "What makes the spaces where you receive care feel inaccessible or feel unsafe?" All responses are presented as written, with identifying information redacted.

• Hospital was so full beds are in the hallway and unsafe , hours go by before someone realizes your there.
• tiny rooms with no space for wheelchair
• Having to fight almost every single visit in order to get my appointments charged appropriately. They refuse to bill MaineCare on multiple items for my child as well.
• Literally in a hallway for ER
• I go to ER by ambulance. Have difficulties finding rides home and rides to follow up appts
• Bathrooms are not large enough to accomodate my power wheelchair. I have to go very far down the hall to fit in one (or leave the door open to handicap stalls as the chair won't fit. OR in some buildings there is not grab bar by the toilet - even though the rest of the bathroom is accessbile (button on door, sink okay.) Some places have the papertowel and soap too far out of reach for the wheelchair with legs on it. Some healthcare buidlings (dentist, mental health, PCP buildings and bathrooms have the old round doorknobs and heavy spring doors that are impossible to open when in wheelchair or using walker to get into the building or bathroom).
• have to go through multiple people to get to the doctors office (registration of hospital, registration of x ray, registration etc) Communication is hindered
• There is not an expectation that psychiatric spaces have a warm comforting feeling like general medicL care. Mental health care is medical care. System does not behave that way.
• Not masking
• Again, a lack of serious Covid mitigations like respirator mask wearing, social distancing, ventilation, are all problems with accessing safe care while high risk.
• The exam rooms are always tiny, so it's hard to fit my rollator or maneuver my wheelchair
• Everything is good
• Just because a person looks ok..doesn't mean they are..mental illness cannot be seen with the naked eye..and people just assume they are dine because they look fine..their illness cannot be seen
• I was psychotic and put into a room with staff lockers, a bathroom, and people in a locked up unit screaming a door away. While psychotic, this was terrifying and not comforting in the slightest.
• When you have a drug problem you get treated like shit.
• Have you been to the lab at [redacted]? You make it down a longggg hallway and then there is no accessible door. I was using a walker and couldn't get in. 1/2 the doors in that building are inaccessible. That's just one.
• Staff is not respectful or well trained and often make snap judgements
• chairs aren't accessible
• there were stairs to see dr.
• There have been times when I felt it was more like a jail than a medical facility.
• I'm homeless, they treat me like a leper.
• city downtown locations with no private parking; only parking is public street parking or parking garages; too far away from the offices, can't walk that far

• Lack of appropriate placement for pediatric psychiatric patients in an ER setting. [Redacted] places all psychiatric pediatric patients in the same ER as adult psychiatric patients. It feels scary, dangerous, unpredictable, and the staff is not appropriately trained to support pediatric patients.
• no access to therapy or visitors in ER while waiting 30 days for inpatient psychiatry. Minimal access to windows or sunlight. Some inflammatory staff though most were compassionate. Lots of restraints.
• not well trained lots of assumptions
• Inadequate or nonexistent COVID mitigation measures
• need more handicapp spots
• security
• need more handicap spots
• Emotionally after the medical trauma I've experienced, going into a medical setting is extremely triggering for me
• the atmosphere is incredibly triggering towards my sensory needs.
• I have sensory difficulties and the lights in doctors offices and exam rooms are unbearable
• Autism, ADHD, and trauma make expectations and waiting very very difficult. If my appointment is at 2pm I expect to be seen between 2 and 2:15. Sometimes they won't call me up for an hour after my appointment and even then I get put into a room to wait even longer. It's exhausting and by the time they come to examine me I am all out of spoons and sometimes become nonverbal from the distress.
• Too much back ground noise. Music, general noise, white noise.
• Poor public transportation and agoraphobia
• They are too busy treating me disrespectfully, because someone calls up before I get to an appointment.
• Intercom systems to enter the building, I can't hear. Wait forever to be let in
• Any medical/clinician, because they can commit you
• need more handicap spots
• rooms are too small for wheelchair
• need more handicap spaces
• trauma on top of trauma. strip searched in the ER
• My need to hurt myself
• I was there all night before they were done with me.
• violation of HIPPA in waiting room

Open-ended responses to "Is there anything else you would like to share about your experiences with the healthcare system?" that relate to physical spaces. All responses are presented as written, with identifying information redacted.

• Don't always use walker at doctor becasue hard to get around
• Not every providers office space is accessible as it might be.

APPENDIX B

FOCUS GROUP GUIDE

DRM Focus Group Guide

- The facilitator and co-facilitator introduce themselves
- Tell participants about the assessment; why it's happening, what kind of information we're looking for in the focus group, and what will be done with it
    - Disability Rights Maine is undertaking this effort to better understand health equity and access issues for individuals with disabilities across the state of Maine
    - The project includes a survey, focus groups, open forums, and gathering any and all data to help characterize the population and health outcomes/disparities
    - This focus group allows us to understand better the experiences of individuals who have particular disability types
- Set ground rules for the conversation
    - This is an open discussion
    - All views are accepted
    - Listen and speak in equal measure
    - Be open to learning about situations beyond your personal experiences
- Quick round of introductions by participants, if they're comfortable

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Question 1: We want to start by asking about your experiences getting the health care that you need - health care includes not just primary care, but also mental health, substance use, dental care, urgent care, etc. How easy is it for you to make an appointment, or get the care that you needed?

> *Probes:* What sort of care is easiest to get? What is most difficult?
> If it was easy – what sorts of things made it easy?
> If it was difficult – what barriers did you face?

Question 2: We want to know about what it's like to communicate with your health care providers. How easy or difficult is it to communicate with them – about your needs/concerns, about your condition, etc.?

Question 3: What about the physical spaces where you receive care – is it easy and comfortable for you to be in those spaces?

Question 4: Do you feel treated with respect when you interact with the healthcare system?

> Probe for specific examples of what makes them feel respected AND disrespected

Question 5: Is there anything else you'd like to share about your experience with the health care system?

> Probes: Is there something you wish providers would/could do to create a more positive experience?
> If you had a magic wand, what's the one thing you wish to change about the healthcare system?

APPENDIX C

RECOMMENDATIONS BY RESPONSIBLE ENTITY

State and Federal Policymakers

Recommendation	Potential Strategies
Make disability status a standard demographic indicator in data collection and surveillance efforts.	Establish rules and guidelines for all state-funded grants and surveillance efforts to include disability as a demographic indicator.
	Require self-reported disability status as part of standard demographic information collected in electronic health records.
	Tie state Medicaid and block grant funding to substantive evidence of health equity for people with disabilities.[1]
	Improve the quality of disability data through cross-agency collaboration on data collection/sharing to include standardized questions on disability.
Individuals with disabilities must be represented in public health surveillance efforts.	Ensure that individuals with disabilities are represented statewide and on state-level advisory councils to direct statewide guidance related to health care planning, health equity, and assessment processes.
	Advocate for better representation of people with disabilities in national surveillance efforts, such as the Behavioral Risk Factor Surveillance System (BRFSS) and the American Community Survey (ACS).
	Require that surveillance efforts engage individuals with disabilities residing in group homes or other institutional placements.
Increase opportunities to access funding, resources, and technical assistance to better care for people with disabilities.	Expand efforts that identify Health Professional Shortage Areas (HPSAs) to include urgent care, specialty care, and home health services, which would give centers the ability to expand specialized services.
	Designate people with disabilities as a medically underserved population through the Health Resources and Service Administration (HRSA) to increase opportunities to access funding and technical assistance support at federally qualified health centers through a Governor's Designation.[2]
Communication devices and technologies should always be working and available for use.	Develop and implement state-level guidelines for the use of ASL Video Remote Interpreting in medical settings.
Create accessibility guidelines that go beyond the basic minimum requirements and provide additional access whenever the needs of the population go beyond those minimum standards.	Require that healthcare organizations routinely assess and report on the accessibility of their building (e.g., parking lots, waiting areas, exam rooms).

Health Care Policy Organizations, Health Systems, Providers, and Personnel

Recommendation	Potential Strategies
Ensure that individuals with disabilities are represented as decision-makers and subject matter experts in spaces where education and training curricula are established.	Establish guidance for hospital systems to include people with disabilities within their Diversity, Equity, and Inclusion efforts and patient and family advisory boards.
Train health care personnel to provide comprehensive and high-quality care to patients with all types of disabilities.	Implement licensing requirements that include ongoing provider education about providing care to individuals with disabilities.
	Embed requirements for direct service/practice experiences with individuals with disabilities in health care training and continuing education programs.
	Require that didactic education in health care fields include content on a range of disabling conditions and human responses.
	Continuing education on working with people with disabilities should be available and encouraged.
Increase the number of individuals with disabilities employed in health care settings.	Pilot programs that support individuals with disabilities to enter the healthcare workforce.
Improve the quality of care for people with disabilities.	Require that health care organizations provide disability specific training on an annual basis.
	Require that health care providers complete all routine aspects of care for people with disabilities (e.g., asking about mental health, substance use, and sexual health).
	Incorporate trauma-informed care approaches at all points of contact.
Provide navigation and supportive services to people with disabilities and their families/caregivers.	Nurture peer navigation and support programs that pair individuals with disabilities with peers who have expertise and experience successfully navigating the health system.
	Explore opportunities to offer or expand case management and care coordination services for individuals with disabilities with both public and private insurance plans.
	Advocate for supportive services for parents and caregivers of children with disabilities.
	Incentivize partnerships between health care providers and community-based organizations to address common barriers to care (e.g., transportation barriers).
Explore mechanisms to improve timelier access to care.	Expand after-hours and weekend care at primary care practices, including federally qualified health centers.
	Use telehealth technologies, such as virtual visits and remote consultations, to deliver health care services to patients in remote or underserved areas to reduce travel time and costs, and enhance access to care for individuals with limited mobility or transportation options.
	Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.

Equip health care personnel with the necessary knowledge and tools to have positive interactions with patients with disabilities.	Require that all health care personnel, from administrative staff to physicians, receive formal training on effective methods for communicating with patients with disabilities.
	Conduct training on legal obligations providers have when interacting with patients with disabilities.
	Develop provider educational materials (e.g., guides, toolkits, checklists) that providers and staff can use to ensure accessibility during appointments.
Individuals with disabilities must be represented in decision-making bodies to ensure communication needs are addressed sufficiently.	Require that hospital Patient Advisory Councils include people with disabilities, to solicit and encourage improvements related to effective communication and patient access.
Inform individuals with disabilities of the rights afforded to them.	Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available to them.
Communication devices and technologies should always be working and available for use.	Examine the accessibility of health care technologies (e.g., kiosks, patient portals, telephone systems, video conferencing, websites) prior to implementation.
	Ensure that health care facilities have contracts for on-site and video interpreters in place before a request for interpreters is received.
	Develop and implement state-level guidelines for the use of ASL Video Remote Interpreting in medical settings.
All communications (e.g., forms, questionnaires, educational materials, instructions) should be accessible, easy to complete, and representative of people with disabilities.	Offer patients the opportunity to fill out all forms (electronically or in hard copy) prior to their appointment.
	Require that all materials distributed to patients during the visit are audited for accessibility.
	Ensure that all online data and information are provided in formats that can be interpreted by screen readers.
	Ensure the facility and providers have the ability to offer large-print versions of all printed materials (font size 18 pt or larger).
	Include images of people with disabilities in all educational and promotional materials.
Consider communication needs and privacy concerns when interacting with patients in health care facilities.	Implement more discrete communication strategies that do not rely on hearing a person's name called (e.g., distributing pagers instead of calling names in a waiting room).
	In places where masking is required and implemented, ensure all staff has easy access to clear masks and communicate that patients can ask for staff to wear them.
	Schedule longer appointments for patients with disabilities to accommodate diverse communication needs, styles, cognition levels, and use of interpreters/communication devices.
	Explore opportunities to be more flexible in allowing for longer patient visits.
Create, implement, and improve mechanisms for notifying providers and staff of patient accommodations and needs.	Embed questions about accommodation needs at the point of first contact (scheduling, registration, triage, etc.).
	Proactively communicate with patients ahead of health care visits to assess potential accessibility needs and accommodations for individuals with disabilities.
	Clearly and prominently identify patient accommodation needs in Electronic Health Records.

	Enable Electronic Health Record pop-up notifications at log-in, advising of accommodation needs (including whether an interpreter is needed), and that require an action such as clicking an acknowledgment button to dismiss the pop-up.
	Provide regular reports to administrative staff and providers that identify upcoming patient appointments where accommodations or accessible equipment is needed.
Equip all health care organizations with tools, assistive devices, medical equipment, and personnel that allow for universal access to all recommended screening and diagnostic tests and treatments.	Ensure that an on-site "Access Coordinator" is appointed and available at all times. This person should be on-the-ground and responsible for providing immediate assistance to staff to locate and implement communication aids and services, schedule interpreters, and assist/troubleshoot issues.
Create accessibility guidelines that go beyond the basic minimum requirements and provide additional access whenever the needs of the population go beyond those minimum standards.	Require that healthcare organizations routinely assess and report on the accessibility of their building (e.g., parking lots, waiting areas, exam rooms).
	Increase the number of accessible parking spaces at health care facilities, rather than meeting ADA minimum requirements.[3]
	Increase availability of accessible medical equipment (e.g., height adjustable examination tables, accessible mammography equipment, accessible weight scales, and lift equipment).[4]
Ensure that patients are fully aware of the accessibility-related services available to them.	Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available.

Other Stakeholders (e.g., Community Organizations, Councils on Aging, etc.)

Recommendations	Potential Strategies
Provide navigation and supportive services to people with disabilities and their families/caregivers.	Nurture peer navigation and support programs that pair individuals with disabilities with peers who have expertise and experience successfully navigating the health system.
	Explore opportunities to offer or expand case management and care coordination services for individuals with disabilities with both public and private insurance plans.
	Advocate for supportive services for parents and caregivers of children with disabilities.
	Incentivize partnerships between health care providers and community-based organizations to address common barriers to care (e.g., transportation barriers)
Explore mechanisms to improve timelier access to care.	Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.
	Use telehealth technologies, such as virtual visits and remote consultations, to deliver services to patients in remote or underserved areas to reduce travel time and costs, and enhance access to care for individuals with limited mobility or transportation options.
	Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.

