America FORWARD

PETER & ELIZABETH **TOWER FOUNDATION**

Landscape Analysis: Advocacy for Impact

Table of Contents

This ***Landscape Analysis: Advocacy for Impact*** contains ten Sections presented in thematic order. Because key information from one Section is often relevant to others, Sections include cross-references to related content throughout the document. This allows readers to navigate the Landscape Analysis Sections in the order that best meets their needs. Readers can access content either by scrolling through the document sequentially or by clicking on the Section titles below.

SECTION I: OVERVIEW

SECTION II: DEFINITIONS: SYSTEMS CHANGE, ADVOCACY, LOBBYING

SECTION III: LAWS GOVERNING 501(c)(3) ORGANIZATIONS' ADVOCACY AND LOBBYING ACTIVITIES

SECTION IV: METHODOLOGY

SECTION V: SUMMARY RECOMMENDATIONS

SECTION VI: INTERVIEW FINDINGS AND INSIGHTS

SECTION VII: FEDERAL: LANDSCAPE, POLICY CONTEXT, ADVOCACY OPPORTUNITIES

SECTION VIII: MASSACHUSETTS: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES

SECTION IX: NEW YORK: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES

SECTION X: APPENDIX

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Landscape Analysis: Advocacy for Impact

SECTION I

OVERVIEW

Landscape Analysis

SECTION I
OVERVIEW

INTRODUCTION

The Peter and Elizabeth C. Tower Foundation (hereinafter "Tower Foundation" or "Foundation") has long demonstrated a deep commitment to strengthening the programs and systems that support young people with intellectual disabilities, learning disabilities, mental health conditions, and substance use disorders. In recent years, these programs and systems have come under increasing strain. Federal and state public funding volatility, shifting policy priorities, and heightened implementation uncertainty have altered the availability, stability, and accessibility of many essential services for young people in need, both nationally and throughout the Foundation's catchment area. At the same time, community-based organizations, including many Tower Foundation grant partners, are navigating a rapidly changing ecosystem that requires deciphering complex and sometimes contradictory information, contending with uncertainty in public funding streams, and navigating significant changes in public policy that directly affect their programs and the people they serve.

To most effectively advance its mission, achieve optimal impact, and support its current and future grant partners, the Tower Foundation recognized the need for a comprehensive and actionable assessment of the current policy landscape – one that cuts through conflicting information; addresses present and emerging public funding conditions; analyzes the current federal, state, and local policy landscapes; and identifies high-impact advocacy opportunities for strategic philanthropic and nonprofit action in the Foundation's core issue areas.

This report, ***Tower Foundation Landscape Analysis: Advocacy for Impact*** (hereinafter "Landscape Analysis"), prepared by America Forward, provides a user-friendly assessment designed to highlight federal and state policy and funding shifts most relevant to the Foundation's priority issue areas and identify strategic advocacy opportunities. The goal of this Landscape Analysis is to help inform and support the Foundation's future strategic systems change decision-making across its program areas, while strengthening the Foundation's ability to most effectively support current and future grant partners, partner with peer organizations, engage in field leadership, and further the Foundation's critical mission.

How this Project Advances the Foundation's Strategy

In keeping with the Foundation's strategic direction, this project was designed to further the Foundation's commitment to investing in research and data collection on the conditions (particularly policy conditions) that affect the Foundation's core work. It was also designed to contribute to the public good, both by helping to hone the Foundation's high-impact grantmaking and by identifying viable and timely policy advocacy opportunities that benefit the larger ecosystem of organizations focusing on youth intellectual disabilities, learning disabilities, mental health, and substance use disorders.

This project supports the Foundation's vision of fostering healthy communities in which "all young people are included, accepted, and valued," and reflects the Foundation's key role as a long-term, trusted partner to community-based organizations. The project is also grounded in the Foundation's commitment to improving systems by advancing cross-sector collaboration, elevating lived experience and practitioner insight, and addressing the structural conditions that shape young people's lives. Positioned at the intersection of practice, policy, and philanthropy, the Tower Foundation is well situated to help translate on-the-ground experience into broader systems-level impact.

"Landscape Analysis: Advocacy for Impact" Grant

This ***Tower Foundation Landscape Analysis: Advocacy for Impact*** was produced as part of a grant agreement with America Forward, a nationally recognized nonpartisan leader in policy development, collective advocacy, advocacy capacity-building, and public engagement. (Additional information about America Forward can be found at the end of this Overview Section.)

In accordance with the grant design, this Landscape Analysis:

- Distills current policy and advocacy research, government funding and policy information, expert analysis, and numerous stakeholder interview findings into a user-friendly playbook for action;
- Illuminates changes in public funding streams relevant to the Foundation's core issue areas and explores how these changes are affecting young people and the organizations that serve them;
- Examines the system-level impact of enacted and pending federal and state public policy changes in the Foundation's core issue areas and communities;
- Identifies policy advocacy opportunities on the federal and state level, as well as other advocacy opportunities, in which philanthropic investment can be most impactful and catalytic;
- Illustrates how the Foundation can most effectively engage in and/or support policy advocacy, consistent with its mission, values, and relevant law – whether mounting robust defense to preserve public funding streams; advancing promising public policies (both legislative and regulatory); or laying the groundwork for future policy action – and engage in other advocacy efforts, such as advocacy capacity-building, coalition-building, communications and public engagement, and convenings consistent with its mission, values, and internal guidelines.

Ultimately, this Landscape Analysis is intended not simply to describe the current environment, but to guide action. It is therefore designed as both a reference document and a practical and adaptable playbook for action — one that can inform priority-setting, shape future grantmaking and partnership strategies, and support thoughtful decision-making about how the Foundation chooses to support and engage in advocacy

work going forward. In doing so, it aims to assist the Tower Foundation in anticipating challenges, supporting grantees most effectively, and advancing systems-change efforts central to its mission and values — ultimately contributing to better, and more equitable, outcomes for young people and the communities and program providers that support them.

Landscape Analysis Table of Contents

This ***Tower Foundation Landscape Analysis: Advocacy for Impact*** contains the following Sections:

SECTION I:	OVERVIEW
SECTION II:	DEFINITIONS: SYSTEMS CHANGE, ADVOCACY, LOBBYING
SECTION III:	LAWS GOVERNING 501(c)(3) ORGANIZATIONS' ADVOCACY AND LOBBYING ACTIVITIES
SECTION IV:	METHODOLOGY
SECTION V:	SUMMARY RECOMMENDATIONS
SECTION VI:	INTERVIEW FINDINGS AND INSIGHTS
SECTION VII:	FEDERAL: LANDSCAPE, POLICY CONTEXT, ADVOCACY OPPORTUNITIES
SECTION VIII:	MASSACHUSETTS: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES
SECTION IX:	NEW YORK: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES
SECTION X:	APPENDIX

While these Sections are presented in thematic order, critical information from one Section is included and/or referenced in other Sections, where relevant, to enable readers to approach the Landscape Analysis Sections in the order that best meets their needs.

America Forward

America Forward is honored to partner with the Tower Foundation on this important project. Like the Tower Foundation, America Forward believes that every young person deserves the opportunity to thrive and achieve their personal goals, regardless of the challenges and systemic inequities they face. America Forward also shares the Foundation's belief in the power of strong programs, effective public policy, collective advocacy, advocacy capacity-building, community engagement, reliable resources, and proximate voice as core elements of effective systems change. With America Forward's track record in effective, innovative, and results-driven policy development, collective advocacy, capacity building, and public engagement, we are honored to collaborate with the Foundation and help further the Foundation's vision of vital communities where all young people are included, accepted, and valued.

In preparation of this Landscape Analysis, America Forward draws upon close to 20 years of policy expertise and advocacy experience; our deep knowledge base and network relating to the core issue areas addressed in the Landscape Analysis; bespoke research conducted specifically for this Analysis; consultation with leading national policy, advocacy, government affairs, and legal experts; and, most importantly, critical information

and insights gathered from numerous interviews with Foundation grant partners, peer organizations, and the Foundation's Trustees, leadership, and staff. The methodology underlying this Landscape Analysis is presented in detail in Section IV. Background information about America Forward can be found on our website, in our one-page summary, and in the box below. Any questions arising from this Landscape Analysis should be directed to policy@americaforward.org.

While this Landscape Analysis was prepared in close partnership with Foundation leadership, the analysis and recommendations are those of America Forward and America Forward bears responsibility for all conclusions. This Landscape Analysis reflects the policy environment as of its submission date to the Foundation: April 30, 2026.

About America Forward

America Forward is a national nonpartisan policy and advocacy organization that unites social entrepreneurs with policymakers to advance a public policy agenda that champions innovative and effective solutions to our country's most pressing social problems and expands opportunity for all. With close to 20 years of experience and expertise driving systems change on the national and state levels, America Forward has become a nationally recognized leader in social innovation public policy and advocacy.

America Forward leads the America Forward Coalition, a network of 100+ of the nation's most impactful and innovative non-governmental organizations that develop and collectively advocate for more effective public policies that foster innovation, reward results, and catalyze cross-sector partnerships in: youth mental health and well-being; substance use disorders; early learning, K-12, and postsecondary education (including intellectual disabilities and learning disabilities); economic mobility and workforce development; and civic participation.

To help Coalition organizations become better, bolder advocates, America Forward leads the America Forward Advocacy Institute, a robust series of virtual and in-person applied advocacy trainings and substantive policy briefings. America Forward also publishes a biweekly Policy Pulse newsletter, that provides a curated overview of current federal policy activity related to the Coalition's priority policy issues, and produces numerous policy publications and white papers throughout the year.

Since 2007, America Forward's community of visionary program and philanthropic leaders has played a leading role driving the national dialogue on social innovation policy and impact. Working together, America Forward has advocated for policies that leveraged over $2.2 billion for social innovation and directed millions of public resources toward programs achieving measurable outcomes for children, families, and communities. America Forward Coalition members are delivering results in more than 15,000 communities across the country, touching the lives of over 10 million Americans each year.

America Forward believes that innovative policy development and collective advocacy, supported by effective capacity-building and public engagement, can successfully transform local results into national change, increase opportunity for all, and propel all of America forward.

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Landscape Analysis: Advocacy for Impact

SECTION II

DEFINITIONS: SYSTEMS CHANGE, ADVOCACY, LOBBYING

Landscape Analysis

SECTION II
DEFINITIONS: SYSTEMS CHANGE, ADVOCACY, LOBBYING

OVERVIEW

Throughout this Landscape Analysis, America Forward uses the terms “systems change,” “advocacy,” and “lobbying.” These terms are often used differently (and sometimes even interchangeably) in various philanthropic, nonprofit, and social science research contexts. For the purposes of this Landscape Analysis, we utilize these terms as described below.

Systems Change

“Systems change,” as practically defined by the Social Innovation Generation (SIG) in Canada and popularized through the social impact consulting firm FSG's Water of Systems Change framework, is the process of shifting the conditions that are holding a social problem in place. Over the past decade, foundations and nonprofits are increasingly utilizing systems change strategies to achieve greater impact. This shift is based on the acknowledgment that exclusively funding and scaling effective programs, while critically important, is not sufficient to achieve lasting change. Rather, a combined strategy is required that both supports innovative, effective programs and supports efforts to improve and change the systems in which those programs operate. The philanthropic sector, in particular, has recognized that complex social problems often remain intractable due to external constraints that surround the various promising and effective programs in which foundations invest. These external factors can include government policies, social norms, market force incentives, knowledge gaps, and more.

FSG developed a helpful visual model that identifies key conditions of systems change depicted in an inverted pyramid. Specifically, they recognize six interdependent conditions that often hold social problems in place, and these conditions vary in how explicit or implicit they are within a given system. These six conditions of systems change include: policies, practices, and resource flows (the three most explicit conditions, depicted at the top of the inverted pyramid); relationships & connections, and power dynamics (two semi-explicit conditions, depicted in the middle of the inverted pyramid); and mental models (the most implicit condition, depicted at the base of the inverted pyramid). Philanthropies and nonprofit organizations often achieve success by focusing on the most explicit “top” levers and working to inform and change government policy, promote more effective practices, and direct financial and human capital towards these efforts. At the same time, shifting power dynamics and building relationships across sectors (including across the political aisle) can also yield catalytic results, as these efforts can forge cross-sector coalitions, create new alliances, and expand relationships. Finally, influencing mental models (the most implicit lever), can be the most challenging

and time-consuming, but it can also deliver the most durable and wide-spread societal change as public narratives shift. This is especially true when the mental models of those in power (including policymakers) evolve.

This paradigmatic shift towards systems change in the philanthropic sector has been accompanied by a corresponding evolution in the nonprofit sector, in which many organizations' strategies now include both scaling their programs and engaging in systems change efforts (most often through policy advocacy and communications efforts). Accordingly, philanthropies and nonprofits have increasingly focused on building the capacity of organizations to effectively engage in systems change work as well.

Advocacy

For purposes of this Landscape Analysis, we use a colloquial definition of "advocacy." At its core, advocacy is an effort to change minds and hearts, and it includes both policy advocacy and other types of advocacy. In the context of foundations and nonprofit program providers, Bolder Advocacy, an initiative of the Alliance for Justice, helpfully describes "advocacy" as *any effort to influence public policy, systemic conditions, or public opinion in service of an organization's mission*. These efforts can include: policymaker education, regulatory comments, lobbying (subject to specific limits and rules under federal and state law), coalition building, research and publication distribution, public education, community organizing, convenings, litigation, narrative change, media engagement and other communications efforts, storytelling, field leadership, and grassroots engagement.

Most (though not all) of the advocacy opportunities referenced in this Landscape Analysis focus on policy advocacy intended to influence public policy and shape public debate. As discussed in detail in Section III of this Landscape Analysis, the range of advocacy activities available to both public charities and private foundations that *do not constitute "lobbying"* under federal tax law is expansive. As discussed in more detail in Section III, all types of 501(c)(3) organizations may engage in advocacy to:

- **Educate policymakers and the public about issues relevant to the organization's mission**, including publishing research reports, issuing policy analyses, and hosting convenings.
- **Meet with legislators to discuss the scope and impact of the organization's work or to educate them about a broad range of issues** (without expressing views on a specific legislative proposal, as discussed in more detail in Section III).
- **Influence the adoption of agency regulations, executive orders, and administrative rules that interpret existing laws**. (While this is not lobbying under federal tax law, it can trigger state registration and reporting requirements, as discussed in Section III.)
- **Conduct public education campaigns, coalition-building, and community organizing**.
- **Respond to written requests for testimony** from legislative committees or bodies. (This exception is nuanced, and is discussed in more detail in Section III.)
- **Convene nonprofits and policymakers** to discuss broad topics and shared goals.
- **Build relationships with legislators** and help grantees build and sustain those relationships.
- **Produce nonpartisan research and analysis** widely available to the public, even if the research reaches specific policy conclusions.
- **Train grantees on how to lobby**.
- **Engage in litigation**, sign on to amicus briefs, or **fund litigation** to challenge or enforce laws.

- **Influence the policies of school boards**, housing authorities, zoning boards, and other special-purpose bodies with limited jurisdiction (these are not considered legislative bodies under federal tax law, so communicating with them is not deemed lobbying).
- **Engage in self-defense activities**. (This relates to attempts to influence legislation that would directly affect the organization's existence, powers, duties, tax-exempt status, or the deductibility of contributions to it and is discussed in more detail in Section III).

Lobbying

This Landscape Analysis utilizes the IRS 501(h) definition of lobbying. "Lobbying" has a specific legal definition under the federal tax code that includes both direct lobbying and grassroots lobbying. "Direct lobbying" is *a communication with a legislator or legislative staff that expresses a view about specific legislation.* For this purpose, "legislator" includes *members of Congress, state legislators, and their staff, as well as executive branch officials who participate in the formulation of legislation* (such as a governor when vetoing a bill). It does not include members of administrative bodies. Importantly, this means that contacting executive branch officials about rulemaking or regulations does not count as lobbying under federal tax law. "Grassroots lobbying" is *a communication with the general public that expresses a view about specific legislation and includes a call to action* (i.e., that asks recipients to contact legislators, provides contact information for legislators, provides a mechanism for contacting legislators, or identifies a legislator as being opposed to or undecided about the organization's position).

There are different federal rules governing public charities' and private foundations' lobbying activities. These laws focus both on "whether" a 501(c)(3) entity can lobby and the "amount" of lobbying the entity can engage in. In general, and as discussed in more nuanced detail in Section III of this Landscape Analysis, all public charities can lobby (within legal limits), and private foundations are effectively prohibited from lobbying (because their lobbying efforts are subject to a prohibitive excise tax), but private foundations can fund organizations that lobby (within particular parameters). In addition, state laws do not restrict or cap lobbying activity, but they do establish registration and reporting requirements. A comprehensive discussion of federal and state laws governing 501(c)(3) organizations' advocacy and lobbying activities can be found in Section III of this Landscape Analysis.

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Landscape Analysis: Advocacy for Impact

SECTION III

LAWS GOVERNING 501(C)(3) ORGANIZATIONS' ADVOCACY AND LOBBYING ACTIVITIES

Landscape Analysis

SECTION III

LAWS GOVERNING 501(C)(3) ORGANIZATIONS' ADVOCACY AND LOBBYING ACTIVITIES

INTRODUCTION

Federal, state, and local laws can impact organizations' advocacy and lobbying activities. This Section of the Landscape Analysis focuses exclusively on federal tax law.[1] A brief summary of the federal law discussed in this Section is at the end of page 5.

There are **two types of 501(c)(3)** organizations: **public charities** (e.g., most of the Foundation's grant partners and likely some of the grant partners' funders) and **private foundations** (e.g., the Tower Foundation and likely some of the grant partners' funders).[2] While the rules governing public charities and private foundations are similar regarding advocacy activities, there are some important differences relating to lobbying activities. Those similarities and differences are addressed below.

Advocacy: A Broad and Largely Unrestricted Activity

Public charities can engage in advocacy and can fund other public charities that advocate. Similarly, private foundations can engage in advocacy and can fund public charities that advocate. Essentially, there are no federal tax law restrictions on advocacy, with the one notable exception noted below regarding partisan political/election activity.

Much of the most impactful policy advocacy work that nonprofits do, including educating policymakers, engaging in executive branch advocacy, submitting regulatory comments, engaging in public education, and building coalitions, does not constitute lobbying and is freely available to all 501(c)(3) organizations. This is because these policies will not be voted on by a legislature and the drafters are not "legislators" under the IRS definitions.[3]

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[1] The federal IRS rules discussed in this Section of the Landscape Analysis govern how much lobbying a 501(c)(3) organization may do. State and local lobbying laws serve a different and complementary purpose: they are transparency and disclosure rules designed to inform the public about who is spending money to influence government decisions and how much they are spending. An organization must comply with both frameworks simultaneously, but the rules measure different things and the definitions of "lobbying" sometimes differ between the IRS and the relevant state. Organizations should ensure their recordkeeping systems satisfy both sets of requirements. (See Alliance for Justice's (AFJ) 50 state guides.)

[2] Community foundations and public foundations are classified as 501(c)(3) public charities as well.

[3] At the state level, executive branch advocacy sometimes needs to be reported (not to the IRS, but to the state enforcement agency), depending on the particular state's rules. AFJ's 50 state guides indicates whether executive advocacy is included in each state's reporting requirements.

Advocacy is a broad category that includes many different types of activities intended to shape public debate, influence policy, and advance an organization's mission. The range of permissible **advocacy** activities available to both public charities and private foundations is expansive. For example, 501(c)(3) organizations of both types may:

- Educate policymakers and the public about issues relevant to the organization's mission, including publishing research reports, issuing policy analyses, and hosting convenings.
- Meet with legislators to discuss the scope and impact of the organization's work or to educate them about a broad range of issues, without referencing a specific legislative proposal.[3]
- Influence the adoption of agency regulations, executive orders, and administrative rules that interpret existing laws. This is expressly not lobbying under federal tax law, but it might trigger state reporting requirements. (The state rules are transparency and disclosure rules, so while executive advocacy can trigger state registration requirements, the state laws do not restrict or cap the amount of executive advocacy activity.) (See this AFJ blog post on how advocacy for/against executive orders is not deemed "lobbying.")
- Conduct public education campaigns, community organizing, and coalition building.
- Engage in litigation, sign on to amicus briefs, or fund litigation to challenge or enforce laws.
- Produce nonpartisan research and analysis widely available to the public, even if the research reaches specific policy conclusions. (See AFJ's fact sheet on this exception.)
- Train grantees on how to lobby.
- Influence the policies of school boards, housing authorities, zoning boards, and other special-purpose bodies with limited jurisdiction (these are not considered legislative bodies under federal tax law, so communicating with them is not deemed lobbying).
- Respond to written requests for testimony from legislative committees or bodies. This exception is nuanced, as various conditions need to be met (e.g., the invitation must come from the chair or full committee and the materials need to be available to all members). (See a helpful AFJ blog post on this topic.)
- Convene nonprofits and policymakers to discuss broad topics and shared goals.
- Build relationships with legislators and help grantees build and sustain those relationships.
- Engage in self-defense activities.[4] This exception relates to attempts to influence legislation that would directly affect the organization's existence, powers, duties, tax-exempt status, or the deductibility of contributions to it. (See AFJ's fact sheet on this exception.)

Prohibited Activity: Partisan Political/Election Activity

As noted above, the exception is advocacy intended to influence election outcomes by supporting or opposing candidates for public office. This is prohibited for all 501(c)(3) organizations under the political campaign intervention prohibition of Section 501(c)(3) of the Internal Revenue Code. Because this topic is beyond the scope of this Landscape Analysis, it is not discussed in detail here. (AFJ's recent blog post and checklist offer helpful guidance on permitted and prohibited election-related activities.)

Lobbying: Permissible with Limitations

While both public charities and private foundations can engage in advocacy without limitation (other than the election prohibition noted above), there are specific restrictions on **lobbying**.

Under federal tax law, **lobbying** consists of two types of communication, both of which must involve a view about **specific legislation**. More specifically, this term means a bill or resolution that has been introduced in a legislative body, or a specific proposal to solve a problem (even if not yet formally introduced or written down). Specific legislation includes anything that will be voted on by the legislature (e.g., budget, appropriations, tax, judicial and executive nominations, etc.). As noted above, it does not include rulemakings, promulgation of regulations, executive orders, litigation, or attempts to enforce existing laws; advocacy in these forms does not constitute lobbying at the federal level.

- **Direct lobbying** is a communication with a legislator or legislative staff that expresses a view about specific legislation. For this purpose, "legislator" includes members of Congress, state legislators, and their staff, as well as executive branch officials who participate in the formulation of legislation (such as a governor when vetoing a bill). It does not include members of administrative bodies like school boards, housing authorities, or zoning boards.
- **Grassroots lobbying** is a communication with the general public that expresses a view about specific legislation and includes a **call to action** – meaning it asks recipients to contact legislators, provides contact information for legislators, provides a mechanism for contacting legislators (such as a petition or postcard), or identifies a legislator as being opposed to or undecided about the organization's position.[4]

Communications to an organization's own members urging them to contact legislators about specific legislation are treated as direct lobbying, not grassroots lobbying. Ballot measure activity (i.e., working to support or oppose a referendum, ballot initiative, or bond measure) is considered direct lobbying under federal tax law, since the voting public serves as the legislature for this purpose.

Public Charities: Lobbying Limits

Public charities can lobby but they must track lobbying expenditures (to report on their 990 tax form) and stay within one of two sets of limits, depending on which test they use:

- **501(h) Expenditure Test (recommended)**: A public charity may elect to measure its lobbying under Section 501(h) of the Internal Revenue Code by filing the simple Form 5768 with the IRS. This election provides clearer definitions and more generous limits than the default test. Under the 501(h) test, overall lobbying expenditures are capped based on the organization's annual expenditures: up to 20% of the first $500,000 of exempt purpose expenditures, with a sliding scale for larger organizations, and an overall cap of $1,000,000. Of the overall lobbying limit, no more than 25% may be spent on grassroots lobbying; the full amount may be spent on direct lobbying. Under this test, only expenditures count. Volunteer time and other cost-free activities do not count against the lobbying limit. (See AFJ's fact sheet on the 501(h) election.)

[4] These definitions are the 501(h) test definitions. If an organization has not made the 501(h) election, their definition will be a bit more broad. (See this helpful fact sheet on the insubstantial part test prepared by AFJ.)

- **Insubstantial Part Test (default)**: Organizations that do not make the 501(h) election are subject to the insubstantial part test, which requires that lobbying not constitute a "substantial part" of the organization's overall activities. Unlike the 501(h) test, this test considers both time and expenditures, and its definition of lobbying is broader and less clear. The IRS has not defined "substantial," but most tax practitioners advise that organizations can safely devote no more than 3–5% of their overall activities to lobbying under this test, making it significantly more restrictive in practice than the 501(h) election.

Private Foundations: Essentially Prohibited from Lobbying

Under Section 4945 of the Internal Revenue Code, **lobbying expenditures by a private foundation are treated as "taxable expenditures" subject to a prohibitive excise tax,** making direct and grassroots lobbying effectively off-limits. There are four exceptions: self-defense, technical assistance, nonpartisan analysis, and broad discussions of social, economic, or other similar problems. The most notable of these is the exception for self-defense activity: a foundation may attempt to influence legislation that directly affects its own existence, powers, duties, tax-exempt status, or the deductibility of contributions to it. While private foundations can incur a prohibitive tax on lobbying expenditures, lobbying is only one type of advocacy, and there are many permissible advocacy avenues for private family foundations as noted above.

The Bolder Advocacy initiative of AFJ published a helpful fact sheet on Private Foundations that is attached to this Section at the end of the Addendum.

Private Foundations May Support Organizations that Lobby

Although family foundations are essentially prohibited from engaging in lobbying, **family foundations may still support grantees that lobby.**[5] A family foundation cannot make an earmarked lobbying grant, but **it may make two types of permissible grants – general support and specific project grants** — that when executed correctly are **not considered a lobbying** expenditure by the foundation, even if the grantee uses the funds for lobbying. Specifically:

- **General support grants:** A private foundation may make a general operating support grant to a public charity that lobbies, provided the grant is not earmarked for lobbying. The grant agreement does not need to prohibit the grantee from using funds for lobbying; it simply cannot designate the funds specifically for lobbying purposes. In other words, if a grant is not earmarked for lobbying or any other specific project, the foundation is not responsible for grantee lobbying.
- **Specific project grants:** A private foundation may fund specifically identified non-lobbying components of a project that also includes lobbying, provided the grant is limited to and used for the non-lobbying portions of the project, and the grant amount does not exceed the budget for the non-lobbying work. In other words, if a grant is less than or equal to a project's non-lobbying component, the grant is not a lobbying expenditure. (See AFJ's helpful Project Grant Rule Hub.)

[5] See AFJ's Focus on Foundations hub with detailed information.

The project-specific grant safe harbor also enables two foundations to fund the same non-lobbying portion of an advocacy grant. For example, if a project with a $100k budget includes $40k for lobbying and $60k for non-lobbying expenses, and the grantee receives $50k from foundation 1 and $50k from foundation 2, both of the gifts can be considered non-lobbying expenditures because they can both count toward the $60k non-lobbying budget. (This would require the grantee to have sufficient unrestricted funds to cover the lobbying portion of the grant.)

SUMMARY

In sum, **all 501(c)(3) organizations can engage in unlimited advocacy activities** (with the exception of partisan political activity attempting to influence elections), and **both public charities and private foundations can fund unlimited advocacy activities.**

Lobbying activity is a subset of advocacy activity and it is subject to limits. **Public charities can engage in a limited amount of lobbying** (depending on which test they adopt) and **private foundations incur a tax for lobbying** (unless in self defense or one of the other three exceptions applies).

Public charities can fund lobbying activities, though earmarked lobbying grants count against both the grantor's and grantee's lobbying limits. **Private foundations cannot directly fund lobbying. However, they can provide general support grants and/or fund the non-lobbying portions of advocacy grants.**

For further information, please see the Addendum to this Section that includes AFJ graphics that provide helpful visual summaries of some of the key material discussed above relating to private foundations. [Note: America Forward received express permission from Alliance for Justice to reproduce these graphics for this Landscape Analysis.]

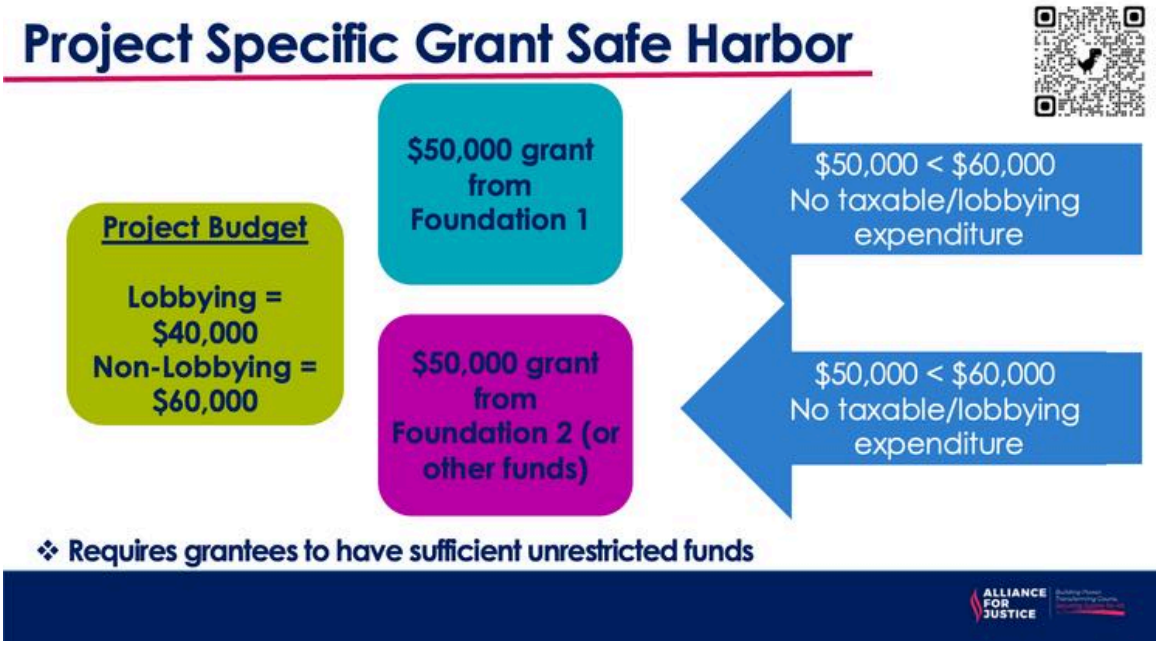
Landscape Analysis Section III Addendum



	Public Foundation	Private Foundation
Lobbying Grant: must count against the foundation's own lobbying limit	✓	⊘
General Support Grant	✓	✓
Project Specific Grant: Fund non-lobbying portions of advocacy projects	✓	✓
Expenditure Responsibility: Fund non-501(c)(3)s, must prohibit lobbying, VR & partisan political activities		✓

ALLIANCE FOR JUSTICE


Private foundations should not **earmark** grants for lobbying, but private foundations may fund grantees that **lobby**
$$$
If a grant is not earmarked for lobbying or any other specific project, the foundation is not responsible for grantee lobbying.
General Support Grants
Project Specific Grants
If a foundation grant is less than or equal to a project's non-lobbying component, the grant is not a lobbying expenditure.
ALLIANCE FOR JUSTICE


Project Specific Grant Safe Harbor
Project Budget
Lobbying = $40,000
Non-Lobbying = $60,000
$50,000 grant from Foundation 1
$50,000 grant from Foundation 2 (or other funds)
$50,000 < $60,000
No taxable/lobbying expenditure
$50,000 < $60,000
No taxable/lobbying expenditure
❖ Requires grantees to have sufficient unrestricted funds
ALLIANCE FOR JUSTICE

BOLDERADVOCACY

Family Foundations May Advocate

Family Foundations May Engage in Advocacy

Family foundations may participate in many forms of advocacy activities and may fund advocacy. Although family foundations do incur a prohibitive tax on any lobbying expenditure, lobbying is only one type of advocacy and there are many permissible advocacy avenues for private family foundations. For example, a family foundation could:

- Influence the adoption of agency regulations that interpret existing laws
- Build relationships with legislators or help grantees build and sustain these relationships
- Convene nonprofits and decision-makers to discuss a broad topic (e.g., how to balance the economy, development, and the preservation of endangered species)
- Educate legislators about a broad range of issues, without referencing a specific legislative proposal
- Meet with legislators to discuss the scope and impact of the foundation's work
- Sign on to an *amicus* brief, file a lawsuit to challenge a law or enforce a law, or fund litigation to challenge the constitutionality of a particular law
- Train grantees on how to lobby
- Influence school board policies or the policies of any other "special purpose body" that has limited jurisdiction (e.g., housing authorities, sewer and water districts, zoning boards, and other similar federal, state, or local body)
- Conduct public education campaigns that do not include calls to action or mention specific legislation
- Offer technical assistance to legislators in response to a written request for oral or written testimony from a legislative body
- Produce a comprehensive, accurate study or analysis of an issue (often referred to as a "nonpartisan analysis study or research report") that is widely distributed and provides enough information about the issue to allow the reader to draw their own conclusions, even if the report contains specific legislative conclusions
- Attempt to influence any legislation that impacts the family foundation's existence, its powers and duties, its tax-exempt status, or the deductibility of contributions (often referred to as "self-defense" lobbying)[1]

Family Foundations Cannot Engage in or Directly Support Lobbying

Family foundations cannot engage in lobbying or directly support lobbying through earmarked lobbying grants. Under federal tax law, there are two types of lobbying – direct and grassroots. Direct lobbying is a communication with a legislator (federal, state, or local or similar international body) or her staff, that expresses a view about specific legislation. Grassroots lobbying is a communication with the public that expresses a view about specific legislation and includes one of four calls to action.

[1] The foundation may wish to consult with an attorney to confirm the legislation would actually impact the foundation in this way prior to engage in any attempts to influence the legislation.

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Family Foundations May Support Charities That Lobby

Although family foundations are essentially prohibited from funding or engaging in lobbying, family foundations **may still support grantees that lobby**. A family foundation cannot make an earmarked lobbying grant, but it may make two types of grants – general support and specific project grants – that when done correctly would not be considered a lobbying expenditure by the foundation, even if the grantee uses the funds for lobbying.

Family Foundations May Support Election-Related Activities

Family foundations are 501(c)(3) organizations and are, therefore, absolutely prohibited from engaging in activity that supports or opposes a candidate for public office. Family foundations may, however, support nonpartisan voter education activity, like candidate debates and forums or issue advocacy. Family foundations have special restrictions for funding voter registration activities.

Family Foundations Can Support Nonpublic Charities

Family foundations are permitted to fund the work of nonpublic charities, if the foundation exercises what is called expenditure responsibility.

The information contained in this fact sheet and any attachments is being provided for informational purposes only and not as part of an attorney-client relationship. The information is not a substitute for expert legal, tax, or other professional advice tailored to your specific circumstances, and may not be relied upon for the purposes of avoiding any penalties that may be imposed under the Internal Revenue Code. Alliance for Justice publishes plain-language guides on nonprofit advocacy topics, offers educational workshops on the laws governing the advocacy of nonprofits, and provides technical assistance for nonprofits engaging in advocacy. For additional information, please feel free to contact Alliance for Justice at 866-NPLOBBY.