[1] Fong, M. "Mind the Gap: A White Paper on Maine's Missing COVID-19 Surveillance Data, How They Perpetuate Health Disparities of Maine's Citizens with Disabilities, and What Can Be Done to Increase Maine's Public Health Data & Service Equity." University of Maine Center for Community Inclusion and Disability Studies, 2023. Accessed via https://ccids.umaine.edu/resource/mind-the-gap-a-white-paper-on-maines-missing-covid-19-surveillance-data/.

[2] U.S. Department of Health and Human Services, "HPSA and MUAP Shortage Designation Types," https://www.hhs.gov/guidance/document/hpsa-and-muap-shortage-designation-types.

[3] U.S. Department of Justice. 2010 ADA Standards for Accessible Design. https://www.ada.gov/law-and-regs/design-standards/2010-stds/

[4] National Council on Disability. Health Equity Framework for People with Disabilities. 2022. Retrieved from https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf

G. PAIMI Budget - Actual

PAIMI Budget

Planning Period From **10/1/2022** to **9/30/2023**

In this section, provide actual expenditures for the FY. Refer to the PAIMI Application [Appendix C] submitted to SAMHSA/CMHS for the same FY. For additional information regarding this Section, please review the PPR Instructions.

PAIMI BUDGET-ACTUAL

* Indicates a required field

I. Personnel/Name/Title (Active for PAIMI Supervisor only)

In the section below for each funded staff position provide the name, title, annual salary, level of effort - full time equivalent charged to the PAIMI grant, and the costs billed to the PAIMI grant for each position. Please only include the current FFY's budget figures and use the footnotes to describe methodology and any additional funding carried over from previous years.

Personnel/Name/Title *	Annual Salary * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Executive Director	$ 150,000.00	$ 29,700.00	19.8 %	Kim Moody
Intake Specialist	$ 62,400.00	$ 14,976.00	24.0 %	Sara Squires
Intake Specialist	$ 56,829.00	$ 13,638.00	24.0 %	Fern Nadeau
Attorney	$ 71,000.00	$ 1,420.00	2.0 %	Ben Jones
Attorney	$ 71,000.00	$ 48,280.00	68.0 %	Kevin Voyvodich
Attorney	$ 96,720.00	$ 9,103.00	9.4 %	Peter Rice
Other (List title in the Comments box)	$ 81,600.00	$ 7,344.00	9.0 %	Atlee Reilly, Legal Director
Administration	$ 24,000.00	$ 3,408.00	14.2 %	Sheila Hansen
Senior Staff Attorney	$ 93,600.00	$ 84,240.00	90.0 %	Mark Joyce
Attorney	$ 67,080.00	$ 4,695.00	7.0 %	Clayton Adams
Administration	$ 48,000.00	$ 6,816.00	14.2 %	Suzzanne Martin Doiron
Director of Finance	$ 80,000.00	$ 8,800.00	11.0 %	Shannon Crocker
Business Operations Manager	$ 52,000.00	$ 1,040.00	2.0 %	Erik Monty
Administration	$ 40,250.00	$ 5,715.00	14.2 %	Susan Schroeder
Administration	$ 51,000.00	$ 8,936.00	17.5 %	Tammy Cunningham
Administration	$ 47,036.00	$ 6,679.00	14.2 %	Linda Leighton
Other (List title in the Comments box)	$ 72,600.00	$ 13,794.00	19.0 %	Katrina Ringrose - Deputy Director
Advocate/Case Manager	$ 43,639.00	$ 4,363.00	10.0 %	Keenan Weischedel
Advocate/Case Manager	$ 44,253.00	$ 4,900.00	11.1 %	Mary Myshrall
Administration	$ 42,432.00	$ 424.00	1.0 %	Bridget Campbell
Attorney	$ 55,000.00	$ 35,276.00	64.1 %	Shianne Bowlin
Administration	$ 24,000.00	$ 3,648.00	15.2 %	Jeanne Curtin
Other (List title in the Comments box)	$ 60,000.00	$ 3,000.00	5.0 %	Julia Endicott, Communications Director
Advocate/Case Manager	$ 60,000.00	$ 30,000.00	50.0 %	Catherine Bustin
Advocate/Case Manager	$ 50,769.00	$ 508.00	1.0 %	Mary Green
Advocate/Case Manager	$ 47,608.00	$ 2,380.00	5.0 %	Carlene Mahaffey
Attorney	$ 74,110.00	$ 3,705.00	5.0 %	Matthew Main
Advocate/Case Manager	$ 15,530.00	$ 1,244.00	8.0 %	Jane Moore
Advocate/Case Manager	$ 48,000.00	$ 4,800.00	10.0 %	Brittany Ritter
	$ 1,730,456.00	$ 362,832.00		

II. Fringe Benefits

Please only include the current FFY's budget figures and document all other figures in the footnote. Please also describe methodology in the footnotes.

Fringe Breakdown *	Annual Salary * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Other (Describe the line item in the Comments box)	$ 15,522.00	$ 2,817.45	18.2 %	Cash Benefit in lieu of Health Insurance
FICA/Medicare	$ 194,311.00	$ 25,439.65	13.1 %	FICA
Other (Describe the line item in the Comments box)	$ 304,567.00	$ 30,445.22	10.0 %	Healthcare
Dental Insurance	$ 23,876.00	$ 2,414.11	10.1 %	Dental Insurance

State Unemployment Insurance	$ 10,814.00	$ 1,038.69	9.6 %	Unemployment Insurance
Other (Describe the line item in the Comments box)	$ 1,622.00	$ 164.55	10.1 %	Life Insurance
Workers Compensation	$ 7,083.00	$ 629.06	8.9 %	Workers Compensation
Employer Match-Retirement	$ 101,600.00	$ 10,995.58	10.8 %	Retirement - Employer Match
Long Term Disability Insurance	$ 9,398.00	$ 1,264.93	13.5 %	Long Term Disability Insurance
	$ 668,793.00	$ 75,209.24		

III. Travel Expenses

Please only include the current FFY's budget figures and document all other figures (carryover) in the footnote. Using the comment field or footnote, provide the purpose of travel number of staff, PAIMI Advisory Council or board members traveling for each event, and per diem: describe the number of nights and purpose. There is a 10% limit on training, technical assistance and travel expenses [42 CFR 51.6 (3) (e)].

Travel Expenses *	Actual Cost * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Lodging for Meetings	$ 2,459.79	$ 2,459.79	100.0 %	NARPA and other overnights as necessary
Mileage	$ 65,476.15	$ 7,762.43	11.9 %	10065 Miles for 12 staff Rate of $0.585 per mile Distance travelled can range up to 600 miles round trip
	$ 67,935.94	$ 10,222.22		

IV. Equipment

Include communications and rental equipment directly related to PAIMI project activities. Please only include the current FFY's budget figures and use the footnote to describe any additional funding carried over from previous years.**

Equipment *	Actual Cost * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Other (Describe the line item in the Comments box)	$ 37,225.96	$ 5,720.87	15.4 %	Repair & Maintenance
Equipment Rental	$ 16,840.52	$ 4,442.89	26.4 %	Copier and postage machine through Pitney Bowes
	$ 54,066.48	$ 10,163.76		

** Per 45 CFR Part 75: Equipment means tangible personal property (including information technology systems) having a useful life of more than one year and a per-unit acquisition cost which equals or exceeds the lesser of the capitalization level established by the non-Federal entity for financial statement purposes, or $5,000. See also Capital assets, Computing devices, General purpose equipment, Information technology systems, Special purpose equipment, and Supplies.

V. Supplies

Please list the supplies (both the category of items and the value) expended through using PAIMI funds. Use the comments field to describe the supplies.

Supplies *	Actual Cost * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Maintenance/Supplies	$ 29,178.57	$ 4,181.81	14.3 %	Supplies
Other (Describe the line item in the Comments box)	$ 7,929.14	$ 797.29	10.1 %	Printing
Network/Computer	$ 18,577.13	$ 2,480.31	13.4 %	Telephone
Internet Services	$ 3,839.52	$ 479.42	12.5 %	Internet/Email
Postage	$ 8,111.22	$ 1,071.60	13.2 %	Postage
Other (Describe the line item in the Comments box)	$ 5,800.28	$ 502.15	8.7 %	Library Fees
	$ 73,435.86	$ 9,512.58		

VI. Contractual/Consultant Costs

In the section below provide budget expenditure information for each contractual arrangement for PAIMI program services. Any sub-contract that exceeds $25,000 must be pre-approved by SAMHSA Grants Management Officer. Only include the current FFY's budget figures and use the footnote to describe any additional funding carried over from previous years.

Position or Entity*	Service Provided*	Actual Cost* "A"	Total PAIMI Share* "B"	Percent to PAIMI "B" / "A" = "C"	Comments
Suncontractors		$ 121,671.22	$ 5,854.65	4.8 %	Five subcontractors, two of which are being paid more than $25k but are not being paid out of PAIMI
Misc		$ 4,786.04	$ 955.16	20.0 %	Miscellaneous
Interpreters		$ 27,711.40	$ 1,452.99	5.2 %	Interpreters
Casual Labor		$ 29,479.23	$ 3,900.65	13.2 %	Casual Labor
		$ 183,647.89	$ 12,163.45		

VII. Technical Assistance/Training Costs

In the section below provide technical assistance and training costs for staff, governing board and advisory council members. Explain the training costs in the comment field (i.e. number of meetings, number of participants, explanation of staff travel cost). Only include the current FFY's budget figures; document all other figures in the footnotes. There is a 10% limit on training, technical assistance and travel expenses [42 CFR 51.6 (3) (e)].

Technical Assistance/Training Costs * (explain costs in the comment field i.e number of meetings and number of participants)	Actual Cost * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Other (Describe the line item in the Comments box)	$ 51,742.31	$ 3,854.84	7.5 %	Staff Trainings
Advisory Council meetings	$ 6,457.57	$ 6,457.57	100.0 %	Advisory Council Expenses. Including meetings, travel, trainings, etc as needed.
Other (Describe the line item in the Comments box)	$ 27,630.00	$ 19,988.26	72.3 %	Audit
Governing Board meetings	$ 174.69	$ 23.70	13.6 %	Board Expenses
	$ 86,004.57	$ 30,324.37		

VIII. Other Expenses

Please include any other expenses that used Federal PAIMI funds but do not fit into the prior categories. "Litigation" is an example. Please be as specific as possible the nature of other indicated expenses.

Other Expenses *	Actual Cost * "A"	Total PAIMI Share * "B"	Percent/Level of Effort to PAIMI "B" / "A" = "C"	Comments
Rent ? Office Space: (1) Location ? identify full address	$ 148,527.75	$ 30,108.26	20.3 %	Occupancy
Other (Describe the line item in the Comments box)	$ 11,219.64	$ 1,432.45	12.8 %	Janitorial
Other (Describe the line item in the Comments box)	$ 8,267.35	$ 1,241.36	15.0 %	Utlities
Other (Describe the line item in the Comments box)	$ 7,641.72	$ 982.58	12.9 %	Litigation & Client Expense
Other (Describe the line item in the Comments box)	$ 9,801.70	$ 1,055.31	10.8 %	Payroll Services
Dues and Memberships	$ 51,410.80	$ 7,518.40	14.6 %	Dues and Memberships, DAD, PANDA, Westlaw, etc
Insurance	$ 24,863.00	$ 2,629.59	10.6 %	Insurance - business
Other (Describe the line item in the Comments box)	$ 1,189.00	$ 23.36	2.0 %	Legal Expenses
Other (Describe the line item in the Comments box)	$ 38,377.35	$ 3,685.68	9.6 %	Agency Development
Other (Describe the line item in the Comments box)	$ 814.35	$ 0.00	0.0 %	Bank Services
Other (Describe the line item in the Comments box)	$ 8,782.74	$ 947.55	10.8 %	Admin Fees
Other (Describe the line item in the Comments box)	$ 6,982.72	$ 23.17	0.3 %	Annual Meeting
Other (Describe the line item in the Comments box)	$ 3,151.00	$ 398.16	12.6 %	Recruitment
	$ 321,029.12	$ 50,045.87		

IX. Indirect Costs

Attach a copy of the approved rate agreement. Federally approved IDC rate.

No Data Available

X. Carryover of PAIMI Funds Only

Carryover for FY 2022	$ 98,040.52

Please upload your budget plan for 2022 carryover funds

	Total Actual Cost	Total PAIMI Share
Total PAIMI Costs	$ 3,185,368.86	$ 560,473.49

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Footnotes:

	$	98,040.52	
	Remainder Carryover		

1	Personnel			
	Executive Director	$	5,195.25	Kim
	Intake Specialist	$	2,619.67	Sara
	Intake Specialist	$	2,385.62	Fern
	Attorney	$	11,865.09	Kevin
	Attorney	$	1,592.34	Peter
	Legal Director	$	1,284.64	Atlee
	Administration	$	596.14	Sheila
	Attorney	$	18,155.62	Mark
	Attorney	$	821.27	Clayton
	Administration	$	1,192.28	Vacant
	Director of Finance	$	1,539.33	Shannon
	Administration/Operations	$	999.69	Susan
	Administration	$	1,563.12	Tammy
	Administration	$	1,168.32	Linda
	Deputy Director	$	2,412.91	Katrina
	Advocate	$	857.13	Mary M
	Administration	$	74.17	Bridget
	Administration	$	638.12	Jeanne
	Communications Director	$	524.77	Julia
	Advocate	$	5,247.73	Catherine
	Advocate	$	88.86	Mary G
	Advocate	$	416.32	Carlene
	Attorney	$	648.09	Matthew
	Advocate	$	839.64	Brittany
	Advocate	$	217.61	Jane
		$	62,943.74	

2	Fringe			
	Other	$	436.20	Cash Benefit
	FICA	$	3,938.61	FICA
	Other	$	4,713.58	Health
	Dental	$	373.76	Dental
	SUI	$	160.81	SUTA
	Other	$	25.48	Life Ins
	Workers Comp	$	97.39	Workers Comp
	Employer Match	$	1,702.36	Retirement
	LTD	$	195.84	LTD
		$	11,644.03	

3	Travel			
	Lodging	$	-	NARPA
	Mileage	$	1,347.18	
		$	1,347.18	

4	Equipment			
	Other	$	992.87	R&M
	Equipment Rental	$	771.07	
		$	1,763.94	
5	Supplies			
	Supplies	$	623.97	
	Other	$	138.37	Printing
	Network Computer	$	430.46	5535 Telephone
	Internet	$	83.20	5536 Internet
	Postage	$	884.18	
	Other	$	87.15	Libraries
		$	2,247.33	
6	Contractual			
	Subcontractors	$	1,016.08	5252 SubCon
	Misc	$	234.92	5600 Misc
	Interpreters	$	252.17	
	Casual Labor	$	676.96	
		$	2,180.14	
7	Technical Assistance			
	Other	$	2,703.90	Staff Trainings
	Advisory Council meetings	$	1,120.72	
	Other	$	3,468.99	Audit
	Governing Board meetings	$	4.11	
		$	7,297.73	
8	Other Expenses			
	Rent	$	5,225.33	Occupancy
	Other Expenses	$	248.60	Janitorial
	Other Expenses	$	215.44	Utilities
	Other Expenses	$	120.16	Litigation
	Other Expenses	$	183.15	Payroll Services
	Dues	$	780.43	Dues & Membership
	Insurance	$	456.37	Insurance
	Other Expenses	$	54.42	Legal Expenses
	Other Expenses	$	4.02	Annual Meeting
	Other Expenses	$	-	
	Other Expenses	$	639.66	Agency Development
	Other Expenses	$	-	Bank Services
	Other Expenses	$	164.45	Admin Fees
		$	8,616.44	
		$	98,040.52	

Carryover for FY 20XX	
Carryover FY23 to FY24	98040.52
Total Carryover	98040.52

G. PAIMI Budget - Actual

PAIMI Expenditures and Revenues

PAIMI Expenditures	
1. Does your P&A have an approved Federal indirect cost rate? If yes, what is the approved rate?	○ Yes ● No 0.05% %
2. Total indirect costs	$0
3. Total of all PAIMI program costs listed in **I - VIII** in the Budget	$0
Total	**$0**

Income sources and other resources (PAIMI program only)			
1. PAIMI program carryover of grant funds identified by FY.			
Enter the last two digits of the Fiscal Year	FY	2022	$184,814
2. Program income (PAIMI only)			$0
3. State			$0
4. Other funding sources [identify each source]			
Total of all PAIMI Program resources.			**$184,814**

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Footnotes:

H. Statement of Priorities & Objectives

PAIMI Program Statement of Priorities and Objectives - Report

The PAIMI Program Statement of Priorities and Objectives (SPOs) **must be specific** to individuals with significant mental illness (adults) and/or significant emotional impairment (children/youth), as determined by a mental health professional qualified under the laws and regulations of the state in accordance with 42 U.S.C.A. § 10802(4) (A). The SPOs in the PPR **must match** the same format and order approved in the FY 2023 PAIMI Application.

Priority/Goal Description: PRIORITY 1 – Abuse, Neglect and Rights Violations: PAIMI-eligible individuals will be safe from abuse and neglect, and will be guaranteed personal rights.

Objective: OBJECTIVE 1.1 DRM will assist PAIMI-eligible individuals who are being abused or neglected or whose rights are being violated. This will be limited to PAIMI-eligible individuals living in facilities who are being physically, sexually, seriously verbally abused or financially exploited; • PAIMI-eligible individuals living in the community who are being physically or sexually abused by individuals who have an affirmative duty to protect, treat, care for, educate or provide services; • PAIMI-eligible individuals living in facilities or in the community who are being neglected through the deprivation of essential goods and services by individuals who have an affirmative duty to protect, treat, care for, educate or provide services individuals who are denied due process of law when restricted in the exercise of basic rights; and, • PAIMI-eligible individuals whose rights with respect to governmental benefits or services or to critical services are violated. Critical services include health services; legal services; education; transportation; telecommunications; and other services without which the client would be at risk of injury or at risk of entering a restrictive facility.

Strategies Used: Collaboration,Systemic Litigation,Rights-Based Individual Advocacy Services,Educating Policy Makers,Investigations of Abuse and Neglect,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population: Target Population: PAIMI-eligible individuals who are subject to abuse, neglect or financial exploitation and who are living in facilities; PAIMI-eligible individuals living in the community, who are subject to abuse or neglect by a person with an affirmative duty; PAIMI-eligible individuals who are denied due process of law when restricted in the exercise of basic rights; PAIMI-eligible individuals who are wrongfully denied governmental or critical services.

Expected Target: 40

Expected Outcome: 40

Actual Outcome: 96

Achieved: (●) **Not Achieved:** ( )

Reason why priority/goal was not achieved or was partially achieved:

Results narratives of P&A activities and accomplishments related to above priority:

A 32-year-old woman, whose mother was her guardian and was an involuntary patient at a psychiatric hospital. State officials reviewed her care and changed her plan from moving back to her supported apartment to placement in a nursing home. Both the client and her mother objected to this plan. DRM met with state officials, her clinical team, the client, and the guardian. After discussions, a decision was reached to discharge the client back to her apartment with additional supports, avoiding placement in a nursing home for this 32-year-old woman.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 54-year-old man, an involuntary patient at a psychiatric hospital, had been taken into protective mental health custody by law enforcement, leading to his transfer to a hospital located 100 miles away. As per standard protocol, the police had his car towed from the side of the road by a towing company. The client received notice from the towing company that unless he paid $2000 for storage fees, the title to his car would eventually be transferred to them. Lacking the funds, and with the vehicle valued at $20,000 being his sole asset and crucial for successful discharge from the hospital, DRM collaborated with the towing company, state officials, and hospital staff. Through the intervention, the state agreed to pay the $2,000 from an emergency fund, and the car was towed to the hospital where there was ample room for parking

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 43-year-old woman under state guardianship, previously diagnosed with a significant mental illness or emotional impairment by a qualified

Maine mental health professional, resided in a mental health group home. The group home had a communal mailbox situated on the side of the road, and when mail arrived, they would distribute it to the residents, except for this particular client. Instead, the home had a special box in the office where they stored her mail, only allowing her to receive it if her state guardian approved. The client was receiving mail without her knowledge, thus violating several state and federal regulations .DRM educated the guardian and the group home on the specific regulations and requirements governing mail handling, emphasizing the procedures involved if the home or the guardian had cause to delay or restrict access to the mail. As a result of this intervention, the group home began adhering to the regulations, discarding the box they were using in the office to withhold the client's mail.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 64-year-old woman, an involuntary patient at a psychiatric hospital, became the subject of a clinical review panel for the hospital's attempt to obtain an order for forcibly administering psychotropic medications. However, the hospital failed to inform the patient of the hearing date until just one day prior, violating several of the client's procedural due process rights. DRM intervened and notified the hospital that their process did not comply with state law. In response, the hospital withdrew its request for a hearing until they could ensure compliance with the procedural protections outlined in the laws.

Objective: OBJECTIVE 1.2 DRM, in coordination with the PAC and other organizations, will conduct projects that promote the protection of PAIMI-eligible individuals from abuse, neglect and rights violations.

Strategies Used: Collaboration,Educating Policy Makers,Investigations of Abuse and Neglect,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population:	Target Population: PAIMI-eligible individuals who are subject to abuse, neglect, exploitation, or restriction of their rights. Target: DRM will conduct at least 5 projects.
Expected Target:	5
Expected Outcome:	5
Actual Outcome:	10
Achieved: (●) **Not Achieved:** ( )	

Reason why priority/goal was not achieved or was partially achieved:

Results narratives of P&A activities and accomplishments related to above priority:

The Maine Department of Corrections has an American with Disabilities Act Coordinator responsible for processing all reasonable accommodation requests within the prison system, including those related to psychiatric disabilities. DRM holds quarterly meetings with the coordinator to discuss issues pertaining to trends in these accommodation requests.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

DRM holds quarterly meetings with the president and clinical staff of one of the largest behavioral health organizations in the state. These meetings serve as a platform to discuss common interests, including any challenges or issues DRM has encountered with the organization's various programs across the state. Additionally, it provides an opportunity for the behavioral health organization to seek information on pertinent issues from DRM.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

DRM, in collaboration with Attorney Ruth Lownekron, the Director of Disability Justice for the New York Lawyers for Public Justice, delivered a presentation during a brown bag lunch at the University of Maine School of Law. The presentation focused on emergency involuntary commitment, addressing the disproportionality of individuals affected by these laws, particularly in relation to class and race.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

DRM, in collaboration with the Maine Commission on Indigent Legal Services, served as a presenter in a Continuing Legal Education event titled "Not Criminally Responsible (NCR) Proceedings Minimum Standards Training." During DRM's portion of the training, the discussion focused on the relationship between DRM's hospital-based advocates, who have frequent contact with individuals found NCR, and the attorneys representing them.

Priority/Goal Description: PRIORITY 2 – Community Inclusion: PAIMI-eligible individuals will live in the communities of their choice and be fully included in all aspects of community life as they may choose

Objective: OBJECTIVE 2.1 Obtain increased community inclusion for PAIMI-eligible individuals who are living in or at risk of entering facilities and who are being denied opportunity to live in the community of their choice or who are being denied opportunity to participate in community life.

Strategies Used: Collaboration,Rights-Based Individual Advocacy Services,Educating Policy Makers,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population: PAIMI-eligible individuals living in or at risk of entering restrictive facilities who wish to live in more inclusive environments. PAIMI-eligible individuals whose supports, treatment or treatment plans impede participation in community life.

Expected Target: 10

Expected Outcome: 10

Actual Outcome: 40

Achieved: ◉ **Not Achieved:** ○

Reason why priority/goal was not achieved or was partially achieved:

Results narratives of P&A activities and accomplishments related to above priority:

A 63-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, faced difficulties traveling to her medical appointments due to the refusal of her new community mental health case manager to provide support. The case manager cited a misunderstanding of Medicaid billing rules as the reason for the refusal. DRM promptly contacted the case manager and her supervisor, providing education on the fact that such transportation support was not disallowed based on the services outlined in her treatment plan. The case manager agency verified this information, and as a result, the client was able to receive the assistance she needed to access her medical appointments.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

The discharge of a 60-year-old man, a patient at a psychiatric hospital, was being delayed due to the client's need for a mental health group home. However, he was unable to access it as his assets exceeded the limit for means-tested assistance, yet were not sufficient for him to pay out of pocket. This predicament left him stuck in the psychiatric hospital. DRM arranged for the client to have a consultation with an attorney specializing in special needs trusts to help him navigate this situation. Eventually, with the assistance provided, the client was able to discharge from the hospital.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 37-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was residing in a mental health group home. The client frequently took walks in the community without informing the group home of their duration. This lack of communication prompted group home staff to call the police on multiple occasions, leading to the client being located and brought to the emergency room for evaluation. This situation caused stress for the client and increased the risk of hospital admission.
DRM attended a treatment team meeting where a plan was developed to address this issue. The plan involved ensuring that the client had a cell phone and would call to check in if he was away for more than 2 hours, enhancing his safety. The implemented plan successfully resolved the problem.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 50-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, experienced the loss of both his mental health services and housing, resulting in an emergency involuntary mental health hold in an emergency department. DRM met with the client in the emergency department, and the client was subsequently transferred as a voluntary patient to a psychiatric hospital. DRM continued to assist the client, and he was later discharged to a supported apartment with a new community mental health provider.

Objective: OBJECTIVE 2.2 DRM, in coordination with the PAC and other organizations will conduct projects that promote community inclusion for PAIMI-eligible individuals.

Strategies Used: Collaboration,Educating Policy Makers,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population:	PAIMI-eligible individuals living in unnecessarily restrictive facilities or at risk of entering such facilities. PAIMI-eligible individuals who receive less than adequate service or treatment and discharge planning, such that achievement of community integration is compromised. PAIMI-eligible veterans with mental health needs who are excluded from or having difficulty obtaining community mental health related services
Expected Target:	6
Expected Outcome:	6
Actual Outcome:	7
Achieved: (●) **Not Achieved:** ( )	

Reason why priority/goal was not achieved or was partially achieved:

Results narratives of P&A activities and accomplishments related to above priority:

The Maine Association of Peer Support and Recovery Centers (MAPSARC) holds monthly meetings, bringing together representatives from the 8 statewide centers, representatives from the state managing contracts for these centers, and representatives from the Consumer Council System of Maine—a quasi-governmental agency providing an independent consumer voice to the state. DRM regularly attends these meetings, offering updates on DRM's work and being available to address any questions from the group.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

The Together Place Peer Center Collaborative, in partnership with Wabanaki Public Health and Wellness, organized a community festival featuring backyard games, horse and wagon rides, and a dunk tank. The festival aimed to uplift the community and disseminate information about available resources. DRM actively participated by hosting a table at the event, offering information about DRM and its activities to all attendees.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

The National Association of Rights Protection and Advocacy (NARPA) is a nationwide organization dedicated to supporting individuals with psychiatric diagnoses in exercising their legal and human rights. NARPA's mission includes goals such as abolishing forced treatment and ensuring autonomy, dignity, and choice. At the 2023 annual meeting of NARPA, DRM presented a workshop titled "Peer Support Specialist as P&A Advocates: A Powerful Combination."
The workshop featured two psychiatric survivors from Maine who had been trained and worked as intentional peer support (IPS) specialists and are currently employed as advocates by DRM. The session provided an interactive presentation and discussion on how integrating the training, skills, and experiences of working as Certified Intentional Peer Support Specialists into the role of P&A advocates offers a unique and better-informed approach to mental health advocacy

Priority/Goal Description:	PRIORITY 3 – Housing: PAIMI-eligible individuals will live in safe, accessible, affordable housing
Objective:	OBJECTIVE 3.1 DRM will assist PAIMI-eligible individuals in obtaining or maintaining housing when they are being discriminated against. DRM will also represent PAIMI-eligible individuals at risk of becoming or remaining homeless or at risk of entering or remaining in a facility when their rights pertaining to housing are otherwise being violated or they are at risk of losing a disability related housing subsidy. This assistance may include assisting individuals in obtaining reasonable accommodations
Strategies Used:	Collaboration,Rights-Based Individual Advocacy Services,Educating Policy Makers,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population:	Target Population: PAIMI-eligible individuals who experience discrimination in housing or whose rights relating to housing otherwise need protection in order to avoid homelessness or entering or remaining in a facility. Target: 1. Represent at least 15 PAIMI-eligible individuals.
Expected Target:	15
Expected Outcome:	15