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Landscape Analysis: Advocacy for Impact

SECTION IV

METHODOLOGY

Landscape Analysis

SECTION IV
METHODOLOGY

OVERVIEW

This Landscape Analysis is designed to provide a strategic overview of the current policy conditions, funding context, and advocacy opportunities relevant to the Tower Foundation's core issue areas: youth substance use disorders, mental health, intellectual disabilities, and learning disabilities.

The Analysis was informed by a mixed-methods approach that combined desk research, quantitative data analysis, and qualitative stakeholder and expert interviews. Together, these methods were designed to surface both macro-level trends and on-the-ground perspectives relevant to the Foundation's current priorities and its growing interest in systems change and policy advocacy efforts.

Findings from research, data analysis, and interviews were cross-checked against each other to identify where sources agreed and where they diverged, strengthening the reliability of key conclusions. This approach helped ensure that recommendations were grounded in both empirical evidence and practitioner experience. Preliminary insights were refined through ongoing dialogue with Tower Foundation leadership to confirm accuracy, relevance, and alignment with the Foundation's strategic goals. Taken together, this methodology was intentionally designed not only to assess the current landscape, but to translate evidence, practitioner and expert insights, and stakeholder perspectives into a practical playbook for action that identifies concrete, timely opportunities to inform the Tower Foundation's philanthropic and advocacy engagement going forward.

The analysis and recommendations in this Landscape Analysis, while informed by Foundation stakeholders, are those of America Forward.

Stakeholder Interviews

In preparing this Landscape Analysis, America Forward conducted virtual and in-person interviews with Tower Foundation Trustees, leadership, and staff; Tower Foundation grant partners and peer organizations; federal and state policy, advocacy, and government affairs experts; and legal experts. America Forward led all interviews with Foundation leadership, staff, peer organizations, and policy, advocacy, government affairs, and legal experts. Foundation program officers led the interviews with Foundation grant partners, with one or two America Forward staff members participating in the vast

majority of those interviews as well. Foundation leadership facilitated America Forward's discussion with Foundation Trustees.

In total, this Landscape Analysis included 27 formal interviews with 61 individuals from 40 organizations. This included: 11 interviews with 35 individuals from 30 Foundation grant partner organizations; 7 interviews with 9 Foundation peer organizations; 1 group discussion with Tower Foundation Trustees; 6 interviews with Tower Foundation staff; and 2 formal interviews with Tower Foundation leadership, along with multiple informal discussions with Tower Foundation Executive Director Tracy Sawicki and Chief Program Officer Don Matteson during bi-weekly grant meetings. In addition, as discussed in more detail below, the America Forward project team conducted multiple informal discussions with policy, advocacy, government affairs and legal experts from Capitol Hill Partners, Tremont Strategies Group, The Parkside Group, and the Alliance for Justice – bringing the total number of individuals that the project team engaged to 67.

The organizations and individuals interviewed were intentionally selected by Tower Foundation staff and leadership to represent Foundation stakeholders most actively engaged and knowledgeable about policy issues and advocacy strategies relating to the Foundation's issue areas. The interviews enabled the team to capture lived experience from a diverse group of stakeholders, along with operational insights and strategic perspectives not reflected in published data alone. Because only a fraction of the Foundation's total grant partners and peer organizations were interviewed, the interview findings and insights contained in Section VI of the Landscape Analysis are limited to the views of this subset of organizations.

While the majority of interviews were conducted virtually, America Forward staff visited the Foundation's headquarters in Buffalo, New York at the outset of the project to interview Tower Foundation staff and three peer organizations. This project launch day at the Foundation included an introduction to America Forward, individual interviews with each Foundation Program Officer, and a joint interview with the Tower Foundation's Executive Director and Chief Program Officer. During a second in-person interview day, America Forward staff joined Foundation Executive Director Tracy Sawicki in conversation with leaders of the Health Foundation for Western and Central New York, the Patrick P. Lee Foundation, and the John R. Oishei Foundation.

Virtual interviews with Foundation grant partners and peer organizations ranged from 60 to 120 minutes, with most lasting approximately 90 minutes. To support accuracy and consistency, each interview included at least one notetaker, and all interviews were recorded and included an artificial intelligence (AI)-generated summary. Interviewees were asked between 10 and 20 questions that were shared in advance by either Tower Foundation or America Forward staff. Interview questions and protocols generally followed two scripts — one for grant partners and one for peer organizations — though the scripts allowed for variability during conversations to reflect each stakeholder's area of interest and expertise. All interviews explored themes relating to current policy and funding conditions; the impact of those conditions on organizations, programs, and community members; policy priorities; advocacy opportunities; advocacy capacity-building; and the role of philanthropy in policy advocacy and systems change. Prior to conducting interviews, America Forward led a session with Foundation Program Officers focused on interview protocols to maintain consistency. Conversations with policy, advocacy, government relations, and legal experts did not follow a formal protocol given long-standing relationships.

Upon completion of the interviews, America Forward staff reviewed interview notes, AI-generated summaries, and recordings to identify salient issues, including policy challenges and advocacy opportunities. This methodology informed the development of Section VI: Interview Findings and Insights.

A roster of all individuals and organizations interviewed can be found in Addendum A to this Section. In addition, interview questions can be found in the following Addenda: Questions for Grant Partners (Addendum B); Questions for Peer Organizations (Addendum C); Questions for Tower Foundation Staff and Leadership (Addendum D); Questions for Tower Foundation Trustees (Addendum E).

Expert Input, Research, and Data Analysis

The America Forward project team contributing to this Landscape Analysis included: Deborah Smolover, Executive Director (Project Lead); Ariette Agnew, Advocacy Manager; Nicole Hall, Communications Manager; Heather Rieman, former Advocacy Director; Chase Sackett, Policy Director; and Lee Foley, Senior Policy Advisor, along with individual members of America Forward's Policy Council with relevant subject matter expertise. America Forward Staff and Policy Council biographies can be found here.

In addition to information obtained from stakeholder interviews, America Forward's senior policy and advocacy staff drew upon decades of institutional expertise, conducted extensive research, and engaged in discussions with a number of leading government relations firms, including: Capitol Hill Partners (on federal policy), Tremont Strategies Group (on Massachusetts policy), and The Parkside Group (on New York policy), along with the Alliance for Justice (on legal rules relating to advocacy and lobbying, as discussed in Section III of the Landscape Analysis).

The project team conducted a comprehensive review of existing research, policy analyses, and public data related to federal and state funding streams, policy developments, advocacy opportunities, and system-level trends affecting youth substance use disorders, mental health, intellectual disabilities, and learning disabilities. Sources included federal and state budget and appropriations documents, agency guidance, legislative analyses, philanthropic and nonprofit sector research and publications, and issue-specific reports from advocacy organizations and intermediaries. The project team also examined quantitative data related to funding levels and system capacity to identify patterns, changes over time, and areas of emerging opportunity. Data were used to contextualize interview findings and help distinguish between isolated organizational challenges and broader systemic dynamics affecting multiple organizations or regions. This in-depth review provided the baseline context for the full analyses of recent and anticipated policy and funding shifts and emerging advocacy opportunities, and it formed the basis for Sections V (Recommendations), VII (Federal Analysis), VIII (Massachusetts Analysis), and IX (New York Analysis) of the Landscape Analysis.

Caveat

Given the rapidly evolving policy environment – particularly related to federal and state budget and appropriations processes, executive orders, regulatory actions, and litigation — findings reflect the best available information during the project period extending through April 30, 2026.

While this Landscape Analysis identifies potential opportunities for philanthropic and advocacy engagement, it does not constitute legal or compliance guidance. Any actions undertaken by the Foundation or its partners should be assessed in accordance with applicable laws, regulations, and internal policies.

Landscape Analysis Section IV
Addendum A - Interview Roster

1. Interviews with Grant Partners

Date	Organization
January 7, 2026	Massachusetts Advocates for Children (MAC)
January 9, 2026	Center for Public Representation (CPR)
January 13, 2026	Erie County Anti-Stigma Coalition • Compeer • Mental Health Advocates • Prevention focus
January 16, 2026	Center for Law and Education
January 21, 2026	Melmark Northeast Arc
January 21, 2026	Children's Mental Health Campaign • Massachusetts Society for Prevention of Cruelty to Children (MSPCC) • Massachusetts Association for Mental Health (MAMH) • Boston Children's Hospital - Behavioral Health • Parent/Professional Advocacy Leagues (PPAL)
January 22, 2026	People Inc.
January 26, 2026	Community Catalyst Legal Action Center (LAC)
January 28, 2026	Center for Self Advocacy (CSA) Self-Advocacy Association for New York State (SANYS)

January 30, 2026	Value Network • Buffalo Federation of Neighborhood Centers • Endeavor Health Services • Rural Outreach Center • Recovery Options Made Easy • BestSelf Behavioral Health • Horizon Health Services Developmental Disabilities Alliance of WNY (DDAWNY) • Community Services for Every1 • New York Alliance for Inclusion and Innovation • Suburban Adult Services, Inc.

2. Interviews with Peer Organizations

Date	Organization
November 3, 2025	Patrick P. Lee Foundation Health Foundation for Western & Central New York John R. Oishei Foundation
January 6, 2026	Patrick P. Lee Foundation
January 7, 2026	Health Foundation for Western and Central New York
January 15, 2026	RIZE Massachusetts
January 30, 2026	Liftoff WNY Schuyler Center The Children's Agenda
February 12, 2026	Blue Cross Blue Shield Foundation of Massachusetts
February 18, 2026	Scattergood Foundation
January 28, 2026	Center for Self Advocacy (CSA) Self-Advocacy Association for New York State (SANYS)

3. Interviews with Tower Foundation Trustees, Leadership, and Staff

Date	Organization
November 3, 2025	Tower Foundation Staff • Tracy Sawicki, Executive Director • Don Matteson, Chief Program Officer • Charles Colston, Jr., Program Officer • Megan McDavey, Program Officer • Nicholas Randell, Program Officer
February 27, 2026	Tower Foundation Leadership • Tracy Sawicki • Don Matteson Note: In addition to formal interviews, America Forward participated in biweekly meetings with Tower Foundation leadership during the course of this project, and those conversations provided additional valuable guidance and insights beyond the information relayed in formal interviews.
March 4, 2026	Tower Foundation Board of Trustees • Allen Booker • Mollie Byrnes • Peter Byrnes • Marie Cannon • Cynthia Doyle • Robert Doyle • Beth Francis • Jacqueline Hall • Patricia Meservey • TJ Quinn • Randy Treece

Landscape Analysis Section IV
Addendum B - Questions for Interviews with Grant Partners

Introduction: Purpose

"The purpose of this interview is to better understand how Tower Foundation grant partners are experiencing the current policy and funding environment. We are particularly interested in learning about your policy and advocacy goals and activities; your policy and advocacy capacity; and what supports might strengthen your systems change work. Results from these interviews will help inform a Landscape Analysis for the Tower Foundation – that in turn will help inform the Foundation's systems change, policy, and advocacy strategy."

Background (Some of this can be completed by program officers in advance)

- Name of interviewer
- Name and title of interviewee
- Organization name and description: mission, model, and geographic area served
- What populations (e.g., clients, constituents) do you serve?
- What are your main areas of focus right now?

Engagement with Government Funding/Programs

- How has your organization, or the population you serve, been impacted by the current political or policy context – including, specifically, federal or state funding cuts?
- Are there key federal or state funding streams or policies your work relies on or that are essential to your mission? Or that the people you serve rely on?
- Has your organization ever applied for a government grant or received government funding (via a grant or contract)? If so, can you tell us about that experience?
- Which upcoming policy or funding decisions are you most concerned or hopeful about?

Systems Change: Current Engagement

- Does your organization currently engage in policy advocacy or systems-change work (including education, awareness-building, lobbying)? What are your current policy or advocacy priorities and how do you advance them?
- Do you have staff dedicated to policy, advocacy, or government affairs? If so, how many?
- Are you part of any policy or advocacy coalitions or networks? Please describe.
- Do you work with external lobbyists or consultants? If so, who? What do they work on?

Systems Change: Past Activities

- Have you or your partners ever:
  - Met with state or federal legislators, governors, or agency policymakers?
  - Written to or organized a letter-writing or call in campaign to policymakers?
  - Testified at a hearing or submitted public comments?
  - Written op-eds, blog posts, or other communications regarding policy issues?
- Have you or any coalition you're part of had policy or advocacy "wins"? What made those efforts successful?

Information and Resources

- Who do you turn to for trusted federal or state policy or advocacy information (including newsletters, list serves, conferences, webinars)?
- Are there key advocacy partners, associations, or coalitions whose work you follow closely?
- In the current context, would you find it helpful to have distilled, reliable information about what is happening at the federal level on policy and funding that affect the nonprofit sector generally and/or the populations you serve?

Support and Capacity Building

- Would you be interested in having more resources/support for more policy or advocacy work? Would you or someone on your team benefit from participating in a future high quality training or fellowship focused on building advocacy skills?
- What additional supports, training, tools, or information would help you engage more effectively in advocacy or systems-change work (e.g., funding, advocacy training, introductions, information, communications support, collective engagement with likeminded organizations that provide economies of scale, etc.)?

Proximate Voice and Lived Experience

- Have you ever created opportunities for the youth or families you serve to share their stories or experiences with policymakers?
- Would you be interested in lifting up proximate voices—the direct experiences of those you serve—in future policy or advocacy work?

Closing

- If you could change any additional policy or system that most affects the people you serve, what would it be?
- Is there anything else you'd like to share about how the Tower Foundation or other funders could better support your policy or systems-change goals?

TOWER STAFF ONLY

Post-interview reflection

Your perspective is deeply valued. From what you heard, what is the strongest opportunity for policy/advocacy engagement for this grantee?

Landscape Analysis Section IV
Addendum C - Questions for Interviews with Peer Organizations

Introduction: Purpose

"Thank you for taking the time to speak with us. The purpose of this interview is to understand how the Tower Foundation's partners and peer organizations are experiencing the current policy and funding environment; to learn about your past and current policy, advocacy and systems-change activities; and to identify opportunities, barriers, and supports that you believe could strengthen systems change goals and collective policy impact. What we hear across these interviews will help inform a Landscape Analysis, which in turn will help guide the Foundation's future approach to systems change, policy, and advocacy efforts. We are conducting similar interviews with Tower Foundation grantees, but we believe learning from peer organizations is equally important to help inform the Foundation's systems change strategy going forward. We have a series of 12 questions and we anticipate this conversation will take approximately 1 hour. With your permission, we will record the conversation. We will not utilize any quotes or include any information for attribution without your express consent. Thank you again for your time and your willingness to speak with us."

Questions

- Tell us a little about your organization – your areas of focus and model. Do you currently partner with the Tower Foundation in any way – either formally or informally?
- How is your organization currently engaged in systems change work – including policy and advocacy? For example, do you provide grants to policy and advocacy organizations? Do you engage in advocacy on behalf of your own organization? Can you share some examples of how your foundation/organization has engaged—directly or indirectly—in policy or advocacy efforts? What has felt most effective, and what has been most challenging?
- Why do you invest in policy and advocacy work and why is systems change work part of your 2026 (and future) strategy?
- How is the current policy and funding environment shaping your foundation's priorities and impacting your grantees – particularly those working with young people or other vulnerable populations? Across your grantee portfolio, are there common themes or system-level challenges you're seeing emerge right now—particularly related to funding, policy, or organizational capacity—that you think are important for other funders to understand?
- In your state, who do you view as the leading advocacy or lobbying organizations (including government relations entities) working in the Tower Foundation's core areas (youth mental health, substance use disorders, intellectual disabilities, and learning disabilities) and what roles do they play in shaping policy?
- What kinds of intermediaries (coalitions, advocacy organizations, policy shops, or field-builders) have you found most effective in translating philanthropic investment into real policy impact?
- Do you provide advocacy training to your grantees? Do you rely on others to do so? If so, which advocacy training programs do you think have added the most value?
- How do you incorporate the perspectives and lived experiences of young people, families, or communities most impacted by these systems into your systems-change, policy, or advocacy strategies? What has helped—or hindered—meaningful proximate voice in this work?

- Is there anything you think the Tower Foundation should consider to help guide its future approach to systems change, policy, and advocacy—particularly related to partnerships, intermediaries, or the kinds of supports needed to be effective in this work?
- Crystal Ball: Where do you see the Tower Foundation adding the most value in the policy/advocacy space as a funder? What does success look like in 2 - 3 years?
- Broader Sector: Looking forward, where do you see the greatest opportunities (either unmet needs or a need for additional voices) for philanthropic collaboration or alignment to strengthen systems-level impact?
- Is there anything else you'd like to share?

Landscape Analysis Section IV
Addendum D - Questions for Interviews with Tower Foundation Staff & Leadership

1. Interviews with Grant Partners

Introduction: Purpose

"This interview is part of a Landscape Analysis that explores the most promising avenues for the Foundation's future policy/advocacy/systems change engagement. It will also touch on capacity-building and the skills necessary to make successful policy/advocacy engagement possible."

Background

- Personal introductions
- What is your role at the Tower Foundation?
- What issue area(s) do you focus on?
- How did you get into this work?

Grant Portfolio

- How many and what types of grants are in your portfolio?
- From the grants you oversee, which do you see as the most promising/impactful?
- Given your deep understanding of your grantees and their priorities, what would you say is most important to your grantees right now?

Current Context/Systems Change

- How are your grantees being impacted by the current political/policy context?
- Are there common policy or funding barriers/opportunities you hear about repeatedly from your grantees?
- Are there key federal funding streams that you know your programs rely on or have been most essential for their work?
    - Ex: Medicaid; Title I, Individuals with Disabilities Education Act (IDEA); Substance Use Prevention, Treatment, and Recovery Services Block Grant (SUPTRS BG/SUBG); Home and Community Based Services (HCBS); Supplemental Security Income SSI; etc.
- If your grantees aren't being impacted directly, are they being impacted by funding cuts to the larger system (i.e. many cuts to education that impact school districts)?
- Do any of your grantees do policy advocacy or systems change work?
    - If so, which organizations and what do they focus on? Do they have staff that focus on policy? Do they utilize external lobbyists?
    - If not, which grantees do you think might be the most well-equipped and/or interested in being involved with advocacy/systems change work?
    - If not, which grantees do you think might be the most well-equipped and/or interested in being involved with advocacy/systems change work?

  - Are there any past policy engagement "wins" or efforts your grantees have been engaged in that you can share with us?
  - Are your grantees part of any policy/advocacy coalitions or networks?
- What types of supports would be most useful to Tower grantees to help them engage in advocacy/systems change work?
  - Ex: Information sharing/awareness building, capacity building/advocacy trainings, opportunities to amplify their on the ground experiences, collective advocacy support, policy engagement, direct advocacy opportunities
- Do you know of any grantees that provide opportunities for their constituents to have a chance to share their experience with policymakers or really focus on proximate voices? Which grantees do you think are most interested in that?
- What do you think might be some of the biggest barriers for grantees to participate in advocacy/systems change work?

Partnership Landscape/Future Thinking

- Who are other key organizational partners in your work? Key advocacy partners?
- How do you currently learn about policy changes that affect your grantees?
- Who do you turn to for trusted policy or advocacy information?
- Are there regional, state, or national advocacy organizations that you see as particularly effective?
- Where have you seen advocacy or system change efforts work - among grantees, or other foundations or organizations?
- If you had a crystal ball and were looking 3-5 years into the future, how would you like to see the Tower Foundation supporting grantees in advocacy and systems change?
- What role (if any) would you like to see the Foundation itself play in advocacy work (issuing statements, engaging in advocacy, funding advocacy, thought leadership, convening)?

2. Questions for Executive Director and Chief Program Officer: Initial Interview

- How would you describe the Tower Foundation's theory of change or approach to systems change – with a specific focus on policy advocacy?
- Tell us more about the interest in advocacy and systems change from Foundation Trustees?
  - What's driving this increased interest? Is the interest in state or federal policy or both?
  - How would you define success?
  - How would the Trustees define success and who on the Board has policy/advocacy experience?
  - Describe the interest in advocacy/systems change on your staff. Who on your staff has policy/advocacy experience?
- As the Foundation considers advocacy opportunities, what factors might influence whether/when/how to engage? (Trustee/staff/grant partner interest, issue alignment, potential impact, grantee skills and capacity, ability to get support from a broader Coalition, etc.)

- Based on the Foundation's current activities, how would you describe the Foundation's current engagement in advocacy/system change? What future level do you aspire to?
  - For example (from least involved to most involved):
    - Awareness/Information sharing
    - Relationship and Capacity Building
    - Collective Advocacy and Coalition Support
    - Policy Influence and Engagement
    - Direct Advocacy/Lobbying by Grantees or by the Foundation
- Many of your grant partners are direct service organizations. Is your interest in helping existing programmatic grantees gain advocacy skills and engage in collective advocacy? Do you want to deepen your investment in individual advocacy organizations? In advocacy coalitions? How significantly could the Foundation expand its investment in policy advocacy going forward?
- What would success look like 3-5years from now if the Tower Foundation deepened its advocacy engagement?
  - Policy advocacy engagement across grantee portfolio of core group of 24 organizations
  - Policy and advocacy engagement with broader coalition support
  - Engagement within issue verticles
  - Engagement among individual organizations
  - Individual leader engagement
  - Engagement limited to the Foundation itself
- What's your vision for the future of the Tower Foundation?

2. Questions for Executive Director and Chief Program Officer: Follow Up Interview

- What are the Foundation's key systems change/policy/advocacy goals?
- What are your top federal and state policy priorities and issue areas (including both substantive policy and funding policy) that you want to devote resources to over the next 2.5 years?
- How would you define the Foundation's policy/advocacy success in 2.5 years?
- What role do you want the Foundation itself to play in policy/advocacy?
- How would you prioritize the importance of building advocacy capacity among grantees (including both organizations, constituents, and youth)?
- How would you prioritize investing in collective advocacy efforts versus investing in individual advocacy organizations?
- How close to the "lobbying" line is the Foundation willing to go?
- What are the top "takeaways" you'd like to see come out of the Landscape Analysis?
- What do you see as the Trustees' deepest policy/advocacy interests?
- What else should we be asking to help us prepare the Landscape Analysis that is of most help to you?

Landscape Analysis Section IV
Addendum E - Questions for Discussion with Tower Foundation Trustees

- We've heard a lot of excitement about the Foundation deepening its engagement in systems change work. But people have different ideas about the most important levers of systems change. It could be: policy and advocacy engagement (at the federal, state, or local levels); educating public officials; collective advocacy lifting up the voices of impact-driven nonprofits; building advocacy capacity among those groups or the people they serve; cultivating champions; changing mental models and public opinion; or narrative change.

  What do you see as the Foundation's core systems-change goals? What are the types of policy and advocacy activities that you think are most important and that you'd like to see the Foundation engage in more deeply?

- In our conversations, a resounding theme we heard was that while investing in programs is important, investing in policy advocacy work was also essential at this particular time. I think we heard the phrase "now more than ever" 100 times.

  What are the top policy areas that you would want to see the Foundation devote resources to over the next 2 -3 years? Some examples might be: (1) protecting or increasing public funding (like SAMHSA funding); (2) addressing regulations that make it easier/harder to deliver treatment for eligible individuals; (3) policies that make it harder to return to the community after incarceration or extended time off for inpatient mental health treatment; (4) immigration policies that affect both students and the mental health workforce.

- The Foundation is extremely intentional about setting clear goals while also adapting strategies to the times. We saw that in how quickly the Foundation pivoted to rapid response grants.

  Looking ahead, if you had a crystal ball, how would you define the Foundation's systems change success in 2 -3 years?

- One difference we've seen among peer entities is that some organizations like to have a prominent outward facing presence, whereas others lead from behind.

  What role do you see the Foundation and its leaders playing in policy/advocacy?

- We've heard a lot about the lack of adequate policy and advocacy training – particularly among program staff who don't have prior policy or advocacy expertise. This is particularly true with organizations cutting back on staff. We've also heard about the importance of policymakers hearing from community members themselves about their lived experience.

  How would you prioritize the importance of building advocacy capacity among grantees and how important is it to include constituents – particularly young people – in advocacy training to build the next generation of leaders?

- Many grantee partners understand that nonprofits CAN lobby, but they are also hungry for reliable information about guidelines and guardrails. Also, different foundations take different approaches on how expansive they're willing to be while staying within legal limits.

  How comfortable is the Foundation with the rules governing how private family foundations can engage in and support advocacy efforts? How close to the "lobbying" line is the Foundation willing to go?

- We've heard from Tracy and Don that this Landscape Analysis should be like a GPS (rather than a fixed roadmap) and it should be actionable.

  What are the top "takeaways" you'd like to see come out of the Landscape Analysis so that it is of optimal actionable use?

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Landscape Analysis: Advocacy for Impact

SECTION V

RECOMMENDATIONS

Landscape Analysis

SECTION V
RECOMMENDATIONS

OVERVIEW

Based on bespoke research, in-depth policy analysis, numerous Foundation stakeholder interviews, and comprehensive discussions with policy, advocacy, government affairs, legal, and field experts conducted as part of this Landscape Analysis project (as detailed in Section IV: Methodology), America Forward offers the following five summary recommendations to inform the Tower Foundation's ongoing systems change strategy. (For more detailed discussion of a number of the recommendations below, please see Section VI: Interview Findings and Insights, Part 4: The Importance of Advocacy in Systems Change and Philanthropy's Critical Role.)

1. Invest in Organizations that Engage in Impactful Policy Advocacy Efforts

Supporting organizations that champion innovative and effective public policies and advocate to sustain essential public funding in the Foundation's core issue areas is a critical component of an effective systems change strategy. As discussed in Section VI: Interview Findings and Insights, Foundation stakeholders overwhelmingly agree that philanthropy can achieve greater impact with systems change investments (and, particularly, policy advocacy investments) than with programmatic grantmaking alone. While philanthropy cannot fill potentially vast public funding gaps or address the full scope of community challenges, philanthropy can leverage its impact and play a critical role supporting advocacy efforts to maintain or increase public funding levels and advance innovative, effective substantive policy. Accordingly, many Foundation grant partners and peer organizations not only express appreciation for the Tower Foundation's current leadership in this space, they also strongly encourage the Foundation to increase its investment and involvement in policy advocacy. By supporting advocacy efforts, philanthropic dollars can have a catalytic and sustainable impact, influencing the systems that ultimately determine whether essential community programs that support young people are available, accessible, and sustainable in the long run. More specifically, the Foundation should:

- **Continue Funding Organizations that Engage in Advocacy.** Stakeholder interviews underscore that the Tower Foundation has an impressive track record selecting grant partners that are well-respected and effective leaders in their fields. However, while the Tower Foundation has a particularly strong commitment to supporting advocacy efforts, Foundation stakeholders express frustration with the depth and pace at which philanthropy more generally invests in policy advocacy, to the detriment of the communities they serve.

Stakeholders report that many of the challenges that service providers currently face are a direct result of policy and funding decisions at the federal and state levels, and they emphasize that the need for policy and advocacy support is more important now than ever. The Tower Foundation should continue to serve as a leader and exemplar in the philanthropic sector supporting policy and advocacy entities – including organizations that primarily focus on advocacy as their program model, organizations that include advocacy as a part of their systems change strategy, and organizations that lead or engage in collective advocacy with coalitions to leverage their impact.

- **Increase Funding of Collective Advocacy Efforts.** By supporting collective advocacy efforts, philanthropy can leverage its grantmaking impact: organizations advocating together can pool and share resources and benefit from economies of scale; coalitions can attract and engage strong visionary, strategic, and administrative leadership; collective action can provide individual organizations with group "cover" to mitigate risks; combining voices can amplify policy priorities with the public; and collective advocacy can expose policymakers to a larger group of diverse, but united, constituent voices; and philanthropic investments in collective advocacy focused on appropriations can yield significant returns by increasing public funding. Engaging in collective advocacy also enables foundations to allocate resources effectively and assume either a leadership role (i.e., being a "lead voice") or a supportive role (i.e., being "a voice in the chorus"), depending both on the policy issue salience for the foundation and the depth and breadth of the existing advocacy field. For collective advocacy efforts to gain traction, it is important to have a core group of Tower Foundation grant partners, peer organizations, and network organizations committed to collective advocacy. The Foundation should consider prioritizing investments both in collective advocacy leadership organizations and programmatic organizations that have the appetite and ability to engage in collective advocacy to maximize their impact.

- **Utilize Multi-Year Unrestricted Grants.** Policy advocacy and systems change work require sustained, long-term engagement that annual restricted grants often cannot support. Multi-year unrestricted general operating grants give advocacy organizations and collective advocacy efforts the stability and flexibility to respond to rapidly shifting policy conditions, pursue longer-term goals, and engage in the full range of permissible advocacy activities – including lobbying within legal limits. Accordingly, the Foundation should consider increasing its utilization of multi-year unrestricted general operating grants to organizations engaged in collective policy advocacy.

2. Invest in "Backbone" Organizations that Effectively Lead Collective Policy Advocacy Efforts

Collective advocacy efforts offer compelling advantages, including economies of scale, leveraged resources, amplified voices, and expanded impact (as discussed above). But collective advocacy only works well when it is well-led. Effective coalitions require adept and adaptive leadership with deep policymaker relationships and proven track records of strategic success. Investing in capable backbone organizations that can coordinate and align action across broad networks is one of the most cost-effective and high-impact systems change strategies, enabling foundations to extend their reach, alliances, and influence beyond their grant portfolios without having to build something new. The Foundation should prioritize investment in high-capacity "backbone" organizations that have deep expertise leading effective policy coalitions and experience quarterbacking successful collective advocacy efforts across the Foundation's core issue areas.

The Foundation should establish criteria for selecting and investing in collective advocacy backbone organizations. As a baseline, strong candidates should be coalition-based systems change organizations with national reach; deep policy expertise in youth substance use disorders, mental health, intellectual disabilities, and/or learning disabilities; and strong reputations among both policymakers and nonprofit advocates. Relevant experience should include: (a) successful defensive advocacy: protecting critical public funding streams from cuts or restructuring; (b) effective affirmative advocacy: developing and championing promising new substantive policy and funding proposals; and (c) strategic forward-looking advocacy: laying the groundwork for future policy action, including major bill reauthorizations and appropriations efforts. Additional hallmarks of effective backbone organizations include experience building and sustaining coalitions across large and diverse groups of nonprofit organizations; developing federal and state policy platforms and building consensus in support of those platforms; strengthening the advocacy capacity of engaged organizations; elevating proximate voice by connecting young people and community leaders directly with policymakers; and forging durable relationships between advocates and decision-makers at the federal and state levels.

3. Identify a Limited Number of Actionable Advocacy Priorities

A key to advocacy success is developing a right-sized, actionable, and impactful advocacy agenda. The Federal, Massachusetts, and New York Sections (Sections VII, VIII, and IX respectively) of this Landscape Analysis highlight dozens of viable advocacy opportunities across the Foundation's four core issue areas – youth substance use disorders, mental health, intellectual disabilities, and learning disabilities. Making strategic selections among these (and potentially other) advocacy opportunities will require an intentional process of prioritizing issues and resources within the context of a shifting political and policy landscape.

To aid this process, the Foundation should partner with a backbone organization and Foundation grant partners to identify and select among the advocacy opportunities presented in this Landscape Analysis (and potentially others as well). The Foundation should also consider codifying its key advocacy priorities in biennial policy platforms (aligned with the two-year political and legislative cycle) to ensure sustained alignment among stakeholders. This process could include surveys of grant partners and other stakeholders; discussions with Foundation Trustees, leadership, and staff; and government relations guidance provided by the backbone organization.

When selecting among advocacy opportunities, the Foundation should consider:

- **Grant Partner Priorities.** Throughout grant cycles, approximately 60-70% of the Foundation's grants are awarded to repeat or returning grant partners. Given these longstanding relationships, grant partners' policy priorities should provide an important anchor for the Foundation's advocacy agenda.

- **Likelihood of Success.** The Foundation should prioritize advocacy opportunities for which there is a reasonable path to cultivating policymaker champions and achieving legislative, regulatory, or administrative success given the current political and policy climate.

- **Time Horizon.** It is helpful to focus on a combination of near-term policy wins and longer-term policy plays that lay the groundwork for future policy successes and durable systems change.

- **Value Added.** The Foundation should focus on advocacy opportunities where the Foundation's leadership and engagement are meaningful and impactful, either because the issue is high-stakes (even if other advocates are active in the space) or because the Foundation's role is distinctive (even if the issue is narrower in scope).

- **Strategic Balance.** A sound advocacy strategy should include a mix of defensive strategies (e.g., protecting existing funding and policy gains) and affirmative strategies (e.g., advancing new policy proposals).

- **Issue Area Balance.** The Foundation should consider maintaining issue-area balance consistent with the Foundation's grant-making strategy when selecting advocacy opportunities.

- **Sector Strengthening.** The Foundation should consider extending its advocacy efforts beyond its four core issue areas and joining advocacy efforts focused on strengthening, stabilizing, and sustaining the philanthropic and nonprofit sectors more broadly.

- **Cross-Cutting Opportunities.** Selected advocacy opportunities could include supporting policy strategies that cut across issue areas – such as promoting innovation, rewarding results, and advancing evidence-based policymaking, and supporting advocacy on adjacent policy issues (e.g., housing).

4. Invest in Advocacy Capacity-Building

The Tower Foundation has a longstanding commitment to supporting capacity-building efforts designed to strengthen organizations that work to change systems. High-quality, applied policy and advocacy capacity-building training can help organizations and individuals build the skills and gain the tools they need to become effective advocates. As a number of Foundation stakeholders note in interviews, now is a particularly important time for policymakers to hear the voices of the communities they serve and for organizations to build their advocacy capacity so that they can navigate the current volatile political and policy environment, engage effectively with policymakers on both sides of the aisle, master adaptive skills, and take strategic steps to ensure sustainability. The Foundation should consider partnering with experienced policy and advocacy capacity-building entities and initiatives that have established track records creating and running innovative and effective trainings dedicated to helping social innovators, program leaders, and the community members they serve become better, bolder advocates.

When selecting capacity-building partners, the Foundation should consider entities that offer:

- **Bespoke Programs.** Advocacy capacity-building programs are most effective when they are customized to participants and intentionally curated to reflect their particular interests and needs. The Foundation should prioritize programs that have the ability to customize trainings and create bespoke tracks for the Foundation's grant partners and the community members they serve.

- **Applied Trainings.** As many Foundation stakeholders note in interviews, trainings are most effective when they are applied and not purely academic. Capacity-building efforts are most effective when they "train for action" and include opportunities for participants to deploy the skills they develop in the field. This could include multi-day "from the classroom to the capitol" trainings in which interactive classroom trainings are followed by a series of state Capitol Days and/or federal Hill Days in which participants meet with policymakers' staff. Interviewees also note that "one and done" training opportunities are less effective than trainings offered as part of a series. State Capitol Days and federal Hill Days staff meetings, for example, should include follow up strategies including written communications, meetings with policymakers, and formal briefings for groups of legislative and regulator policymakers and staff.