Actual Outcome: 22

Achieved: (●) **Not Achieved:** ( )

Reason why priority/goal was not achieved or was partially achieved:

Results narratives of P&A activities and accomplishments related to above priority:

A 49-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, had been living in her car for over a year. She was eligible for a state funded housing voucher but due to several administrative issues, she had not been able to access this voucher. DRM intervened and negotiated with the agency responsible for administering the voucher to address these issues. As a result, not only was the client awarded a housing voucher, but the voucher's value was also increased to better accommodate the market conditions in the area where the client was living

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

.A 51-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was homeless and at risk of losing his Section 8 voucher. The danger arose from his inability to secure an apartment within the time frames mandated by HUD regulations. His housing search had been impeded by his involuntary admission to a psychiatric hospital, which limited his ability to search for apartments.
DRM submitted a reasonable accommodation request to the Housing Authority administering his voucher for an extension. The request was granted, and the client was provided with a three-month extension on his voucher, offering him more time to secure stable housing

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 41-year-old man, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was residing in a homeless shelter. He had been awarded a state-funded housing voucher,. However, the market rate for all apartments in his area exceeded the monthly rental amount the voucher would allow.DRM filed a reasonable accommodation request with the state office handling Americans With Disabilities Act (ADA) requests. The request aimed to increase the amount of his voucher. The office granted the accommodation request, allowing the client to submit paperwork for any apartment he considered to the local agency administering the voucher. The agency would then approve a waiver request for the overage amount, aligning with the market rate in the area where the apartment was located.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 54-year-old woman, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was facing eviction due to a bed bug infestation in her apartment, which caused her to fall short of her landlord's cleanliness requirements for tenancy. Her inability to meet this requirement stemmed from her disability.
Prior to the eviction hearing, DRM requested a reasonable accommodation from her landlord, seeking permission for her to remain in the apartment with the assistance of community supports designed to address the issue. The proposal also included an agreement for periodic inspections. The landlord agreed to the accommodation, and the parties presented the agreement to the court. As a result, the court continued the case in accordance with the agreement, allowing the client to continue living in her apartment.

Objective: OBJECTIVE 3.2 DRM, in coordination with the PAC and other organizations, will conduct projects that: promote the protection of PAIMI-eligible individuals from rights violations in housing or that promote the availability of housing options

Strategies Used: Collaboration,Educating Policy Makers,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population: PAIMI-eligible individuals who experience difficulty in obtaining and maintaining decent, safe and affordable housing. DRM will conduct at least 5 projects that promote the protection of PAIMI-eligible individuals from discrimination in housing or that promote the availability of housing options.

Expected Target: 5

Expected Outcome: 5

Actual Outcome: 6

Achieved: (●) **Not Achieved:** ( )

Reason why priority/goal was not achieved or was partially achieved:

Results narratives of P&A activities and accomplishments related to above priority:

The HOPE conference is an annual Statewide Recovery/Wellness Conference for Persons in Recovery from Substance Use and Mental Health Challenges and Service Providers. DRM presented a workshop at this conference entitled "Housing Rights Advocacy: Not all Assistance is created equal." This workshop provided information on the various types of housing assistance that individuals can apply for or may currently be receiving, along with the rights associated with each type of assistance.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

DRM partnered with the Maine Human Rights Commission for Fair Housing Month and presented two separate training webinars. In collaboration with the Executive Director of the Maine Human Rights Commission and an attorney from Pine Tree Legal Assistance, Maine's Legal Services Organization, DRM conducted webinars on assistance animals in housing and reasonable accommodations in housing.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

DRM partnered with the Project for Assistance in Transition from Homelessness (PATH) program to conduct outreach to Maine's growing homeless population. The outreach aimed to provide information about DRM's services to clients served by PATH, including individuals living in tents. Specifically, the outreach focused on providing information about a state voucher program, eligibility for which is restricted to individuals with severe and persistent mental illness.

Priority/Goal Description: PRIORITY 4 – Education: PAIMI eligible children and young adults are entitled to a Free and Appropriate Public Education in the least restrictive environment without threat of inappropriate discipline.

Objective: OBJECTIVE 4.1 DRM will assist PAIMI eligible students who have been suspended, expelled or otherwise excluded from school, who are harassed or bullied and not protected by the school, or who are placed in unnecessarily noninclusive environments. DRM will also assist in obtaining appropriate transition plans and services for students residing in facilities who are between the ages of 16-19 and who have not yet graduated from school.

Strategies Used: Collaboration,Rights-Based Individual Advocacy Services,Educating Policy Makers,Investigations of Abuse and Neglect,Other Systemic Advocacy,Monitoring,Training/Outreach

Target Measures

Target Population: PAIMI-eligible students who are excluded from school, who are not being protected from harassment or bullying, who are being educated in unnecessarily non-inclusive environments or who are between the ages of 16 and 19, live in facilities and have inadequate transition plans

Expected Target: 28

Expected Outcome: 28

Actual Outcome: 20

Achieved: ○ **Not Achieved:** ●

Reason why priority/goal was not achieved or was partially achieved:

Assessment of the number of cases was not accurate. It will be revisited in FY 2024.

Results narratives of P&A activities and accomplishments related to above priority:

A 12-year-old boy, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, had been suspended from school. His parents alleged that this was due to behaviors related to his disability and bullying, and that the school had not adequately investigated their complaints. DRM assisted the parent in filing a complaint against her son's school district with the U.S. Department of Education's Office for Civil Rights ("OCR"). The parent and the DRM attorney developed a draft complaint together, and the parent filed it. OCR responded and confirmed that they accepted all three of the parents' allegations for investigation. The family was pleased with DRM's assistance.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 15-year-old boy, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, had ended his school year with only 2 hours of virtual tutoring per day with no full-time in-person services or supports. During the following summer, the client had a number of psychiatric placements, and the parent was concerned that he would not be offered

appropriate services when school started. DRM represented the student at an IEP meeting, and when he was discharged from a psychiatric hospital during the start of the school year, he was able to begin attending school in the district for the full school day. .

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 12-year-old girl, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was expelled from school with no re-entry plan. The family asserted that she had been expelled due to behaviors that were manifestations of her disability, but the school had found otherwise. DRM met with the family, reviewed records, and provided information about the student's right to FAPE in the LRE (Free Appropriate Public Education in the Least Restrictive Environment) and the disciplinary protections for students with disabilities. The family put into writing their concerns around the manifestation determination review, her eligibility for special education, and a demand for a re-entry plan, which eventually led to the girl being back in school full-time.

Other qualitative narrative related to above priority (significant activity for which there were no quantifiable results go here):

A 7-year-old girl, previously diagnosed with a significant mental illness or emotional impairment by a qualified Maine mental health professional, was not receiving the services from her school district that she was entitled to under her 504 plan. DRM met with the family, provided information on the student's rights, and reviewed records they provided. DRM assisted the family in writing to the school district to make clear that they wanted the student evaluated for special education, and in the meantime, for the school district to provide positive behavior supports so the student is not excluded from the classroom for disability-related behaviors. The student was found eligible for special education services, and positive behavior supports were put in place.

Objective: OBJECTIVE 4.2 DRM will develop a handout on educational rights for PAIMI-eligible adolescents in hospitals and residential settings for distribution during monitoring and outreach visits.

Strategies Used:

Target Measures

Target Population:	PAIMI eligible school age children in hospitals and residential facilities in need of information regarding their educational rights Target: DRM will develop at least one educational handout and distribute it during at least two outreach and monitoring visits to hospitals and residential facilities.
Expected Target:	2
Expected Outcome:	2
Actual Outcome:	0
Achieved: ○	**Not Achieved:** ◉

Reason why priority/goal was not achieved or was partially achieved:

This project goal was deleted in FY 2022

Results narratives of P&A activities and accomplishments related to above priority:

Priority/Goal Description: PRIORITY 5 – Employment Discrimination: PAIMI-eligible individuals will have access to employment without being subject to unlawful disability based discrimination.

Objective: DRM will assist PAIMI-eligible individuals who have been discriminated in employment.

Strategies Used:

Target Measures

Target Population:	PAIMI-eligible individuals discriminated against in employment.
Expected Target:	8
Expected Outcome:	8
Actual Outcome:	0
Achieved: ○	**Not Achieved:** ◉

Reason why priority/goal was not achieved or was partially achieved:

This priority was deleted in FY 2022. .

Results narratives of P&A activities and accomplishments related to above priority:

Objective: OBJECTIVE 5.2 DRM, in coordination with the PAC and other organizations, will conduct projects that promote the protection of PAIMI-eligible individuals from rights violations in employment or that that promote the availability of employment options.

Strategies Used:

Target Measures

Target Population:	DRM will conduct at least 2 projects that promote employment for PAIMI-eligible individuals and their protection from discrimination.
Expected Target:	2
Expected Outcome:	2
Actual Outcome:	0
Achieved:	**Not Achieved:** ●

Reason why priority/goal was not achieved or was partially achieved:

This priority has been deleted. On September 16, 2022 the PAIMI Advisory Council voted to delete it. In the event receives a significant amount cases that have merit regarding employment reinstated the priority will be reconsidered.

Results narratives of P&A activities and accomplishments related to above priority:

0930-0169 Approved: 07/27/2023 Expires: 07/31/2026

Footnotes:

Advisory Council Report

Advisory Council Report

Advisory Council Report (ACR)

The Advisory Council Report (ACR) section of the annual PAIMI Program Performance Report, to the Secretary of the U.S. Department of Health and Human Services, **is due by January 1**. The ACR is mandated under the PAIMI Act at 42 U.S.C. 10805 (a) (7). The ACR is the PAIMI Advisory's Council's (PAC) **independent assessment** of their protection and advocacy system's for the previous fiscal year. **The ACR must be prepared by the PAC and signed and dated by the PAC Chairperson.**

Please use the box below to indicate areas of technical assistance needed related to this section.

0930-0169 Approved: 07/27/2023 Expires: 07/31/2026

Footnotes:

OMB Approval: 0930-0169

Expiration Date: 06/30/2023

The ADVISORY COUNCIL REPORT (ACR) Section of the ANNUAL PAIMI PROGRAM PERFORMANCE REPORT (PPR)	
STATE	FISCAL YEAR

The Advisory Council Report (ACR) section of the annual PAIMI Program Performance Report (PPR) is due by January 1. The ACR is an independent assessment by the PAIMI Advisory Council (PAC) of their state P&A system's PAIMI Program operations. The ACR must be signed and dated by the PAC Chairperson.

For ACR assistance, please contact the PAIMI Program Officer

Please read and follow the instructions in each section and use the attached glossary in to complete the form.

Public reporting burden for the ACR section of the annual PAIMI PPR is estimated to average 10 hours per response. This includes the time needed to review the instructions, to search existing data sources, to gather the data needed, and to complete and review the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to SAMHSA Reports Clearance Officer; Paperwork Reduction Project (0930-0169); CBHSQ, Room 15E21B; 5600 Fishers Lane, Rockville, MD 20857. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is (0930-0169).

The ACR Section of the ANNUAL PAIMI PPR

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The ACR Section of the Annual PAIMI PPR	
SECTION A. GENERAL INFORMATION	
Fiscal Year:	2023
State:	Maine
Name of P&A system:	Disability Rights Maine
PAC Report Prepared By: Provide the name [Print First, Middle and Last Name] Title of the preparer: Phone Number:	April Kerr & PAC members PAC Chair Aprillkerr2020@gmail.com (207) 491-0381
Name of PAC Chair: [Print First, Middle, and Last Name] Provide updated contact information if the PAC Chair is different than the person listed on the most recent PAIMI Application.	April Kerr aprillkerr2020@gmail.com
Telephone Number:	(207) 491-0381
E-Mail Address:	aprillkerr2020@gmail.com
Date Submitted:	December 28, 2023
By signing this document, the Chair certifies that this report reflects the consensus of the PAC members.	

SECTION B. The PAIMI ADVISORY COUNCIL (PAC)		
*Under Primary ID, select *ONLY ONE* (1) primary identity for each PAC member position **[B.1.b. - B.1.h.] that** is mandated per the PAIMI Act & Rules).		**Primary Identification**
B.1.a. The TOTAL number of seats on the PAC.		**Total 13**
B.1.b. Individuals who are recipients/former recipients (R/FR) of mental health services.		7

B.1.c. Family members of individuals who are recipients/former recipients (R/FR) of mental health services.	1
At least one (1) PAC member shall be a B.1.d.	
B.1.d. Family members of a minor child or youth (under 18 years old) who has received or is receiving mental health services.	1
B.1.e. Mental health service providers.	1

2

B.1.f. Mental health professionals:		
B.1.f.1. Social Workers		
B.1.f.2. Psychologists	1	
B.1.f.3. Psychiatric Nurses		
B.1.f.4. Psychiatrists		
B.1.f.5. Psychiatric Nurse Practitioners		
B.1.f.5. Peer Support Specialists		
B.1.g. Attorneys.	1	
B.1.h. Individuals from the public knowledgeable about mental illness.		
B.1.i. Others (please identify by position held).		
B.1.j. Vacancies as of 9/30. [identify each vacant position & the date it was vacated].	1	
B.1.k. TOTAL number of PAC members serving on 9/30.	**Total 12**	
B.1.l. Number of PAC members who are either R/FR of MH services or family members of these individuals (count each PAC member only once).	9	
B.1.m. Percentage of PAC members who are either R/FR of MH services or family members of these individuals [B.1. k. divided by B.1.l.]	69%	
B. 2. REPRESENTATION OF THE PAC CHAIRPERSON		
B.2. Is the PAC Chair an individual who has received or is receiving mental health services, or a family member of an individual who has received or is receiving mental health services?	**Yes X**	**No**
B. 3. PAC TERMS of Appointment		
B.3.a. Term of Appointment (number of years)	4	

B.3.b. Maximum Number of Terms a Member May Serve	2
B.3.c. Frequency of Meetings	6 per year
B.3.d. Number of Meetings Held in the FY [3 is the mandated minimum].	5
B.3. e. Number (%Average) of PAC members present at Meeting.	67%

SECTION C. PAC ETHNICITY & RACIAL DIVERSITY

Please refer to the **GLOSSARY** for definitions. The following information is self-reported or self identified and uses two separate questions. The data on race and ethnicity are collected SEPARATELY; provision shall be made to report the number of respondents in each category who are Hispanic or Latino. Collection of greater detail is encouraged; however, any collection that uses more detail shall be organized in such a way, that the additional information can be aggregated into these minimum categories for data on race and ethnicity.