- **Diverse Learning Communities.** Capacity-building trainings often are most effective when they create diverse learning communities. Advocacy trainings should include organization leaders, staff and representatives from the community members the organizations serve. They should also include organizations and individuals with varying levels of advocacy experience so that less experienced participants can learn from their more experienced peers. The Foundation could also consider extending capacity-building trainings beyond its grant network and offer trainings to similarly-situated service delivery programs and peer organizations to help build the advocacy field and amplify the Foundation's policy priorities. In addition, trainings should be offered on a cyclical basis so that new staff members can take advantage of training opportunities (given frequent nonprofit staff turn-over), and past participants can repeat training sessions (since participants' experiences between sessions alter their perspectives and impact what they take away from revisited trainings).

- **Numerous Training Options.** The Foundation should conduct stakeholder surveys to ascertain which trainings would be most relevant and impactful. Training topics could include:

  - Nonprofit Lobby Rules: The rules governing public charities' and private foundations' permissible engagement in advocacy and lobbying activity.
  - The Role of Proximate Voice: The importance of elevating the voice of lived experience and cultivating engagement of program stakeholders.
  - Policy 101: Understanding the legislative and regulatory processes and their impact on nonprofit service providers and the individuals they serve.
  - Budget & Appropriations: Making sense of the annual budget and appropriations cycles, including the earmark process.
  - Bipartisan Engagement: How to effectively communicate with policymakers on both sides of the aisle in the current political climate.
  - Board Mapping: How to assess and leverage nonprofit Board members' political, policy, and thought-leadership assets.
  - Communications: How advocacy efforts reach hearts (e.g., through storytelling) and minds (e.g., through data and evidence).
  - Advocating Across Levels of Government: Connecting federal and state advocacy strategy from the state house to Capitol Hill.
  - Topical Issues: Bespoke sessions on topical issues (e.g., immigration issues or tax policy changes affecting the nonprofit sector).
  - Blending Systems Change Strategies: How to blend collective advocacy, public engagement, narrative change, and cross-sector collaboration.

- **A Focus on Youth Advocacy.** Effective advocacy efforts center the voices of people with lived experience. Individuals most directly affected by policies and systems have unique expertise and are often well-positioned to identify gaps, propose solutions, and communicate what works best in practice. The Foundation should consider building on its participatory grantmaking work by investing in specialized trainings focused on youth advocacy. Engaging youth voice is not simply about inclusion; it is about efficacy. Advocacy on issues affecting young people – including youth substance use disorders, mental health, intellectual disabilities, and learning disabilities – is stronger and more effective when grounded in the lived experience of young people and when policymakers hear directly from their community members affected by specific policies.[3]

- **Bespoke Youth Fellowship.** The Foundation also should consider investing in a new youth advocacy fellowship to help strengthen the next generation of advocates. This could take the form of a one year customized fellowship in which a select group of young community leaders work on bespoke advocacy issues. Participants could be selected from the Foundation's Community Experts Team of young adults referred to the Foundation by grant partners. Fellows would meet regularly as a cohort, receive customized advocacy training, learn from one another, and receive hands-on advocacy from an organization with experience leading year-long fellowships. Each fellow would select an advocacy issue of particular relevance to them, devise an advocacy strategy, build an advocacy case (including both data and storytelling), hone their communications skills, and prepare materials supporting a policy "ask." Associated elements could include individual coaching, role-plays with volunteer legislative staff, and meetings with policymakers. This Fellowship would be a strong companion to the current Community Experts Team practice of designing Foundation grant opportunities.

- **Associated Resource Materials.** Capacity-building trainings should include distribution of clear and accurate resources curated for participants. Resources could range from white papers and publications on salient policy issues, to data on public funding streams, to appropriations tool kits, to fact sheets on lobbying rules, to playbooks for engaging policymakers in their district offices when on recess.

5. Deepen the Foundation's Direct Role in Advocacy

While investing in policy advocacy organizations, collective advocacy coalitions, and capacity- building efforts is critically important, the Foundation itself can also directly engage in policy advocacy and other forms of advocacy as part of its systems change strategy. As discussed in the Legal Section (Section III) of this Landscape Analysis, private foundations' advocacy activities have few legal constraints beyond lobbying and partisan activity restrictions. The type of advocacy activities that best suit the Foundation's goals will depend on its internal capacity, cultural norms, desired public profile, and the advocacy interests and priorities of its Trustees, leadership, and staff – all of which are important factors for the Foundation to assess as part of an intentional internal planning process. To aid the Foundation's determination of the advocacy role its leadership and staff could play, the Foundation should engage in an intentional internal process in which the following menu of advocacy options are explicitly considered:

- **Policy Advocacy.** Consistent with applicable federal law and state guidelines, Foundation leadership and staff could engage in targeted advocacy efforts to educate policymakers – for example, through meetings with legislators and providing comments to regulators – provided that this engagement does not constitute lobbying under applicable federal tax law (see Section III for guidance on this distinction).

- **Public Engagement Efforts.** In addition, the Foundation's advocacy efforts could focus on public engagement, including: communications efforts – such as op-eds and blog posts; research efforts – such as scholarly papers and analyses on timely policy issues (like the Foundation's existing Think Bigger Do Good Policy Series); and narrative change efforts – such as public awareness and education media campaigns focused on narrative change (particularly to combat stigma). These public engagement efforts can build public will, shift the narrative surrounding the Foundation's core issue areas, and further leverage the Foundation's already-established credibility as a trusted partner and respected voice in the field for programmatic information and policy insights, complementing and amplifying the advocacy work of its grant partners.

- **Resource Development and Distribution.** The Foundation could partner with policy experts in the development of reliable resources to meet Foundation stakeholder's expressed need for clear, concise, relevant and reliable resources that are both prepared by policy experts and user-friendly for program staff. The Foundation could also support trusted partners' distribution of resources including: policy newsletters, advocacy updates, webinars, action alerts, and "ask me anything" sessions with policy experts and government relations professionals on timely topics of interest to the Foundation and its grant partners.

- **Leveraging Board Relationships.** Whether or not the Foundation itself engages with policymakers, it could be helpful to engage Foundation Trustees in a power-mapping exercise – a structured process designed to map Board members' relationships with policymakers, thought-leaders, and influential stakeholders who could advance the Foundation's and its grant partners' policy priorities and communications interests.

- **Convenings.** The Foundation could serve as a convener, creating learning communities among grant partners and other stakeholders, sponsoring conferences on salient policy issue areas, and hosting convenings that bring together practitioners, policymakers, and advocates to advance shared priorities. These convenings could also include applied advocacy training for grant partners and other stakeholders and events, such as Hill Days, that connect Foundation stakeholders with policymakers.

- **Field Leadership through Coalition-Building.** To further leverage the Foundation's impact, the Foundation could take an active field leadership role building advocacy coalitions among grant partners, peer organizations, other service providers, and collective advocacy leaders; helping to identify coalition opportunities; and lending its credibility and relationships to sustain advocacy coalitions in its core issue areas.

- **Elevating Proximate Voices.** As Foundation stakeholders consistently emphasized in interviews, and as discussed above, advocacy grounded in proximate voice is both more authentic and more effective. The Foundation could create structured opportunities for young people with lived experience – including youth and young adults with substance use disorders, mental health conditions, intellectual disabilities, and learning disabilities – to share their stories directly with policymakers and the public. This could include developing advocacy fellowships, storytelling programs, and leadership development initiatives that build the capacity of young people to advocate on behalf of themselves and their communities.

America FORWARD

PETER & ELIZABETH **TOWER FOUNDATION**

Landscape Analysis: Advocacy for Impact

SECTION VI

INTERVIEW FINDINGS & INSIGHTS

INTERVIEWS WITH FOUNDATION STAKEHOLDERS:

BestSelf Behavioral Health | Blue Cross Blue Shield Foundation of Massachusetts | Boston Children's Hospital-Behavioral Health | Buffalo Federation of Neighborhood Centers | Center for Law and Education | Center for Public Representation | Center for Self Advocacy | Children's Mental Health Campaign | Community Catalyst |Community Services for Every1 | COMPEER | Developmental Disabilities Alliance of WNY | Endeavor Health Services | Erie County Anti-Stigma Coalition | Health Foundation of Western and Central NY | Horizon Health Services | Legal Action Center | Liftoff WNY | Massachusetts Advocates for Children | Massachusetts Association of Mental Health | Massachusetts Society for Prevention of Cruelty to Children | Melmark | Mental Health Advocates | New York Alliance for Inclusion and Innovation | Northeast Arc | Parent/Professional Advocacy League | Patrick P. Lee Foundation | The Children's Agenda | People Inc. | Peter and Elizabeth C. Tower Foundation Trustees, Leadership, and Program Officers | Prevention Focus | Recovery Options Made Easy | RIZE Massachusetts | Rural Outreach Center | Scattergood Foundation | Schuyler Center |Self Advocacy Association for NYS | Suburban Adult Services, Inc. | Value Network

Landscape Analysis

SECTION VI
INTERVIEW FINDINGS & INSIGHTS

INTRODUCTION

This "Interview Findings & Insights" Section of the Landscape Analysis presents findings and insights from interviews conducted with a sample of Tower Foundation stakeholders, including: grant partners; peer organizations; and Foundation staff, leadership and Trustees. All interviews were conducted between November 2025 - March 2026. Names of individuals and organizations interviewed can be found in Section IV (Methodology) of the Landscape Analysis.

Please note that interview findings concerning policy challenges and advocacy opportunities, and interview insights regarding the importance of advocacy and the role of philanthropy, presented in this Section are not intended to constitute a comprehensive overview of all relevant challenges and opportunities related to the Foundation's core issue areas. Rather, the findings reported below solely reflect comments that Foundation stakeholders shared in their interviews. Because only a sample of the Foundation's grant partners and peer entities participated in interviews, this Section is intended to provide the Foundation with an initial sense of its stakeholders' views. Accordingly, this Section takes the form of a narrative summary rather than a quantitative analysis. For a more comprehensive analysis of current Federal, New York, and Massachusetts policy challenges and advocacy opportunities relevant to the Tower Foundation's core issue areas, please see the Federal (Section VII), Massachusetts (Section VIII), and New York (Section IX) portions of this Landscape Analysis. Those Sections include the broader insights of the America Forward advocacy team, including both our internal policy and advocacy staff and our federal and state government relations partners.

Additionally, please note that in their interviews, stakeholders focus almost exclusively on policy advocacy rather than other forms of advocacy, such as communications, convenings, narrative change work, public engagement efforts, power mapping, and field leadership. Accordingly, this Section focuses on policy advocacy. Section II of this Landscape Analysis (Systems Change: The Role of Policy Advocacy) discusses the role of policy advocacy as a core element of effective systems change, and Section III of this Landscape Analysis (Legal Context: Law Governing the Engagement of Private Foundations and Public Charities in Lobbying and Advocacy Activities) discusses the law governing nonprofits' advocacy activities and details the distinction between permissible advocacy and lobbying activities.

The interview findings and insights presented below are organized as follows:

1. **Federal Funding Challenges, Policy Shifts, and Advocacy Opportunities**
2. **State Funding Challenges, Policy Shifts, and Advocacy Opportunities**
3. **Cross-Cutting Systemic Issues**
4. **The Importance of Advocacy in Systems Change & Philanthropy's Critical Role**

1. FEDERAL FUNDING CHALLENGES, POLICY SHIFTS, AND ADVOCACY OPPORTUNITIES

Across all of the Foundation's core issue areas, grant partners, peer organizations, and Foundation stakeholders identify federal funding uncertainty and policy shifts as some of the most significant challenges they now face. Grant partners particularly emphasize that anticipated federal funding shifts and workforce shortages could have a negative impact on the breadth and depth of their work, posing challenges to service providers, staff, and the communities they serve.

However, while stakeholders name federal funding and policy uncertainty as a significant challenge, when they are asked to identify opportunities for action, they frequently emphasize the need for guidance on how most effectively to engage in federal policy advocacy – whether defending against potential funding cuts, taking advantage of emergent federal opportunities, or laying the groundwork for future affirmative policy advocacy. In addition, stakeholders note that with so much information (and misinformation) available, they face challenges accessing reliable resources that offer clear guidance. Stakeholders also identify challenges making strategic decisions about when to lead or actively engage in advocacy and when simply to lend support to others as a "voice in the chorus."

As discussed in more detail in the Landscape Analysis Recommendations (Section V), given these findings, stakeholders see identifying ripe federal advocacy opportunities and supporting stakeholders' engagement in collective advocacy efforts as critically important roles that the Tower Foundation could fill. In some instances, this could mean the Foundation actively engaging in or directly supporting grant partners' advocacy efforts (e.g., by educating policymakers or funding collective advocacy); in other instances, this could mean having other entities assume advocacy leadership while the Foundation and its stakeholders lend support (e.g., through sign-on letters, communications efforts, or convenings).

A. IMPACTS OF H.R.1/ ONE BIG BEAUTIFUL BILL ACT (OBBBA)

In numerous interviews, Foundation grant partners report that they are bracing for the impact of OBBBA, and they express concern about new work requirements under Medicaid, updated cost-sharing guidance, and lapsing Affordable Care Act (ACA) subsidies.

i. Work Requirements, Exclusions, and Cost-Sharing

By way of background, the One Big Beautiful Bill Act (OBBBA), signed into law in July 2025, mandates significant changes to Medicaid and the Supplemental Nutrition Assistance Program (SNAP) that threaten participation by individuals with low-incomes. As discussed in detail in the Federal Section of this Landscape Analysis (Section VII), these changes account for an estimated $1 trillion in cuts to Medicaid (amounting to a 15% reduction in projected federal Medicaid spending), along with a reduction of an estimated $187 billion in SNAP spending, over the next 10 years. The Congressional Budget Office (CBO) estimates these changes could cause 10 million Americans to lose Medicaid coverage, particularly in states that expanded Medicaid for low-income adults under the ACA,[1] with large impacts expected on rural hospitals. The Urban Institute projects that more than 22 million families will lose some or all of their SNAP benefits.

More specifically, OBBBA: (1) mandates that able-bodied adults without dependents work, volunteer, or participate in training for 80 hours per month to maintain coverage; (2) reduces the cap on state provider taxes from 6% to 3.5% by 2032, limiting a key source of state funding and reducing federal matching funds; and (3) restricts coverage for certain lawfully present immigrants, including refugees and asylum seekers. Many Foundation stakeholders voice widespread concern that the community members they serve, particularly individuals with disabilities and immigrants, are disproportionately likely to lose their coverage due to the new Medicaid work requirements and exclusions and cumbersome reporting processes. In addition, since OBBBA imposes similar work requirements for SNAP participant eligibility, some grant partners note that new SNAP work requirements will pose additional challenges for members of the communities they serve.

The OBBBA policy changes also pose complex administrative challenges for grant partners and participants. While individuals who receive Supplemental Security Income (SSI) are automatically enrolled in Medicaid in Massachusetts and New York, roughly two-thirds of people with disabilities in Massachusetts and New York do not receive SSI and qualify for Medicaid through separate non-disability pathways. Consequently, a high proportion of people with disabilities in Massachusetts and New York will face burdensome new administrative requirements. A number of grant partners serve individuals who receive Medicaid through both Modified Adjusted Gross Income (MAGI) and non-MAGI pathways, and they note that individuals who receive services do not always have the Age, Blind, and Disabled (ABD) designation.

In addition, substance use disorder (SUD) treatment is particularly at-risk for disruption. In Medicaid expansion states like Massachusetts and New York, 67% of Medicaid-covered adults who receive SUD treatment are covered through Medicaid expansion. While individuals with SUD and other "disabling" mental health conditions should be exempt from the new Medicaid work requirements due to the "medical fragility" exemption, this exemption is dependent on currently unreleased federal guidance. Moreover, individuals with mental health disorders, including SUD, are more likely to face housing insecurity,[2] employment instability,

[1] The ACA allowed states to extend Medicaid eligibility to nearly all low-income adults with incomes up to 138% of the Federal Poverty Level. Participation is voluntary for states, with the federal government covering 90% or more of the cost.

[2] HUD's planned Continuum of Care (CoC) changes will likely only intensify housing insecurity as HUD continues its shift toward a treatment-first model, transitioning focus from permanent to emergency housing, capping Permanent Supportive Housing funding at 30% of renewals (down from 90%), and prioritizing law enforcement partnerships. These changes are part of a larger transition that began in late 2025 when HUD actively shifted federal homelessness policy away from a "housing first" model toward a "treatment-first" model, emphasizing transitional housing with work requirements and mandatory addiction and mental health treatments, and cutting funding for permanent supportive housing.

and other barriers that could make the new work and reporting requirements more difficult. Additionally, the **Legal Action Center (LAC)**, a Foundation grant partner, expresses deep concern about the impact that Medicaid changes could have on individuals who have substance use disorders and who are incarcerated. While LAC has focused on robust and evidence-based Medication-assisted Treatment (MAT) programs in jails and prisons, MAT is no longer effective if individuals transitioning from incarceration do not have access to their medications because they no longer qualify for Medicaid.

Finally, grant partners express concern about the potential effects of new Medicaid cost-sharing guidance that will reduce state-directed payments (SDPs).[3] While this provision of OBBBA is top of mind for many providers, it does not go into effect until 2028, and states have discretion on how they will structure and implement the requirement. At the same time, OBBBA reduces the cap on state provider taxes from 6% to 3.5% by 2032, limiting a key source of state funding and reducing federal matching funds. Grant partners particularly stress that Medicaid cuts will undermine mental health programs, community supports, and nursing services for children with medically complex needs. While they emphasize the harmful effects of Medicaid cuts on the populations they serve, they also express concern about the deleterious impact of Medicaid cuts on their staff.

ii. ACA Subsidies

OBBBA did not extend the enhanced ACA subsidies originally passed in 2021, resulting in major cost increases for many households. Behavioral health workers' wages are often low enough that many will be substantially affected by the expiration of enhanced subsidies. While grant partners are exploring ways to support their staff members through various employer-sponsored insurance plans, they note that the lapsed subsidies will lead to a decrease in health coverage for their staff. A number of grant partners report that up to 50% of their staff members are also recipients of their services, making ACA subsidies a dual concern – both for their staff members and the individuals they serve.

Related Advocacy Opportunities Cited by Interviewees:

- **Rural Health Transformation (RHT) Program:** The OBBBA authorized the Rural Health Transformation (RHT) Program, a program that allows the Centers for Medicare and Medicaid Services (CMS) to provide approved states with funding to improve rural healthcare delivery by supporting innovative care models, encouraging technology-driven solutions, and attracting and retaining a highly skilled workforce. All 50 states applied for and were awarded grants. Massachusetts has a stated goal of strengthening the full continuum of care, supporting community-led prevention efforts, and increasing service availability. New York has stated goals of establishing rural health partnerships, expanding access to telehealth care, and improving rural access to primary care. Some grant partners note advocacy opportunities encouraging and supporting states to reach these goals.

[3] SNAP will similarly impose major cost-sharing requirements on states over the next several years that have alarmed many state leaders.

- **Reentry Act of 2025:** Grant partners also identify a ripe advocacy opportunity to urge Congress to support the Reentry Act of 2025. This bipartisan legislation would allow states to restore access to health care, including mental health and substance use treatment, to Medicaid-eligible individuals up to 30 days before their release from incarceration, helping ensure continuity of care upon their release.
- **Engaging in Collective Action:** Grant partners and peer organizations acknowledge that the Medicaid-related advocacy space is crowded and that sometimes the most effective action is to join existing collective advocacy efforts, sign on to advocacy letters written by others, and leverage their voices by following the lead of established collective advocacy experts in the field.

B. Executive Order (EO)

Grant partners voice concern over President Trump's July 2025 Executive Order "Ending Crime and Disorder on America's Streets" that expands civil commitment and calls for the institutionalization of people experiencing homelessness and individuals engaging in harm reduction. Among other provisions, the EO encourages the Secretaries of Health and Human Services, Housing and Urban Development, and Transportation to reallocate funding away from certain evidence-based programs (such as harm reduction and housing-first programs) and towards cities and states that criminalize substance use disorder, punish people for sleeping outdoors, or enforce other laws targeting unhoused people.

At HHS, this EO led (both directly and indirectly) to a series of actions that threatened access to effective SUD services. As discussed in detail in the Federal Section (Section VII), following the issuance of the EO, HHS published subsequent guidance excluding federal Substance Abuse and Mental Health Services Administration (SAMHSA) grants from funding certain harm reduction programs, including evidence-based programs like Syringe Services Programs (SSPs), which are associated with an estimated 50% reduction in HIV and Hepatitis C incidence and a five-times greater likelihood of individuals entering drug treatment programs. (SAMHSA later clarified that overdose reversal drugs such as naloxone would remain a priority.) Grant partners note that this policy change reverses decades of narrative change work emphasizing that individuals living with substance use disorders are deserving of dignity, compassion, and agency.

Related Advocacy Opportunities Cited by Interviewees:

- **Protecting Harm Reduction Programs:** Grant partners express interest in identifying meaningful advocacy channels to address policy and funding shifts stemming from this EO. Renewed efforts to reinforce narrative change could be part of an overarching advocacy strategy as well.

C. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

Many grant partners also voice concerns about the reliability and sustainability of ongoing, long-term funding of programs and policies overseen by HHS.

i. Medicaid Reimbursement

Beyond OBBBA cuts and changes, persistently low Medicaid reimbursement rates are one of the challenges grant partners, peer organizations, Foundation staff, and Trustees most frequently raise in interviews. While the Center for Medicare and Medicaid Services (CMS) at HHS establishes reimbursement guidance for adequacy, access, and efficiency, individual states set reimbursement rates for providers in their state. In fact, many states are in the process of, or considering, cutting reimbursement rates even lower on account of cost pressures accelerated by the cuts and state provider tax caps under OBBBA.

As discussed in detail in the Federal Section (Section VII), reimbursement rates are inextricably linked to access to care. For example, the Center for Disease Control's (CDC) National Health Interview Survey found that every $10 increase in Medicaid reimbursement per visit is associated with a 0.5 percentage point increase in the likelihood of parents reporting no difficulty finding a provider for their Medicaid-insured children. Rate increases are also associated with a decreased likelihood that adult patients report being told their providers did not accept their insurance coverage or were not accepting new patients. Research also shows that increased primary care reimbursement rates reduce substance use disorders and mental health conditions for Medicaid-covered adults under 65.

Numerous Tower Foundation peer organizations and stakeholders emphasize the negative impacts that low Medicaid reimbursement rates have on the youth and young adults they serve across the Foundation's core issue areas. For example, **Northeast Arc** relies on Medicaid funding for their clinical services, including 24/7 in-home nurses. Reductions in Medicaid reimbursement rates could force program reductions for individuals relying on home health care services.

Low reimbursement rates pose a particular challenge for dental care beyond existing coverage gaps. As discussed in detail in the Federal Section (Section VII), while the Medicaid Early and Periodic Screening, Diagnostic, Treatment benefit (EPSDT) requires states to provide comprehensive and preventive health care services, including dental coverage, to individuals under 21 years of age receiving Medicaid, only half of children covered by Medicaid actually use dental services each year. Although the federal government allows states to determine if they offer dental benefits to adults receiving Medicaid, Massachusetts and New York have chosen to provide Medicaid recipients with extensive dental coverage. Grant partners, however, comment that dental services have even lower reimbursement rates, ultimately leading to only 41% of dental providers accepting Medicaid.

ii. Section 504

The Rehabilitation Act of 1973 is a landmark piece of disability rights legislation that paved the way for the Americans with Disabilities Act (ADA). In 2024, HHS released a long-awaited final rule implementing Section 504 of the Rehabilitation Act. This rule, the first comprehensive update since the initial Section 504

regulation was implemented more than 50 years ago, requires the provision of services in the most integrated setting appropriate to the needs of individuals with disabilities and prohibits the use of health care value assessment methods that discount the value of individuals' life extension on the basis of theirdisability. The update creates a powerful tool in combatting discrimination based on disability in programs receiving federal financial assistance and those conducted by federal agencies in the areas of health care, public education, child welfare, and transportation.

However, the promise of this new rule is under serious threat due to a legal challenge by nine states. Grant partners are preparing themselves for the potential impact of a successful lawsuit challenging the rule, which could significantly roll back federal anti-discrimination and community integration requirements for people with disabilities. In early March, the parties requested that the court set a schedule for summary judgment filings this summer.

It is interesting to note that Section 504 is a compelling example of federal programming that has historically drawn support from across the political spectrum – including, in particular, from college-educated suburban Republican women. This dynamic has created openings for bipartisan engagement, and this cohort of supporters and advocates has been part of recent successful advocacy efforts with Republican Members of Congress and Administration leaders on disability rights issues.

iii. Cuts for Immigrants

Throughout stakeholder interviews, numerous grant partners express profound concern about the immigrant populations they serve. Following new eligibility restrictions for immigrants under OBBBA, HHS expanded its list of health and social programs that are considered "federal public benefits," as defined by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA). Expanding the definition of "federal public benefits" has the effect of restricting access to services for a large number of lawfully present foreign nationals, including DACA recipients and individuals with Temporary Protected Status.

HHS's updated rule adds to the list of restricted federal public benefits critical programs such as Head Start, Certified Community Behavioral Health Clinics, Community Mental Health Services Block Grant, Community Services Block Grant (CSBG), and SAMHSA-funded SUD prevention and recovery services. While HHS intended this rule to take effect upon publication in July 2025, New York, Massachusetts and 19 other states and the District of Columbia sued the federal government and were granted a preliminary injunction. Again, grant partners express concern about the potential impact of excluding immigrants from such programs and ongoing policy uncertainty.

iv. SAMHSA Cuts

As discussed in detail in the Federal Section (Section VII), SAMHSA abruptly cut approximately $2 billion in federal grants in January 2026 before quickly restoring funding following widespread, bipartisan outcry from members of Congress and the advocacy community. Although HHS reversed the threatened SAMHSA cuts, grant partners and peer organizations express deep concern that the initial announcement of attempted cuts might not bode well for some programs supporting mental health and substance use treatment and might foreshadow a policy shift in the focus of future SAMHSA grants.

Related Advocacy Opportunities Cited by Interviewees:

- **New SAMHSA Grant Priorities:** Multiple grant partners express interest in better understanding SAMHSA's current and future funding priorities (in light of the recent threatened elimination and restoration of $2 billion in grants) and finding effective ways to advocate for innovative, evidence-based, effective programs. (For a comprehensive analysis of current and future SAMHSA funding priorities, and what can be learned from the recent cancellation and restoration of funds, see the Federal Section of this Landscape Analysis (Section VII: Federal Landscape, Policy Context, Advocacy Opportunities.)
- **Innovation in Behavioral Health (IBH):** Grant partner Value Network describes that it was chosen as a partner for the Center for Medicare and Medicaid Services' (CMS) Innovation in Behavioral Health (IBH) model. New York was one of three states awarded grants by CMS. This is a seven year model (2025-2032) that will be implemented in Western New York, with Value Network as the implementation partner. Under the IBH Model, patients will receive more integrated, person-centered care that addresses their full range of health needs, supporting better long-term health, fewer hospitalizations, and improved physical and behavioral health outcomes. This powerful opportunity highlights the importance of advocating to protect federal funding, including funding for innovative approaches. This is especially true for Center for Medicare and Medicaid Innovation (CMMI) funding (a specialized, legislative-driven stream within the broader CMS budget), since CMMI invests in testing new, innovative, and often alternative pay-for-outcomes models to reduce healthcare costs and improve quality.
- **Medicaid Section 1115 Waivers:** Both Massachusetts and New York have Medicaid Section 1115 demonstration waivers that expire in 2027 and will be up for renewal in 2028. Section 1115 Waivers are approved by CMS and give states flexibility to test and operate innovative programs to improve access and quality of healthcare. Current demonstrations in Massachusetts and New York focus on improving continuity of coverage, reducing health inequities, and increasing Medicaid payment rates for behavioral health providers. Because waivers often reflect the current Administration's priorities, grant partners express concern that waivers that grant partners view as meaningfully improving care might not be approved. As part of Massachusetts' waiver extension development, Massachusetts' Executive Office of Health and Human Services hosts virtual sessions to gain community feedback, and it will share the waiver for public comment in Summer/Fall 2026, before submitting the waiver to CMS at the end of the year. Engaging in upcoming community feedback sessions presents a potential advocacy opportunity.

D. DEPARTMENT OF LABOR (DOL) & WORKFORCE ISSUES

Foundation stakeholders name long-standing concerns about compensation and working conditions, along with ongoing concerns about the subminimum wage, as key challenges that are ripe for advocacy.

i. Compensation and Working Conditions

Workforce shortages – and the ability to attract, retain, and support high-quality staff – emerge as a consistent theme across stakeholder interviews. While behavioral health jobs previously were compensated at 3-4 times the state minimum wage, grant partner **New York Alliance for Inclusion and Innovation** reports that the average rate among providers in their partner agencies is currently $18.55, just slightly above the $16.00 minimum wage in New York.[4]

Beyond compensation challenges, grant partners, peer organizations, Tower staff, and Trustees also stress that workers supporting individuals with intellectual disabilities are still widely undervalued. Grant partners particularly note that direct support professionals (DSPs) experience high rates of stress and burnout stemming from low wages, outsized workload, and a general lack of support for the profession, ultimately resulting in decreased job satisfaction and increased turnover.

ii. Subminimum Wage

The Fair Labor Standards Act (FLSA) currently allows employers to apply for section 14(c) waivers that permit them to pay people with disabilities a subminimum wage. Grant partner **Center for Public Representation** submitted a comment supporting a notice of proposed rulemaking (NPRM) issued by the Biden Administration to phase out the subminimum wage waiver certificate – a step toward ensuring dignity for individuals with disabilities and providing them with competitive, integrated employment (CIE). While the NPRM resulted in over 17,000 public comments during the Biden Administration, it was ultimately withdrawn by the Trump Administration. Ending the subminimum wage has been a major issue of bipartisan interest among congressional leaders as well, including House Education and the Workforce Ranking Member Bobby Scott (D-VA).

Related Advocacy Opportunities Cited by Interviewees:

- **Transformation to Competitive Integrated Employment Act (TCIEA):** Grant partners recognize a current advocacy opportunity to urge Congress to support the Transformation to Competitive Integrated Employment Act (TCIEA). Building upon the goals outlined by the Workforce Innovation and Opportunity Act (WIOA), this piece of legislation would provide grants to states and employers to transition away from subminimum wage employment, prohibit the approval of new 14(c) certificates, and phase out subminimum wages within five years. The bill has bipartisan sponsors, including Representative William R. Keating (D-MA-9) and Representative Nicole Malliotakis (R-NY-11) in the House, and Senator Kristen Gillibrand (D-NY) and Elizabeth Warren (D-MA) in the Senate. TCIEA has received support from many organizations that serve people with disabilities, including the American Association of People with Disabilities (AAPD), Autistic Self-Advocacy Network, and the National Disability Rights Network.
- **Phasing out Subminimum Wage:** The NPRM discussed above built on the Workforce Innovation and Opportunity Act's (WIOA) foundational measures to incentivize CIE and limit the use of subminimum

[4] Excluding NYC, Long Island, and Westchester

wage for people with disabilities. WIOA also requires vocational rehabilitation (VR) agencies to reserve at least 15% of funding for pre-employment transition services for youth with disabilities. Twenty states have passed legislation to end or phase out the subminimum wages for people with disabilities. Massachusetts and New York have not done so, although the Massachusetts Department of Developmental Services has phased out the subminimum wage for a specific subset of individuals and employers. Members of the New York State Legislature have introduced legislation phasing out subminimum wages in the past five legislative sessions; and, as noted above, this issue has gained bipartisan support in Congress, with Ranking Member Bobby Scott naming it as a priority. Continuing to cultivate champions on this issue presents an advocacy opportunity.

Grant partners and peer organizations also identify education issues related to disabilities, school discipline, civil rights, and program administration as policy challenges in need of advocacy engagement.

i. IDEA Funding

The Individuals with Disabilities Education Act (IDEA) authorizes the federal government to pay 40% of the "excess cost" of educating children with disabilities (i.e., 40% of the cost above the national average per-pupil expenditure (APPE) for regular education), but actual federal funding is dramatically lower. In FY2025, the federal government covered only 10.2% of APPE, the lowest amount of coverage since 1997. This equates to a funding gap of over $2 billion in New York and over $600 million in Massachusetts. Foundation stakeholders highlight the continuous burden placed on states to cover the shortfall.

ii. IDEA Age Limits

IDEA requires states to provide early intervention services to children under 2 and special education services between "the ages of 3 and 21, inclusive." States have varying interpretations of "21 inclusive," and both Massachusetts and New York recommend or require students to receive services through their 22nd birthday, or high school graduation, whichever comes first. Numerous Foundation stakeholders cite insufficient transition support during the "disability cliff," and grant partner **Melmark** reports that its clients often transition to adult services with insufficient support or clinical sophistication to meet their ongoing needs; unfortunately, some even end up at state institutions after aging out of their special education schools at age 22.

iii. School Discipline

Foundation stakeholders also express concern about exclusionary discipline policies that disproportionately affect students with disabilities. The "school-to-prison pipeline" (or special education-to-prison pipeline) disproportionately affects students with disabilities, decreasing academic achievement and increasing engagement with the criminal legal system. Although correctional facilities are required to provide students with a free, appropriate public education (FAPE) and comply with IDEA, grant partners note that less than half of students in correctional facilities receive appropriate services.

iv. Autism Diagnoses Wait Times

While Medicaid mandates screening for children through Early and Periodic Screening, Diagnostic, Treatment requirements (EPSDT), and IDEA requires services for students with Autism Spectrum Disorder (ASD), grant partners note that children often experience wait times of up to 18 months to see a provider and receive an ASD diagnosis. After receiving a diagnosis, some children wait over 18 months on waitlists for access to Applied Behavior Analysis (ABA) programs. Citing funding barriers, screening gaps, and equity concerns, a number of stakeholders emphasize the need for universal screening.

v. Office of Civil Rights

Since President Trump took office in 2025, the Department of Education's Office of Civil Rights (OCR) has lost over half of its staff. Grant partners comment that they are already witnessing the impact of this staff reduction on OCR cases, with major implications for the populations they serve. Recently, OCR has routinely dismissed ongoing cases (particularly those related to disability accommodations); pursued those cases that are easiest to resolve; switched its focus to transgender student policies (including challenging existing policies that allow transgender students to use facilities or participate in sports teams that align with their gender identity); doubled down on reverse racial discrimination cases (investigating DEI initiatives and race-conscious programming); and rescinded guidance that interpreted Title IX to protect LGBTQ+ students.

vi. Interagency Agreements

Grant partners also express apprehension about various interagency agreements (IAAs) that are part of the Trump Administration's effort to dismantle the Department of Education and "return" education authority to the states. IAAs announced in 2025 and 2026 move core education programs to other federal agencies, with the stated goal of greater efficiency and decreased federal bureaucracy. Although IAAs only shift administrative responsibility and do not actually end current ED programs, grant partners are concerned about the impact of weakened program management, accountability, and oversight.

vii. Career and Technical Education

Congressional education leaders have expressed strong support for career and technical education under the Perkins Act and interest in reauthorizing the law given major changes in the labor market and education sector since its last reauthorization in 2018. However, despite discussion in the past two Congresses, significant legislative action to strengthen Perkins has not emerged as a top priority and total funding remains low relative to policymakers' expressions of support. Grantees reference interest in ongoing CTE advocacy in light of the potential for productive bipartisan engagement.