C. A. ETHNICITY	**Number of PAC Members**
C. A. 1. Hispanic or Latino	0
C. A. 2. Not of Hispanic Origin	12
(add C.A.1 & C.A.2., the total should be the same as the one listed in B.1.k. (members serving as of 9/30).	**Total** 12
C. B. RACE	
C. B. 1. American Indian or Alaska Native	**1**

C. B. 2. Asian	**0**
C. B. 3. Black or African American	**0**
C. B. 4. Native Hawaiian/Other Pacific Islander	**0**
C. B. 5. White	**11**
C. B. 6. Two or More Races	**0**
C. B. 7. = C.B.1 through C.B.6.	**Total 12**
Members may select as many racial identifications as they want.	

C. C.1. Total Number of PAC member vacancies on September 30.	**Total PAC Vacancies**
	1

SECTION D. Sex of PAC Members	
D.1 MALE 2	D.2 FEMALE 10
D.3. UNKNOWN/WOULD NOT DISCLOSE	
D.3. TOTAL	

SECTION E. GOVERNING BOARD INFORMATION		
E. 1. FOR STATE-OPERATED P&A SYSTEMS ONLY:		
E.1.a. Is this a State-operated P&A system?	Yes	No X
E.1.b. Does this State-operated system have a Governing Board/Authority authorized by State statute? If the answer is NO, proceed to Section F.	Yes	No
E.1.c. If the answer to item E.1.b. is YES, does the PAC Chair sit on the Governing Board/Authority as a full voting member?	Yes	No
E.1.d. If the answer to item E.1.c. is no, briefly explain (e.g., State statute determines Governing Board/Authority composition, etc.).		
E.2. For PRIVATE, Not-for Profit P&A SYSTEMS only		
E. 2.a. Does the P&A system have a multi-member Governing Board?	Yes X	No
If you answered YES to E.2.a., please answer the questions E.2.b. 1. - 3.		
E.2.b.1. Number of Governing Board members.	Total 13	
E.2.b.2. Is the PAC Chair a full voting member of the Governing Board?	Yes X	No

E.2.b.3. If you answered No to E.2.b.2., then explain why the PAC Chair is not a full voting member of the Governing Board as mandated by the PAIMI Rules at 42 CFR 51.22(b)(3).		
E.2.b.4. Do any other PAC members hold seats on the Governing Board? If Yes, how many seats? ____	Yes	No X

SECTION F. PAC ACTIVITIES [See, PAIMI Act - 42 U.S.C. 10805(7)]		
F.1. Are P&A program staff invited to attend PAC meetings?	Yes X	No
F.1.a. Did any of the invited program staff attend?	Yes X	No
F.2.a. If the answer to F.1. is Yes, please identify the positions of staff (e.g., PAIMI Coordinator, Mental health advocate, etc.) usually invited to attend. Executive Director, PAIMI Director, Attorneys and Advocates		
F.2.b. If the answer to F.1.a. is Yes, please identify the positions of the program staff in attendance (e.g., one advocate, one attorney) and their role at the meetings, e.g., information sharing, etc. Information is shared about the organization, financial condition, cases, projects, and priorities. A standing item on the PAC agenda is something called PAC-TION. They are specific projects that are designed with PAC members and DRM staff that address issues in the community and institutions. We have also added a standing agenda item to hear from PAC members about what is going on in their communities etc., so the PAIMI staff become aware of issues from the members.		
F.2.c. If the answer to F.1. is No, you *MAY* provide a brief explanation.		
F. 3. a. Were governing board members, excluding the PAC Chair, invited to PAC meetings?	Yes X	No
F.3.b. If you answered Yes to F.3.a., which governing board members were invited, for what purpose (e.g., informational, etc.), and did they attend? There is a standing invitation for Board members to attend. The PAC chair restates this invitation at the Board meetings.		
F.3.c. Did any of the invited governing board members attend?	Yes	No X

F.4. Did the PAC work jointly with the governing board to develop the annual PAIMI priorities? [42 CFR 51.23(a) (2)].	Yes X	No*
F.4.a. If Yes, briefly describe these joint activities. The PAC chair is also the chair of the Governing Board and participates in all board meetings.		

SECTION F. PAC ACTIVITIES [See, PAIMI Act - 42 U.S.C. 10805(7)]		
F.4. b. If No, PAC's affiliated with private, non-profit P&A systems must provide a brief explanation.		
F.5. Did PAC members attend any in-state or out-of-state trainings or educational presentations related to PAIMI Program activities? *[42 CFR 51.27 - payments for PAC and Governing board/authority members by a State P&A system are optional]*.		
F.5.a. In-State Trainings/Educational Activities.	Yes X	No
If Yes, list each activity by number and provide a brief description of PAC involvement, e.g., Activity 1 – Attendance at local NAMI training.		
F.5.b. Out-of-State Trainings/Educational Activities.	Yes X	No
If yes, list each activity by number and provide a brief description of PAC involvement, e.g., Activity 1 – Attendance at NDRN annual conference.		
F.6. Does the P&A system have established written policies and procedures for reimbursing PAC members for expenses that takes into account the needs of the individual council members, available resources and applicable restrictions on use of grant funds, including the restrictions cited in and the restrictions in 51.31(e) and 51.6(e)? [See, 42 CFR 51.23 (d) (1)].		

F.6.a.1. Yes X F.6.a.2. No* F.6.a.3. Don't Know.*

F.6.b. Brief explanation needed for F.6.a.2. or F.6.a.3. responses].

SECTION F. PAC ACTIVITIES [See, PAIMI Act - 42 U.S.C. 10805(7)]

F.7. If the answer to F.6. was Yes, were PAC members reimbursed for expenses incurred for PAIMI Program related activities, consistent with the P&A system's policies and procedures.

F.7.a.	1.Yes X	2. No*	3. Don't Know*

F.7.b. *Brief explanation required for either F.7.a. 2. No *or F.7.a*. 3. Don't Know responses.

All PAC meetings were held virtually so there was no mileage reimbursement.
DRM paid the registration, travel, and lodging (including meal stipend) for 2 PAC members to attend the National Association of Rights Protection and Advocacy Conference that was held in New Orleans, Louisiana this year.

F. 8. REIMBURSEMENT OF EXPENSES – If PAC member expenses were reimbursed, please complete the following chart. [42 CFR 51.23(d) (1)]. Under the Activity column, list the activity by the number used in above F.5.a. – In-State or F.5.b. – Out-of-State. Example: F.5.b. Out-of-State activity # 1, – 5 PAC members attended the NDRN annual meeting, 2 members reimbursed by the P&A; 2 self-paid, 1 NDRN scholarship.

a. ACTIVITY	b. # ATTENDING	c. P&A	d. SELF	e. OTHER
NARPA Conference Out of State New Orleans, LA	2 PAC members	2 P&A Staff		

SECTION F. PAC ACTIVITIES [See PAIMI Act at 10805(7)]

F.9. Did the P&A system provide the PAC with reports, materials, & fiscal data to enable review of the following: [42 CFR 51.23(c)].

F.9.a. Existing program policies, priorities, and performance outcomes.	Yes X	No *
F.9.b. If Yes, were the submissions (of P&A system documents referenced in F.9.a.) made at least annually and (shall) report expenditures for the past two (2) FISCAL *YEARS?*	Yes X	No *
*F.9.c. If the answer to F.9. a. or F.9.b. is 'No", a brief explanation is required.		
F.9.d. If you answered Yes in F.9.a., did the P&A system documents referenced also *INCLUDE THE PROJECTED EXPENSES FOR THE NEXT FISCAL YEAR (FY) IDENTIFIED BY BUDGET CATEGORY*, e.g. salary & wages, contracts for services, administrative expenses, including, the amount allotted for training of the PAC, the governing board and staff?	Yes X	No *

F.9.d.1. If No*, a brief explanation is required].

SECTION F. PAC ACTIVITIES [See, PAIMI Act at 10805(7)]		
F.9.e. The PAIMI Rules mandate that members of the public shall be given an opportunity, on an annual basis, to comment on the priorities established by and the activities of the P&A system. Procedures for public comment must provide for notice in a format accessible to individuals with mental illness, including such individuals who are in residential facilities, to family members and representatives of such individuals with disabilities. [42 CFR at 51.24(b)].		
F.9.e. Does the P&A have procedures established for public comment?		
F.9.e. 1. Yes X	F.9.e. 2. No*	F.9.e.3. Don't Know*
F.9.e.4. *Brief explanation required for F.9.e.2. No or F.9.e.3. Don't know responses.		

F.9.f. Was the PAC provided a copy of these procedures?		
F.9.f.1. Yes X	F.9.f.2. No*	F.9.f.3. Don't Know*
F.9.f.4. *Brief explanation required for F.9.f.2. No or F.9.f.3.Don't know responses.		

SECTION F. PAC ACTIVITIES [See, PAIMI Act at 10805(7)]		
F.9.g. The PAIMI Rules, at 42 CFR 51. 24(b), mandate that the public shall be given an opportunity, on an annual basis, to comment on the priorities established by and the activities of the P&A system. *WAS THE PUBLIC PROVIDED AN OPPORTUNITY FOR PUBLIC COMMENT?*		
F.9.g. 1. Yes# X	F.9.g. 2. No*	F.9.g.3. Don't Know*

F.9.g 4. #If the answer to F.9.g.1. is Yes, briefly describe activities the P&A system used to obtain public comment.

The Agency solicits input through its web page, newsletter, in surveys, PAC members are asked to solicit input through their constituencies, This year DRM presented at a statewide HOPE conference virtually, that was organized by the Consumer Council System of Maine which some members are also members of the PAC

F.9.g. 5. *If the answer to F.9.g.2. is NO, explain why public comment was not obtained.

F.9.g. 6. *If the answer to F.9.g.3. is DON'T KNOW, please explain (e.g., PAC needs training, etc.)

F.10. ***COMPLETION OF THIS SECTION (F.10 a. –e.) IS OPTIONAL.*** However, if you choose to respond, please describe in the spaces below any other PAC activities, *other than* mandated PAC membership meetings.

F.10.a. Briefly describe, governing board or PAC committee work.

F.10.b. Briefly describe any training or educational presentations to either constituency groups or the general public.

HOPE Conference The Consumer Council System of Maine holds an annual event called the HOPE conference. It is held at the Augusta Civic Center. The HOPE conference was created to help participants gain a greater understanding of what recovery/wellness is from the many paths and different perspectives on the journey of life.

This conference is designed by consumers and allies, in conjunction with the Maine Office of Behavioral Health

There are several members of the PAC who are part of the CCSM. This year's HOPE conference was in person. PAC Chair April Kerr and PAC member Vickie McCarty presented a workshop entitled: Choosing to Use Your Voice in a Powerful Way in the Legislative Process. Several members of the PAC also attended this conference. There were also 3 DRM staff who presented at this conference. Attached as Attachment #1 is a copy of the HOPE Conference Flyer.

National Association of Rights and Protection and Advocacy (NARPA) Annual Conference. NARPA held their annual conference in New Orleans, Louisiana. The PAC chair April Kerr and PAC member Kelly Staples attended. Including attending the Pre Conference Institute for PAIMI Advisory Council Members entitled: PAIMI Advisory Councils as Leaders for Systemic Reform. Attached as Attachment #2 is the Agenda for this institute.

National Disability Rights Network (NDRN) ELEVATE. NDRN launched a new Learning Management System (LMS) called "Elevate." A number of PAC members registered for this service. This system offers training content, online communities, resources, upcoming events, and more.

Creation of PAC Logo. PAC member Melissa Caswell created a logo for the PAC to be used at outreach events in the community.

Mental Health Matters. Peer Advocate Legislative Education Day. The PAC, in collaboration with peer organizations, participated in the Peer Advocate Legislative Day at the Hall of Flags in the Maine Capitol building where legislators travel to and from their meetings, etc. The PAC had its own informational table and used the new logo on the table. Attached as Attachment #3 is the flyer for this event and a picture of the PAC table with the PAC logo.

Disability Awareness Day: Consumer Council System of Maine (CCSM) and DRM had tables at the annual Disability Awareness Day at the Hall of Flags in the Maine Capitol building. A number of PAC members (some who are also members of CCSM) participated in this event.

SECTION F. PAC ACTIVITIES [See, PAIMI Act – 42 U.S.C.10805(7)]

F.10.d. Briefly describe any special projects (e.g., institutional monitoring).

F.10.e. Briefly describe any other activities, e.g., fund raising, public relations, etc.

Disability Pride Day: DRM puts together an annual Disability Pride Day that promotes cross disability awareness, education and celebration. Many PAC members attend this event. PAC member Vickie McCarty was a speaker at this event. Attached as Attachment #4 is the flyer for this event and links to the news coverage for the event. Over 200 people attended this event.

SECTION G. PAC ASSESSMENT OF PAIMI PROGRAM OPERATIONS
G.1. ***Please provide a NARRATIVE SUMMARY of the PAC'S ASSESSMENT of the PAIMI priorities (goals) and objectives included in the PPR for this Fiscal Year.***
Include in the narrative an assessment of the following items:
G.1.a. The PAIMI Priorities (Goals) and Objectives selected.
G.1.b. The activities conducted towards achieving these priorities (goals) and objectives.
G.1.c. The outcomes.
G.1.d. Examples of individual or systemic cases, applicable legislative activities, and participation in State mental health planning activities.
G.1.e. Any recommendations regarding future priorities (goals) and objectives.