Related Advocacy Opportunities Cited by Interviewees:

- **Keep Our Promise to America's Children and Teachers Act:** The Keep Our Promise to America's Children and Teachers Act (Keep our PACT Act) has been introduced in the House and Senate for the past 2 decades. The Keep Our PACT Act creates a 10 year plan for the federal government to gradually meet its obligation to fully fund IDEA. Senator Chris Van Hollen (D-MD) originally introduced the bill in 2003 as a House member (D-MD-8), and he has reintroduced the bill in each Congress. Although the

legislation is supported by a plethora of nonprofits – including the National Council for Learning Disabilities, The Arc, and others, the legislation has never gained bipartisan support or been called for a vote. (Given the political climate, it is worth noting that this issue has strong support among many Republican community advocates.) In addition, the National Education Agency (NEA) shared an action alert for stakeholders to contact their Members of Congress and urge them to pass the legislation, presenting an advocacy opportunity for Foundation stakeholders. Specifically, grant partners and peer organizations could elevate community voices in this ongoing effort, helping to provide a local, on-the-ground perspective on the impact of funding shortfalls and the need for public investment.

- **Returning Education to the States Tour:** Education Secretary Linda McMahon is completing her "Returning Education to the States" tour, in which she is visiting all 50 states to hear from students, teachers, and families. Grant partners note that this is a potential opportunity for nonprofit organizations, including Tower stakeholders, to uplift their priorities and underscore the importance of supporting youth mental health and students with disabilities.
- **Career and Technical Education:** As noted above, Foundation stakeholders observe that career and technical education (CTE) has largely been a bipartisan issue, and this is therefore an area where federal legislative action seems plausible. Grant partners express interest in upcoming advocacy opportunities regarding high quality CTE.

F. Department of Justice (DOJ)

Foundation stakeholders elevate concerns about major funding and staff cuts at DOJ and the implication of those cuts on the communities they serve in Massachusetts and New York.

i. DOJ Funding Cuts

In addition to the impacts of OBBBA, grant partners are experiencing funding uncertainty and programmatic concerns as a result of the Trump Administration's cuts to Department of Justice (DOJ) grants.

Grant partner Mental Health Advocates of Western New York (MHAWNY), for example, relies on the DOJ Office of Juvenile Justice and Delinquency Prevention's (OJJDP) grant funding of Court Appointed Special Advocates/Guardians ad Litem (CASA/GAL). CASA is one of MHAWNY's core programs to provide mental health support for youth, including children with disabilities. While the recently threatened CASA/GAL grant terminations were eventually reinstated, MHAWNY had already laid off staff members as a result of the lapse, and potential termination, of funding. Concern about funding uncertainty and service volatility (both at DOJ and elsewhere) is a recurring theme among grant partners.

ii. DOJ Staff Cuts

Some grant partners are also anticipating challenges resulting from the 70% reduction in lawyers in the DOJ Civil Rights Division since President Trump took office in 2025, namely lapsed enforcement of civil rights laws – particularly involving cases protecting the rights of people with disabilities. This concern is only heightened given similar cuts to the Office for Civil Rights at the Department of Education.

[5] Secretary McMahon visited New York on January 9, 2026.

Civil Rights Division since President Trump took office in 2025, namely lapsed enforcement of civil rights laws – particularly involving cases protecting the rights of people with disabilities. This concern is only heightened given similar cuts to the Office for Civil Rights at the Department of Education.

Related Advocacy Opportunities Cited by Interviewees:

- **Encouraging Enforcement of Disability Rights:** While Foundation stakeholders do not identify specific DOJ-related advocacy opportunities, those that work with the legal system point to the importance of advocating for meaningful enforcement of civil rights laws.

G. Department of Homeland Security

Many Foundation stakeholders express deep concerns about the Administration's immigration policies and practices.

i. Immigration

Throughout numerous interviews, Foundation stakeholders identify significant challenges related to current immigration policy and describe the deleterious impact on both program staff and the communities grant partners serve. Specifically, grant partners who are behavioral health providers and community based organizations report that the increased presence of U.S. Immigration and Customs Enforcement (ICE) in their communities, alongside the unprecedented rise in enforcement efforts, has made community members less likely to seek out and access services.

While grant partners note that they do not question those they serve about their immigration status, immigrants needing services have become increasingly hesitant to travel even 30 minutes to access services. Some providers also attribute an increase in requests for telehealth services to an increased fear of immigration enforcement. Additionally, grant partners comment that immigration policy is having a negative impact on how comfortable parents, including those of children with disabilities or mental health needs, feel interacting with their children's school and support systems. Some grant partners and peer organizations also express deep concern about young children, and children who are nonverbal, being detained by ICE and having no support or supervision. Stakeholders also stress the disturbing connection between immigration enforcement and increased levels of childhood trauma, anxiety, and fear.

Grant partners also observe that the negative impact of current immigration enforcement practices extends far beyond undocumented individuals and reaches the entire community. Some grant partners also report experiencing workforce challenges as a result of uncertainty in the U.S. visa system and ongoing Trump Administration immigration policy shifts. For example, roughly 400 of grant partner **Northeast Arc's** 1,495 staff members are "non-immigrants" (i.e., individuals temporarily authorized to be in the United States) – leaving approximately a quarter of the staff unable to plan for their futures and **Northeast Arc** unable to anticipate its workforce needs. While applying for asylum puts a hold on removal or deportation (though not detention), some grant partners are concerned that the Trump Administration could attempt to change that policy. Finally, many grant partners raise concerns that increased immigration enforcement makes it difficult to recruit and retain skilled workers.

Related Advocacy Opportunities Cited by Interviewees:

- **Education and Resources:** While numerous Foundation stakeholders raise immigration policy as a significant challenge, they express uncertainty about potential effective responses. Rather, they uniformly describe the need for education and access to reliable resources in order to determine appropriate advocacy opportunities in this complex policy and political environment.

H. Additional Federal Policy Challenges

In addition to referencing specific federal policy issues, grant partners and peer organizations in both Massachusetts and New York express general concerns about the effects of rapid shifts in federal policy, and they note that these shifts impact their inability to plan ahead. Grant partners are apprehensive about the reliability and sustainability of previously guaranteed funding streams, and some voice fear that the Trump Administration might withdraw federal funding from largely Democratic states and target those states for investigation. Other stakeholders voice anticipatory concern over the Trump Administration's proposal to require that federal funding applicants and recipients submit signed certifications prohibiting DEI programs.

Finally, a few grant partners also mention: passthrough funds from HUD (Section 8 vouchers and project-based subsidies) and passthrough funds from HHS – including Delivery System Reform Incentive Payment (DSRIP); Home and Community Based Services (HCBS); Low-Income Home Energy Assistance Programs (LIHEAP); and Preadmission Screening and Resident Review (PASRR) – as areas of ongoing concern in which access to reliable resources and advocacy advice would be helpful.

2. STATE FUNDING CHALLENGES, POLICY SHIFTS, AND ADVOCACY OPPORTUNITIES

During interviews, while Foundation grant partners and peer organizations focus the majority of their comments on a wide range of federal policy issues, Foundation stakeholders also comment on a number of targeted state policy issues and advocacy opportunities, as described below.

A. Massachusetts

Grant partners in Massachusetts express frustration with the current pace of spending of opioid settlement funds. The latest reports show that Massachusetts municipalities have only distributed 17% of the $113.7 million in settlement funds, and grant partners observe that funds are being used to cover decreasing hospital budgets and to supplement funding for police departments as opposed to targeted, effective SUD activities. While stakeholders do not specifically identify other Massachusetts challenges in much detail, they express a general interest in understanding the advocacy landscape in the Commonwealth and note a series of potential advocacy opportunities identified below.

Related Advocacy Opportunities Cited by Interviewees:

- **Opioid Settlement Funds:** Grant partner Legal Action Center sees an advocacy opportunity supporting the direction of opioid settlement dollars to fund harm reduction programs that would close without additional funding.
- **Behavioral Health for Children and Adolescents (BHCA):** The Children's Mental Health Campaign (CMHC) continues advocacy efforts for the Behavioral Health for Children and Adolescents (BHCA) benefit. The BHCA benefit requires private insurers to cover behavioral health services for youth, including mobile crisis intervention, in-home behavioral services, and Community-Based Acute Treatment (CBAT). Despite BHCA being established in 2019, many families are still struggling to access these services.
- **Protect Education Equity Act:** Massachusetts Advocates for Children (MAC) played a leading role in a statewide coalition of more than 50 organizations, including grant partners Center for Public Representation (CPR) and Center for Law and Education (CLE), that successfully advanced the Protect Education Equity Act, which became law in August 2025 and strives to ensure equitable access to educational services, including for students with disabilities. As mentioned above, the legislation comes at a time when federal protections for students with disabilities and students from immigrant families are increasingly uncertain. Governor Healey highlighted the law as an example of Massachusetts's commitment to "fostering safe and inclusive schools." Ongoing advocacy efforts are needed to support strong implementation across the Commonwealth so that the promises of this law translate into real, lasting change for students and families.
- **Clean State Legislation:** Stakeholders recognize an opportunity to urge lawmakers in Massachusetts to support Clean Slate legislation introduced this legislative session, sent to study order, and poised for reintroduction next session. The bill would create an automated system to seal eligible Criminal Offender Record Information (CORI) once individuals meet the required waiting periods, removing the need to file petitions or navigate complicated administrative processes. By automating record sealing, the legislation aims to reduce barriers to employment, housing, and education for individuals with past records.
- **Treatment, Not Incarceration:** Grant partners and peer organizations identify a current advocacy opportunity to urge Massachusetts lawmakers to support the Treatment, Not Incarceration legislation. This legislation would require courts to prioritize substance use treatment for individuals on probation or pretrial release and prohibit incarceration when relapse is the only violation and the individual is engaged in treatment.

B. New York

A number of grant partners in New York express gratitude that New York State officials have reaffirmed their commitment to diversity, equity, and inclusion programs, but they also express fear of retaliation from the Trump Administration. Although previous retaliation efforts have resulted in states bringing lawsuits and the federal government dropping their appeals, grant partners and partner organizations express concern that the State's refusal to comply with Executive Orders, such as President Trump's Executive Orders relating to K-12 education, will lead to a reduction in funding for core programs.

Additionally, grant partners in New York are still recovering from the effects of illegal work stoppages from New York State Department of Corrections and Community Supervision (DOCCS) staff. Twelve people died during a prison guard strike orchestrated in response to Governor Hochul signing of the Humane Alternatives to Long-Term Solitary Confinement Act (HALT). The HALT Act limits the number of consecutive days in which someone who is incarcerated can remain in solitary confinement and bans solitary confinement for people with disabilities.

While stakeholders do not specifically identify other New York state challenges in much detail, they express a general interest in understanding the state advocacy landscape and note a couple of potential advocacy opportunities detailed below.

Related Advocacy Opportunities Cited by Interviewees:

- **Cultivating Policymaker Champions in District:** Grant partners highlight that U.S. Congressman (and former New York State Senator) Tim Kennedy (D-NY-26) is a strong advocate and supporter of policies that empower people with disabilities. As the only occupational therapist in Congress, Representative Kennedy uses his voice to champion early intervention services and funding for IDEA and other programs that fund special education. Grant partners note the importance of cultivating like-minded champions in the state of New York.
- **Transitional Reentry Act:** The New York Legislature has introduced the Transitional Reentry Act. The legislation would require state prisons and local jails to enroll Medicaid-eligible individuals in Medicaid prior to their release, ensuring they can access essential health care as soon as they return to their community. The Legal Action Center (LAC) published a fact sheet and sign-on letter encouraging the state legislature to pass this bill.

3. CROSS-CUTTING SYSTEMIC ISSUES

A. Stigma and Bias

Multiple grant partners, peer organizations, Tower staff, and Trustees emphasize the urgent need to reduce stigma relating to disabilities and mental health treatment. Grant partners note that stigma and bias (stemming from both healthcare providers and the community) prevents people living with substance use and mental health disorders from seeking help, participating in evidence-based harm reduction programs, and communicating honestly with their healthcare providers about their conditions. For people with mental health conditions, stigma can result in delayed diagnoses, isolation, and increased suicide risk. People with intellectual disabilities also experience a high level of stigma from healthcare providers that can diminish the quality of care, the accuracy of diagnoses, and the quality of service delivery. Young people can also experience stigma from their parents and family members, creating additional barriers to access. Beyond the healthcare context, stigma can contribute to feelings of unworthiness, community exclusion, and housing and employment discrimination.

B. Policy Silos

While the Tower Foundation's priority issue areas are interconnected in multiple ways, a recurring theme in interviews is that the systems relating to each issue area largely operate independently of one another. This siloing leads to redundancies, creates service inefficiencies, and perpetuates gaps in policy. Grant partner **Children's Mental Health Campaign (CMHC)**, for example, observes that what affects children, affects the entire family; yet relevant policy remains disconnected. Grant partners, peer organizations, Tower staff, and Trustees all express a need to de-silo systems and capitalize on advocacy opportunities for collaboration and integration, with the goal of furthering better outcomes for youth.

C. Incentivizing Innovation, Rewarding Results, and Including Nonprofits' Voice in Policy Decision-making

Foundation stakeholders also raise concerns about the way government currently funds programs, and they urge an increased focus on innovation, evidence-based policymaking, and the inclusion of the nonprofit community in policymaking.

Related Advocacy Opportunities Cited by Interviewees:

- **Fund Innovation:** In response to the stigma individuals with intellectual disabilities face from healthcare providers, grant partner **Melmark** has developed bespoke medical practices for their clients. Melmark shared that conventional practices are not respectful of people with high acuity medical and behavioral needs. They are relying on philanthropic dollars to fund this practice, and they have built out partnerships with specialty care providers. This insight highlights an opportunity to advocate for sustained funding for innovation.

- **Prioritize Evidence-Based Policy Making:** Multiple stakeholders also cite the need to advance evidence-based policymaking and fund programs that have demonstrated efficacy.
- **Include Nonprofit Program Providers:** Grant partners and peer organizations repeatedly stress the need for policymakers to take into account the expertise of nonprofit community program providers when making policy decisions directly affecting communities. A few stakeholders also encourage more participatory budgeting processes that include community organizations' input.

4. THE IMPORTANCE OF ADVOCACY IN SYSTEMS CHANGE & PHILANTHROPY'S CRITICAL ROLE

Please note that for this final segment focusing on "The Importance of Advocacy in Systems Change & Philanthropy's Critical Role," all the "Related Advocacy Opportunities Cited by Interviewees" are consolidated at the end.

A. Need for Reliable Resources

Grant partners and peer organizations report that they frequently feel overwhelmed by the number of government funding streams and the scope of public policies relevant to their work, and they find it challenging to effectively track sometimes conflicting information without assistance. Some grant partners express concern that there are not enough readily available resources with clear, reliable, and accurate information; other grant partners express feeling overwhelmed by the volume of information available; and other stakeholders express frustration with their inability to discern materials' credibility.

B. Need for Philanthropic Funding of Policy Advocacy

Throughout the vast majority of interviews, stakeholders echo a theme that organizations' need to engage in policy advocacy, and the associated need for philanthropy to fund policy advocacy efforts, is "more important now than ever." [6] Multiple stakeholders explain that philanthropy can achieve more impact with systems change investments than with grant-making alone, and they further note that while philanthropy cannot fill potentially vast public funding gaps, philanthropy can play a critical role helping organizations advocate for public funding to remain intact (or even increase). Speaking more specifically, numerous grant partners and peer organizations expressly encourage the Tower Foundation to increase its investment and involvement in policy advocacy.

[6] As noted in the Introduction to this Section, in interviews, stakeholders focus almost exclusively on policy advocacy rather than other forms of advocacy such as communications, convenings, narrative change work, public engagement efforts, power mapping, and field leadership. Section II of this Landscape Analysis (Systems Change: The Role of Policy Advocacy) specifically discusses the role of policy advocacy as a key element of systems change, and Section III of this Landscape Analysis (Legal Context: Law Governing the Engagement of Private Foundations and Public Charities in Lobbying and Advocacy Activities) details the distinction between permissible "advocacy" and "lobbying" activities.

Although many grant partners are not exclusively policy or advocacy organizations, they report that many of the challenges they are experiencing as direct service providers are a result of policy and funding decisions at the federal, state, and local levels. Grant partners express frustration about the depth and pace at which philanthropy is funding policy and advocacy efforts and the effect that could have on the communities they serve. Concerned about potential decreases in public funding for programs serving children and young adults, grant partners anticipate that states will fund fewer discretionary programs, including access to early intervention and prevention services. Grant partners observe that this will not only increase the need for philanthropic funding of community-based programs, it will also increase the need for significant philanthropic investment in policy advocacy initiatives. As multiple grant partners and stakeholders observe, while philanthropic dollars and charitable giving will always be necessary, philanthropic dollars can not come close to replacing federal funding, so it is critical that philanthropy increase its commitment to policy and advocacy efforts – particularly those focused on preserving public funding.

Many grant partners specifically note that the needs of the populations they serve are far too large for philanthropic funding to address alone, and they emphasize that it is essential that philanthropy fund policy and advocacy work designed to influence government appropriations in order to achieve outsized impact. The **Scattergood Foundation** notes that "if advocacy is a lever," its leverage can be "way bigger than the endowment" of many foundations by focusing on public funding. Echoing the importance of investing in systems change, the **Schuyler Center** explains that "if you want to stop the bleeding, you do direct service; and if you want to prevent the bleeding in the first place you change the landscape." **Blue Cross Blue Shield of Massachusetts Foundation**, likewise makes clear that there is "definitely room for philanthropy" in systems change. Emphasizing the need for philanthropy to engage in systems change, **Liftoff Western New York** states that "philanthropy has a role, but not the only role. For us to have systemic change, [philanthropy] has to engage our government and policymakers."

> *"If advocacy is a lever, its leverage can be way bigger than the endowment of many foundations."*
> **– Scattergood Foundation**
>
> *"If you want to stop the bleeding, you do direct service; and if you want to prevent the bleeding in the first place you change the landscape."*
> **– Schuyler Center**

Grant partners also comment on the types of grants foundations make to support systems change work. Some stakeholders emphasize that when funders make investments beyond direct service, it is helpful when foundations allow their grantees a degree of flexibility to adapt to changing policy circumstances. Other stakeholders note that philanthropic funding of systems change work – particularly through unrestricted general operating grants – should permit community organizations to advocate to the full extent allowed under relevant tax law, and convene, build momentum, and leverage impact, rather than focus exclusively on a continuous cycle of grant applications and deliverables. Grant partners also highlight that many funders

unnecessarily restrict lobbying and advocacy work in their grant agreements, leaving organizations unable to engage fully in critical advocacy work as allowed under relevant law.

Grant partners and peer organizations also note that by supporting advocacy, philanthropic dollars have a broader and more sustained impact. By supporting efforts to shape policy, philanthropy can support their grantees in influencing the systems that ultimately determine whether services are available, accessible, and sustainable. Stakeholders also comment that funding advocacy efforts dedicated to protecting federal funding streams (that is, "playing defense") is just as important as funding individual programs, and the Foundation's Board of Trustees suggests that success in systems change could look like ensuring that the government continues to fund evidence-based programs that support the Tower Foundation's core populations.

Finally, in addition to urging philanthropy to fund policy advocacy efforts through their grantmaking, many stakeholders also suggest that foundations themselves should engage in systems change work – whether through advocacy, communications, convenings, resource distribution, or field leadership.

C. Need for Collective Advocacy & Coalitions

Foundation stakeholders emphasize that philanthropy should not approach advocacy solely by acting on its own or by investing exclusively in individual organizations' advocacy efforts. Rather, grant partners and peer organizations observe that by supporting collective advocacy, philanthropy can take advantage of economies of scale, and by supporting advocacy coalitions, philanthropy can leverage its investment in experienced advocacy leaders. Grant partners note that philanthropic support of coalitions is particularly important when the advocacy space on a given issue is crowded with multiple organizations. Some interviewees also note that foundations are most effective when they build deep relationships and support advocacy organizations, coalitions, and intermediaries that already have expertise in policy and advocacy. This can include funding advocacy organizations, supporting collective advocacy coalitions, and helping elevate the voices of groups of nonprofit leaders and community members. Reflecting on this theme, the Health Foundation for Western and Central New York notes that "the worst thing philanthropy can do is" act on its own and "charge in without having relationships in the space."

Some grant partners report having multiple staff members engaging in policy and advocacy work. However, many others report having limited policy capacity and rely on other organizations, including partnership networks, to meet some of their needs (such as CMHC and Value Network). Multiple grant partners also emphasize the cost effectiveness of collective advocacy and the "insurance" or "coverage protection" that comes with raising a collective voice. Working in coalitions also allows partner organizations to combine their staff capacity and more effectively engage in large scale advocacy efforts. While grant partners and peer organizations soundly endorse collective efforts, many also emphasize the need for a capable, experienced lead organization to coordinate, align, and sustain collective advocacy efforts in order for a collective to achieve its advocacy goals.

Some grant partners express difficulty identifying funders who are willing to fund systems change work that might not have immediate impact – which is often unrealistic given the variable pace of policy change. This concern about immediate impact was echoed by organizations that note that their Boards often focus solely on advocacy efforts that have a measurable impact that can be reported by the end of a one to three year

grant period. Some peer organizations also share that they have witnessed a division among what philanthropies are prioritizing in the midst of an uncertain federal funding environment. Some funders are responding to federal uncertainty by prioritizing funding direct service work, while others are responding by strengthening funding for advocacy capacity-building, while some are doubling down on their support for collective advocacy. Foundation stakeholders note that the latter emphasis on collective advocacy can prove to be an especially cost-effective and high-impact approach for philanthropy.

Grant partners, peer organizations, staff, and Trustees also emphasize that systems change requires coordinated efforts across organizations with capable leadership rather than isolated action. As The Children's Agenda observes, the most trusted and best policy change organizations are "those that embrace and exist in coalition." When organizations only advocate for their own priorities, groups are often left out. For example, Liftoff Western New York notes that without a children-focused collaborative like theirs, children are often left out of conversations about policy change. Additionally, collective advocacy is necessary to spread responsibilities across multiple organizations. In the current climate, many providers are overworked, and they often lack time or resources to engage in deep systems change work. Peer organizations also note that while there are many advocacy voices, there is a clear gap in the space because there is not one organization that convenes all of the grant partners in any of the Tower Foundation's issue areas. Grant partners and peer organizations express confidence that the Tower Foundation can be a leader in helping to close that gap. Stakeholders routinely cite leadership development and coalition building as necessary tools to build the relationships and collaboration needed to pursue long term policy change. Patrick P. Lee Foundation also shares that while foundations often shy away from systems change because they feel like their voices are not the most meaningful, they actually have a responsibility to "lift up the voices of those they serve and hold the microphone" to amplify community needs.

> *"[The most trusted and best policy change organizations are] those that embrace and exist in coalition."*
> **– The Children's Agenda**
>
> *"[Foundations should] lift up the voices of those they serve and hold the microphone."*
> **– Patrick P. Lee Foundation**

Finally, a number of Foundation stakeholders note that while the **Think Bigger Do Good Policy Series** provides extremely insightful, helpful, and clear recommendations to advance the delivery of mental health and substance use disorder care, the policy series itself has not yet yielded concrete policy change. They note that this underscores the importance of complementary investments in collective advocacy and coalition-building to translate strong innovative policy recommendations into meaningful policy change. This investment would further leverage the Foundation's already established credibility as a trusted partner and respected voice in the field for programmatic information and policy insights.

D. Need for Systems Change

Foundation stakeholders emphasize that systems change is necessary because many of the barriers facing nonprofits are structural and cannot be solved through direct service programs alone. While nonprofits provide essential services, they also operate within systems that are fragmented, underfunded, or difficult to navigate. Without changes to those systems, even effective programs are often unable to sustain their impact over time. As the Tower Foundation Board notes, changing systems requires explicit structural change. The **Health Foundation for Western and Central New York** echoes this view, observing that while funding organizations doing direct service is necessary, the effects of those organizations' work will not be sustainable if the systems surrounding the work do not change.

Throughout many interviews, multiple stakeholders express their shared understanding that meaningful progress requires addressing the policies and structures that shape service delivery. Stakeholders also underscore that the policy systems directly shape the work of Tower grant partners. Changes to funding streams and regulatory requirements can quickly affect whether or not nonprofits are able to provide services or expand their programs. Foundation stakeholders are clear that advocacy is necessary not only to advance new policy solutions, but also to protect current systems that are working. The Schuyler Center notes that working toward systems change usually has a "pretty big return on investment" for philanthropic dollars. The Health Foundation for Western and Central New York also notes that "anything that is going to turn the curve has to be done at scale, and you can't have anything at scale unless the system is supporting it." If the system itself does not change, even well-designed, evidence-based, effective programs and interventions will remain limited. They further explain that even if you "give grants for something amazing, it is not sustainable if the systems around it don't change."

> *"Anything that is going to turn the curve has to be done at scale, and you can't have anything at scale unless the system is supporting it."*
> **– Health Foundation for Western and Central New York**
>
> *"[Working toward systems change usually has] a pretty big return on investment for philanthropic dollars."*
> **– Schuyler Center**

Stakeholders note that narrative change and communications work can be important complements to policy advocacy efforts in a holistic systems change strategy – particularly when combatting stigma in various issue areas.

E. Need for Advocacy Capacity-Building

Grant partner organizations that do not focus exclusively on advocacy note a wide range of staff capacity for policy and a strong appetite for advocacy capacity-building and applied training. Although many Foundation stakeholders speak about the importance of policy advocacy, when asked in interviews about advocacy capacity, they observe that grant partners and philanthropies often lack the capacity and training needed to

confidently engage in advocacy work. Advocacy requires a specific set of skills, and stakeholders describe the need for training that includes: understanding legislative processes, mastering policy issues, devising a compelling advocacy strategy, communicating effectively with policymakers (reaching both "head and heart" with storytelling and data), making a policy "ask," engaging the proximate voices of the constituents organizations serve, and understanding the laws governing nonprofits' and private foundations' engagement in advocacy and lobbying. Many grant partners note that they do not have the resources or capacity to feel confident leading or engaging in advocacy without appropriate capacity-building training.

One of the challenges most often cited by stakeholders is confusion about the laws governing advocacy and lobbying. Grant partners evidence a strong appetite for capacity-building training that focuses on advocacy and lobbying rules relevant to nonprofits, and the Tower Foundation staff, leadership and Board expresses interest in better understanding advocacy rules relating to private family foundations. While some grant partners express concern about unintentionally "crossing the line" and putting themselves at risk, others note that this fear can unnecessarily discourage organizations from engaging in critical advocacy, and still others note their determination to engage in advocacy "up to" (but not over) legal limits. Both seasoned and newer advocates emphasize the importance of access to training that clarifies the legal rules and guidelines relating to nonprofits' and foundations' advocacy engagement.

Participants also point to the importance of broader advocacy capacity-building. This includes training on how policy change happens, how to participate effectively in coalitions, and how to communicate policy priorities to decision-makers. Grant partners and peer organizations note that they value programs that help organizations better understand legislative processes and develop strategies for policy engagement.

In addition to staff training, Foundation stakeholders emphasize that Boards often need additional support and education around advocacy. Peer organizations and Tower Trustees specifically observe that it is often Board members, not staff, who feel the most hesitant about engaging in policy work, particularly if they are unfamiliar with the rules governing nonprofit advocacy. Accordingly, numerous stakeholders stress the importance of providing training and resources to nonprofit and foundation boards to help build their comfort and confidence in advocacy efforts and to help ensure that the organizations they lead feel supported in pursuing critical systems change work. A number of grant partners also note that capacity-building efforts should include powermapping Board assets (including Board members' relationships with policymakers) so that organizations can effectively cultivate political champions.

Additionally, numerous Foundation stakeholders highlight that advocacy capacity-building training should include an emphasis on effective communication and storytelling. Being able to clearly communicate the experiences of the communities nonprofits serve and explain how policies affect those communities is critical to shaping public understanding and influencing decision-makers. Foundation staff also highlight the importance of building the advocacy and communication capacity of young people and empowering the next generation of advocates.

While a number of grant partners report having engaged in one-off advocacy capacity-building opportunities, they also often report that the trainings they joined were disconnected from an ultimate advocacy goal, lacked follow through, or were missing a clear application to their organizations' bespoke priorities. Accordingly, when asked in interviews about prior capacity-building experiences, stakeholders report mixed

reviews with past advocacy training. Foundation stakeholders uniformly note that to be truly useful, advocacy capacity-building trainings and briefings should be "applied" so that participants can put to use the knowledge they gain.

F. Need to Elevate the Voices of People with Lived Experience

Foundation stakeholders consistently emphasize the importance of centering the voices of people with lived experience in advocacy and systems change work. Stakeholders universally recognize that those most directly affected by policies and systems have unique expertise, and they are often best positioned to identify gaps, propose solutions, and communicate what is actually working in practice. **RIZE Massachusetts**, for example, explains that people with lived experience often have unique insight into the right questions to ask and effective levers to pull when engaging in systems change work. Several grant partners highlight how their organizations are already building this approach into their work. The Tower Foundation's staff and Trustees similarly point to the Foundation's Community Experts Team as an exemplar of engaging and elevating the voices of those most proximate to the challenges the Foundation seeks to address. Stakeholders also highlight advocacy and leadership programs that are designed to equip community members to speak for themselves and engage in policy discussions, with one interviewee emphasizing the importance of "helping people learn how to help themselves" while strengthening their ability to express their experiences clearly and effectively.

Grant partners and peer organizations also acknowledged that elevating lived experience requires intentional investment and infrastructure. The **Health Foundation for Western and Central New York** describes a "wholesale vs. retail" approach, where instead of supporting individuals, they support organizations that work directly with individuals and help bring those perspectives into broader advocacy efforts. Other stakeholders point to the importance of creating structured opportunities for community members to engage, such as peer advocacy programs, storytelling opportunities, and leadership development efforts that build confidence and self-advocacy skills over time. Many stakeholders note that without this level of support and intentionality, the perspectives of people most affected by systems and policies are often underrepresented.

Foundation stakeholders also comment that elevating lived experience is not just about inclusion, but also about effectiveness. Advocacy is stronger and more effective when grounded in lived experience and when decisionmakers, including policymakers, hear directly from those affected by specific policies. When framed this way in interviews, centering lived experience is often described as a core component of effective advocacy, not an optional add on. Foundation stakeholders further express that elevating proximate voices in policy and advocacy requires ongoing investment from philanthropy and grant partners to ensure that these voices are not only heard, but meaningfully integrated into policy and advocacy efforts.

Related Philanthropic Opportunities Cited by Interviewees:

- **Support the Development and Distribution of Reliable Resources:** To meet stakeholders' expressed need for clear, concise, relevant, and reliable resources that are both prepared by policy experts and user-friendly for program staff, philanthropy can support trusted partners' development and distribution of resources, including: policy newsletters, advocacy updates, webinars, action alerts, and "ask me anything" sessions with policy experts and government relations professionals.

- **Support Advocacy Efforts:** Stakeholders uniformly express strong support for philanthropy increasing its investment in policy advocacy efforts, including the direct funding of advocacy organizations and initiatives with unrestricted dollars. Stakeholders also encourage foundations themselves to consider how best they can engage in systems change work – whether through advocacy, communications, convenings, resource distribution, or other field leadership efforts.
- **Invest in Collective Advocacy Organizations:** Grant partners and peer organizations stress the need for philanthropy to invest in collective advocacy efforts with strong leadership, including intermediary or backbone organizations that lead effective advocacy coalitions. By supporting collective advocacy efforts, philanthropy can leverage and amplify its impact; organizations benefit from economies of scale; collectives can engage strong leadership; organizations are provided with group "cover;" and policymakers are exposed to a larger group of diverse but united voices.
- **Invest in Capacity-Building:** Foundation stakeholders repeatedly express the need for high quality, applied advocacy training that equips their staff with the tools they need to become better, bolder advocates. To meet this need, philanthropy can invest in bespoke, intentionally curated advocacy capacity-building initiatives that are customized to the needs of specific organizations, that educate participants, and that apply learning "from the classroom to the Capitol."
- **Elevate Proximate Voices:** Grant partners and Foundation stakeholders suggest that philanthropy can invest in elevating the proximate voices of community members by developing bespoke advocacy training and engagement opportunities, particularly for young people. This could include developing specialized advocacy fellowships where young leaders work on a "real world" advocacy issue in their community with coaching and support from policy experts skilled in applied advocacy and working with young leaders.
- **Lend Support to the Nonprofit Sector:** Finally, stakeholders, including Foundation leadership, note the importance of supporting the nonprofit sector generally and lending the Foundation's voice to advocacy efforts designed to strengthen and stabilize the philanthropic sector.

America FORWARD

PETER & ELIZABETH **TOWER FOUNDATION**

Landscape Analysis: Advocacy for Impact

SECTION VII

FEDERAL: LANDSCAPE, POLICY CONTEXT, ADVOCACY OPPORTUNITIES



Landscape Analysis

SECTION VII

FEDERAL: LANDSCAPE, POLICY CONTEXT, ADVOCACY OPPORTUNITIES

INTRODUCTION

This Section of the Landscape Analysis provides an overview of the federal landscape and identifies significant policy challenges and advocacy opportunities relating to youth substance use disorders, mental health, intellectual disabilities, and learning disabilities. Section VI of the Landscape Analysis (Interview Findings and Insights) contains detailed information about federal policy challenges and opportunities, and Sections VIII (Massachusetts) and IX (New York) contain multiple references to federal policy as well. In order to avoid repetition, federal policy challenges and advocacy opportunities that are discussed in greater detail elsewhere in this Landscape Analysis receive lighter treatment here.

1. Federal Landscape

Policy and funding decisions at the federal level provide the essential architecture for systems supporting youth and young adults who have substance use disorders (SUD), mental health challenges, intellectual disabilities, and learning disabilities. While services are often delivered at the state and local levels in Massachusetts and New York, federal statutes and matching formula funding dictate the underlying structures of program eligibility, service capacity, and workforce stability. Engaging in federal policy advocacy is therefore an important component of any effective youth wellbeing systems change strategy.

The youth wellbeing federal policy landscape has shifted dramatically since President Trump's inauguration. Yet, despite changes in policy priorities, administrative disruption, and personnel upheaval, overall federal funding levels have remained surprisingly stable – with the notable exception of major upcoming cuts to Medicaid. At the same time, the roster of national policymakers representing Massachusetts and New York remain strong leaders on the Foundation's core issue areas.

A. The Administration

Across the country, from an operational perspective, the Administration's recent actions have threatened critical investments in youth wellbeing and have disrupted the operations of governments and community-based organizations responsible for the implementation of critical programs.