The current priorities are 1. Abuse, Neglect & Rights Violations, 2. Community Inclusion, 3. Housing, and 4. Education. We are satisfied with the priorities that we have developed. We believe these priorities continue to represent the highest need for individuals with mental illness in Maine.

SECTION G. PAC ASSESSMENT OF PAIMI PROGRAM OPERATIONS

G.2. OTHER COMMENTS CONCERNING PAIMI SYSTEM OPERATIONS:

Briefly describe any special initiatives, problem solving techniques, or innovative practices that may help other State P&A systems.

We would like to highlight the outstanding work that the Community Advocates continue to do out in the community in the State of Maine. These positions were created in the ongoing settlement work on Maine's Mental Health Consent Decree and have helped more individuals in Maine than can be counted.

We also want to point to the excellent work being done by attorneys and advocates who work in Maine's various psychiatric facilities. They have been very dedicated to doing education around rights training with both staff and patients, as well as helping patients file grievances, and help problem solve in the moment when issues arise between staff and patients.

PAC members are kept informed of the work that has been done by the members of the PAIMI team through extensive reports and ongoing in-person conversations with them. This has been helpful in the collaborative work of the PAC.

The DRM website and social media interaction have also helped reach out to the people.

G.3. Please list any training & technical assistance needs identified by the PAC.

SECTION H. GRIEVANCE PROCEDURES [42 CFR Section 51.25]

Pursuant to the PAIMI Rules at 42 CFR 51.25, the P&A systems shall establish procedures to address grievances from: individuals at 42 CFR 51.25*(a)(1) – clients or prospective clients . . . ; and systems complaints at 42 CFR 51.25(a)(2) – individuals who have received or are receiving mental health services in the state, family members or representatives of such individuals . . . .*		
H.1. Is the PAC aware of and knowledgeable of the above referenced policies and procedures?	Yes X	No*
H.1.a. If you answered No to H.1. provide a brief explanation.		
H.2. The number of grievances filed by PAIMI-eligible clients, including representatives or family-members of such individuals receiving services during this fiscal year.	Total 0	
H.3. The number of grievances filed by prospective PAIMI-eligible clients (those who were not served due to limited PAIMI Program resources or because of non-priority issues).	Total 0	
H.4. Add H.2 & H.3 **[42 CFR Section 51.25(a)(1),(2)]**	Total 0	
H.5. The Number of Grievances Appealed to:		
H.5. a. The Governing Board (the PAC Chair of a private, non-profit P&A system should have this information).	Total 0	
H.5.b. The Executive Director	Total 0	
H.5 c. The number of Grievances appealed [H.5.a. + H.5.B = H.5.c.].	Total 0	
H.6. The number of reports sent to the Governing Board AND the PAC (*at least one annually*) that describe the grievances received, processed, and resolved.	Total 1	

SECTION H. GRIEVANCE PROCEDURES [42 CFR Section 51.25]

H.7. Please identify all individuals, by name & title, responsible for P&A system grievance reviews.

Kimberly Moody, Executive Director
Atlee Riley, Litigation Director

Mark Joyce, PAIMI Director

H.8. What is the timetable (in days) used to ensure prompt notification of the grievance procedure process to clients, prospective clients or persons denied representation, and ensure prompt resolution. **[42 CFR 51.25(B)(4)]**		Days 10
H.9. Were written responses sent to all grievants?	Yes X	No*
H.9.a. *If you answered No, to H.9, briefly explain.		
H.10. Was client confidentiality protected? ____. If not, explain below. **[42 CFR 51.25(B)(6)]**	Yes X	No*
H.10.a. *If you answered No, to H.10, briefly explain.	Yes	No*

GLOSSARY

Closed Case - is when the advocate/attorney closes the client record or case file after providing advocacy interventions on behalf of a client, and determining that the client either has no need of further intervention services or that the agency has no other services available to address the issue(s) or complaint(s) for which the case was initially opened.

Grievance Procedures - are policies and procedures developed by the P&A system to ensure that its clients and prospective PAIMI-eligible clients, their family members, or representatives have full access to the system services and that the system is fully compliant with the provisions of the PAIMI Act and Rules.

Information and Referral (I&R) Services - is the provision of brief written or oral information, such as generic information about the P&A, including information about additional programs and resources external to the P&A that relate to the individual's service needs and statutory or constitutional rights as a person with a disability. I &R services are generally of short duration, typically range from a few minutes to an hour, do not involve direct advocacy intervention by staff, and any type of staff follow-up. I&R services may include mailing generic agency information. Individuals receiving I &R services are not counted as PAIMI clients.

Intervention Strategies:

Abuse/Neglect Investigations - a systemic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are undertaken to determine if

there is a basis for administrative or legal action on behalf of the client. Investigations require a significant allocation of time to interview witnesses, gather factual information, and to issue a written report of findings.

Administrative Remedies - includes the use of any systems for appeal within an agency or facility, or between agencies, which does not involve adjudication by a court of law.

Legal Remedies - the legal representation of clients in litigation in court processes concerned with rights, grievances, or appeals of such rights or grievances.

Legislative/Regulatory Advocacy - activities involve monitoring, evaluating, and commenting upon the development and implementation of Federal, State, and local laws, regulations, plans, budgets, taxes and other actions which may affect individuals with mental illness. [The PAIMI Rules at 42 FCR at 51.24 mandates that legislative activities shall also be addressed in the development of program priorities].

Negotiation/Mediation - is an informal, non-legal intervention by a PAIMI representative, attorney or case manager used to resolve problems with facility staff or other agency representatives; (does not involve a formal appeal).

- Short Term Assistance - Time limited advice and counseling assistance, which may include reviewing information, counseling a client on actions one may take, and assisting the client in preparing letters, documents or making telephone calls to resolve the issue.

- Technical Assistance - includes the provision of information, referral or advice to clients by a PAIMI Program representative, attorney, or advocate, (e.g., coaching the client in self-advocacy, explaining service delivery system(s) available to meet needs, dissemination of information and materials to client, etc.). Follow-up is required.

Objectives - are activities undertaken to achieve annual program priorities (goals). All objectives required to have measurable outcomes and the use of numerical targets is encouraged. Each objective must clearly state why the activity was undertaken, who will benefit from the objective (the target population), how the activity will be accomplished, and what is the expected outcome for the activity? Generally, with the exception of litigation, legislative or regulatory activities, objectives shall be attainable within the fiscal reporting period (within one (1) fiscal year).

Open Case - is when a PAIMI-eligible individual with a complaint is accepted as a client by the P&A system. A case record or case file is opened for that individual. System staff maintain all intervention services provided to the client and other information t are maintained in this case record/file.

Outreach - is an activity that targets information on PAIMI Program activities to specific populations (e.g., cultural, ethnic and racial minorities, and other underserved or un-served populations, etc. The activity is linked to an objective of a specific annual priority.

PAIMI Clients (for purposes of this report) - are individuals who meet the PAIMI eligibility criteria as defined in the PAIMI Act [42 U.S.C. 10802(4) and its Rules at 42 CFR 51.2 Definitions, who have a complaint, for whom demographic data is collected, and for whom the PAIMI Program, or any of its subcontractors, provides an intervention (as reported under Intervention Strategies in this form).

Priorities (Goals) - are broad general descriptions of short term activities for the P&A system to accomplish within one (1) fiscal year (FY). [The exceptions are generally regulatory, legislative, and litigation activities]. The priorities must be directly related to the purpose of the enabling Federal legislation and the requirements of the Federal-funding agency and consistent with the priorities included in the PAIMI Application for the

same FY. [See PAIMI Act at 42 U.S.C. 10801, PAIMI Rules at 42 CFR 51.24 (a) – Program Priorities, and the Children's Health Act of 2000 at 42 U.S.C. at 290ii-ii-1 and 290jj-jj-2].

Public Awareness Activities - provide general information on disability rights and the purpose and mission of the P&A system. Public awareness activities include public service announcements, newsletters, radio or television, publications in legal journals, web site services, general distribution of agency brochures, etc.

Public Education and Constituency Training - is the dissemination of information to one or more persons through an interactive event, which often promotes a greater understanding of the constitutional or statutory rights of persons with disabilities. Contrasted to Public Awareness Activities, education and training must be specifically targeted to meet the unique need of the group(s) trained.

Racial/Ethnic Background - The following minimum standards shall be used for all federal administrative reporting and grants reporting or record keeping requirements that include data on race and ethnicity [http://www.whitehouse.gov/omb/fedreg_1997standards/].

CATEGORIES AND DEFINITIONS:

Ethnicity:

Hispanic or Latino - A person of Cuban, Mexican, Puerto Rican, South or Central American descent.

Not of Hispanic Origin.

Race:

American Indian or Alaska Native (include tribal affiliation for the Alaska native when possible) - A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian - A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand and Vietnam.

Black or African American - A person having origins in any of the Black racial groups of Africa.

Native Hawaiian or Other Pacific Islander - A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific islands.

White - A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Respondents have the option of selecting one or more racial designations.

Resolution of Complaint/Problem Area – is in a client's favor when (1) the client is satisfied with the result of the intervention or (2) the expressed wish or stated goal of the client is either fully attained or negotiated to an agreeable outcome, or (3) the violation in the stated case complaint/problem area was remedied.

Systemic Advocacy Activities – are the efforts taken to implement changes in policies and practices of systems that impact persons with mental illness. These "systems" include, but are not limited to, State agencies, various public and private residential care and treatment facilities, and other service providers, etc.

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[The PAIMI Rules at 42 CFR 51.24 (a) PAIMI Priorities state that systemic activities shall be addressed in the development and implementation of program priorities].

ATTACHMENT 1. HOPE CONFERENCE FLYER

NARPA

Pre-Conference Institute for PAIMI Advisory Council Members:
PAIMI Advisory Councils as Leaders for Systemic Reform

Wednesday September 6, 2023

1:00 - 5:30 pm

PART 1

1 – 1:30 pm	WELCOME

PAIMI 101

WHAT IS PAIMI?

1:30 – 2:30 pm	History of the PAIMI Act
2:30 – 2:45 pm	Break

PART 2

PAC 101

2:45 – 3:45 pm	A discussion of the PAC's role and responsibilities; how to effectively engage with your P&A. Should NDRN develop standards of practice for PAIMI Advisory Councils?

PAC Values Exchange

3:45 – 4:30 pm	Identifying and building upon the strengths of your PAIMI Advisory Council; Snapshots of several PACs – and their approaches to community outreach and education; how they utilize workgroups and sub-committees
4:30 – 4:45 pm	Value exchange discussion

Future PAC

4:45 – 5:00 pm	Moving forward: Linking PAC members in a growing community of practice; How we continue our discussions and stay connected via Signal and Zoom…

PEER ADVOCATE LEGISLATIVE DAY

PAC MEMBER SIMONNE MALINE BEING INTERVIEWED DURING PEER ADVOCATE LEGISLATIVE EDUCATION DAY.

DRM PAC TABLE AT

PEER ADVOCATE LEGISLATIVE EDUCATION DAY

ATTACHMENT # 4 DISABILITY PRIDE DAY

Fifth annual Disability Pride Day in Augusta celebrates accomplishments, diversity

"It's just a great reminder that we're doing great work, but there's more to be done," event speaker Connor Archer said.

Author: newscentermaine.com
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https://www.newscentermaine.com/video/news/disability-pride-530pm/97-58b7846e-8813-4376-86d2-1222f63c0567

https://www.foxbangor.com/news/local/disability-rights-maine-host-annual-disability-pride/article_7ae3918c-2811-11ee-8dfd-6b608083ac3c.html

https://wgme.com/news/local/mainers-mark-disability-pride-month-with-a-celebration

Disability Pride Maine 2023

YouTube · Disability Rights Maine · Sep 19, 2023

YouTube

PAC MEMBER VICKIE McCARTY SPEAKING AT DISABIILTY PRIDE DAY 2023

https://www.youtube.com/watch?v=QcunO8I8-F8


DISABILITY
RIGHTS
MAINE
Save the Date!
Disability Pride
SPEAKERS · MUSIC · ART ·
RESOURCE TABLES · DANCING ·
CELEBRATING DISABILITY
July 21, 2023
11AM - 3PM
AT MILL PARK
AUGUSTA, ME 04330

OMB Approval: 0930-0169

Expiration Date: 06/30/2023

The ADVISORY COUNCIL REPORT (ACR) Section of the ANNUAL PAIMI PROGRAM PERFORMANCE REPORT (PPR)	
STATE	FISCAL YEAR

The Advisory Council Report (ACR) section of the annual PAIMI Program Performance Report (PPR) is due by January 1. The ACR is an independent assessment by the PAIMI Advisory Council (PAC) of their state P&A system's PAIMI Program operations. The ACR must be signed and dated by the PAC Chairperson.

For ACR assistance, please contact the PAIMI Program Officer

Please read and follow the instructions in each section and use the attached glossary in to complete the form.

Public reporting burden for the ACR section of the annual PAIMI PPR is estimated to average 10 hours per response. This includes the time needed to review the instructions, to search existing data sources, to gather the data needed, and to complete and review the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to SAMHSA Reports Clearance Officer; Paperwork Reduction Project (0930-0169); CBHSQ, Room 15E21B; 5600 Fishers Lane, Rockville, MD 20857. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is (0930-0169).

The ACR Section of the ANNUAL PAIMI PPR

TABLE of CONTENTS

The ACR Section of the Annual PAIMI PPR	
SECTION A. GENERAL INFORMATION	
Fiscal Year:	2023
State:	Maine
Name of P&A system:	Disability Rights Maine
PAC Report Prepared By: Provide the name [Print First, Middle and Last Name] Title of the preparer: Phone Number:	April Kerr & PAC members PAC Chair Aprillkerr2020@gmail.com (207) 491-0381
Name of PAC Chair: [Print First, Middle, and Last Name] Provide updated contact information if the PAC Chair is different than the person listed on the most recent PAIMI Application.	April Kerr aprillkerr2020@gmail.com
Telephone Number:	(207) 491-0381
E-Mail Address:	aprillkerr2020@gmail.com
Date Submitted:	December 28, 2023
By signing this document, the Chair certifies that this report reflects the consensus of the PAC members.	

SECTION B. The PAIMI ADVISORY COUNCIL (PAC)		
*Under Primary ID, select *ONLY ONE* (1) primary identity for each PAC member position **[B.1.b. - B.1.h.] that** is mandated per the PAIMI Act & Rules).		**Primary Identification**
B.1.a. The TOTAL number of seats on the PAC.		**Total 13**
B.1.b. Individuals who are recipients/former recipients (R/FR) of mental health services.		7

B.1.c. Family members of individuals who are recipients/former recipients (R/FR) of mental health services.	1
At least one (1) PAC member shall be a B.1.d.	
B.1.d. Family members of a minor child or youth (under 18 years old) who has received or is receiving mental health services.	1
B.1.e. Mental health service providers.	1

2

B.1.f. Mental health professionals:		
B.1.f.1. Social Workers		
B.1.f.2. Psychologists	1	
B.1.f.3. Psychiatric Nurses		
B.1.f.4. Psychiatrists		
B.1.f.5. Psychiatric Nurse Practitioners		
B.1.f.5. Peer Support Specialists		
B.1.g. Attorneys.	1	
B.1.h. Individuals from the public knowledgeable about mental illness.		
B.1.i. Others (please identify by position held).		
B.1.j. Vacancies as of 9/30. [identify each vacant position & the date it was vacated].	1	
B.1.k. TOTAL number of PAC members serving on 9/30.	**Total 12**	
B.1.l. Number of PAC members who are either R/FR of MH services or family members of these individuals (count each PAC member only once).	9	
B.1.m. Percentage of PAC members who are either R/FR of MH services or family members of these individuals [B.1. k. divided by B.1.l.]	69%	
B. 2. REPRESENTATION OF THE PAC CHAIRPERSON		
B.2. Is the PAC Chair an individual who has received or is receiving mental health services, or a family member of an individual who has received or is receiving mental health services?	**Yes X**	**No**
B. 3. PAC TERMS of Appointment		
B.3.a. Term of Appointment (number of years)	4	

B.3.b. Maximum Number of Terms a Member May Serve	2
B.3.c. Frequency of Meetings	6 per year
B.3.d. Number of Meetings Held in the FY [3 is the mandated minimum].	5
B.3. e. Number (%Average) of PAC members present at Meeting.	67%

SECTION C. PAC ETHNICITY & RACIAL DIVERSITY

Please refer to the **GLOSSARY** for definitions. The following information is self-reported or self identified and uses two separate questions. The data on race and ethnicity are collected SEPARATELY; provision shall be made to report the number of respondents in each category who are Hispanic or Latino. Collection of greater detail is encouraged; however, any collection that uses more detail shall be organized in such a way, that the additional information can be aggregated into these minimum categories for data on race and ethnicity.

C. A. ETHNICITY	**Number of PAC Members**
C. A. 1. Hispanic or Latino	0
C. A. 2. Not of Hispanic Origin	12
(add C.A.1 & C.A.2., the total should be the same as the one listed in B.1.k. (members serving as of 9/30).	**Total** 12
C. B. RACE	
C. B. 1. American Indian or Alaska Native	**1**

C. B. 2. Asian	**0**
C. B. 3. Black or African American	**0**
C. B. 4. Native Hawaiian/Other Pacific Islander	**0**
C. B. 5. White	**11**
C. B. 6. Two or More Races	**0**
C. B. 7. = C.B.1 through C.B.6.	**Total 12**
Members may select as many racial identifications as they want.	
C. C.1. Total Number of PAC member vacancies on September 30.	**Total PAC Vacancies**
	1

SECTION D. Sex of PAC Members	
D.1 MALE 2	D.2 FEMALE 10
D.3. UNKNOWN/WOULD NOT DISCLOSE	
D.3. TOTAL	

SECTION E. GOVERNING BOARD INFORMATION		
E. 1. FOR STATE-OPERATED P&A SYSTEMS ONLY:		
E.1.a. Is this a State-operated P&A system?	Yes	No X
E.1.b. Does this State-operated system have a Governing Board/Authority authorized by State statute? If the answer is NO, proceed to Section F.	Yes	No
E.1.c. If the answer to item E.1.b. is YES, does the PAC Chair sit on the Governing Board/Authority as a full voting member?	Yes	No
E.1.d. If the answer to item E.1.c. is no, briefly explain (e.g., State statute determines Governing Board/Authority composition, etc.).		
E.2. For PRIVATE, Not-for Profit P&A SYSTEMS only		
E. 2.a. Does the P&A system have a multi-member Governing Board?	Yes X	No
If you answered YES to E.2.a., please answer the questions E.2.b. 1. - 3.		
E.2.b.1. Number of Governing Board members.	Total 13	
E.2.b.2. Is the PAC Chair a full voting member of the Governing Board?	Yes X	No

E.2.b.3. If you answered No to E.2.b.2., then explain why the PAC Chair is not a full voting member of the Governing Board as mandated by the PAIMI Rules at 42 CFR 51.22(b)(3).		
E.2.b.4. Do any other PAC members hold seats on the Governing Board? If Yes, how many seats? ____	Yes	No X

SECTION F. PAC ACTIVITIES [See, PAIMI Act - 42 U.S.C. 10805(7)]		
F.1. Are P&A program staff invited to attend PAC meetings?	Yes X	No
F.1.a. Did any of the invited program staff attend?	Yes X	No
F.2.a. If the answer to F.1. is Yes, please identify the positions of staff (e.g., PAIMI Coordinator, Mental health advocate, etc.) usually invited to attend. Executive Director, PAIMI Director, Attorneys and Advocates		
F.2.b. If the answer to F.1.a. is Yes, please identify the positions of the program staff in attendance (e.g., one advocate, one attorney) and their role at the meetings, e.g., information sharing, etc. Information is shared about the organization, financial condition, cases, projects, and priorities. A standing item on the PAC agenda is something called PAC-TION. They are specific projects that are designed with PAC members and DRM staff that address issues in the community and institutions. We have also added a standing agenda item to hear from PAC members about what is going on in their communities etc., so the PAIMI staff become aware of issues from the members.		
F.2.c. If the answer to F.1. is No, you *MAY* provide a brief explanation.		
F. 3. a. Were governing board members, excluding the PAC Chair, invited to PAC meetings?	Yes X	No
F.3.b. If you answered Yes to F.3.a., which governing board members were invited, for what purpose (e.g., informational, etc.), and did they attend? There is a standing invitation for Board members to attend. The PAC chair restates this invitation at the Board meetings.		
F.3.c. Did any of the invited governing board members attend?	Yes	No X

F.4. Did the PAC work jointly with the governing board to develop the annual PAIMI priorities? [42 CFR 51.23(a) (2)].	Yes X	No*
F.4.a. If Yes, briefly describe these joint activities. The PAC chair is also the chair of the Governing Board and participates in all board meetings.		

SECTION F. PAC ACTIVITIES [See, PAIMI Act - 42 U.S.C. 10805(7)]		
F.4. b. If No, PAC's affiliated with private, non-profit P&A systems must provide a brief explanation.		
F.5. Did PAC members attend any in-state or out-of-state trainings or educational presentations related to PAIMI Program activities? *[42 CFR 51.27 - payments for PAC and Governing board/authority members by a State P&A system are optional]*.		
F.5.a. In-State Trainings/Educational Activities.	Yes X	No
If Yes, list each activity by number and provide a brief description of PAC involvement, e.g., Activity 1 – Attendance at local NAMI training.		
F.5.b. Out-of-State Trainings/Educational Activities.	Yes X	No
If yes, list each activity by number and provide a brief description of PAC involvement, e.g., Activity 1 – Attendance at NDRN annual conference.		
F.6. Does the P&A system have established written policies and procedures for reimbursing PAC members for expenses that takes into account the needs of the individual council members, available resources and applicable restrictions on use of grant funds, including the restrictions cited in and the restrictions in 51.31(e) and 51.6(e)? [See, 42 CFR 51.23 (d) (1)].		

F.6.a.1. Yes X F.6.a.2. No* F.6.a.3. Don't Know.*

F.6.b. Brief explanation needed for F.6.a.2. or F.6.a.3. responses].

SECTION F. PAC ACTIVITIES [See, PAIMI Act - 42 U.S.C. 10805(7)]

F.7. If the answer to F.6. was Yes, were PAC members reimbursed for expenses incurred for PAIMI Program related activities, consistent with the P&A system's policies and procedures.

F.7.a.	1.Yes X	2. No*	3. Don't Know*

F.7.b. *Brief explanation required for either F.7.a. 2. No *or F.7.a*. 3. Don't Know responses.

All PAC meetings were held virtually so there was no mileage reimbursement.
DRM paid the registration, travel, and lodging (including meal stipend) for 2 PAC members to attend the National Association of Rights Protection and Advocacy Conference that was held in New Orleans, Louisiana this year.

F. 8. REIMBURSEMENT OF EXPENSES – If PAC member expenses were reimbursed, please complete the following chart. [42 CFR 51.23(d) (1)]. Under the Activity column, list the activity by the number used in above F.5.a. – In-State or F.5.b. – Out-of-State. Example: F.5.b. Out-of-State activity # 1, – 5 PAC members attended the NDRN annual meeting, 2 members reimbursed by the P&A; 2 self-paid, 1 NDRN scholarship.

a. ACTIVITY	b. # ATTENDING	c. P&A	d. SELF	e. OTHER
NARPA Conference Out of State New Orleans, LA	2 PAC members	2 P&A Staff		

SECTION F. PAC ACTIVITIES [See PAIMI Act at 10805(7)]

F.9. Did the P&A system provide the PAC with reports, materials, & fiscal data to enable review of the following: [42 CFR 51.23(c)].

F.9.a. Existing program policies, priorities, and performance outcomes.	Yes X	No *
F.9.b. If Yes, were the submissions (of P&A system documents referenced in F.9.a.) made at least annually and (shall) report expenditures for the past two (2) FISCAL *YEARS?*	Yes X	No *
*F.9.c. If the answer to F.9. a. or F.9.b. is 'No", a brief explanation is required.		
F.9.d. If you answered Yes in F.9.a., did the P&A system documents referenced also *INCLUDE THE PROJECTED EXPENSES FOR THE NEXT FISCAL YEAR (FY) IDENTIFIED BY BUDGET CATEGORY*, e.g. salary & wages, contracts for services, administrative expenses, including, the amount allotted for training of the PAC, the governing board and staff?	Yes X	No *

F.9.d.1. If No*, a brief explanation is required].

SECTION F. PAC ACTIVITIES [See, PAIMI Act at 10805(7)]		
F.9.e. The PAIMI Rules mandate that members of the public shall be given an opportunity, on an annual basis, to comment on the priorities established by and the activities of the P&A system. Procedures for public comment must provide for notice in a format accessible to individuals with mental illness, including such individuals who are in residential facilities, to family members and representatives of such individuals with disabilities. [42 CFR at 51.24(b)].		
F.9.e. Does the P&A have procedures established for public comment?		
F.9.e. 1. Yes X	F.9.e. 2. No*	F.9.e.3. Don't Know*
F.9.e.4. *Brief explanation required for F.9.e.2. No or F.9.e.3. Don't know responses.		

F.9.f. Was the PAC provided a copy of these procedures?		
F.9.f.1. Yes X	F.9.f.2. No*	F.9.f.3. Don't Know*
F.9.f.4. *Brief explanation required for F.9.f.2. No or F.9.f.3.Don't know responses.		

SECTION F. PAC ACTIVITIES [See, PAIMI Act at 10805(7)]		
F.9.g. The PAIMI Rules, at 42 CFR 51. 24(b), mandate that the public shall be given an opportunity, on an annual basis, to comment on the priorities established by and the activities of the P&A system. *WAS THE PUBLIC PROVIDED AN OPPORTUNITY FOR PUBLIC COMMENT?*		
F.9.g. 1. Yes# X	F.9.g. 2. No*	F.9.g.3. Don't Know*

F.9.g 4. #If the answer to F.9.g.1. is Yes, briefly describe activities the P&A system used to obtain public comment.

The Agency solicits input through its web page, newsletter, in surveys, PAC members are asked to solicit input through their constituencies, This year DRM presented at a statewide HOPE conference virtually, that was organized by the Consumer Council System of Maine which some members are also members of the PAC

F.9.g. 5. *If the answer to F.9.g.2. is NO, explain why public comment was not obtained.

F.9.g. 6. *If the answer to F.9.g.3. is DON'T KNOW, please explain (e.g., PAC needs training, etc.)

F.10. ***COMPLETION OF THIS SECTION (F.10 a. –e.) IS OPTIONAL.*** However, if you choose to respond, please describe in the spaces below any other PAC activities, *other than* mandated PAC membership meetings.

F.10.a. Briefly describe, governing board or PAC committee work.

F.10.b. Briefly describe any training or educational presentations to either constituency groups or the general public.

HOPE Conference The Consumer Council System of Maine holds an annual event called the HOPE conference. It is held at the Augusta Civic Center. The HOPE conference was created to help participants gain a greater understanding of what recovery/wellness is from the many paths and different perspectives on the journey of life.

This conference is designed by consumers and allies, in conjunction with the Maine Office of Behavioral Health

There are several members of the PAC who are part of the CCSM. This year's HOPE conference was in person. PAC Chair April Kerr and PAC member Vickie McCarty presented a workshop entitled: Choosing to Use Your Voice in a Powerful Way in the Legislative Process. Several members of the PAC also attended this conference. There were also 3 DRM staff who presented at this conference. Attached as Attachment #1 is a copy of the HOPE Conference Flyer.

National Association of Rights and Protection and Advocacy (NARPA) Annual Conference. NARPA held their annual conference in New Orleans, Louisiana. The PAC chair April Kerr and PAC member Kelly Staples attended. Including attending the Pre Conference Institute for PAIMI Advisory Council Members entitled: PAIMI Advisory Councils as Leaders for Systemic Reform. Attached as Attachment #2 is the Agenda for this institute.