First, the Administration has attempted to make significant funding cuts to congressionally-appropriated grant funding. For example, in January 2026, the Substance Abuse and Mental Health Services Administration (SAMHSA) at the U.S. Department of Health and Human Services (HHS) abruptly cut approximately $2 billion in federal grants. HHS quickly reversed the threatened SAMHSA cuts in response to widespread public outcry and bipartisan objections from members of Congress – demonstrating, among other things, the critical importance of advocacy. Nonetheless, these abrupt policy shifts have raised alarm among youth SUD and mental health service providers who are concerned that the attempted cuts might foreshadow a dramatic policy shift in the focus of future SAMHSA grants. More broadly, these funding disruptions have fostered chronic uncertainty about whether and how funding will reach communities, making it increasingly challenging for organizations to plan for the future.

Second, the Administration has instituted dramatic staffing cuts that have substantially disrupted federal agency capacity. Specifically, the Department of Education (ED) implemented widespread personnel cuts, reducing its workforce by nearly 50%. These cuts resulted in an enormous loss of longstanding expertise, including in: the Office of Elementary and Secondary Education (OESE), impacting K-12 oversight; the Office of Special Education and Rehabilitative Services (OSERS), which oversees Individuals with Disabilities Education Act (IDEA) compliance; and the Office of Civil Rights (OCR), which is responsible for enforcing federal civil rights laws in schools. The Department also downsized regional offices in Boston and New York. In addition, earlier this year, HHS revealed plans to effectively dismantle the Office of Planning, Research, and Evaluation (OPRE) at the Administration for Children and Families, despite OPRE's critical role in driving evidence-based research and practice in programs like Head Start.

Third, the Administration has attempted to reorganize federal agencies' responsibilities through a series of interagency agreements (IAAs). Most prominently, the Administration plans to outsource implementation of the programs administered by the Department of Education to HHS, including special education programs. In addition, the Department of Labor (Labor) is now tasked with managing most K-12 grant programs, distributing more than $20 billion annually to schools — including the $18.4 billion Elementary and Secondary Education Act (ESEA) Title I program that funds about 95% of school districts serving low-income students, as well as Title II teacher development funds, Title III English learner services, and Title IV after-school programs.[1] While administration of these programs has not yet fully shifted to Labor, the transition is in progress, and states, districts, and other grantees continue to raise concerns that they lack clarity on roles, governing rules, technical systems, and timelines. They fear this lack of clarity is leading to inevitable breakdowns in on-time and accurate funding flow and unclear guidance for program implementation.

Fourth, as discussed in more detail below, the Administration has made sweeping policy changes that threaten the quality and scope of key youth services – from the Administration's actions on immigration enforcement that have significantly impacted schools, mental health program providers, and the children and families they serve, to SAMHSA's issuance of guidance that would effectively exclude key harm reduction programs from receiving funding. Currently, there is little effective opposition to these actions

[1] It is worth noting that ESEA Title IV-B focuses on academic enrichment during non-school hours and is administered through formula grants to states then from states to local districts. This funding has not grown significantly. However, Title IV-A, which focuses on enhancing student achievement and is administered through formula grants, has grown by 450% since its inception in 2017. This provides a ripe area of opportunity since it is intended to promote a variety of strategies supporting diverse learning experiences, particularly for students who struggle academically.

coming from Congress; while outside Congress, legal challenges continue. However, if Democrats were to win one or both chambers of Congress in the 2026 midterm elections, they could utilize congressional oversight power, as well as legislative efforts, to impact or delay certain Administration actions.

B. Annual Federal Appropriations

At the same time, despite the turmoil in implementation, annual congressional appropriations for youth wellbeing programs – including youth SUD, mental health, intellectual disabilities, and learning disabilities – have remained largely stable, notwithstanding the Administration's and House Republicans' proposals to make significant cuts. In February 2026, Congress passed, and the President signed, a bipartisan, bicameral Fiscal Year 2026 appropriations package that for the most part funds education, workforce, housing, and health programs at levels similar to past years. This outcome demonstrates that with the current close divisions in the House and Senate, there is still not sufficient support in Congress to make significant cuts to key youth-serving programs.

More specifically, the final Fiscal Year 2026 (FY26) appropriations package includes largely level funding for SAMHSA-administered programs at HHS, and for special education programs administered by the Office of Special Education and Rehabilitative Services (OSERS), including its Office of Special Education Programs (OSEP), at ED under the Individuals with Disabilities Education Act (IDEA). In addition, the appropriations bill includes specific language requiring federal agencies to release state formula grant funding, including IDEA grants, on time, addressing bipartisan concerns about the disruption stemming from the Administration's erratic funding actions (as discussed in more detail below). That said, in an environment of rising service costs and workforce shortages, even level funding can result in an effective reduction in capacity, leaving systems strained and unable to meet the rising demand for services for youth with complex and intersecting needs.

On April 3, 2026, the Administration released the President's proposed budget for the upcoming 2027 Fiscal Year. This budget proposes major changes to programs related to youth wellbeing, including eliminating funding for some programs under SAMHSA (and dissolving SAMHSA and folding its functions into a new Administration for a Healthy America (AHA)); decreasing funding for mental health, suicide prevention, and substance use prevention and treatment services; and cutting education programs for immigrant youth.[2] The budget also includes a Make Education Great Again (MEGA) $2 billion state block grant that would reserve at least 25% of funding for evidence-based literacy instruction and 25% for evidence-based mathematics instruction, while eliminating most other education funding streams outside of ESEA Title I and IDEA (e.g., ESEA Title II, ESEA Title III, 21st Century Community Learning Centers, State Assessments, Comprehensive Literacy State Development Grants, etc.) with the justification that "[s]tates and localities, not the Federal government, are best suited to determine whether to support the activities authorized under this program or similar activities within their own budgets and without unnecessary administrative burden imposed by the Federal government." At the same time, the Administration proposes to increase funding for IDEA State Grants and IDEA Grants for Infants and Families program, demonstrating strong bipartisan interest in funding for disability programs.

[2] Congress rejected many of the same proposals in the FY2026 budget cycle, and the same dynamic is expected this cycle.

Looking ahead, it seems very unlikely that the Administration's proposed cuts and appropriations funding changes will become law while President Trump is in office. The proposals are similar to the President's FY26 proposals, and Congress rejected them then. Members of Congress are now looking ahead to the November elections, and present polling suggests that Democrats likely will pick up numerous seats, leading to an even narrower margin for a Congressional Republican majority or a divided government. In either scenario, the President's FY27 budget proposals will likely face an even less favorable environment than the President's proposals faced in the recently-completed FY26 appropriations cycle.

In addition, changes in the composition of Congress are likely to spur action to rein in the Administration's efforts to redirect, freeze, or cancel programs. Looking toward the FY27 funding cycle, a number of leaders in the House, including Ranking Member of the House Appropriations Committee Rosa DeLauro (D-CT-03), have expressed their hope to pass multiple appropriation bills before the election, provided that the bills contain very directive guidance to federal agencies.

C. Implementation of the One Big Beautiful Bill Act and Medicaid

In contrast to the federal appropriations process, changes under the 2025 One Big Beautiful Bill Act (OBBBA) pose serious threats to youth wellbeing through massive upcoming cuts to Medicaid [3] that are likely to substantially reduce participation and have a significant impact on SUD and mental health services as discussed in more detail below.

OBBBA institutes three critical changes to Medicaid participation and coverage that account for an estimated $1 trillion in cuts to Medicaid, and a 15% reduction in projected federal Medicaid spending, over 10 years. These include:

- A mandate that able-bodied adults without dependents (more specifically, expansion adults ages 19-64 who do not qualify for a specific exemption) work, volunteer, or participate in training for 80 hours per month to maintain coverage. This change will also pose serious logistical complexities for program providers and participants. For example, while individuals who receive Supplemental Security Income (SSI) are automatically enrolled in Medicaid in Massachusetts and New York, roughly two-thirds of people with disabilities in Massachusetts and New York do not receive SSI and qualify for Medicaid through separate non-disability pathways. In practice, this means that a high proportion of people with disabilities in Massachusetts and New York will face burdensome new administrative requirements.

[3] The One Big Beautiful Bill Act (OBBBA), signed into law in July 2025, mandates significant changes to Medicaid and the Supplemental Nutrition Assistance Program (SNAP) that threaten participation by individuals with low-incomes. These changes account for an estimated $1 trillion in cuts to Medicaid (amounting to a 15% reduction in projected federal Medicaid spending), along with a reduction of an estimated $187 billion in SNAP spending, over the next 10 years. The Congressional Budget Office (CBO) estimates these changes could cause 10 million Americans to lose Medicaid coverage, particularly in states that expanded Medicaid for low-income adults under the ACA, with large impacts expected on rural hospitals. The Urban Institute projects that more than 22 million families will lose some or all of their SNAP benefits.

- A reduction in the cap on state provider taxes from 6% to 3.5% by 2032, limiting a key source of state funding, alongside a reduction in federal matching funds.[4]
- A restriction in coverage for certain lawfully present immigrants, including refugees and asylum seekers.

The Congressional Budget Office (CBO) estimates these changes could cause 10 million Americans to lose Medicaid coverage, particularly in states like Massachusetts and New York that expanded Medicaid for low-income adults under the Affordable Care Act (ACA), with large impacts expected on rural hospitals. At the same time, OBBBA did not extend the 2021 enhanced ACA subsidies, resulting in major cost increases for many households after those subsidies expired at the end of 2025. Additionally, work requirements for the Supplemental Nutrition Assistance Program (SNAP) and new SNAP cost sharing provisions for states threaten access to a major benefit for households with low incomes. In total, the Urban Institute projects that more than 22 million families will lose some or all of their SNAP benefits as a result of changes under OBBBA. Notably, the law also creates an uneven landscape for aging-out foster youth who often have disproportionate rates of mental health challenges, substance use disorders, intellectual disabilities, and learning disabilities: while they retain their Medicaid work requirement exemption through age 26, they lose their prior SNAP work requirement exemption that had been extended through age 24 — leaving them exposed to food insecurity at a critical time of life transition.

Turning to the political context, it is important to note that OBBBA was a purely partisan bill driven by congressional Republicans and the President through the complex budget reconciliation process that eliminated the need to overcome a Senate filibuster, provided that Republicans mustered at least 50 votes in the Senate. Narrow Republican margins in the House posed significant procedural challenges, however, as one or two members could apply outsized influence there. In contrast, the federal appropriations process, particularly in the Senate, is by necessity a bipartisan effort. Moving forward, Republicans have discussed a potential second and third reconciliation bill, though the potential bill elements and path to passage remain unclear.

D. Federal Champions

Massachusetts and New York members of Congress have played a prominent role in federal policy on youth wellbeing issues critical to the Tower Foundation and its stakeholders. Given that Members of Congress are particularly attuned to the input and perspectives of their constituents, Foundation stakeholders are well-positioned to educate their Members and help inform the development of new policy proposals relevant to the Foundation's core issue areas.

[4] States levy taxes on hospitals, nursing homes, and other healthcare providers to generate their share of Medicaid costs. Because the federal government matches every state Medicaid dollar spent, each dollar raised through provider taxes effectively unlocks additional federal funding. Cutting the cap therefore produces a compounding loss: states can raise less through provider taxes, and receive less in federal matching funds as a result. Massachusetts and New York both rely heavily on this financing mechanism, so the impact on both states' Medicaid programs could be substantial.

Key federal leaders representing Massachusetts and Essex, Barnstable, Dukes, Nantucket, and other Counties include:

House of Representatives:

- **Rep. Katherine Clark (D-MA-05)** represents Middlesex and Suffolk Counties. She is a key congressional leader on school mental health issues and in 2024 co-led introduction of the Elementary and Secondary School Counseling Act and the Trauma-Informed Schools Act, two comprehensive bicameral bills addressing the youth mental health crisis by expanding access to school counselors and trauma-informed professionals in schools. She has also addressed the SUD treatment workforce pipeline by introducing the Substance Use Disorder Workforce Loan Repayment Act. Rep. Clark sits in a key role in House leadership, serving as Minority Whip (the second-highest position in House Democratic leadership), making her ideally positioned to advance legislation on these issues. If Democrats were to retake the House in the 2026 midterm election, Rep. Clark would likely become House Majority Leader.
- **Rep. Lori Trahan (D-MA-03)** represents parts of Essex County as well as Middlesex and Worcester Counties. She is a key congressional leader on youth mental health issues and co-chairs the Congressional Bipartisan Mental Health and Substance Use Disorder Task Force. She co-led the bipartisan reauthorization of the the Garrett Lee Smith (GLS) Memorial Act, the federal government's foundational youth suicide prevention grant program, through the Energy and Commerce Committee and into law in 2023. In addition, Rep. Trahan co-led the Medication Access and Training Expansion (MATE) Act, enacted in 2023, that standardized SUD training requirements for prescribers. Rep. Trahan sits on the Energy and Commerce Committee's Health Subcommittee, which has jurisdiction over SAMHSA, the Public Health Service Act, Medicaid behavioral health provisions, and the healthcare workforce.
- **Rep. Seth Moulton (D-MA-06)** represents Essex County. He is forfeiting his seat to challenge Senator Ed Markey in the Democratic primary in 2026. Rep. Moulton has spoken publicly about confronting mental health challenges after returning from the Iraq War, and he is a champion of improving access to high quality mental health care and ending mental health stigma. He was a lead sponsor of the National Suicide Hotline Designation Act, which created the new 988 mental health lifeline.
- **Rep. Bill Keating (D-MA-09)** represents Barnstable, Dukes, Nantucket, and Plymouth Counties. While he has been less engaged in direct bill sponsorship, he participates in the Addiction, Treatment, and Recovery (ATR) Caucus, ensuring the unique needs of the Cape and Islands youth remain on the radar.

Senate:

- **Sen. Elizabeth Warren (D-MA)** is the most active Massachusetts legislator on substance use disorder issues. Across multiple Congresses, she has continually co-led the reintroduction of the Comprehensive Addiction Resources Emergency (CARE) Act, the most ambitious SUD legislation in Congress, which would provide state and local governments with $125 billion in federal funding over ten years for prevention, treatment, harm reduction, and recovery.
- **Sen. Ed Markey (D-MA)** is very active on youth mental health issues and sits on the relevant Senate Health, Education, Labor, and Pensions (HELP) Committee. As chair of the HELP Subcommittee on Primary Health and Retirement Security, Sen. Markey introduced the Student Mental Health Rights Act, which would require the Department of Education to publish guidance supporting students with mental health diagnoses and SUD. He has also urged HHS to strengthen disability nondiscrimination protections specifically to ensure people with disabilities have equitable access to SUD and mental health treatment facilities.

Key federal leaders representing New York and Erie, Niagara, and other Counties include:

House of Representatives

- **Rep. Hakeem Jeffries (D-NY-08)** represents central and south Brooklyn, East New York, Brownsville, Bedford-Stuyvesant, Canarsie, Coney Island, and Brighton Beach. Currently, Rep. Jeffries is the House Minority Leader (the highest-ranking Democrat in the House). If Democrats take the House in 2026, he is very likely to become Speaker of the House (the highest position in the chamber and second in the line of presidential succession). Rep. Clark (as noted above) would then move up from Minority Whip to House Majority Leader (the #2 position under Rep. Jeffries). While not a noted leader on Foundation issue areas, as the likely Speaker of the House, Rep. Jeffries would be positioned to advance the Democratic agenda on the Foundation's core issue areas through his control of the floor schedule and committee assignments.
- **Rep. Nick Langworthy (R-NY-23)** represents the southern and rural parts of Erie County along with Chautauqua, Allegany, Cattaraugus, Tioga, Schuyler, and Steuben Counties. He has demonstrated some interest in the Foundation's core issue areas, including introducing the bipartisan CTE Student Mental Health and Wellness Act to expand suicide grant prevention funding to cover career and technical schools.
- **Rep. Tim Kennedy (D-NY-26**) represents parts of Erie and Niagara counties, including the cities of Buffalo, Lackawanna, Niagara Falls, Tonawanda, and North Tonawanda. Rep. Kennedy is a licensed occupational therapist. Representative Kennedy has championed early intervention services and funding for IDEA and other programs that fund special education.
- **Rep. Claudia Tenney (R-NY-24)** represents most of Niagara County along with Orleans, Genesee, Wyoming, and other counties stretching from Western New York through the Finger Lakes and North Country. Notably, Rep. Tenney co-led the REACHING Improved Mental Health Outcomes for Patients Act, which was included as part of the broader Restoring Hope for Mental Health and Well-Being Act, a bipartisan package that passed the House by a large margin in 2022. Rep. Tenney has been vocal about post-COVID mental health needs and expanding opioid and SUD treatment access. She is on the powerful House Ways and Means Committee's Subcommittee on Health that has jurisdiction over Medicaid and tax provisions related to health.
- **Rep. John Mannion (D-NY-22)** represents Syracuse. A freshman member of Congress, Rep. Mannion is the strongest congressional champion in the New York delegation on youth intellectual disabilities and learning disabilities. He served nearly 30 years as a special education classroom teacher and was a leader in the New York state legislature, serving as founding Chair of the New York State Senate Committee on Disabilities and amassing a decade-long state-level record on intellectual and developmental disabilities issues. His background influenced his first bill in Congress, the Protecting Students with Disabilities Act, designed to prevent restructuring of ED's special education programs under the current Administration. He also played a co-lead role on the bipartisan Science of Reading Act of 2026, which recently passed the Education and Workforce Committee unanimously and has direct relevance to students with dyslexia and learning disabilities. Rep. Mannion's seat on the Committee on Education and the Workforce gives him jurisdictional leverage on many of the Foundation's key issues.

- **Rep. Paul Tonko (D-NY-20)** represents Albany. Rep. Tonko is Chair of the Congressional Addiction, Treatment, and Recovery (ATR) Caucus. Rep. Tonko has consistently highlighted the risks posed by reductions to SAMHSA funding and has frequently criticized efforts to scale back mental health programs. In particular, Rep. Tonko is the lead sponsor for the Reentry Act of 2025, key bipartisan legislation that would allow states to restore access to health care, including mental health and substance use treatment, to Medicaid-eligible individuals up to 30 days before their release from incarceration.
- **Rep. Mike Lawler (R-NY-17)** represents a suburban district north of New York City and has demonstrated interest in SUD issues. In 2025, he co-introduced the bipartisan Keeping Drugs Out of Schools Act alongside Rep. Linda Sánchez (D-CA), which would combat youth opioid use by enabling school partnerships with current or former Drug-Free Communities.
- **Rep. Nicole Malliotakis (R-NY-11)** represents Staten Island. Rep. Malliotakis has led on multiple bills calling for the expansion of mental health and substance use services under Medicaid.

Senate:

- **Senator Charles Schumer (D-NY)** serves as Minority Leader of the Senate and has been one of the most vocal opponents of federal cuts threatening the Foundation's core issue areas, including strong support for full IDEA funding and harm reduction approaches to substance use disorders. Following the passage of the OBBBA, he introduced the Protecting Health Care and Lowering Costs Act to repeal the law's Medicaid cuts in their entirety. If Democrats retake the Senate in the 2026 midterms, Sen. Schumer would likely become Senate Majority Leader; if they do not, he is expected to continue as Minority Leader.
- **Senator Kirsten Gillibrand (D-NY)** is a leading congressional voice on youth mental health. She was a strong supporter of the 2022 Bipartisan Safer Communities Act (BSCA) legislation that helped schools hire and expand the workforce of school-based mental health professionals (grants that were eliminated by the Trump administration in 2025 and are now the subject of a multistate lawsuit), and she was active in calling for the Trump Administration to restore funding under the bill to New York communities. She has also supported the Mental Health Professionals Workforce Shortage Loan Repayment Act, which would incentivize mental health professionals to practice in underserved areas by offering student loan forgiveness.

2. Four Issue Areas: Policy Context and Advocacy Opportunities

The following section addresses the federal policy context and current advocacy opportunities relating to youth SUD, mental health, intellectual disabilities, and learning disabilities.

A. Substance Use Disorders (SUD)

i. Policy Context

Youth substance use disorder (SUD) services currently operate within a fragmented network of federal health, education, and justice-related funding streams. As discussed above, the major federal funding streams for youth SUD services face very different outlooks: while significant cuts to Medicaid are on the horizon, Congress has protected SAMHSA funding in the Fiscal Year 2026 appropriations at $7.4 billion, a slight increase over the prior year.

First, Medicaid, along with the Children's Health Insurance Program (CHIP), provide the core financing mechanisms for SUD services. Medicaid and CHIP cover medically necessary screenings and treatments under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. As a mandatory entitlement, EPSDT requires states to provide all medically necessary behavioral health and developmental services, distinguishing it as the only federal program with an explicit obligation to identify and treat needs early. However, because the specific scope of covered services is left to state discretion, access remains inconsistent across the country, with Massachusetts and New York ranked among the highest performers.

SUD treatment under Medicaid is particularly at-risk for disruption under changes enacted by the One Big Beautiful Bill Act (OBBBA). In Medicaid expansion states like Massachusetts and New York, 67% of Medicaid-covered adults who receive SUD treatment are covered through Medicaid expansion. While individuals with SUD and other "disabling" mental health conditions should be exempt from the new Medicaid work requirements due to the "medical frailty" exemption, this exemption is dependent on currently unreleased federal guidance. Moreover, individuals with mental health disorders, including SUD, are more likely to face housing insecurity, employment instability, and other barriers that could make the new work and reporting requirements more difficult. Additionally, as some Foundation stakeholders attest, Medication-Assisted Treatment (MAT) programs in jails and prisons would no longer be effective if individuals transitioning from incarceration do not have access to their medications because they no longer qualify for Medicaid.

Second, while the current SAMHSA funding level largely has been protected in the FY26 appropriations agreement, the funding level remains inadequate relative to the scope of national need. In addition, states and providers lack certainty about future funding, as SAMHSA funding is dependent on annual appropriations, and it has faced erratic threats from the Administration, making it challenging for states and providers to plan strategically. Moreover, while SAMHSA's funding includes youth-focused set-asides, resources remain predominantly designed for adult populations. This systemic adult-bias forces youth-serving providers to attempt to braid multiple, often incompatible, funding sources to address the unique developmental needs of adolescents and transition-age youth, including a volatile mix of time-limited discretionary grants from the Department of Justice and the Department of Education for school-based initiatives and diversion programs. Key SAMHSA funding streams include:

- **The SAMHSA** Substance Use Prevention, Treatment, and Recovery Services Block Grant ($2 billion in FY26) includes a 20% primary prevention set-aside that primarily targets youth and at-risk individuals. While this program serves as the primary formula-based resource for state prevention efforts, it is often stretched thin, as its $2 billion allotment is small relative to the need across the nation.
- **The SAMHSA** State Opioid Response Grants ($1.6 billion in FY26) address the opioid overdose crisis by providing resources to states and territories for increasing access to FDA-approved medications for the treatment of opioid use disorder (MOUD) (a specific subset of Medication-Assisted Treatment (MAT)), and for supporting the continuum of prevention, harm reduction, treatment, and recovery support services for opioid use disorder (OUD) and other concurrent substance use disorders.
- **The** National Institute on Drug Abuse ($1.7 billion in FY26) funds significant youth-focused SUD research.
- **The SAMHSA** Drug Courts program ($75 million in FY26) serves as a key intervention point for justice-involved youth with SUDs.

President Trump's July 2025 Executive Order (EO) "Ending Crime and Disorder on America's Streets" has compounded the disruptions of the annual appropriations process by threatening some of the most effective SUD harm reduction strategies. The EO encourages the Secretaries of Health and Human Services (HHS), Housing and Urban Development, and Transportation to reallocate funding away from certain evidence-based programs (such as harm reduction and housing-first programs) and toward cities and states that criminalize substance use disorder, punish people for sleeping outdoors, or enforce other laws targeting unhoused people.

Following this EO, HHS issued guidance excluding SAMHSA grants from funding certain harm reduction programs, including evidence-based programs like Syringe Services Programs (SSPs), which are associated with an estimated 50% reduction in HIV and Hepatitis C incidence and a five-times greater likelihood of individuals entering drug treatment programs. (SAMHSA later clarified that overdose reversal drugs such as naloxone would remain a priority.) This change undermines years of evidence-based substance use disorder public policy.

Taken together, the combination of Medicaid restructuring, the pivot away from harm reduction, and the loss of federal grant stability has created a landscape of deep uncertainty for SUD services for youth — but also a landscape that presents meaningful openings for effective advocacy engagement.

ii. Advocacy Opportunities

In light of the recent sudden elimination and restoration of $2 billion in SAMHSA grants, a key advocacy opportunity is rooted in engaging with SAMHSA leadership, deeply understanding SAMHSA's current and future funding priorities, and then identifying effective ways to advocate for innovative, evidence-based programs that align with the new SAMHSA priorities. Alongside annual congressional appropriations efforts, key advocacy opportunities exist to protect harm reduction programs and address policy and funding shifts stemming from the Administration's Executive Order on Ending Crime and Disorder on America's Streets.

Related Advocacy Opportunities:

- **Demonstrate the Importance of Broader, and More Effective, Investment in Youth SUD Programs:** There are some voids in the federal advocacy space supporting youth SUD programs. Particularly, there is limited federal-level advocacy leadership related to Medicaid and SAMHSA funding from the unique perspective of nonprofit community-based organizations. This creates a significant opportunity for Tower Foundation stakeholders to define the advocacy narrative with an on-the-ground, practitioner- and participant-focused lens. In practice, this could mean leveraging advocacy tools such as policy-focused narrative-building spotlights of grant partners' efforts, and more technical policy pieces that identify barriers in current legislation, regulation, and guidance and highlight opportunities for improvement. This type of advocacy effort could also include in-depth policymaker education, elevating local lessons and perspectives. A key message for policymakers would focus on how fragile state treatment networks are and how unsustainable they could become without at least the current baseline of federal funding. Given the many New York and Massachusetts members of Congress with deep interest in these issues, there is significant untapped potential for positive policymaker advocacy, education, and engagement.

- **Protect Harm Reduction Programs:** There is a pressing need for federal advocacy to counter the Administration's shift away from harm reduction (as Tower Foundation grant partners echo in their interviews). Advocates could work to preserve funding for evidence-based programs like Syringe Services Programs and ensure that federal grant language does not exclude proven prevention strategies. Related advocacy activities could include public case-making, narrative storytelling, and targeted education of key federal officials to demonstrate the value of these federal investments.
- **Support the Reentry Act of 2025:** Advocates could urge Congress to support the Reentry Act of 2025, bipartisan legislation that would allow states to restore access to health care, including mental health and substance use treatment, to Medicaid-eligible individuals up to 30 days before their release from incarceration, helping to ensure continuity of care upon their release. This could include public communications demonstrating the need for underlying components of the legislation, both by the Tower Foundation itself as well as its grant partners, alongside targeted education of key legislators.
- **Protect New SAMHSA Grant Priorities and Innovation in Behavioral Health (IBH):** The Centers for Medicare and Medicaid Services (CMS) Innovation in Behavioral Health model presents a powerful opportunity. New York was one of three states awarded IBH grants, with implementation planned for Western New York under a seven-year model (2025–2032). Under the IBH model, patients will receive more integrated, person-centered care that addresses their full range of health needs. The IBH model is administered through the Center for Medicare and Medicaid Innovation (CMMI), a dedicated office within CMS created by the ACA to test new payment and delivery models (including pay-for-outcomes approaches) that can be scaled nationally if proven effective. This makes CMMI funding particularly consequential: a successful IBH demonstration in Western New York could ultimately influence how integrated behavioral health care is reimbursed across the country. However, CMMI has been a target of the current Administration's cost-cutting efforts, raising concerns about whether multi-year models like IBH will be permitted to run their full course. Protecting federal investment in CMMI, and ensuring New York's IBH grant is not curtailed, is a critical near-term advocacy priority. More generally, this highlights the importance of advocating to protect federal funding for innovative approaches, especially CMMI funding, since CMMI invests in testing new, innovative, and often alternative pay-for-outcomes models.
- **Engage in Targeted Outreach with the Administration:** There are ripe opportunities to positively inform the Administration's actions at HHS. Specifically, Administration leaders have recently expressed an interest in a more nuanced reshaping of SAMHSA funding priorities to focus on innovation and metric-backed outcomes, creating a significant funding opening for agile, local nonprofits that may have previously been left out of federal funding opportunities. This could reverse a decades-long approach that frequently funded the same legacy programs regardless of performance. As the Administration begins to direct funding to programming that was not previously a federal priority, a vacuum has emerged. For Tower Foundation grant partners and other local providers that were once "locked out" behind legacy formulas, this new outcomes-based paradigm offers programs a meaningful opportunity to compete for federal resources, provided that they can align their reporting with the Administration's focus on measurable economic and clinical results.

- **Build Longer-Term Support to Reverse OBBBA Changes:** It is extremely unlikely that OBBBA's disruptive, counterproductive changes to Medicaid will be reversed under the present Administration, even if the composition of Congress shifts dramatically following the November 2026 elections, as the President would likely veto any such congressional action. However, looking ahead, it is critical to develop specific policy changes, justifications, and public education and case-making to reverse these changes – and, potentially, even devise a stronger system moving forward than existed pre-OBBBA. The Foundation's grant partners and stakeholders could be important participants in such an effort: they could engage with other national stakeholders developing a plan that is ready for implementation, should such an opportunity emerge, and they could engage in narrative case-making to ready the field.
- **Support Youth Opioid Prevention in Schools:** The Keeping Drugs Out of Schools Act, introduced in 2025 by Rep. Mike Lawler (R-NY-17) and Rep. Linda Sanchez (D-CA-38) with bipartisan Senate companions, would authorize a new grant program enabling Drug-Free Communities (DFC) coalitions to partner with elementary, middle, and high schools to deliver evidence-based opioid prevention education, with a particular focus on the dangers of fentanyl and other synthetic opioids. Foundation stakeholders could support passage of this legislation by documenting the need for school-based prevention partnerships – particularly in rural Western New York and on Cape Cod and the Islands, where geographic isolation and limited school-based prevention infrastructure make community coalition partnerships especially valuable. Given Rep. Lawler's sustained interest in youth SUD prevention, and that Rep. Langworthy (R-NY-23) represents rural Erie County communities where fentanyl-related overdoses have been particularly devastating, there is a meaningful opportunity for Foundation stakeholders to engage both Members in support of this legislation and related school-based prevention investments.
- **Support the Comprehensive Addiction Resources Emergency (CARE) Act:** The Comprehensive Addiction Resources Emergency (CARE) Act, championed in the Senate by Sen. Elizabeth Warren (D-MA) across multiple Congresses, represents the most ambitious federal SUD legislation currently before Congress. The bill would provide state and local governments with $125 billion over ten years for the full continuum of prevention, treatment, harm reduction, and recovery support services — a funding level that would represent a transformational shift in the federal government's commitment to addressing substance use disorders. Unlike existing block grant and formula funding streams, the CARE Act is explicitly designed to reach underserved communities and to fund the kinds of community-based, evidence-driven approaches that Foundation stakeholders deliver on the ground. Foundation stakeholders are particularly well-positioned to advance this legislation: as constituents of Sen. Warren and with deep on-the-ground experience documenting the gap between current federal investment and community need, they can serve as credible and compelling voices for the scale of investment the CARE Act envisions. Advocacy activities could include direct policymaker education with Sen. Warren's office and with Massachusetts and New York Senate and House members who sit on relevant committees, as well as public narrative-building that makes the case for why the current patchwork of federal SUD funding is structurally insufficient to meet the need.

- **Restore SNAP Work Requirement Exemption for Foster Youth:** SNAP work requirements are particularly onerous for older foster youth. Advocacy opportunities include restoring SNAP work requirement exemptions for aging-out foster youth through age 24. This issue is narrow, bipartisan in potential appeal, and directly relevant to a number of Foundation stakeholders (and related to the following youth mental health section as well).
- **Engage in Collective Action in Federal Appropriations Efforts:** Given the importance of protecting multiple SUD-related federal funding streams, collective advocacy efforts focusing on appropriations have the advantage of economies of scale, leveraging diverse voices, capitalizing on each group's unique issue-area expertise, and "building a tent" that includes a broad range of recommendations and perspectives. Participating in collective advocacy efforts that utilize effective lead organizations overseeing broad-based coalitions can be a particularly effective means to engage in important, but often crowded, appropriations advocacy spaces.

B. Youth Mental Health

i. Policy Context

As with SUD programs, Medicaid serves as the foundational cornerstone for youth mental health programs through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. As a mandatory entitlement, EPSDT requires states to identify and treat behavioral health needs for low-income, disabled, and foster youth. Beyond Medicaid, the youth mental health system benefits from having more clearly defined, youth-specific federal pillars that facilitate site-based integration than does the SUD system. Key federal funding sources for youth mental health include:

- **The SAMHSA** Community Mental Health Block Grant ($1 billion in FY26) funds state systems of care for children with Serious Emotional Disturbance (SED) and adults with Serious Mental Illness (SMI). States must use funds for children and adolescents as a priority population alongside adults.
- **The SAMHSA** Project AWARE (Advancing Wellness and Resiliency in Education) program ($140 million in FY26) develops sustainable infrastructure for school-based mental health programs and services.
- **The SAMHSA** Garrett Lee Smith (GLS) Youth Suicide Prevention Grant Program ($52 million in FY26) funds state, tribal, and campus grants for youth (up to age 24) suicide prevention and early intervention across schools, juvenile justice, and community settings.
- **SAMHSA's investment in the** 988 Suicide and Crisis Lifeline ($535 million in FY26) is particularly relevant for youth, given a dedicated LGBTQ+ youth specialized services line that the Administration eliminated in July 2025, and for which Congress directed and funded restoration in the FY26 appropriations legislation.
- **Individuals with Disabilities Education Act (IDEA)** Part B ($14.2 billion in FY26) and **Title I of the Elementary and Secondary Education Act (ESEA)** ($18.4 billion in FY26) formula grants to states include support for specialized instruction and mental health services within the K–12 system. IDEA funds embed counseling and behavioral supports directly into the K–12 environment, offering a level of daily, school-based integration that provides an infrastructure that SUD prevention and recovery often lack. However, as discussed in more detail below, IDEA has never been fully-funded, leaving states and districts responsible for a significant portion of the funding gap.

- **The School-Based Mental Health Services Grant Program** (along with the Mental Health services Professional Demonstration Grant Program) at ED ($164 million in FY26) provides competitive grants to states and school districts to increase the number of credentialed mental health services providers providing school-based mental health services to students in local education agencies (LEAs) with demonstrated need.

Despite these established structures, the youth mental health system still faces serious threats. Persistently low Medicaid reimbursement rates present one of the most significant challenges to the survival of nonprofit behavioral health providers. This chronic underfunding creates a paradox in which providers delivering successful clinical outcomes are forced to close their doors. Indeed, SAMHSA Principal Deputy Assistant Secretary Chris Carroll recently observed that these rate gaps are a primary driver of insolvency among behavioral health nonprofits. While the Centers for Medicare & Medicaid Services (CMS) at HHS establishes reimbursement guidance for adequacy, access, and efficiency, individual states set reimbursement rates for providers — and many states are in the process of, or are considering, cutting reimbursement rates even lower due to cost pressures accelerated by the cuts and state provider tax caps under OBBBA.

Reimbursement rates are inextricably linked to access to care. The CDC's National Health Interview Survey found that every $10 increase in Medicaid reimbursement per visit is associated with a 0.5 percentage point increase in the likelihood of parents reporting no difficulty finding a provider for their Medicaid-insured children. Research also shows that increased primary care reimbursement rates reduce substance use disorders and mental health conditions for Medicaid-covered adults under 65. Without a shift in how these services are valued, the federal promise of support for youth mental health care remains underfunded.

Low reimbursement rates pose a particular challenge for dental care beyond existing coverage gaps. While the EPSDT benefit requires states to provide comprehensive dental coverage to individuals under 21 receiving Medicaid, only half of children covered by Medicaid actually use dental services each year. Despite Massachusetts and New York choosing to provide extensive Medicaid dental coverage, dental services have even lower reimbursement rates, ultimately leading to only 41% of dental providers accepting Medicaid.

In addition, the mental health workforce is facing an acute crisis driven in part by shifting immigration policies. Aggressive enforcement actions have created a chilling effect within the behavioral health sector. Providers and caregivers, fearing encounters with U.S. Immigration and Customs Enforcement (ICE), are increasingly absent from the workforce, leaving large gaps in service delivery. This pervasive fear extends to families as well: many young people in need of support are reluctant to seek care due to concerns that interacting with public systems could lead to dire immigration consequences, and many parents are reluctant to engage with mental health workers in schools. The increased presence of ICE in communities also has made community members less likely to seek out in-person services, and some providers are reporting a rise in requests for telehealth services. These unmet mental health needs are exacerbated by additional immigration-related stressors and trauma to children, families, and the workforce – potentially leading to additional strains on the system and increased costs.

Finally, despite the relatively stronger federal funding structure for youth mental health services, current funding is still insufficient, and federal funding streams could achieve significantly more leverage by supporting innovative, evidence-based approaches.

ii. Advocacy Opportunities

There are significant near- and long-term opportunities to engage in federal advocacy efforts to advance a more effective, inclusive, and well-resourced youth mental health system.

While structurally more integrated than the SUD landscape, the youth mental health system remains vulnerable to the same macro-risks: level funding that amounts to effective cuts given rising service costs and workforce shortages, structural changes to Medicaid that threaten to further strain capacity, and immigration enforcement that is simultaneously depleting the workforce and deterring families from accessing care. These compounding pressures make federal advocacy engagement both urgent and strategically important.

Ensuring adequate access to youth mental health services requires moving beyond full reliance on public-pay models. One potential path forward is the mixed population approach, in which nonprofits qualify themselves to work with private insurance that offers more robust reimbursement rates. By serving a blend of indigent and insured individuals (and maintaining important guardrails to ensure that the most vulnerable clients are not displaced), organizations can create a programmatically superior and financially sustainable model that is not entirely dependent on fluctuating Medicaid rates. Moreover, the broader eligibility criteria under the Children's Health Insurance Program (CHIP) provides a strategic avenue to capture younger populations who might fall just outside of traditional Medicaid thresholds.

In addition, advocates have a unique opportunity to clarify the scope of eligibility for federal programs. Despite the current political climate, many federal programs for youth mental health, substance use disorders, and intellectual and learning disabilities still remain accessible to non-citizens. Strategic advocacy opportunities include educating providers on these eligibility rules.

Related Advocacy Opportunities:

- **Renew Medicaid Section 1115 Waivers:** Both Massachusetts and New York have Medicaid Section 1115 demonstration waivers that expire in 2027 and must be renewed. Current demonstrations in both states focus on improving continuity of coverage, reducing health inequities, and increasing Medicaid payment rates for behavioral health providers. Because waivers often reflect the current Administration's priorities, there is a risk that waivers that meaningfully improve care might not be approved on the same terms or may be conditioned on changes that weaken current demonstrations. Engaging in upcoming community feedback sessions and submitting public comments on waiver extensions in the Summer and Fall of 2026 present meaningful near-term advocacy opportunities.
- **Support the Rural Health Transformation (RHT) Program:** The OBBBA authorized the Rural Health Transformation Program, which allows CMS to provide approved states with funding to improve rural healthcare delivery. All 50 states applied for and were awarded grants. Massachusetts has a stated goal of strengthening the full continuum of care and supporting community-led prevention efforts, while New York has stated goals of establishing rural health partnerships and expanding access to telehealth These programs present advocacy opportunities to encourage and support states to reach these goals.

In addition, it is worth noting that House Republicans, recognizing that this OBBBA provision would not fully fill gaps resulting from other OBBBA provisions impacting designated critical access hospitals and other rural health providers, opened up House earmarks for FY27 to nonprofits providing healthcare in rural areas even though nonprofits are otherwise ineligible for House earmarks. This opening could benefit some Foundation stakeholders.

- **Support the Innovation in Behavioral Health (IBH) Model):** As noted above, the CMS Innovation in Behavioral Health model, with New York as one of three awarded states and implementation planned for Western New York under a seven-year model (2025–2032), presents a powerful opportunity to advocate for the protection of federal funding for innovative, alternative pay-for-outcomes models under the Center for Medicare and Medicaid Innovation (CMMI).
- **Engage in Collective Action:** There are numerous closely-aligned allies in the youth mental health space exploring innovative models and partnerships. As one example, the Jed Foundation recently partnered with America's Promise Alliance (an America Forward Coalition member) to launch the Institute for Youth Mental Health to embed mental health supports into community-based organizations where teens and young adults already spend time; the Schultz Family Foundation, Pinterest, and AmeriCorps (along with America Forward) launched the Youth Mental Health Corps that deploys Corps Members to schools and community centers to support youth while also providing professional on-ramps to behavioral health careers; and Mental Health America plays a key role in building support for programs like the Mental Health Block Grant and investments in youth mental health research. Building alliances with these types of national efforts can be an effective complement to bespoke policy advocacy efforts.
- **Participate Early in the FY2027 Appropriations Cycle:** As with SUD advocacy, given Rep. Rosa DeLauro's stated goal of passing appropriations bills before the November 2026 election with directive agency guidance language, there is a specific near-term window (roughly spring through summer 2026) when Foundation stakeholders could engage meaningfully in the appropriations process relating to youth mental health – including such priorities as: Project AWARE, GLS, the School Mental Health Programs, and the 988 LGBTQ+ line.

C. Intellectual Disabilities

i. Policy Context

Federal support for youth with intellectual disabilities is anchored in a highly integrated "birth-to-adulthood" framework that blends mandatory education entitlements with critical health insurance. Within this framework, IDEA serves as a central pillar of support for youth with intellectual disabilities and provides the necessary funding for specialized instruction and the behavioral supports required for classroom inclusion. In FY26, Congress rejected the Trump Administration's proposal to convert these programs into block grants.

Key intellectual disabilities federal funding sources include:

- **For infants and toddlers, IDEA Part C** ($540 million in FY26) provides state formula grants that fund early intervention services, ensuring that speech, occupational, and physical therapies are delivered in home settings, under Individualized Family Services Plans (IFSPs) during the most critical developmental windows.
- **IDEA Part B** ($14.2 billion in FY26) supports children with disabilities as they transition to and enroll in K-12 education. IDEA Part B is the single most significant funding stream for students with intellectual disabilities, funding Individualized Education Programs (IEPs), related services (speech, occupational therapy, behavioral supports), placement in least restrictive environments, and required transition planning beginning at age 16. Notably, IDEA Part B includes dedicated funding for preschool grants ($420 million in FY26) that supports special education and related services for preschool-age children with disabilities before they enter K–12, serving as a critical entry point for children with intellectual disabilities or developmental delays who benefit most from early, intensive intervention.
- **IDEA Part D** ($259 million in FY26) supports critical nationwide, complementary activities to the other parts of IDEA that train the special education workforce and support families of children with intellectual disabilities. Key programs include State Personnel Development Grants ($39M), Technical Assistance and Dissemination ($39M), Personnel Preparation ($115M), Parent Training and Information Centers ($33M), and Educational Technology/Media ($31M). Notably, President Trump's FY26 budget proposed eliminating these programs before Congress ultimately maintained them in appropriations.

Even though Congress has declined to cut federal IDEA funding, states, districts, and schools still face persistent funding gaps. Congress originally committed to fund 40% of the average per-pupil cost of special education when IDEA was enacted in 1975. However, the federal share is now less than 12%, passing those significant costs off to states and localities. Data suggests that Massachusetts' funding gap exceeds $500 million, while New York's exceeds $1 billion.

IDEA age limits present additional transition challenges. Both Massachusetts and New York recommend or require students to receive services through their 22nd birthday or high school graduation, whichever comes first, but there is insufficient transition support during the "disability cliff," with providers reporting that clients often transition to state institutions after aging out of special education schools at age 22. Exclusionary discipline policies that disproportionately affect students with disabilities also remain a significant concern: the "school-to-prison pipeline" (or special education-to-prison pipeline) decreases academic achievement and increases engagement with the criminal legal system, and less than half of students in correctional facilities receive appropriate services despite being entitled to free appropriate public education (FAPE). Autism diagnoses wait times present yet another barrier, with children often experiencing wait times of up to 18 months for an autism spectrum disorder (ASD) diagnosis and additional delays for access to Applied Behavior Analysis (ABA) programs, underscoring the need for universal screening.

In addition to IDEA, several other funding streams provide critical support for youth with disabilities:

- **Early Head Start and Head Start** ($12.4 billion in FY26) constitute the most significant federal funding stream for early childhood education. Head Start programs are required to reserve at least 10% of enrollment for children with disabilities, making this a significant — and often underrecognized — pathway for young children with developmental delays who may not yet have formal diagnoses.

- **Medicaid** plays a critical complementary role. While Medicaid is the primary payer in the mental health sector, in the disability space, it functions as a secondary stream that bridges the funding gap in schools. Through the EPSDT benefit, Medicaid finances medically necessary therapies that schools are legally mandated to provide but are rarely fully funded to deliver. Despite this multi-agency structure, the system remains under chronic pressure.
- **The Maternal, Infant, and Early Childhood Home Visiting program (MIECHV)** ($650 million in FY26) is primarily an early childhood and maternal health program, delivered through formula grants to states with a requirement that states spend funds on programs with a strong evidence base or those under evaluation. MIECHV is effectively the federal system's earliest detection and prevention layer for developmental risk, as MIECHV home visits are often the first point of professional contact that leads to IDEA Part C referral and early intervention.
- **Vocational Rehabilitation (VR)** ($4.5 billion in FY26), administered by the Rehabilitation Services Administration at ED, helps individuals with physical or mental disabilities prepare for, secure, retain, or regain employment. Under the Pre-Employment Transition Services (Pre-ETS) set-aside, at least 15% of each state's VR allotment must be reserved for students with disabilities ages 14–21 still in school, accounting for about $675 million nationally dedicated to school-age youth with disabilities for job exploration, work-based learning, workplace readiness, self-advocacy, and postsecondary enrollment support.

Beyond federal funding streams, there are a number of critical contextual issues relating to youth intellectual disabilities policy. First, complementing IDEA, Section 504 of the Rehabilitation Act establishes the legal right to a free appropriate public education (FAPE). The regulatory landscape for Section 504 represents an important concern. In 2024, HHS under the Biden Administration released a long-awaited final rule implementing Section 504 of the Rehabilitation Act — the first comprehensive update in more than 50 years — which requires the provision of services in the most integrated setting appropriate to the needs of individuals with disabilities and prohibits the use of health care value assessment methods that discount the value of individuals' life extension on the basis of their disability. However, the promise of this new rule is under serious threat due to a legal challenge by nine states, with the parties requesting that the court set a schedule for summary judgment filings this summer. It is worth noting that Section 504 is a compelling example of federal programming that has significant bipartisan constituent support— including among college-educated suburban Republican women who have been part of recent successful federal advocacy efforts with Republican Members of Congress and Administration leaders.

Second, the U.S. Department of Education's extensive reduction in force effectively gutted staffing at the Office of Special Education and Rehabilitative Services (OSERS), the body responsible for overseeing nearly $15 billion in federal special education funding. While a 2026 bipartisan spending deal eventually reinstated most staff, the episode significantly degraded federal capacity for oversight and technical assistance. This instability was exacerbated by a $30 million cut to IDEA Part D training streams and an attempt to eliminate $1 billion in grants for school-based mental health professionals. Although these funds were largely restored after significant stakeholder advocacy and public pressure, the volatility has left state agencies and providers in a state of high alert.

Third, a significant attitudinal rift has emerged regarding the scope of federal disability law. The current Administration has shown strong support for funding biological and neurological disorders — such as autism and defined intellectual disabilities — while remaining deeply skeptical of supporting social emotional learning (SEL). This pivot away from holistic approaches and broader behavioral mandates toward evidence-based, clinically defined disabilities marks a shift in how discretionary funds are being prioritized. While funding for core intellectual disabilities remains a bright spot with bipartisan appeal, the broader support systems for youth behavior, wellness, and "whole child" approaches are increasingly vulnerable.

Finally, workforce challenges are particularly acute in the intellectual disabilities space. Behavioral health jobs that were previously compensated at 3–4 times the state minimum wage have seen significant wage erosion. Workers supporting individuals with intellectual disabilities remain widely undervalued, with direct support professionals (DSPs) experiencing high rates of stress and burnout stemming from low wages, outsized workloads, and a general lack of support for the profession, ultimately resulting in decreased job satisfaction and increased turnover. The Fair Labor Standards Act still allows employers to apply for section 14(c) waivers that permit them to pay people with disabilities a subminimum wage. While a Biden-era notice of proposed rulemaking to phase out these waivers generated over 17,000 public comments, it was ultimately withdrawn by the Trump Administration.

ii. Advocacy Opportunities

This federal retreat is forcing a new normal where state leadership, particularly in Massachusetts and New York, must assume a greater fiscal and administrative burden. However, this shift could also present a critical opportunity. While still unlikely, if federal education funding is transitioned into block grants (as the Administration has proposed) states would gain unprecedented flexibility to align funds with state-specific objectives. This could allow for more innovative, localized braiding of health and education dollars that was previously restricted by rigid federal silos.

A strategic advocacy path forward could include maintaining relentless pressure on the appropriations process to ensure that SAMHSA and IDEA remain level-funded at a minimum. By working through established champions in Congress, advocates can help safeguard these essential streams from wholesale consolidation while helping local providers navigate the shift toward a more clinical, outcomes-based reporting environment. The goal is to ensure that even as the federal government steps back from oversight, the legal entitlements to care remain protected through robust state-level implementation and localized expertise.

Related Advocacy Opportunities:

- **Advocate for Full Funding of IDEA (Keep Our PACT Act):** The Keep Our Promise to America's Children and Teachers Act (Keep Our PACT Act) creates a 10-year plan for the federal government to gradually meet its obligation to fully fund its portion of IDEA (and Title I). The legislation is supported by a broad coalition of nonprofits — including the National Council for Learning Disabilities, The Arc, and others— and has strong support among many local Republican advocates despite never gaining bipartisan cosponsorship at the federal level. Advocacy opportunities include Foundation stakeholders contacting their Members of Congress to elevate community voices and provide on-the-ground perspectives on the impact of funding shortfalls. (The National Education Association (NEA) has shared an action alert for stakeholders that could serve as a model.)
- **Protect IDEA Oversight Capacity at ED:** In light of staffing cuts at OSERS and OCR, there is a need to restore and protect IDEA oversight capacity. Advocacy efforts to restore OSERS and OCR staffing and ensure that IDEA compliance monitoring continues are both critical and bipartisan in historical support. Advocacy efforts could include opposing the transfer of Special Education Programs to HHS. The Arc and other national disability advocacy organizations have been vocal that this move would "medicalize" disability and undermine educational inclusion rights built over 50 years.
- **Cultivate Champions for the Transformation to Competitive Integrated Employment Act (TCIEA):** The TCIEA would provide grants to states and employers to transition away from subminimum wage employment, prohibit the approval of new 14(c) certificates, and phase out subminimum wages within five years. The bill has bipartisan sponsors, including Representative William R. Keating (D-MA-9) and Representative Nicole Malliotakis (R-NY-11) in the House, and Senator Kirsten Gillibrand (D-NY) and Senator Elizabeth Warren (D-MA) in the Senate. Ending the subminimum wage has been a major issue of bipartisan interest among congressional leaders, including House Education and the Workforce Ranking Member Bobby Scott (D-VA). Twenty states have passed legislation to end or phase out the subminimum wage, although Massachusetts and New York have not done so. Continuing to cultivate champions on this issue presents a fruitful advocacy opportunity.
- **Engage in Section 504 Protection:** Advocates should monitor and prepare for the potential impact of the ongoing legal challenge to the 2024 Section 504 final rule, which could significantly roll back federal anti-discrimination and community integration requirements for people with disabilities. Given the rule's bipartisan public support, this is an area ripe for advocacy engagement.
- **Encourage Enforcement of Disability Rights:** With a 70% reduction in lawyers in the DOJ Civil Rights Division since President Trump took office and similar cuts at ED's Office for Civil Rights (where OCR has routinely dismissed ongoing cases, particularly those related to disability accommodations), there is a pressing need to advocate for meaningful enforcement of civil rights laws protecting the rights of people with disabilities.

- **Protect Medicaid Reimbursement for IDEA-Mandated Services:** One of the most consequential and least visible federal policy vulnerabilities for students with disabilities is the longstanding practice of using Medicaid reimbursements to fund services mandated under IDEA, including speech, occupational, and physical therapy, mental health counseling, and assistive technology. Schools currently rely on more than $7.5 billion annually in Medicaid reimbursements to deliver these services, but this practice rests on federal acquiescence rather than explicit statutory protection, making it vulnerable to CMS policy changes driven by the Administration's broader effort to constrain Medicaid expenditures. Foundation stakeholders could work to ensure that any CMS guidance or rulemaking related to Medicaid school-based services preserves this reimbursement pathway, and could engage with Rep. Kennedy (D-NY-26) and Rep. Mannion (D-NY-22) to elevate the importance of protecting this resource through appropriations language and oversight.
- **Reauthorize IDEA and ESEA:** Both foundational federal statutes governing education for students with disabilities — IDEA (last reauthorized in 2004) and the Elementary and Secondary Education Act (reauthorized as the Every Student Succeeds Act in 2015) — have authorizations of appropriations that are significantly overdue for reauthorization. Full reauthorization is unlikely under the current Administration, but the process is worth monitoring and engaging with strategically, as it presents both risk and opportunity. On the risk side, an Administration-driven initiative could weaken the entitlement structure that guarantees services to children with disabilities. On the opportunity side, a future bipartisan reauthorization could expand IDEA's scope to better address students with intellectual disabilities, learning disabilities, and behavioral health challenges, and could address the chronic underfunding gap that has persisted since IDEA's original promise to fund 40% of special education costs was made in 1975. The current period leading up to major bill reauthorizations (and a new Congress) presents an important window when bills can be introduced to amend specific parts of IDEA and ESEA and garner sponsors. Foundation stakeholders could engage now with Rep. Mannion (D-NY-22), who sits on the Education and the Workforce Committee to help shape the policy groundwork for a future reauthorization that better serves students with disabilities.
- **Protect University Centers for Excellence in Developmental Disabilities (UCEDDs):** UCEDDs provide foundational infrastructure for intellectual disabilities research, workforce training, early intervention, autism evaluations, and technical assistance to families and providers. The FY2027 budget proposes to eliminate UCEDD funding entirely. While Congress has twice rebuffed these proposals, the threat is real, particularly given the Administration's parallel

efforts to dismantle the Administration for Community Living that houses the UCEDD network. Foundation stakeholders could engage Rep. Kennedy, Rep. Mannion, Sen. Warren, and Sen. Markey to underscore the important role UCEDDs play in supporting the intellectual disabilities workforce and early intervention systems.

- **Engage in the Returning Education to the States Tour:** Education Secretary Linda McMahon's "Returning Education to the States" tour, in which she is visiting all 50 states, presents a potential opportunity for nonprofit organizations to uplift their priorities and underscore the importance of supporting students with intellectual disabilities.

D. Learning Disabilities

i. Policy Context

Funding for youth with learning disabilities, such as dyslexia and ADHD, is predominantly administered by the U.S. Department of Education (ED), relying far less on clinical health systems than the intellectual disability or mental health models. IDEA, as discussed in the preceding section, serves as the primary mechanism for students who meet specific eligibility thresholds, providing the specialized instruction and accommodations required for academic success. However, a significant portion of students with learning differences do not qualify for IDEA and instead rely on ESEA Title I, Part A funds, allocated to districts with high concentrations of low-income households to support supplemental instruction and academic interventions that benefit students regardless of formal disability designations.

This area is characterized by a heavy reliance on braided local funding. Schools often combine Title I resources with general education budgets to implement Section 504 accommodations — which, despite being a federal civil rights requirement, carry no dedicated federal funding stream. This creates a landscape of high variability where access to quality identification and intervention often depends more on local district capacity than on standardized federal support. As identification rates and awareness of learning disabilities grow, the reliance on level-funded federal programs effectively reduces service capacity, underscoring the need for more coordinated investment across early childhood and K–12 systems.

The current federal environment is defined by the same attitudinal rift seen in the intellectual disability space regarding the scope of disability law. The Administration has shown strong support for addressing "biological and neurological" disorders (such as autism and defined learning disabilities), while demonstrating more limited investment in broader learning disabilities. This pivot toward clinically defined disabilities marks a major shift in how discretionary funds are prioritized: while funding for core neurological challenges remains a bipartisan bright spot, the broader support systems for youth behavior and wellness are increasingly vulnerable to consolidation or elimination.

This policy shift is occurring against a backdrop of institutional disruption within the school system. For example, the increased presence of immigration enforcement has significantly impacted school environments. Immigration policy has affected how comfortable parents, including parents of children with disabilities, feel interacting with their children's school and support systems, and there is a disturbing connection between immigration enforcement and rising levels of childhood trauma, anxiety, and fear. Simultaneously, teachers and special education staff face acute workforce shortages because employees are similarly affected by enforcement-related fear and uncertainty, creating a debilitating cycle that impacts both students' ability to learn and schools' ability to serve all students' needs equally.

The effects of the reductions in staff at the Department of Education Office of Civil Rights (OCR) (which has lost over half of its staff since President Trump took office) are already being felt in communities. OCR is now routinely dismissing ongoing cases (particularly those related to disability accommodations), focusing on cases that are easiest to resolve, and rescinding guidance that previously protected students. The Interagency agreements (IAAs) that are part of the Administration's effort to dismantle ED and "return" education authority to the states are adding further uncertainty. Although IAAs only shift administrative responsibility and do not actually end current ED programs, weakened program management, accountability, and oversight are serious concerns.

ii. Advocacy Opportunities

An effective advocacy strategy focused on learning disabilities could have multiple complementary strands. For example, advocates can: continue the drumbeat of support for continued federal investment, including direct grants under IDEA and key complementary national supports; highlight the disruption and negative impact that the Administration's immigration enforcement efforts have had on students with learning disabilities; and develop a refined, longer-term paradigm for systems that support children with learning disabilities, with an eye toward informing potential actions under a new administration and Congress in 2029. Areas of emphasis could include, for example, identifying key research investments and infrastructure to scale-up effective practices.

Related Advocacy Opportunities:

- **Support Career and Technical Education (CTE):** Congressional education leaders have expressed strong support for career and technical education under the Perkins Act and interest in reauthorizing the law given major changes in the labor market and education sector since its last reauthorization in 2018. Because CTE has largely been a bipartisan issue, this is an area where federal legislative action could be promising. Advocates could pursue upcoming opportunities regarding high-quality CTE, ensuring access and strong support for students with learning disabilities.
- **Advocate for Full Funding of IDEA:** As discussed in the Intellectual Disabilities segment above, the Keep Our PACT Act represents a key legislative vehicle for addressing the chronic underfunding of IDEA that disproportionately impacts students with learning disabilities. Advocates could elevate local perspectives on the impact of funding shortfalls.

- **Reauthorize IDEA and ESEA:** Again as discussed above, advocates can begin laying the groundwork for long-overdue IDEA and ESEA reauthorization and develop a set of policy priorities to be included in bills when the large legislative vehicles move.
- **Strengthen Federal Early Intervention Under IDEA Part C:** Early identification of language delays and processing difficulties in the first years of life is among the most effective tools available for preventing the need for more intensive interventions later. Early intervention services for infants and toddlers with developmental delays are authorized and partially funded through IDEA Part C. However, Part C has never been fully funded, and federal oversight of state timely service delivery requirements has been weakened by Administration staffing cuts at OSERS. New York's early intervention system has faced particularly persistent delays and provider workforce shortages that make federal funding and oversight especially consequential. Foundation stakeholders can document early intervention gaps and press for both adequate appropriations in the FY27 cycle and push for meaningful federal compliance oversight.
- **Urge Interagency Agreement Oversight:** As the Administration shifts administrative responsibility for education programs across agencies, advocates could press for congressional oversight to ensure that weakened program management does not undermine services for students with learning disabilities.
- **Encourage Renewed OCR Enforcement:** Given the dramatic reduction in OCR staff and the dismissal of ongoing cases related to disability accommodations, advocates could press for the restoration of meaningful civil rights enforcement for students with learning disabilities.
- **Support the Science of Reading Act:** Supporting the Science of Reading Act of 2026, which passed the Education and the Workforce Committee unanimously, is one of the most concrete, near-term, bipartisan federal legislative opportunities directly relevant to students with dyslexia and learning disabilities, and it has a named champion, Rep. John Mannion (D-NY-22) in the New York delegation. Stakeholders can support passage by documenting local literacy needs in WNY, encouraging constituent engagement with Rep. Mannion's office, and building public support for companion Senate legislation.

E. Additional Federal Areas of Interest: Homelessness, Immigration, Other

Finally, there are a number of additional federal policy issues closely related to the Foundation's core issue areas. First, the Administration has pursued destabilizing changes to the U.S. Department of Housing and Urban Development $4 billion Continuum of Care program, the largest federal grant specifically focused on assisting people experiencing homelessness. For the last four administrations, the metric of success has been moving unhoused women and children off the streets. While this has been successful in reducing homelessness, it has largely failed to move families out of poverty. HUD is now signaling a desire to pivot from permanent supportive housing toward emergency housing paired with treatment for medical conditions underlying homelessness.

The risk of HUD's new approach is high, however, as a poorly executed transition could inadvertently push vulnerable populations back onto the streets. HUD's planned changes will likely intensify housing insecurity

for individuals with mental health disorders, including SUD, as HUD shifts toward a treatment-first model, transitioning focus from permanent to emergency housing, capping renewals of Permanent Supportive Housing funding at 30% (down from 90%), and prioritizing law enforcement partnerships. That said, it is also possible that HUD takes a more nuanced approach and emphasizes evidence-based approaches that shifts toward a model where housing is not the end goal, but a stable foundation for treatment and eventual employment. This approach could align with the broader federal push to integrate wellness with workforce development, viewing the individual's needs through the lens of long-term economic self-sufficiency rather than indefinite maintenance.

Additionally, as noted above, immigration policy represents a cross-cutting federal challenge affecting multiple other policy issue areas. Foundation stakeholders report in interviews that the increased presence of ICE in communities has made community members less likely to seek out and access services, with immigrants becoming increasingly hesitant to travel even 30 minutes to access services. Current immigration policy is also having a negative impact on how comfortable parents feel interacting with their children's school and support systems, and there is a disturbing connection between immigration enforcement and increased levels of childhood trauma, anxiety, and fear. The negative impact of current immigration enforcement practices extends far beyond undocumented individuals and reaches entire communities. Organizations are also experiencing workforce challenges as a result of uncertainty in the U.S. visa system and ongoing Administration immigration policy shifts. While immigration policy is broadly recognized as a significant challenge, there is widespread uncertainty about potential effective responses — underscoring the need for education and access to reliable resources in order to determine appropriate advocacy engagement or support opportunities in this complex policy and political environment.

Finally, rapid shifts in federal policy are creating general uncertainty about the reliability and sustainability of previously guaranteed funding streams. Some advocates voice concern that the Administration might withdraw federal funding from largely Democratic states. Others raise concerns about the Administration's proposal to require that federal funding applicants and recipients submit signed certifications prohibiting DEI programs. Lastly, additional federal policy areas related to the Foundation's core issue areas for which access to reliable resources and advocacy guidance could be helpful include passthrough funds from HUD (housing choice vouchers and project-based subsidies) and passthrough funds from HHS, including: Delivery System Reform Incentive Payment (DSRIP) (a program that provides incentive payments to safety-net providers to support system transformation and improve care delivery); Home and Community Based Services (HCBS) (Medicaid-funded services that help individuals with disabilities and older adults live in their homes and communities rather than in institutional settings); and Preadmission Screening and Resident Review (PASRR) (a federal requirement to evaluate individuals with mental health conditions or intellectual disabilities before admission to a Medicaid-certified nursing facility to ensure that they receive the most appropriate level of care).

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Landscape Analysis: Advocacy for Impact

SECTION VIII

MASSACHUSETTS: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES



Landscape Analysis

SECTION VIII
MASSACHUSETTS: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES

I. MASSACHUSETTS CONTEXT

Massachusetts is often viewed as an exemplar of progressive policy aiming to meet critical social needs. However, recent state funding reductions and the Commonwealth's top-down governance structure have created numerous policy challenges across the Tower Foundation's core issue areas that necessitate a robust, strategic advocacy response. This Section of the Landscape Analysis identifies current Massachusetts policy challenges and significant advocacy opportunities focused on youth substance use disorders, mental health, intellectual disabilities, and learning disabilities – particularly within Essex, Barnstable, Dukes, and Nantucket Counties.[1] To provide context, this Section begins with a brief overview of: (A) the influence of Massachusetts state government relative to local government; (B) how relevant funding flows through Massachusetts government; and (C) unique factors characterizing Essex County and the Cape and Islands.

A. Strong State Government

Massachusetts operates under a unique top-down governance structure characterized by heavy influence of statewide offices and limited influence of county leadership. This governance structure differs significantly from New York State, which features unusually strong local and county influence. Statewide political forces therefore have an outsized impact on policy and funding issues affecting youth and young adults in Massachusetts.

The Commonwealth's Democratic and progressive leanings are reflected in the composition of the state legislature, with only 25 Republican Representatives and 5 Republican Senators serving in the 200-person bicameral legislature. Republican legislators largely represent rural areas, with Democrats dominating urban and suburban areas – including those communities designated as Gateway Cities.[2] Notwithstanding this distinction, Republican state legislators often hold moderate views and vote outside strict party lines.

[1] For the sake of brevity, Barnstable, Dukes, and Nantucket Counties may be referred to as "the Cape and Islands" throughout this Section.

[2] Gateway Cities are characterized as economically disadvantaged and resource-poor municipalities throughout the state, extending from New Bedford in the South to Springfield in the West. This designation was codified in 2009 under Massachusetts state law in an attempt to direct specific grants and earmarked funding to these cities. To qualify for Gateway status, a city must have a population between 35,000 and 250,000, median household incomes below the state average, and college education rates that fall below the state average. Gateway Cities house 27% of all Massachusetts residents and nearly 40% of the state's foreign-born population, and they have collectively been majority-minority since 2020.

Functionally, the state legislature operates on a two-year cycle, with the current legislative session ending in July 2026 and the next cycle beginning in January 2027. Legislators actively engage in policymaking throughout the two-year cycle (in contrast to states with limited sessions), though productive policymaking is often concentrated during the budget process (from February - June each year) and the summer of the second session (before it concludes on July 31). Given this structure, key policy priorities are often delivered through the state's budget bills, as well as through large omnibus legislation packages crafted, in part, through legislative committees. In addition, the state legislature includes significant earmarks for local initiatives in its annual budget, often funding local projects as budget amendments, with millions allocated to community projects favoring districts of legislators close to leadership.[3] Committees of particular note include: the Joint Committee on Children, Families and Persons with Disabilities; the Joint Committee on Education; and the Joint Committee on Mental Health, Substance Use and Recovery. Additionally, the Joint Committee on Ways and Means, Joint Committee on Financial Services, and Joint Committee on Health Care Financing hold broad jurisdiction. Nearly all legislation impacting health care or state finances is referred through one or more of these committees, with Ways and Means often serving as the final stop before a bill – regarding most any subject matter – advances to the floor for consideration.

At an Executive level, Governor Healey is a fierce Democratic champion. While serving as Attorney General prior to serving as Governor, Healey led the state's efforts on securing financial settlements against opioid distributors for their role in the state's opioid crisis. Since becoming Governor, Healey has prioritized combatting the substance use and related mental health crisis and has emphasized the need for leadership in mitigating its toll. Governor Healey enjoys strong polling and appears very likely to secure a second term in the November 2026 election. Meanwhile, Lieutenant Governor Kim Driscoll is from Salem (an Essex County Gateway City), where she previously served as both a City Councilor and Mayor of Salem. Lieutenant Governor Driscoll's familiarity with the needs of Essex County and Gateway Cities is deep, and she has a favorable reputation and strong influence with municipal leaders across the state.

Within the Healey administration, several offices guide policy most relevant to the Foundation. The two most significant are the Executive Office of Health and Human Services (EOHHS) led by Secretary Kiame Mahaniah, and the Executive Office of Education (EOE) led by the newly appointed Salem Public School Superintendent Dr. Stephen Zrike Jr.[4] EOHHS is the primary office handling all health issues in the state – including youth substance use, mental health, intellectual disabilities, and learning disabilities. EOE serves as the keystone organization for the Commonwealth's education services for birth through postsecondary education, including school-based services for substance use prevention and mental health, and as the primary support provider for students with intellectual disabilities and learning disabilities. Together, these two offices oversee a variety of state agencies involved in regulating youth policy, including the Department of Elementary and Secondary Education (DESE), Department of Mental Health (DMH), Department of Developmental

[3] Pursuing earmarks in state legislators' budget proposals is often an effective advocacy strategy when advancing localized priorities.

[4] EOE is currently in the midst of a leadership change. The former EOE Secretary, Patrick Tutwiler, stepped down in early February (2026) after serving in the role for three years. Secretary Tutwiler was popular among the broader education community, and his efforts seemed to favor improving early education and expanding access to early childcare. Replacing Sec. Tutwiler is Dr. Stephen Zrike Jr. – former Superintendent for Salem Schools in Essex County. Meanwhile, EOHHS is led by Secretary Kiame Mahaniah, MD. Dr. Mahaniah is still a practicing physician in the field of addiction and primary care, and his professional experiences are rooted in Essex County, where he practices) medicine at a variety of Community Health Centers throughout the region. Both EOHHS Sec. Mahaniah's and EOE Sec. Zrike's deep familiarity, experience, and personal ties to Essex County bode well for future youth advocacy efforts across the Commonwealth.

Services (DDS), Department of Youth Services (DYS), Department of Public Health (DPH), Office of Youth Mental Health and Wellbeing (OYMH), and the Bureau of Substance Addiction Services (BSAS), among others.

B. Massachusetts Funding Structure

Funding for substance use disorders (SUD), mental health, intellectual disabilities, and learning disabilities in the Commonwealth primarily comes from two sources: federal pass-through dollars administered by the state, including Medicaid, and state investments made through the annual and supplemental budget processes. These funds are distributed by the relevant state agencies and offices and flow directly to regional providers, school districts, and municipalities, bypassing largely non-existent county government structures. More specifically, funding for youth substance use and behavioral health needs commonly flow through DMH, DPH, EOHHS, and EOE. Additionally, Massachusetts covers mental health services and treatment for certain individuals under MassHealth – the Commonwealth's combined Medicaid and State Children's Health Insurance Program (CHIP). DESE serves as the central education funding and guidance agency for pre-K-12 schools. However, EOE and DESE typically do not impose specific requirements on school districts for the use of state education funding, due to the substantial influence of individual districts, superintendents, and teachers' unions who have pushed for flexibility.