National Disability Rights Network (NDRN) ELEVATE. NDRN launched a new Learning Management System (LMS) called "Elevate." A number of PAC members registered for this service. This system offers training content, online communities, resources, upcoming events, and more.

Creation of PAC Logo. PAC member Melissa Caswell created a logo for the PAC to be used at outreach events in the community.

Mental Health Matters. Peer Advocate Legislative Education Day. The PAC, in collaboration with peer organizations, participated in the Peer Advocate Legislative Day at the Hall of Flags in the Maine Capitol building where legislators travel to and from their meetings, etc. The PAC had its own informational table and used the new logo on the table. Attached as Attachment #3 is the flyer for this event and a picture of the PAC table with the PAC logo.

Disability Awareness Day: Consumer Council System of Maine (CCSM) and DRM had tables at the annual Disability Awareness Day at the Hall of Flags in the Maine Capitol building. A number of PAC members (some who are also members of CCSM) participated in this event.

SECTION F. PAC ACTIVITIES [See, PAIMI Act – 42 U.S.C.10805(7)]

F.10.d. Briefly describe any special projects (e.g., institutional monitoring).

F.10.e. Briefly describe any other activities, e.g., fund raising, public relations, etc.

Disability Pride Day: DRM puts together an annual Disability Pride Day that promotes cross disability awareness, education and celebration. Many PAC members attend this event. PAC member Vickie McCarty was a speaker at this event. Attached as Attachment #4 is the flyer for this event and links to the news coverage for the event. Over 200 people attended this event.

SECTION G. PAC ASSESSMENT OF PAIMI PROGRAM OPERATIONS
G.1. ***Please provide a NARRATIVE SUMMARY of the PAC'S ASSESSMENT of the PAIMI priorities (goals) and objectives included in the PPR for this Fiscal Year.***
Include in the narrative an assessment of the following items:
G.1.a. The PAIMI Priorities (Goals) and Objectives selected.
G.1.b. The activities conducted towards achieving these priorities (goals) and objectives.
G.1.c. The outcomes.
G.1.d. Examples of individual or systemic cases, applicable legislative activities, and participation in State mental health planning activities.
G.1.e. Any recommendations regarding future priorities (goals) and objectives.

The current priorities are 1. Abuse, Neglect & Rights Violations, 2. Community Inclusion, 3. Housing, and 4. Education. We are satisfied with the priorities that we have developed. We believe these priorities continue to represent the highest need for individuals with mental illness in Maine.

SECTION G. PAC ASSESSMENT OF PAIMI PROGRAM OPERATIONS

G.2. OTHER COMMENTS CONCERNING PAIMI SYSTEM OPERATIONS:

Briefly describe any special initiatives, problem solving techniques, or innovative practices that may help other State P&A systems.

We would like to highlight the outstanding work that the Community Advocates continue to do out in the community in the State of Maine. These positions were created in the ongoing settlement work on Maine's Mental Health Consent Decree and have helped more individuals in Maine than can be counted.

We also want to point to the excellent work being done by attorneys and advocates who work in Maine's various psychiatric facilities. They have been very dedicated to doing education around rights training with both staff and patients, as well as helping patients file grievances, and help problem solve in the moment when issues arise between staff and patients.

PAC members are kept informed of the work that has been done by the members of the PAIMI team through extensive reports and ongoing in-person conversations with them. This has been helpful in the collaborative work of the PAC.

The DRM website and social media interaction have also helped reach out to the people.

G.3. Please list any training & technical assistance needs identified by the PAC.

SECTION H. GRIEVANCE PROCEDURES [42 CFR Section 51.25]

Pursuant to the PAIMI Rules at 42 CFR 51.25, the P&A systems shall establish procedures to address grievances from: individuals at 42 CFR 51.25*(a)(1) – clients or prospective clients . . . ; and systemic complaints at 42 CFR 51.25(a)(2) – individuals who have received or are receiving mental health services in the state, family members or representatives of such individuals . . . .*		
H.1. Is the PAC aware of and knowledgeable of the above referenced policies and procedures?	Yes X	No*
H.1.a. If you answered No to H.1. provide a brief explanation.		
H.2. The number of grievances filed by PAIMI-eligible clients, including representatives or family-members of such individuals receiving services during this fiscal year.	Total 0	
H.3. The number of grievances filed by prospective PAIMI-eligible clients (those who were not served due to limited PAIMI Program resources or because of non-priority issues).	Total 0	
H.4. Add H.2 & H.3 **[42 CFR Section 51.25(a)(1),(2)]**	Total 0	
H.5. The Number of Grievances Appealed to:		
H.5. a. The Governing Board (the PAC Chair of a private, non-profit P&A system should have this information).	Total 0	
H.5.b. The Executive Director	Total 0	
H.5 c. The number of Grievances appealed [H.5.a. + H.5.B = H.5.c.].	Total 0	
H.6. The number of reports sent to the Governing Board AND the PAC (*at least one annually*) that describe the grievances received, processed, and resolved.	Total 1	

SECTION H. GRIEVANCE PROCEDURES [42 CFR Section 51.25]

H.7. Please identify all individuals, by name & title, responsible for P&A system grievance reviews.

Kimberly Moody, Executive Director
Atlee Riley, Litigation Director

Mark Joyce, PAIMI Director

H.8. What is the timetable (in days) used to ensure prompt notification of the grievance procedure process to clients, prospective clients or persons denied representation, and ensure prompt resolution. **[42 CFR 51.25(B)(4)]**		Days 10
H.9. Were written responses sent to all grievants?	Yes X	No*
H.9.a. *If you answered No, to H.9, briefly explain.		
H.10. Was client confidentiality protected? ____. If not, explain below. **[42 CFR 51.25(B)(6)]**	Yes X	No*
H.10.a. *If you answered No, to H.10, briefly explain.	Yes	No*

GLOSSARY

Closed Case - is when the advocate/attorney closes the client record or case file after providing advocacy interventions on behalf of a client, and determining that the client either has no need of further intervention services or that the agency has no other services available to address the issue(s) or complaint(s) for which the case was initially opened.

Grievance Procedures - are policies and procedures developed by the P&A system to ensure that its clients and prospective PAIMI-eligible clients, their family members, or representatives have full access to the system services and that the system is fully compliant with the provisions of the PAIMI Act and Rules.

Information and Referral (I&R) Services - is the provision of brief written or oral information, such as generic information about the P&A, including information about additional programs and resources external to the P&A that relate to the individual's service needs and statutory or constitutional rights as a person with a disability. I &R services are generally of short duration, typically range from a few minutes to an hour, do not involve direct advocacy intervention by staff, and any type of staff follow-up. I&R services may include mailing generic agency information. Individuals receiving I &R services are not counted as PAIMI clients.

Intervention Strategies:

Abuse/Neglect Investigations - a systemic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are undertaken to determine if

there is a basis for administrative or legal action on behalf of the client. Investigations require a significant allocation of time to interview witnesses, gather factual information, and to issue a written report of findings.

Administrative Remedies - includes the use of any systems for appeal within an agency or facility, or between agencies, which does not involve adjudication by a court of law.

Legal Remedies - the legal representation of clients in litigation in court processes concerned with rights, grievances, or appeals of such rights or grievances.

Legislative/Regulatory Advocacy - activities involve monitoring, evaluating, and commenting upon the development and implementation of Federal, State, and local laws, regulations, plans, budgets, taxes and other actions which may affect individuals with mental illness. [The PAIMI Rules at 42 FCR at 51.24 mandates that legislative activities shall also be addressed in the development of program priorities].

Negotiation/Mediation - is an informal, non-legal intervention by a PAIMI representative, attorney or case manager used to resolve problems with facility staff or other agency representatives; (does not involve a formal appeal).

- Short Term Assistance - Time limited advice and counseling assistance, which may include reviewing information, counseling a client on actions one may take, and assisting the client in preparing letters, documents or making telephone calls to resolve the issue.

- Technical Assistance - includes the provision of information, referral or advice to clients by a PAIMI Program representative, attorney, or advocate, (e.g., coaching the client in self-advocacy, explaining service delivery system(s) available to meet needs, dissemination of information and materials to client, etc.). Follow-up is required.

Objectives - are activities undertaken to achieve annual program priorities (goals). All objectives required to have measurable outcomes and the use of numerical targets is encouraged. Each objective must clearly state why the activity was undertaken, who will benefit from the objective (the target population), how the activity will be accomplished, and what is the expected outcome for the activity? Generally, with the exception of litigation, legislative or regulatory activities, objectives shall be attainable within the fiscal reporting period (within one (1) fiscal year).

Open Case - is when a PAIMI-eligible individual with a complaint is accepted as a client by the P&A system. A case record or case file is opened for that individual. System staff maintain all intervention services provided to the client and other information t are maintained in this case record/file.

Outreach - is an activity that targets information on PAIMI Program activities to specific populations (e.g., cultural, ethnic and racial minorities, and other underserved or un-served populations, etc. The activity is linked to an objective of a specific annual priority.

PAIMI Clients (for purposes of this report) - are individuals who meet the PAIMI eligibility criteria as defined in the PAIMI Act [42 U.S.C. 10802(4) and its Rules at 42 CFR 51.2 Definitions, who have a complaint, for whom demographic data is collected, and for whom the PAIMI Program, or any of its subcontractors, provides an intervention (as reported under Intervention Strategies in this form).

Priorities (Goals) - are broad general descriptions of short term activities for the P&A system to accomplish within one (1) fiscal year (FY). [The exceptions are generally regulatory, legislative, and litigation activities]. The priorities must be directly related to the purpose of the enabling Federal legislation and the requirements of the Federal-funding agency and consistent with the priorities included in the PAIMI Application for the

same FY. [See PAIMI Act at 42 U.S.C. 10801, PAIMI Rules at 42 CFR 51.24 (a) – Program Priorities, and the Children's Health Act of 2000 at 42 U.S.C. at 290ii-ii-1 and 290jj-jj-2].

Public Awareness Activities - provide general information on disability rights and the purpose and mission of the P&A system. Public awareness activities include public service announcements, newsletters, radio or television, publications in legal journals, web site services, general distribution of agency brochures, etc.

Public Education and Constituency Training - is the dissemination of information to one or more persons through an interactive event, which often promotes a greater understanding of the constitutional or statutory rights of persons with disabilities. Contrasted to Public Awareness Activities, education and training must be specifically targeted to meet the unique need of the group(s) trained.

Racial/Ethnic Background - The following minimum standards shall be used for all federal administrative reporting and grants reporting or record keeping requirements that include data on race and ethnicity [http://www.whitehouse.gov/omb/fedreg_1997standards/].

CATEGORIES AND DEFINITIONS:

Ethnicity:

Hispanic or Latino - A person of Cuban, Mexican, Puerto Rican, South or Central American descent.

Not of Hispanic Origin.

Race:

American Indian or Alaska Native (include tribal affiliation for the Alaska native when possible) - A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian - A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand and Vietnam.

Black or African American - A person having origins in any of the Black racial groups of Africa.

Native Hawaiian or Other Pacific Islander - A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific islands.

White - A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Respondents have the option of selecting one or more racial designations.

Resolution of Complaint/Problem Area – is in a client's favor when (1) the client is satisfied with the result of the intervention or (2) the expressed wish or stated goal of the client is either fully attained or negotiated to an agreeable outcome, or (3) the violation in the stated case complaint/problem area was remedied.

Systemic Advocacy Activities – are the efforts taken to implement changes in policies and practices of systems that impact persons with mental illness. These "systems" include, but are not limited to, State agencies, various public and private residential care and treatment facilities, and other service providers, etc.

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[The PAIMI Rules at 42 CFR 51.24 (a) PAIMI Priorities state that systemic activities shall be addressed in the development and implementation of program priorities].

ATTACHMENT 1. HOPE CONFERENCE FLYER

Pre-Conference Institute for PAIMI Advisory Council Members:
PAIMI Advisory Councils as Leaders for Systemic Reform

Wednesday September 6, 2023

1:00 - 5:30 pm

PART 1

1 – 1:30 pm	WELCOME

PAIMI 101

WHAT IS PAIMI?

1:30 – 2:30 pm	History of the PAIMI Act
2:30 – 2:45 pm	Break

PART 2

PAC 101

2:45 – 3:45 pm	A discussion of the PAC's role and responsibilities; how to effectively engage with your P&A. Should NDRN develop standards of practice for PAIMI Advisory Councils?

PAC Values Exchange

3:45 – 4:30 pm	Identifying and building upon the strengths of your PAIMI Advisory Council; Snapshots of several PACs – and their approaches to community outreach and education; how they utilize workgroups and sub-committees
4:30 – 4:45 pm	Value exchange discussion

Future PAC

4:45 – 5:00 pm	Moving forward: Linking PAC members in a growing community of practice; How we continue our discussions and stay connected via Signal and Zoom…

PEER ADVOCATE LEGISLATIVE DAY

PAC MEMBER SIMONNE MALINE BEING INTERVIEWED DURING PEER ADVOCATE LEGISLATIVE EDUCATION DAY.

DRM PAC TABLE AT

PEER ADVOCATE LEGISLATIVE EDUCATION DAY

ATTACHMENT # 4 DISABILITY PRIDE DAY

Fifth annual Disability Pride Day in Augusta celebrates accomplishments, diversity

"It's just a great reminder that we're doing great work, but there's more to be done," event speaker Connor Archer said.

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https://www.newscentermaine.com/video/news/disability-pride-530pm/97-58b7846e-8813-4376-86d2-1222f63c0567

https://www.foxbangor.com/news/local/disability-rights-maine-host-annual-disability-pride/article_7ae3918c-2811-11ee-8dfd-6b608083ac3c.html

https://wgme.com/news/local/mainers-mark-disability-pride-month-with-a-celebration

Disability Pride Maine 2023

YouTube · Disability Rights Maine · Sep 19, 2023

YouTube

PAC MEMBER VICKIE McCARTY SPEAKING AT DISABIILTY PRIDE DAY 2023

https://www.youtube.com/watch?v=QcunO8I8-F8


DISABILITY
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MAINE
Save the Date!
Disability Pride
SPEAKERS · MUSIC · ART ·
RESOURCE TABLES · DANCING ·
CELEBRATING DISABILITY
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