C. The County Caveat

As noted above, the Commonwealth operates under a top-down governance system with a weak county structure. While local needs are identified at the community level, state leadership often serves as the primary avenue for accessing funding, support, and resources. Substantive, authoritative county governments do not exist on a statewide basis in Massachusetts (and have not since the 1990s). In regions where counties are no longer functional, local governance is managed by municipal leadership and/or regional planning agencies.

In the Tower Foundation's catchment area, Essex County government is largely defunct, and its regional needs are met by both the Merrimack Valley Planning Commission and the Metropolitan Area Planning Council, the latter of which also serves Suffolk and Norfolk Counties. However, active county governance remains intact to some extent in Barnstable, Dukes, and Nantucket Counties. This difference requires a bespoke approach as the Foundation contemplates expanding its systems change and policy advocacy strategies in the two geographic regions.

To leverage their influence over state matters, municipalities often participate in the Massachusetts Municipal Association (MMA), a non-profit organization that helps city and town officials collaborate on advocacy and policy development. While the MMA is an influential voice in the state, its core policy priorities include energy and the environment, fiscal affairs, municipal administration, labor relations, public works and transportation – notably no youth-focused policy. Consequently, addressing youth needs relating to SUD, mental health, intellectual disabilities, and learning disabilities requires strong state leadership with individual community partnerships.

i. Essex County

Essex County is the third most populous county in Massachusetts. Located in Eastern Massachusetts, it overlaps with the Boston metropolitan area – the state's political and resource capital. Within Essex County, educational disparities and the youth mental health crisis are most acute in the designated Gateway Cities of Salem, Peabody, Lynn, Methuen, Lawrence, and Haverhill. More detailed information about elected officials representing Essex County is in Addendum A of this Section.

ii. Cape and Islands

In contrast to the urban issues facing Essex County, the Counties of Barnstable, Dukes, and Nantucket grapple with unique challenges stemming from coastal and rural isolation, a graying population, significant seasonal variability, and high housing costs. The largely seasonal nature of the Cape and Islands' population and economy, along with high housing costs, create workforce challenges and significant barriers to the establishment of enduring behavioral health and educational supports. The Cape and Islands region is notably resource-poor in comparison to other parts of the state, and frequently struggles to address community needs ranging from behavioral health to transportation, marked by low housing supply and a transient workforce. These issues create pervasive policy challenges. It is also worth noting that while the Cape and Islands differ from Essex County in many ways, they share some similarities in that the town of Barnstable (in Barnstable County) is classified as a Gateway City. More detailed information about elected officials representing the Cape and Islands is in Addendum B of this Section.

II. FOUR ISSUE AREAS: POLICY CONTEXT, CURRENT CONDITIONS, AND ADVOCACY OPPORTUNITIES

Below is an overview of the Massachusetts policy context, current conditions, and advocacy opportunities relevant to the Foundation's four core issue areas: (A) substance use disorders; (B) youth mental health; (C) intellectual disabilities; and (D) learning disabilities.

A. Substance Use Disorders

i. Policy Context

The stability of substance use disorder (SUD) services for youth and young adults in Massachusetts is fundamentally dependent upon the flow of federal pass-through dollars and Medicaid (as administered under MassHealth). Sustaining federal-level SUD funding through effective advocacy is therefore critical for the wellbeing of young people with substance use disorders in the Commonwealth. Unlike broader healthcare infrastructures, the youth SUD system operates with high operational fragility because its core infrastructure – ranging from school-based prevention to intensive recovery support – is heavily dependent on year-to-year SAMHSA State Opioid Response (SOR) grants and Substance Use Prevention and Treatment Block Grants.

Because these are discretionary federal pass-through funds, rather than mandatory spending or spending within the control of the Commonwealth, they are uniquely vulnerable to federal administrative shifts. The recent 2026 disruption and subsequent restoration of billions in SAMHSA funding (discussed in more detail in Section VII of this Landscape Analysis) serves as a stark reminder that without aggressive defense of federal funding streams, the Commonwealth's SUD response can be hollowed out overnight, leaving providers unable to maintain staffing levels or continuity of care.

Defending ongoing support for Medicaid at the federal level is equally critical, as Medicaid provides the mandatory entitlement floor, ensuring youth have the legal right to treatment. While Opioid Settlement Funds have provided a $1 billion influx to the state, these dollars are intended to supplement – not supplant – foundational funding provided by MassHealth and SAMHSA. If federal policy shifts reduce Medicaid matching rates or cap spending, the state risks having to divert Opioid Settlement Funds to fill basic budget gaps instead of expanding youth-specific, clinical treatment models that the Commonwealth currently lacks. Protecting these federal funding pillars is therefore a critical strategy in ensuring that Massachusetts can move beyond crisis budgeting, and build a permanent, integrated continuum of care for its most vulnerable young people.

State systems' sustainability is also deeply dependent on how the state manages its internal recovery assets. Chief among these assets is the Opioid Recovery and Remediation Fund. This fund, along with the associated Municipal Abatement Payments, originated from over $900 million in funds secured through legal settlements with pharmaceutical companies, distributors, and retailers that manufactured, marketed, and sold prescription painkillers. Through the year 2039, 60% of these resources will be allocated to the state-level fund, while the remaining 40% (approximately $379 million) will be distributed directly to municipalities. At the state level, BSAS manages 76 grant-funded programs across 200 municipalities, prioritizing evidence-based approaches and youth-specific prevention as youth substance use trends downward. Local governments are expected to utilize payments to expand access to treatments for substance use disorders, provide wraparound services, and support prevention education. The local governance structural differences discussed earlier significantly influence how these resources are administered. Unlike in Essex County, where regional needs are met through centralized state leadership and municipal collaborations, Cape and Islands Counties directly administer public health supports, allowing for a more localized approach to youth mental health and SUD services.

ii. Current Conditions

Massachusetts's efforts to address youth SUD exist within a multi-tiered system including a robust statewide infrastructure, strategic public-private partnerships, and specialized regional initiatives.

The keystones of the statewide infrastructure are Community Behavioral Health Centers (CBHCs), which the Commonwealth utilizes as a "front door" for therapy and crisis stabilization. These Centers serve as a critical referral touchpoint for connecting families to qualified youth therapists. Supplementing CBHCs efforts is school programming, including $9.1 million in federal SAMHSA funding that EOHHS recently awarded for early intervention programs in schools, targeting students in grades 4-12 who are at risk for behavioral challenges or substance use.

Complementing these state-led efforts are influential public-private partnerships, most notably RIZE Massachusetts. Funded in part by DPH and BSAS, RIZE has successfully granted $21 million to more than 200 community organizations since its inception in 2017. RIZE's current operational focus is on strengthening "linkages to care" – programs that facilitate and encourage SUD treatment collaboration between hospitals, providers, community-based organizations, and families. Regionally, RIZE has been active in Essex County since 2018, and is funding two SUD and behavioral health projects in Salem ($249,000) and Salisbury ($247,000). In Barnstable County, RIZE has allocated 11 grants, and is currently funding a SUD-management program throughout the Cape and Islands region ($247,000).

In Essex County, local SUD-prevention and treatment efforts include Team Fourteen, a specialized SUD program for adolescents, and Essex County Outreach (ECO), a collaborative involving all 34 police departments in the county to assist individuals with behavioral health challenges. The Essex Sheriff's Department also runs a summer Youth Leadership Academy focused on drug and alcohol awareness for at-risk youth.

In the Cape and Islands, Barnstable County utilizes state grants to address youth substance use through its Department of Human Services and a dedicated Children's Behavioral Health Work Group. Dukes County relies on a Youth Task Force to conduct biannual surveys and train school staff in the iDECIDE program, which teaches the neurobiology of addiction. Nantucket's efforts are largely managed through collaborations between the Sheriff's Office and organizations like Fairwinds Nantucket, providing community-based services under the Children's Behavioral Health Initiative.

iii. Advocacy Opportunities

There are significant opportunities for meaningful advocacy engagement that addresses regional disparities and systemic barriers that currently limit the effectiveness of the Commonwealth's substance use disorder and behavioral health infrastructure.

Related Advocacy Opportunities:

- **Build and Retain the Behavioral Health Workforce:** Advocate for state investment in workforce development and retention programs, with targeted attention to rural and coastal communities where provider shortages are most severe. Specific opportunities include supporting loan forgiveness and scholarship programs for behavioral health professionals who commit to practicing in underserved regions, and encouraging investment in non-clinical personnel – peer support specialists, community health workers, and recovery coaches – as a near-term strategy for expanding access while longer-term clinical workforce gaps are addressed.
- **Build Critical Behavioral Health Infrastructure on the Cape and Islands:** Make the case for the establishment of community-based behavioral health facilities in rural and coastal regions that currently lack facilities – including potentially Community Based Acute Treatment (CBAT) facilities, Recovery High Schools, and mental health urgent care centers. This priority is based on the simple but compelling premise that a young person's ability to access life-saving intervention should not be determined by their geographic distance from the Boston metropolitan area. These efforts align with the state's

broader goal of decentralizing care and should be advanced as an equity imperative, ensuring that the Commonwealth's expanding behavioral health infrastructure reaches its most isolated communities.

- **Direct Municipal Opioid Abatement Funds Toward Youth:** Engage municipal and county leaders to ensure that opioid settlement and abatement funds are explicitly directed toward youth-focused programs, centers, and supports. Advocacy efforts could include developing model language that municipalities can adopt to prioritize young people in their abatement spending plans, closing the gap between where settlement dollars currently flow and where youth need is greatest.
- **Expand and Strengthen Public-Private Partnerships**: Support the growth of public-private partnerships – such as the RIZE model – that help municipalities effectively deploy settlement dollars into community-based SUD treatment and prevention. Advocacy should also push these partnerships to adopt explicit youth-focused mandates, ensuring that young people are centered in program design. Given that the most impactful advocacy efforts are grounded in direct service, rooted in data, and conducted in coalition, this work should include cultivating relationships with local providers and leveraging their expertise and voices to inform and advance broader advocacy and systems-change efforts.
- **Launch Targeted Public Awareness and Prevention Campaigns:** Develop and promote public health campaigns that connect community wellness investments to youth substance misuse prevention, particularly in Barnstable County, where youth substance misuse rates consistently exceed state averages. A 2024 study underscored the persistence of this gap alongside a critical lack of public understanding about how community wellness initiatives correlate to prevention outcomes. Advocacy efforts should focus on bridging this gap through data-driven, locally tailored campaigns that build the public will necessary for sustained investment in prevention infrastructure.

A. Youth Mental Health

i. Policy Context

Youth mental health funding in Massachusetts operates as a complex, interlocking set of systems, with MassHealth (and more specifically, the Massachusetts Behavioral Health Partnership (MBHP)) serving as its foundation. Through its Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, the Commonwealth is legally mandated to provide all medically necessary behavioral health services to eligible youth, creating a dependency on MassHealth that underpins the entire sector. This foundation is further bolstered by the federal Social Security Act Section 1115 Demonstration Waiver that provides the state with the flexibility to fund diversionary services and integrated care models. However, this reliance also means that administrative shifts in federal Medicaid policy – such as proposed funding caps or changes to Section 1115 waivers – can create immediate operational fragility, destabilizing providers who rely on consistent reimbursement to keep their doors open.[5]

[5] The case of Rosie D. vs. Romney was a major force in ensuring HCBS mental health services for Medicaid-covered youth. While the courts have found that the State is compliant, several watchdog organizations continue to ensure compliance with the spirit of the findings.

Looking ahead, the funding landscape remains high-risk, notwithstanding nominal budget increases. Specifically, the system continues to face a level-funding trap in which incremental increases are swallowed by rising operational costs and Chapter 257 provider[6] rate hikes as the overall cost of healthcare rises. These financial pressures, coupled with chronic workforce shortages for K-12 clinicians and specialized therapists, have left many services at or under capacity with current resources being stretched thin. Without a significant shift in federal and state reimbursement rates to attract and retain specialists, the Commonwealth risks moving toward a crisis-based response system rather than the proactive, community-based care envisioned in recent behavioral health reforms. This precarious balance has forced state leadership to step in with targeted investments to shore up the system's foundation.

In light of these pressures, the Healey administration has prioritized the student mental health crisis under the leadership of former EOE Sec. Tutwiler. To address this crisis, the administration has allocated millions of local dollars for youth mental health programming with much of the funding directed toward school and community-based intervention and prevention programs. Notwithstanding these significant investments, parents, educators, and advocates continue to sound the alarm that a substantial share of youth mental health needs in the Commonwealth remain unmet.

The expansion of services is also consistent with Massachusetts's Behavioral Health Roadmap, a multi-year blueprint that commenced implementation in 2023 and was created in response to reported needs for expanded access to treatment, more effective treatment, and improved health equity. The Roadmap prioritizes expanding access to behavioral health treatment by increasing access to care at primary care offices, offering community-based alternatives to emergency rooms, encouraging more providers to accept insurance, and investing in a culturally competent and linguistically diverse workforce.

ii. Current Conditions

Current efforts to expand support for youth mental health are anchored by Governor Healey's Fiscal Year 2027 (FY27) budget proposals, which feature significant investments in student health following the resounding call for increased support throughout 2025. The proposed FY27 budget allocates $16.6 million to bolster mental and social emotional health for students. Specific allocations include $6 million to continue the development of a statewide birth-through-higher-education mental and behavioral health framework, $5 million to maintain Early Childhood Mental Health Consultation services, and $648k to maintain the Safe and Supportive Schools program. In addition, $337 million has been designated for the Children's Behavioral Health Initiative, an interagency state program through MassHealth aimed at providing comprehensive, community-based behavioral health services to children suffering from severe emotional disturbances.[7]

[6] Chapter 257 providers are community-based human and social service organizations that contract with EOHHS and its departments. They provide services such as residential care, mental health support, day care, and vocational training. Chapter 257 sets consistent, fair, and transparent reimbursement rates for these providers based on the actual costs of care.

[7] At the same time, school systems, providers, and community organizations have faced the end of federal COVID-era relief funds, including the Elementary and Secondary School Emergency Relief (ESSER) funds that supported the hiring of essential school-based mental health professionals. While that funding has ended, the increased and persistent need has not.

Additional youth-specific supports are offered through DESE, including the disbursement of the Safe and Supportive Schools program grants and roughly $3.5 million in total for Social Emotional Learning (SEL) and Mental Health Continuation grants designed to build infrastructure for coordinating services between schools and families. Furthermore, DMH maintains Young Adult (YA) Access Centers across the state, which offer unique community spaces where young adults can access mental health supports without the requirement of a referral or insurance. These centers serve as an accessible first touchpoint for youth seeking assistance.

The Commonwealth's approach to behavioral health has also faced notable challenges and shifts in recent years. During the 2025 budget process, for example, Governor Healey's initial proposal to cut youth mental health services due to financial constraints was met with fierce opposition from legislators and community leaders concerned about the potential dire impact on families. In response to the vehement criticisms, the Commonwealth reversed course and moved to expand community-based youth behavioral health services through MassHealth in the fall of 2025 – representing the first expansion of the provider network in over a decade. This expansion offered more options for families, increased access to high-quality behavioral health services, and ensured geographic coverage across the entire state, including for families seeking specialized culturally responsive and linguistically competent care.

In recent months, school systems, providers, and community organizations have also been grappling with the significant mental health impact of current deportations, fear of deportations, family separation, and other disruptions in immigrant communities – factors that have compounded mental health concerns in already at-risk populations. In addition to immigration concerns serving as a significant stressor for youth and families, fears of ICE raids have served as a deterrent for youth and families accessing necessary care in medical and school-based settings. Moreover, because a significant portion of the provider population consists of immigrants, heightened systemic pressures have led to increased absenteeism and staffing shortages that directly compromise the continuity of care.

In Essex County, the majority of mental health counseling services are delivered through private entities, such as East Point Behavioral Health and Beth Israel Lahey Health Behavioral Services, while the state provides direct resources through Community Behavioral Health Centers (CBHCs). These CBHCs act as a state-funded front door for therapy and crisis stabilization and are currently serving Essex through Beth Israel Lahey Health in Lawrence and Eliot Community Human Services in Danvers and Lynn. The Cape and Islands are served by Bay Cove Behavioral Health & Wellness Center in Hyannis, Martha's Vineyard Community Services in Oak Bluffs, and the Fairwinds Center on Nantucket. While these centers serve all individuals, they are critical touchpoints for referring youth to specialized therapists.

Regional support is also provided by the National Alliance on Mental Illness (NAMI), which is organized into three chapters in Essex County – Greater North Shore, Northeast Essex, and Cape Ann – and a consolidated chapter for the Cape and Islands. These NAMI chapters are key stakeholders that provide sponsored classes and support groups, connect individuals with providers, and engage in advocacy at both the local and federal levels to strengthen mental health awareness and policy.

iii. Advocacy Opportunities

There are significant opportunities for advocacy engagement addressing profound regional disparities and systemic barriers that currently limit the effectiveness of the Commonwealth's mental health safety net for youth and young adults.

Related Advocacy Opportunities

- **Address Workforce Shortages:** Advocate for state-level workforce development and retention programs to address the lack of qualified behavioral health providers, which currently leaves families waiting months for treatment. Massachusetts families seeking behavioral health care for their children are routinely forced to wait months for an appointment — not because services do not exist, but because there are not enough qualified providers to deliver the services. There is an opportunity to develop coalitions efforts and advocacy initiatives that would encourage the Commonwealth to invest funds in targeted workforce development and retention initiatives, including loan forgiveness programs for behavioral health clinicians who commit to practicing in underserved regions, pipeline grants to grow the number of licensed counselors and social workers entering the field, and competitive reimbursement rate increases through MassHealth to make provider participation financially sustainable. Without a stable, adequately-staffed provider network, even the most well-funded programmatic investments can fail to reach the families who need them most.
- **Support At-Risk Student Populations:** Push for increased mental health funding – specifically for immigrant communities where deportation and family separation fears are compounding the mental health challenges identified in the state's Behavioral Health Road Map. The mental health crisis among immigrant youth and families has increased significantly in the current climate, creating urgent and layered needs that the current system is ill-equipped to address. Fears of ICE enforcement are actively deterring families from accessing care in school-based and medical settings, while provider absenteeism driven by the same concerns is eroding continuity of care. Advocates should encourage policymakers to direct dedicated mental health funding toward culturally responsive and linguistically competent services for immigrant communities — building on the MassHealth provider network expansion of fall 2025 — and support school-based mental health access models that reduce barriers to care and do not require families to navigate systems that they experience as threatening. Addressing this gap is consistent with the goals outlined in the state's Behavioral Health Road Map.
- **Establish Missing Coastal Infrastructure:** Demonstrate the importance of shifting funds to support critical community efforts and behavioral health workforce efforts in the Cape and Islands. The unequal distribution of resources is stark: while Essex County is home to four Young Adult Access Centers, currently the Cape and Islands region does not have a single one. This gap is particularly concerning given that the coastal and rural isolation of Barnstable, Dukes, and Nantucket Counties creates inherent barriers to the establishment of enduring supports. As previously emphasized, the Cape and Islands region is notably resource-poor and frequently struggles with unique pressures such as transportation needs, a seasonal economy, and a very low housing supply that is further strained by a transient

workforce. These compounding factors necessitate targeted investment in advocacy to ensure that youth in these isolated regions are not left behind as the state expands its behavioral health infrastructure.

- **Retain and Expand School-Based Staffing and Strengthen Curricula:** Advocate for state grants to replace lost federal funding that was previously used to hire essential school-based professionals, such as counselors and social workers, ensuring that all students' mental health needs are supported in their respective school systems regardless of geography. In addition, since school districts currently have full discretion over the SUD prevention curricula and the materials they utilize, there is an advocacy opportunity to work with local schools to ensure they are implementing the most effective, evidence-based tools available. By leveraging the influence of organizations currently involved in mental health advocacy and education efforts, such as the local NAMI chapters, there is an advocacy opportunity to induce the system-wide change necessary to maximize the impact of the Commonwealth's recent investments in student mental health.
- **Strengthen MassHealth Reimbursement and ER Access for Children's Behavioral Health:** Champion increased MassHealth reimbursement rates for children's behavioral health services and reduced emergency room wait times for youth in psychiatric crisis. Current reimbursement rates have contributed to a shrinking provider workforce, making it increasingly difficult for families to access timely outpatient care and pushing more children toward emergency rooms as a last resort. This dynamic is particularly acute in under-resourced regions where the provider pipeline is already thin and ER diversion options are limited. Closing the gap between what MassHealth pays and what sustainable care delivery actually costs is essential to rebuilding capacity, retaining qualified providers, and ensuring that children across the state can access behavioral health support before they reach a point of crisis.

C. Intellectual Disabilities

i. Policy Context

In Massachusetts, the continuum of care for youth with intellectual disabilities is anchored in federal pass-through dollars that help fund the Commonwealth's early childhood and education systems. The stability of these services depends heavily on the defense of the federal Individuals with Disabilities Education Act (IDEA)[8] Part B (Preschool Special Education) and Part C (Early Intervention), both of which are vital for early identification. However, because federal appropriations historically fail to cover the full cost of these mandated services, Massachusetts – like other states across the country – faces a structural underinvestment that places significant financial pressure on state and local budgets. To bridge this gap, Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit serves as a critical federal supplement, financing medically necessary therapies – such as speech and occupational therapy – that schools are required to provide but are not fully funded to deliver. Protecting these critical federal streams is essential to ensuring the Commonwealth is not forced to choose between service quality and fiscal sustainability.

[8] The Individuals with Disabilities Education Act (IDEA) is a federal law that ensures free appropriate public education (FAPE) tailored to individual needs for eligible children with disabilities from birth through age 21. It mandates special education services in the least restrictive environment (LRE) and covers 13 specific disability categories, providing legal rights for parents and procedural safeguards

Beyond direct education funding, the system faces acute operational fragility due to evolving federal regulations and workforce challenges. The defense of Medicaid Home and Community-Based Services (HCBS) Waivers and the stability of the HCBS Settings Rule [9] are paramount, as any restructuring at the federal level could disrupt the community-integrated models Massachusetts has worked to build. Furthermore, the system is currently strained by a cycle of trauma, as discussed earlier, in which federal immigration uncertainty prevents families from accessing services and exacerbates an already dire staffing crisis. Without active engagement at the federal level to secure sustainable reimbursement rates and clear regulatory pathways, the Commonwealth's disability support infrastructure remains vulnerable to workforce collapses and related unintended consequences.

The actual delivery of federal and state resources is filtered through a centralized governance structure, dictating how families experience care. This delivery is led primarily by DESE (within EOE) and DDS (through EOHHS): DESE manages intellectual disabilities support systems that families and students access through school systems, while DDS manages community-based systems of support for families and individuals, taking on significant importance when an individual graduates from the school system. DDS serves more than 43,000 children and adults with intellectual and developmental disabilities, autism spectrum disorder and acquired brain injuries, while DESE serves over 192,000 students with disabilities.

Supports and services offered to individuals with intellectual disabilities and their families are primarily funded through either Medicaid or state level funding – with DDS and DESE serving as the interface for accessing these funds. Although there are regional supports and invested stakeholders in Essex County and the Cape and Islands, local leadership in these areas is significantly less pronounced (compared to local efforts on youth SUD and mental health). This top-down structure offers a unique advocacy window for Foundation stakeholders to offer local expertise while advocating for systems change at the state level.

Both DESE and DDS have undergone relatively recent leadership shifts, with both departments appointing new commissioners within the last year. Pedro Martinez was recently appointed as the new Commissioner of DESE, bringing extensive experience from large, under-resourced school districts in Texas and Illinois. Commissioner Martinez has stated that he intends to focus on resource and funding optimization within the Commonwealth's schools, given the current tight state budget and diminished federal oversight and funding. More specifically, Commissioner Martinez is encouraging districts to maximize existing resources to support students – including high-needs students with IDs – and urging schools to think creatively and proactively about supporting students. In addition, DDS recently appointed Sarah Petersen as Commissioner. Prior to assuming this role, Petersen served as both general counsel and deputy general counsel for DDS, and she has considerable experience in elder and mental health law. Since assuming her position, Petersen has prioritized bracing for federal funding cuts (especially to Medicaid and SNAP), supporting the human services workforce, and grappling with surging demand for DDS services in the state.

[9] The Home and Community-Based Services (HCBS) Settings Rule, enacted by the Centers for Medicare & Medicaid Services (CMS) in 2014, requires that individuals with disabilities receiving long-term services have full access to community life, including control over their personal resources, daily schedules, and living environments. It mandates that services are person-centered, promoting autonomy and community integration rather than isolation, effectively changing how Medicaid-funded services are delivered.

ii. Current Conditions

The Commonwealth's commitment to supporting individuals with intellectual disabilities is evident in the record-breaking budget proposals for FY27. The administration has proposed $802 million – the highest investment ever in the Commonwealth Special Education Reimbursement Program, and a $127 million increase from FY26. This program is also commonly known as the Circuit Breaker Program, and is a state-funded reimbursement program that provides financial assistance to school districts to offset the cost of delivering high-cost special education services to students. Typically, more than 85% of claims are for tuition at out-of-district programs or for transportation to get to those out-of-district programs, but public schools can claim these funds for any program tuition and instructional expenses associated with a student's Individual Education Plan (IEP). To further support neurodiverse individuals, the budget also includes a 33% increase in the Autism Omnibus line item, funding it at $102 million. This line item supports the state's Autism Commission, a permanent state entity charged with making recommendations on policies impacting individuals with autism spectrum disorder (ASD). Also, in the FY27 budget, Governor Healey maintained level funding for DDS's "Turning 22" services at $110 million. "Turning 22" provides support and planning processes for families and young adult individuals with intellectual disabilities as they transition from school-based services into DDS's adult service system.

While these investments signal the state's clear commitment to supporting youth and young adults with intellectual disabilities, even if fully funded for FY27, critical gaps remain. The Turning 22 population in the Commonwealth has been increasing each year, and advocates are concerned that simply keeping the program level-funded will mean the needs of families and individuals will go unmet. Furthermore, a significant human services and special education teacher workforce crisis remains unaddressed. Chapter 257 rates – level-set rates determined by the state for human services workers (including disability providers) – remain low and have contributed to the growing workforce shortage. This shortage is directly impacting access to services for individuals with intellectual disabilities, as waiting lists grow for adult day service provider organizations and special education collaboratives, and the population of students with disabilities continues to grow in Massachusetts. The combined pressures of significantly low rates, workforce shortages in the provider spaces and in special education schools, and level-funding for an increasingly relied upon program are reflected in Foundation stakeholder interviews (see Section V of the Landscape Analysis).

In Essex, Barnstable, Dukes, and Nantucket Counties, DESE and DDS offer a handful of programs and support centers to serve as key touchpoints for youth with intellectual disabilities, including special education collaboratives, special education schools, DDS family support centers (that provide referral services, educational resources, and navigation assistance to families of children and adults living at home who are eligible for DDS services), and DDS autism centers (that provide referral services and resources to children and adults with autism). Essex County has the highest concentration of touchpoints, with two special education collaboratives, eight DESE-approved special education schools, two family support centers, and two autism support centers. Barnstable County serves as the main hub for the entire Cape and Islands region, with one special education collaborative, two DESE-approved special education schools, and one family support center. That said, there is only one family support center located in Dukes County and no autism support centers serving the Cape & Islands, leaving individuals and families on the islands often having to travel to Barnstable County to access support.

iii. Advocacy Opportunities

Significant opportunities for advocacy engagement focused on intellectual disabilities include strengthening workforce stabilization, reducing regional disparities, and providing transition funding.

Related Advocacy Opportunities:

- **Enhance Workforce Stabilization:** Make the case for a legislative increase in Chapter 257 rates to provide competitive wages for human services workers, directly addressing the special education and disability provider shortages. In Essex County particularly, the focus for advocates and funders lies within economically disadvantaged urban centers, where challenges in providing essential wraparound supports for students with intellectual disabilities are compounded by a significant special education teacher workforce crisis. Given DESE Commissioner Martinez's intent to champion resource and funding optimization, there is a strategic opening for external partners to work directly with local school districts to think creatively and proactively about supporting high-needs students.
- **Support Regional Service Equity:** Advocate for the DDS Commissioner to utilize the 33% increase in the Autism Omnibus funding to establish permanent autism support centers on the Cape and Islands, eliminating the need for families in Dukes and Nantucket Counties to travel to Barnstable for basic services. As noted above, the Cape and Islands region faces a crisis of isolation due to its rural and coastal nature, and a workforce shortage due to high housing costs, resulting in a scarcity of enduring supports and a disappearing provider workforce. With no autism support centers serving the region and only one family support center in Dukes County, families are often forced to travel to Barnstable County for basic navigation assistance. Advocacy efforts should prioritize leveraging the 33% increase in the Autism Omnibus and the record investment in the Special Education Circuit Breaker to secure permanent state funding for local programs that bridge these critical gaps in service and infrastructure.
- **Provide Needs-Based Transition Funding:** Urge the state legislature to move the Turning 22 program beyond its current $110 million level-funding to a needs-based model that accounts for the annually increasing population of young adults transitioning into the DDS adult service system.

D. Learning Disabilities

i. Policy Context

The support system for students with learning disabilities in Massachusetts is primarily governed by the education system and a suite of federal civil rights protections, making the defense of IDEA and Title I[10]

[10] Title I, Part A (Title I) of the Elementary and Secondary Education Act, as amended by the Every Student Succeeds Act (ESSA) provides supplemental financial assistance to school districts for children from low-income families. Its purpose is to provide all children a significant opportunity to receive a fair, equitable, and high-quality education, and to close educational achievement gaps by allocating federal funds for education programs and services. Title I allocations to state education agencies and local education agencies (LEAs) are based primarily on annually updated LEA poverty estimates produced by the U.S. Census Bureau. Then, within-LEA allocations to schools are based on school poverty rates, for which a common measure used by LEAs is the number of public school children eligible for free or reduced-price lunch (FRPL).

funding a top priority for the Commonwealth. IDEA Part C and Part B (Section 619) serve as the critical pass-through pillars for early intervention and preschool special education, ensuring that infants and toddlers with developmental delays or learning disabilities, such as dyslexia or ADHD, are identified before reaching kindergarten. Because the federal government has historically underfunded its share of IDEA, Massachusetts relies on DESE's Circuit Breaker funding and federal Elementary and Secondary Education Act (ESEA) Title I, Part A[11] funds to bridge the gap, particularly for students from low-income households who may require supplemental instruction but do not meet strict special education eligibility thresholds.

This funding architecture is currently under significant pressure due to a combination of rising demand and shifting federal priorities. While improved identification has increased the number of students legally requiring services, the aforementioned chronic shortage of special education teachers limits the reach of available federal dollars. Furthermore, emerging conditions at the federal level, including the trauma resulting from federal immigration policy and a policy shift away from Social Emotional Learning (SEL), threaten to disrupt classroom environments and impede academic progress. Without a proactive effort to defend these federal entitlements and secure robust Section 504[12] implementation, the Commonwealth risks a widening equity gap in which the quality of support for a child's learning disability is determined more by their ZIP code than their developmental need.

Within this shifting landscape, Governor Healey has established literacy reform as a cornerstone of her administration's educational agenda, specifically targeting the early identification of learning disabilities to prevent long-term academic barriers. This push is intensified by the recent success of the 2024 ballot initiative (Question 2), which officially eliminated the MCAS (Massachusetts Comprehensive Assessment System) as a mandatory graduation requirement. While students still take the exams to satisfy federal requirements, they no longer need a passing score to earn a diploma. This shift has placed the responsibility of ensuring educational competency and graduation readiness on to individual school districts, leading to a period of significant transition as the Commonwealth works to define new, uniform graduation standards.

The urgency of this transition is underscored by the "sobering" 2025 MCAS results (as described by DESE Commissioner Martinez), which revealed that Massachusetts students remain significantly behind pre-pandemic proficiency levels in math, science, and English. The crisis is most acute in Gateway Cities and under-resourced regions like the Cape and Islands, where achievement gaps for students with learning disabilities – including those affecting reading comprehension, writing, and mathematical operations – continue to widen.[13]

[11] Title I, Part A complements, rather than replaces IDEA by funding supplemental interventions, such as reading specialists, tutoring, and smaller class sizes, designed to help students meet state standards.

[12] Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programs or activities that receive federal financial assistance from the U.S. Department of Education. Section 504 regulations require school districts to provide a "free appropriate public education" (FAPE) to each qualified student with a disability who is in the school district's jurisdiction, regardless of the nature or severity of the disability. Under Section 504, FAPE consists of the provision of regular or special education and related aids and services designed to meet the student's individual educational needs as adequately as the needs of students without disabilities are met.

[13] School districts across the Commonwealth operate with autonomy with respect to their own curricula and resourcing. However, it is likely that the administration, bolstered by support from the legislature, will enforce a set of statewide competencies with which every district will be required to comply. The flexibilities incorporated into those standards and the implementation timeline is still unclear, as the K-12 Graduation Standard Working Group has yet to release their final recommendations.

ii. Current Conditions

Governor Healey established Literacy Launch, an EOE program created in 2024 focused on evidence-based and culturally and linguistically sustaining practices for English language arts and literacy instruction in grades pre-K through 3. Through Literacy Launch, the Healey administration is funding evidence-based literacy curricula updates at the district-level, reviewing and reforming Massachusetts-based educator preparation programs, and identifying best literacy practices and tools for preschools. Literacy Launch is funded at $25 million in Governor Healey's FY27 budget proposal, and is coupled with an additional $25 million for high dosage early literacy tutoring for an estimated 10,000 students in elementary school.

Additionally, to address the acute achievement gaps in high-need regions, the Commonwealth is deploying targeted support through the Partnership for Reading Success – Massachusetts (PRISM) grant program. In late 2025, over $21 million in PRISM I, II, and III grants were awarded to districts identified as "Needs Assistance" or "Needs Intervention," including Lawrence and Lynn in Essex County, and Barnstable on Cape Cod. This funding enables these districts to update their core instructional materials to DESE-approved standards and provide intensive professional development for special education teachers in specialized techniques. In addition, the administration has expanded no-cost, high-dosage early literacy tutoring to over 272 elementary schools, ensuring that students in Gateway Cities have access to the same evidence-based support as their peers in more affluent districts. This regional focus is intended to reverse those "sobering" 2025 MCAS results, which showed that students in under-resourced communities remained significantly behind pre-pandemic proficiency levels.

The administration's literacy efforts are bolstered by a current literacy surge at the legislative level as well. Both chambers of the Massachusetts legislature have passed literacy reform bills aimed at addressing the state's literacy crisis, with a final bill likely to emerge and pass by July 2026. Though the final language has yet to be conferenced between the two chambers, both versions of the bill mandate that all public-school districts utilize evidence-based curricula, specifically focusing on phonics, fluency, vocabulary, and phonemic awareness over cueing methods. Both legislative versions also mandate that DESE establish statewide screening protocols, requiring districts to assess the reading ability of all K–3 students at least twice a year using state-approved diagnostic tools specifically aligned with literacy and dyslexia standards. This reflects the growing awareness and appreciation of early intervention techniques in education.

Following the 2024 ballot initiative that removed the MCAS as a mandatory high-stakes graduation barrier, Governor Healey also created a K-12 Statewide Graduation Council charged with creating a set of recommendations to set graduation standards for Massachusetts graduates. This Council released an updated Statewide High School Graduation Framework in December 2025. This framework aims to replace the singular exit exam with a more equitable, hybrid model for certifying mastery. Instead of relying on a one-day assessment like the MCAS, the proposed system allows neurodiverse students to demonstrate competency through end-of-course (EOC) assessments, cumulative capstone projects, and professional portfolios. Unlike the previous MCAS requirement, failure to pass a single EOC exam will not necessarily prevent a student from receiving a diploma. This multi-modal approach is designed to provide various ways for students with significant learning disabilities to showcase their skills. By emphasizing real-world problem solving and personalized career and academic graduate plans (MyCAP), the state intends to ensure that every graduate is prepared for post-secondary success without the gatekeeping effect of high-stakes testing.

iii. Advocacy Opportunities

The current legislative window presents a critical opportunity for advocates to fundamentally reshape the future of special education and literacy in Massachusetts.

Related Advocacy Opportunities:

- **Standardize Graduation Pathways:** Secure the legislative codification of the new graduation framework to ensure that performance-based portfolios and capstone projects serve as permanent, high-weight alternatives to standardized end-of-course assessments for students with learning disabilities and intellectual disabilities. The new graduation framework is expected in mid to late 2026 for consideration in the next legislative session beginning in 2027. By advocating for performance-based portfolios and other alternative demonstrations of mastery, Foundation stakeholders can ensure that neurodiverse students are not unfairly penalized by new state-administered end-of-course assessments. (This recommendation is relevant to the Intellectual Disabilities section above as well.)
- **Broaden Early Screening Protocols:** Call for the expansion of mandated K–3 screening requirements to include advanced diagnostic tools for a wide range of learning differences. Advocates should also capitalize on the momentum of the "Literacy Launch" initiative to push for universal integration of advanced screening tools. While the current focus is largely on dyslexia, expanding these efforts to include early identification for a broader range of differences will allow schools to address academic barriers before they become more challenging for students.
- **Mandate Professional Development Equity:** Advocate for permanent state funding to establish Literacy Launch hubs in Gateway Cities and on the Cape and Islands to ensure special education teachers in high-need districts have equitable access to high quality literacy supports. Beyond classroom standards, there is a critical need to bridge the resource gap that exists between the Commonwealth's urban hubs and its marginalized regions. Supporting the expansion of Literacy Launch Institutes specifically within Essex County's Gateway Cities will ensure that special education teachers in high-need districts have the same access to "Science of Reading" training and professional development as their peers in more affluent communities. This regional equity is essential for maintaining high and accessible expectations for all students.
- **Develop Oversight Models:** Support the development of community-based oversight models. With the dismantling of federal oversight offices like the Office of Special Education and Rehabilitative Services (OSERS), an opening has emerged for external funders to partner with DESE Commissioner Martinez to develop community-based oversight models. These models can play a vital role in monitoring how individual districts "certify mastery" in the post-MCAS era, providing the systemic checks and balances necessary to ensure that localized standards result in genuine educational equity and improved long-term outcomes.

Landscape Analysis Section VIII
Addendum A

Given Essex County's lack of a formal county governance, a handful of municipalities within Essex County are of particular interest for their strong influence over the region, either due to their size or municipal structure, including the following:

Lawrence – Mayor (chief executive) and nine-member City Council.
Lynn – Mayor and 11-member City Council.
Salem – Mayor and City Council.
Peabody & Beverly – Mayor and City Council cities with similar structures.
Danvers – Town Meeting and Select Board, with a Town Manager.
Saugus – Select Board and Town Meeting.
Andover – Open Town Meeting with Select Board and Town Manager.
North Andover – Open Town Meeting with Select Board and Town Manager.

Essex County is represented at the state and federal levels by the following elected officials:

Essex County State Representatives and Senators
State Senator Pavel Payano (D, 1st Essex)
State Senator Joan Lovely (D, 2nd Essex)
State Senator Brendan Crighton (D, 3rd Essex)
State Senator Bruce Tarr (R, 1st Essex and Middlesex)
State Senator Barry Finegold (D, 2nd Essex and Middlesex)
State Representative Dawn Shande (D, 1st Essex)
State Representative Kristin Kassner (D, 2nd Essex)
State Representative Andres Vargas (D, 3rd Essex)
State Representative Estela Reyes (D, 4th Essex)
[5th Essex seat is currently vacant]
State Representative Hannah Bowen (D, 6th Essex)
State Representative Manny Cruz (D, 7th Essex). *Rep. Cruz is a former Salem School Committee Member, a passionate supporter of youth programming and educational equity, and a Tower Foundation Trustee.*
State Representative Jennifer Armini (D, 8th Essex)
State Representative Donald Wong (R, 9th Essex)
State Representative Dan Cahill (D, 10th Essex.). *Rep. Cahill is a former Lynn School Committee Member.*
State Representative Sean Reid (D, 11th Essex). *Rep. Reid is a former Lynn School Committee Member. He began his career as a substitute educator, and his wife is currently a special education teacher within Lynn Public Schools. Rep. Reid has been open about his parents' struggles with substance use.*
State Representative Thomas Walsh (D, 12th Essex)
State Representative Sally Kerans (D, 13th Essex). *Rep. Kerans currently serves as the Vice Chair of the Joint Committee on Public Health.*

State Representative Adriane Pusateri Ramos (D, 14th Essex)
State Representative Ryan Hamilton (D, 15th Essex)
State Representative Francisco Paulino (D, 16th Essex)
State Representative Frank Moran (D, 17th Essex). *Rep. Moran currently serves as the Second Assistant Majority Leader.*
State Representative Tram Nguyen (D, 18th Essex). *Rep. Nguyen is forfeiting her seat to run for the open MA-06 Congressional seat that is being vacated by Rep. Moulton in 2026.*

U.S. Congress and Senate

Rep. Seth Moulton (D-MA-06). *Rep. Moulton is forfeiting his seat to challenge Senator Ed Markey in the 2026 Democratic primary. Rep. Moulton represents the majority of Essex County.*
Rep. Lori Trahan (D-MA-03). *Rep. Trahan is a leading advocate for youth mental health issues in Congress. Rep. Trahan represents Lawrence, Haverhill, and Methuen in Essex County.*
Senator Ed Markey (D-MA)
Senator Elizabeth Warren (D-MA)

Landscape Analysis Section VIII
Addendum B

Barnstable, Dukes, and Nantucket Counties are represented at the state and federal levels by the following elected officials.

Cape & Islands State Representatives and Senators

State Senator Dylan Fernandes (D, Plymouth and Barnstable)

State Senator Julian Cyr (D, Cape and Islands). *Sen. Cyr currently serves in leadership as Assistant Majority Whip in the Senate, and as Senate Vice Chair of the Joint Committee on Public Health, and is a member of both the Joint Committee on Mental Health, Substance Use, and Recovery and the Joint Committee on Health Care Financing. Cyr has established himself as a staunch champion for mental health and substance use treatment and preventative care, and advocating for the specific needs of rural schools and students.*

State Representative Christopher Flanagan (D, 1st Barnstable)

State Representative Kip Diggs (D, 2nd Barnstable). *Rep. Diggs serves as the Assistant Vice Chair on both the Joint and the House Committees on Ways and Means – an influential role on one the most influential legislative committees.*

State Representative David Vieira (R, 3rd Barnstable)

State Representative Hadley Luddy (D, 4th Barnstable)

State Representative Steven Xiarhos (R, 5th Barnstable).*Rep. Xiarhos serves as Ranking Minority on the Joint Committee on Mental Health, Substance Use and Recovery.*

State Representative Thomas Moakley (D, Dukes, Barnstable, Nantucket)

U.S. Congress and Senate

Rep. Bill Keating (D-MA-09)

Senator Ed Markey (D-MA)

Senator Elizabeth Warren (D-MA)

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Landscape Analysis: Advocacy for Impact

SECTION IX

NEW YORK:

POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES



Landscape Analysis

SECTION IX
NEW YORK: POLICY CONTEXT, CURRENT CONDITIONS, ADVOCACY OPPORTUNITIES

I. NEW YORK CONTEXT

New York State has long positioned itself as a champion of progressive social policy, yet persistent funding gaps, fragmented service delivery, and systemic inequities continue to strain communities across the state. These structural challenges have created meaningful obstacles across the Tower Foundation's core issue areas. This Section of the Landscape Analysis identifies current New York State policy challenges and significant advocacy opportunities focused on youth substance use disorders, mental health, intellectual disabilities, and learning disabilities – particularly within Erie and Niagara Counties.

A. Strong County and State Government

Unlike in Massachusetts, counties in New York State (NYS) have significant governance authority. All 62 NYS counties (excluding the five counties that constitute New York City and function under consolidated city government) exist as functioning governments. All have legislatures or boards of supervisors, and most have an elected county executive or appointed county manager, that establish policy and direct major services – such as Medicaid administration, social services, public health, and property tax collection; and many NYS counties have substantial budgets and numerous administrative agencies.

Erie County and Niagara County constitute the Buffalo-Niagara Falls metropolitan area, the second largest in NYS behind New York City. The counties differ in which political party holds the majority, with Erie being moderately controlled by Democrats and Niagara strongly controlled by Republicans.

Erie County operates like a mid-size regional government. The city of Buffalo makes up about 28% of Erie County's total population (of approximately 950,000), and Buffalo has a newly elected Mayor, Sean Ryan (D), as of January 2026. The County Executive is Mark Poloncarz (D), and the county legislature is controlled by Democrats, with a 7-to-4 seat advantage, led by Chairman Tim Meyers.

Unlike Erie County, Niagara County does not use a county executive governance structure. Rather, it operates under a charter that utilizes a County Manager, Richard Updegrove (R), and the Niagara County Charter grants substantial power to the legislature to determine policy, enact local laws, and appropriate funds. Currently, the Niagara County legislature is majority Republican, with an 11-to-4 split, led by Chairman Michael Hill and Majority Leader Randy Bradt.

Niagara County (with a current population of approximately 210,000) is more rural and politically right-leaning than Erie. The county is also home to the federally recognized Tuscarora Nation, whose reservation spans approximately 9.1 square miles in Lewiston and has a resident population of approximately 1,200.

Governor Kathy Hochul became New York's Governor in August 2021, following Andrew Cuomo's resignation, and was re-elected to a four-year term in November 2022. Governor Hochul is up for re-election in 2026. Some of the Governor's key priorities associated with the Foundation's core issue areas, as highlighted in her 2026 State of the State Address, include: expanding Youth and Teen Mental Health First Aid; integrating care for mental health and substance use disorders; supporting mental health for LGBTQ+ youth; expanding youth safe spaces; recognizing schools providing strong mental health supports; establishing a youth-led substance use prevention symposium; prioritizing young adult recovery residences for individuals recovering from opioid addiction; strengthening suicide prevention programs; creating a statewide Office of Child Care and Early Education; bolstering school-based mental health clinics; increasing high-impact tutoring; and supporting dyslexia screening. In addition, the Governor's budget commits nearly half a billion dollars ($470M) to help districts achieve universal pre-K for 4-year-olds by 2028-29.[1] Highlights of Governor Hochul's related budget priorities are discussed below in the Current 2026-27 State Budget Proposal Section, and relevant state agencies are discussed below in the New York Funding Structure Section.

The NYS legislature (Senate and Assembly) and Executive Chamber are currently controlled by Democrats. The State Senators and Assembly Members that make up the State Legislature serve two-year terms and, like the Governor, are all up for election this year. Senate and Assembly Committees have Democratic Chairs, with over 30 Committees in each house. (Relevant Committees and Chairs in each chamber are noted immediately below.) The legislature convenes its annual session in January and concludes in June, with the state's budget process spanning January through March. Annually, the budget is required to be adopted by the end of the state's fiscal year on March 31st; however, under Governor Hochul, the state budget has passed after that deadline. As is the case this year, the Legislature has passed "extenders" of the current budget, in order to keep the government functioning, until a final budget agreement is reached. More detailed information about elected officials representing Erie and Niagara Counties at the state and federal levels is in Addendum of this Section.

Within the State Senate and State Assembly, Chairs of relevant committees have championed a number of legislative and budget priorities relevant to the Foundation's core issue areas:

- Senate Committee on Alcoholism and Substance Use Disorders. Chair: Senator Nathalia Fernandez (D, Bronx). Priorities include expanding access to medication for substance use disorders, reforming language that creates stigma, creating stable funding for substance use disorder services, and increasing harm reduction and recovery services.
- Assembly Committee on Alcoholism and Drug Abuse. Chair: Assemblymember Phil Steck (D, Albany). Priorities include expanding access to overdose reversal drugs, the Recovery Ready Workplace Program that would help employers build supportive cultures for workers with substance use disorders, and better use of opioid settlement funds.

[1]Although Governor Hochul's proposed FY27 budget does not include Early Intervention (EI) rate increases, the Senate and Assembly one-house budget proposals did acknowledge the need, with the Assembly including an $18M increase, and the Senate including a $13M increase.

- Senate Committee on Mental Health. Chair: Senator Samra Brouk (D, Rochester/Monroe County). Priorities include maternal mental health care and Daniel's Law, a crisis response system that does not involve law enforcement. Daniel's Law received pilot funding through the past two years of state budgets, and Senator Brouk and advocates continue to push for expansion and full bill passage.
- Assembly Committee on Mental Health. Chair: Assemblymember Jo Anne Simon (D, Brooklyn). Priorities include expanding community-based mental health supports such as crisis response teams, children's mental health and access, and advocating against expansion of involuntary psychiatric commitments. Assemblymember Simon previously sponsored legislation on Supported Decision-Making Agreements, enabling young adults with intellectual and developmental disabilities[3] to exercise greater autonomy.
- Senate Committee on Disabilities. Chair: Senator Pat Fahy (D, Albany). Priorities include increasing wages for Direct Support Professionals (DSPs) and expanding employment opportunities and housing access for people with disabilities. She also has introduced legislation to provide grants to employers for adaptive equipment (including equipment to support intellectual and learning disabilities). This bill has passed the Senate disabilities committee but has not moved in the Assembly.
- Assembly Committee on People with Disabilities. Chair: Assemblymember Angelo Santabarbara (D, Schenectady). Priorities include family inclusion, autism spectrum disorders and related youth services, inclusive education and higher education access, and increasing employment opportunities.
- Senate Committee on Education. Chair: Senator Shelley Mayer (D, Westchester). Priorities include funding foundation aid for school districts, financial literacy, strengthening the voice of parents and teachers, and strengthening daycare and Pre-K.
- Assembly Committee on Education. Chair: Assemblymember Amy Paulin (D, Westchester). Priorities include expanding funding for the health workforce, reproductive rights, and protecting healthcare from ongoing federal cuts and attacks. Assemblymember Paulin is known as one of the most effective legislators, carrying and passing more bills than most of her peers.
- Senate Committee on Children and Families. Chair: Senator Jabari Brisport (D, Brooklyn). Priorities include universal child care, housing and tenant rights, and universal healthcare.
- Assembly Committee on Children and Families. Chair: Assemblymember Andrew Hevesi (D, Queens). Priorities include increasing investments into the childcare workforce, and improving kinship and foster care services.
- Senate Committee on Libraries. Chair: Senator Siela Bynoe (D, Long Island). Priorities include creating a $1M pilot program to place social workers in public libraries in economically under-resourced communities to help connect residents with mental health and other supports.
- Assembly Committee on Libraries and Education Technology. Chair: Assemblymember Robert Carroll (D, Brooklyn). Priorities include early literacy, dyslexia and literacy related legislation, education technology, and library capital funding.

B. New York Funding Structure

In Erie and Niagara Counties, services for youth (ages 0–26) with substance use disorders (SUD), mental health conditions, intellectual disabilities, and learning disabilities are funded through a combination of federal dollars, state appropriations, and specialized funding streams such as opioid settlement proceeds. State funding flows through multiple state agencies depending on the service type, with regular crossover of agency involvement due to age and/or dual diagnoses: the NYS Office of Addiction Services and Supports (OASAS) for SUD programs; the NYS Office of Mental Health (OMH) for mental health services; and the NYS Office for People with Developmental Disabilities (OPWDD) for intellectual and developmental disability supports. The Western New York Developmental Disabilities State Operations Office (WNYDDSO), an operational arm of OPWDD based in West Seneca, serves both Erie and Niagara Counties as part of its broader seven-county Western New York service area.

The State Education Department (SED) also plays a role in funding and overseeing services relating to youth mental health, intellectual disabilities, and learning disabilities. SED has an overarching obligation to implement the federal Individuals with Disabilities Education Act (IDEA) and NYS Education Law, which requires that every student (ages 3–21) with a disability receives a free appropriate public education (FAPE). Specifically for youth mental health, SED's role is school-based and educational, providing oversight for school-based mental health clinics and establishing standards for staff working in school settings. Additionally, SED is responsible for providing an Individualized Education Program (IEP) to students with identified learning and behavioral health needs. SED does not operate these services directly. For students with disabilities, SED is responsible for providing a FAPE, and oversees the Committee on Special Education (CSE) process at the district level which evaluates and determines eligibility, then develops IEPs. SED also funds and oversees special education programs, state-supported schools, and preschool special education. Specifically within SED, the Office of Special Education (OSE) is tasked with overseeing policy and law implementation, including IDEA and FAPE, maintaining and updating the IEP framework, and governing the CSE.

SED also runs the ACCES-VR program, which assists individuals with disabilities as young as 14 in achieving and maintaining employment and independent living. ACCES-VR also explicitly serves individuals with psychiatric disabilities and mental health conditions, recognizing that mental illness may impair an individual's ability to obtain or retain employment, in coordination with OMH. The NYS Department of Labor (DOL) complements ACCES-VR through its NY SCION program, which places Disability Resource Coordinators (DRCs) across the state to conduct outreach to businesses promoting inclusive hiring, and connecting job seekers with potential roles. Finally, SED is charged with the identification of students with learning disabilities through the CSE process and ensuring that they receive appropriate specially designed instruction.

The New York State Department of Health (DOH) is the lead agency for the state's Early Intervention Program (EIP) and is responsible for the general administration, oversight, and supervision of the program statewide. DOH establishes eligibility standards, monitors and approves providers, and ensures that children aged 0-3 with confirmed disabilities receive timely and appropriate services. DOH is also responsible for operating the statewide Child Find system (a federally and state mandated program) to identify and evaluate EIP-eligible children – though a 2023 Comptroller audit found that DOH had oversight gaps resulting in inequitable access and delays.

While the Office of Children and Family Services (OCFS) does not directly fund programs within the Foundation's core issue areas, OCFS is tasked with protecting child welfare and overseeing juvenile justice programs. OCFS operates and funds child protective services and prevention programming, foster care programming, and houses the NYS Commission for the Blind. Many children face challenges that cross over the welfare/juvenile justice systems and mental health/disabilities systems, requiring coordination between OMH, SED, OPWDD, and OCFS. Combined, these agencies make up the systems through which state funding reaches youth with substance use disorders, mental health concerns, intellectual disabilities and learning disabilities.

i. Current 2026-27 State Budget Proposals

Governor Hochul's FY 2027 Executive Budget reflects a commitment to protecting New York's residents against the potential impact of significant federal funding reductions. With the federal government proposing deep cuts to Medicaid, behavioral health programs, school-based services, and other safety net investments, the Governor's focus is on preserving New York's capacity to deliver essential services. Notable current budget proposals relating to youth substance use disorders, mental health, intellectual disabilities, and learning disabilities, include:

- Substance Use Disorder (SUD): New York State has significantly expanded access to medication-assisted treatment (MAT), prevention activities, and outreach to underserved individuals, funded in part through the New York State Opioid Settlement Fund — proceeds from legal settlements with opioid manufacturers, distributors, and pharmacies. To date, OASAS has made over $454 million available through the Settlement Fund, with over $310 million projected to remain in the fund as of April 2026. The Governor's proposed 2026-27 budget builds on this foundation by investing in faith-based resources, new youth clubhouses, and Young Adult Recovery Residences that would provide housing and wraparound services for up to 35 young adults with substance use disorder and opioid addiction. The budget also directs OASAS to host a youth-led prevention symposium promoting peer engagement around the dangers of SUD, and to develop a media campaign to educate youth on substance use risks. OASAS maintains an online naloxone ordering portal that the state is committed to continuing. Overall, the budget aims to sustain SUD system stability amid federal funding uncertainty, including by expanding low-threshold treatment models, youth prevention efforts, and recovery supports.

- Youth Mental Health: Governor Hochul proposes an additional $17.5 million in funding for Teen Mental Health First Aid training to be available to all tenth graders. This training equips students with skills to understand and respond to signs of mental health and SUD challenges. It also expands (by $500,000) funding for Youth Safe Spaces that provide young people a place to access behavioral health resources, foster positive relationships with peers, and provide employment and life skills training. Additionally, the proposal includes creating a 'Schools of Distinction in Prevention' Designation, committing $100,000 to OMH to recognize schools that meet key benchmarks in mental health and SUD prevention. The top schools will receive technical assistance and implementation grants. For people over the age of 18, the budget proposes an increased rate of $65 million to assist OMH run supportive housing programs and providers maintaining housing capacity. The state has previously pledged to create 24 new crisis

stabilization centers in the last several years, yet just 9 have opened thus far – including BestResponse[2] in Buffalo, dually certified by OMH and OASAS. The state aims to have five more operational by the end of the year with funding included in the FY26-27 budget.

- Intellectual Disabilities**:** The FY26-27 Governor's proposed budget includes an enhancement to family care rates by 5% to help increase utilization in integrated residential services. The budget also includes the continuation of a previous investment of $25 million to support the development of Regional Disability Clinics, with the goal of increasing accessibility and improving the quality of healthcare for people with intellectual and developmental disabilities.

- Learning Disabilities: Governor Hochul signed legislation in late 2025 establishing the Center for Dyslexia and Dysgraphia within the State Education Department to improve how schools identify and support students with reading and writing challenges. The Center is designed to guide schools through universal screening standards, evidence-based interventions, and teacher training, and is now codified in law rather than subject to annual budget negotiations.

In addition, the state has demonstrated an increased interest in the integration of behavioral health services, noting that integration is critical to increasing positive outcomes. For example, the Governor has proposed a single joint license for providers who deliver mental health and SUD services, and she instructed OMH and OASAS to develop a new Co-Occurring Capable (CoC) designation to help individuals find the best provider for their needs.

The Governor also has proposed a targeted inflationary increase for mental health and SUD providers at 1.7%. In response to the Governor's proposed budget, the Mental Health Association in New York State (MHANYS), along with ten other statewide advocacy organizations, held a press conference in February 2026 arguing that the Governor's budget proposal falls short of community needs. They requested a 2.7% targeted inflationary increase to keep pace with rising costs and workforce shortages. As of April 20th, 2026, there was still no budget agreement in NYS.

Finally, responsive to omissions in the Governor's proposals, advocates continue to call for Medicaid managed care carve-outs. MHANYS, among other behavioral health advocacy groups, has continually pushed for community-based behavioral health services to be carved out of Medicaid managed care in favor of fee-for-service billing, which they note will generate upwards of $400 million for a system that is facing funding and workforce crises.

[2] BestResponse (operated by BestSelf Behavioral Health) was developed in partnership with Erie County Medical Center, Crisis Services of Western New York, the Crisis to Care Collaborative, and local emergency responders. OMH awarded BestSelf $9.6 million to operate BestResponse. Serving Erie, Niagara, Chautauqua, Cattaraugus, and Allegany Counties, it was the fifth intensive crisis stabilization center to open statewide.

ii. County Funding

Both Erie and Niagara Counties play an active role in planning, funding, and overseeing behavioral health and youth development services within their communities in addition to managing pass-through state dollars through their respective county mental health departments and youth bureaus. In Erie County, the Erie County Department of Mental Health (ECDMH) serves as the local governmental unit responsible for planning, administering, and contracting a county-wide integrated system of mental health, substance use, and intellectual/developmental disability services. Services are delivered by over 42 community-based agencies under contract with the Department, including Erie County Medical Center (ECMC), and span inpatient care, clinic treatment, continuing day treatment, residential services, case management, and community support and rehabilitation. The County also operates a Children's Single Point of Access (C-SPOA), which serves as a coordinated entry point for youth with serious emotional disturbance and connects them to the appropriate level of care, including Home and Community-Based Services (HCBS) Waiver programs and Youth Assertive Community Treatment (ACT). Separately, the Erie County Youth Bureau (ECYB), under the Erie County Department of Social Services (ECDSS), grants funding to community-based organizations providing services and programs that meet community needs for positive youth development, runaway and homeless youth services, diversion services and case management, youth sports, and summer programs, primarily funded through the NYS Office of Children and Family Services with County dollars supplementing. The ECYB selects providers through a competitive Request for Proposal process and is guided by a Five Year Comprehensive Plan identifying gaps in youth services countywide. The ECYB also has a volunteer advocacy board that includes youth and adult community members who assist with reviewing and scoring grant proposals.

Erie County has a substantially more developed infrastructure of supports than does Niagara County. In Niagara County, the Niagara County Department of Mental Health and Substance Abuse Services (NCDMH) funds and oversees a network of contracted providers serving children and adults. Unlike Erie County, which primarily contracts out services, NCDMH has two integrated clinics in Lockport and Niagara Falls that offer mental health and SUD services. NCDMH's counseling and wellness services clinics are established Certified Community Behavioral Health Clinics (CCBHC) – a federal designation that comes with enhanced Medicaid reimbursement and quality standards. The Children's Single Point of Access (C-SPOA) serves Niagara County children and youth with serious emotional and behavioral health needs, creating plans to connect youth to appropriate community-based services and developing strategies to prevent psychiatric hospitalization and avoid out-of-home placement. The NCDMH coordinates with schools, OMH, and contracted youth-serving agencies as partners in that system. The Niagara County Youth Bureau receives funding from the NYS Office of Children and Family Services to provide youth development services, and is overseen by a Youth Advisory Board made up of youth and adult members appointed by the County legislature.

Local school districts also have independent obligations under the federal Individuals with Disabilities Education Act (IDEA) which requires them to identify, evaluate, and provide services to youth with intellectual and other disabilities, making local school districts a critical component of the broader service and funding ecosystem.

iii. City Funding

Within Erie County, the City of Buffalo plays a distinct and supplementary role in the youth services landscape through its Department of Community Services and Recreational Programming, which contracts with community-based organizations to support youth social, economic, and physical needs. Funding streams include federal Community Development Block Grant (CDBG) dollars, Emergency Solutions Grant (ESG) funds, and other public service dollars, which vary in availability from year to year. The City's Division of Youth serves at-risk youth through a Youth Counseling Program offering individual, group, and family counseling to youth ages 7 to 20, as well as an Anti-Crime Program, a Code of Conduct Program, and violence prevention workshops. The City of Buffalo also has a separate Youth Bureau, housed within the Department of Community Services (distinct from the Division of Youth), which serves as the local youth bureau eligible for NYS OCFS aid. While the City's role is not primarily clinical, its community infrastructure often functions as a critical first point of contact for families who have not yet engaged with the county mental health system, OPWDD, or school-based supports.

iv. Additional Funding Sources

New York State has secured billions in opioid settlement agreements from manufacturers, distributors, and retailers. In 2021, New York enacted legislation creating a dedicated Opioid Settlement Fund, establishing an Advisory Board appointed by state and local governments to provide recommendations to the legislature in appropriating settlement funds. The 21 members serve three year terms, with the exception of the governmental representatives, and meet quarterly to review opioid settlement fund status updates; receive annual presentations by OMH, OASAS, and Department of Health (DOH) on a range of topics; and develop annual recommendations. Between FY23 and FY26, NYS designated $29.5 million in regional abatement (out of a total of $157 million) to Erie County, Niagara County, the City of Buffalo, the City of Lackawanna, and the Towns of Amherst, Lancaster, and Tonawanda. The funds are distributed through each county's Local Governmental Unit (LGU), with county allocations determined by population, overdose death rates, and mental health and equity indicators. Top spending priorities identified by the Opioid Settlement Fund Advisory Board (OSFAB) include harm reduction, treatment, and grassroots organizations serving communities disproportionately affected by the crisis. However, the system currently faces scrutiny, as the OSFAB's 2025 report found that impacted community members believe the state is not fulfilling its duty to equitably, efficiently, and transparently distribute funds, and a recent Freedom of Information Law (FOIL) request, filed by Robert Kent, former general counsel to (OASAS), revealed that approximately $200 million in settlement dollars have remained unspent. The City of Buffalo has also come under scrutiny for inappropriate use of opioid settlement funds.

NYS also has an independent health insurance ombudsman program for SUD and mental health care, the Community Health Access to Addiction and Mental Healthcare Project (CHAMP), that assists New Yorkers in accessing treatment and insurance coverage. CHAMP is jointly funded by OASAS, OMH, in partnership with the community service society (CSS) and other local organizations.

B. New York Funding Structure

i. Erie County

In addition to funding a wide array of programs (as discussed above), Erie County is tasked with managing and coordinating a comprehensive system of care for youth and families through its Department of Mental Health and Youth Bureau. The Department is led by Mental Health Commissioner Sarah Bonk, and operates under a clearly articulated set of system of care values that guide how services are designed and delivered across the County. These values center youth voice and family leadership in care decisions, prioritize trauma informed and culturally competent practice, and emphasize community-based service delivery grounded in evidence-based best practices.

Stakeholders in Erie County include public departments serving youth as well as behavioral health and treatment service providers in the area, support and advocacy groups, and navigation services. Larger stakeholders and providers in Erie County include: Horizon Health Services, BestSelf Behavioral Health, Mental Health Advocates of Western NY, Hillside, The Arc Erie County, Catholic Charities of Buffalo & Erie County, and Envision Wellness WNY (the first three of which were interviewed as part of this Landscape Analysis). The Western New York Independent Living Family of Agencies is another large service provider for individuals with disabilities.

A sample of current Erie County programs include:

- Erie Path: Erie County has developed a smartphone app to help parents and caregivers address mental and behavioral health challenges faced by children and adolescents. It also includes resources for adult mental and behavioral health services, including housing, childcare, food pantries, employment support, and medical care. Erie Path is funded by the Erie County government, specifically the Erie County Department of Mental Health (ECDMH).
- Kids Escaping Drugs (KED) Face 2 Face Program: The KED program, run by Erie County, provides peer to peer presentations for students in which young people in recovery share their personal stories of addiction and recovery. The program provides 6th-12th grade students with one free early intervention session in which they receive education, an informal assessment, and referrals to services. The program also offers parent presentations and educational seminars for counselors and addiction experts. KED is an independent nonprofit, but is funded through Erie County. KED receives funding from opioid settlement dollars as well as federal funding through the Drug Free Communities CDC grant.
- Erie County Medication Assisted Treatment Clinic (MAT): The MAT Clinic at Endeavor Health Services is specifically tailored to meet the needs of youth with SUD. Endeavor partnered with a prominent children's hospital, pediatrician, and the Erie County Department of Health to bring this program to Western NY. Endeavor receives Medicaid reimbursements and state/county contract funding. Similar MAT services are additionally provided at Horizon Health Services.
- Children Single Point of Access (C-SPOA): Each local government, including Erie, must designate a C-SPOA, which aims to ensure timely and appropriate access to intensive services for children at risk of multiple hospitalizations and out-of-home treatments. The team provides case consultation, navigation systems, and referrals to supports and services. The C-SPOA is directly operated by Erie County.

- Multisystemic Therapy (MST) is a family-centered and community-based treatment used in Erie County that teaches and supports parenting techniques that discourage adolescent truancy. Multiple providers serve Erie such as Harborcreek Youth Services and Catholic Charities. Both programs deliver MST under County contracts. For Catholic Charities, funding is received by the Department of Social Services, Mental Health and/or Probation in Erie and Niagara Counties, and Catholic Charities of Buffalo operates MST through a contract with Erie County. For Harborcreek, Erie County families must be authorized through the Erie County Department of Mental Health through the Family Services Team, Juvenile Delinquency Services Team, or Formal Probation.

ii. Niagara County

Similar to Erie, Niagara County has a Department of Mental Health and Substance Abuse Services (NCDMH) which acts as the primary hub for access to services, crisis intervention, and care coordination for children. NCDMH operates adult and youth mental health outpatient clinics in both Lockport and Niagara Falls, providing individual and group psychotherapy, medication management, trauma counseling, case management, and co-occurring disorder treatment. The Department also leads a 24/7 crisis center, Mobile Crisis Outreach Team, forensic case management for justice-impacted individuals, and the Adult Single Point of Access (A-SPOA) – a centralized entry point for adults needing housing and care management support.

Niagara County's Youth Bureau is a unit within the Niagara County Department of Social Services tasked with planning, coordinating, and supporting the positive development of youth through community organizations. The Bureau has a Resources for Adolescents Program that provides a speaker series for school districts about mental health, suicide awareness, substance use, and vaping. The Mental Health Association in Niagara County (MHANC) is a community-based provider that works to promote wellness through advocacy, education, and community service programs.

Within the County's local service plan goals and objectives for 2024-2027, NCDMH includes providing timely access to care and community-based support services, expanding adult Assertive Community Treatment (ACT), promoting recovery for individuals with co-occurring disorders, and increasing services for individuals transitioning between levels of care.

Compared to Erie County, which has a much denser ecosystem of specialized providers, Federally Qualified Health Centers (FQHCs), and hospital-affiliated behavioral health systems, Niagara County's provider landscape is notably thinner, particularly for youth mental health and SUD services. The County relies heavily on NCDMH as the backbone provider, with a smaller number of contracted community agencies supporting NCDMH.

II. FOUR ISSUE AREAS: POLICY CONTEXT, CURRENT CONDITIONS, AND ADVOCACY OPPORTUNITIES

A. Substance Use Disorders

i. Policy Context

Substance use disorders (SUD) among youth remain a serious public health concern in Erie and Niagara Counties, with rising rates of opioid-related harm and co-occurring mental health conditions for youth and young adults. Nationally, overdose deaths declined nearly 24% in the 12 months ending in September 2024, the steepest single year drop on record. Yet Erie County, by contrast, experienced a record year of overdose fatalities in 2023, with 366 opioid-related overdose deaths and an additional 70 non-opioid overdose deaths. In response, in 2024, Erie County reorganized its Overdose Prevention Task Force and launched Bridge Erie to Harm Reduction, a learning collaborative designed to meet the evolving challenges of the drug and opioid epidemic, emphasizing equity and the inclusion of voices with lived experience.

The rise in fentanyl usage also dramatically changed the SUD landscape in recent years. Youth cocaine usage is far more common than youth heroin usage, and overdose has become a growing area of concern. Erie County's 2024 Local Services Plan reports a significant increase in opioid-related overdose deaths driven by fentanyl and also notes that the local cocaine supply had become contaminated with fentanyl, leading to overdoses and deaths among individuals not primarily using opioids. In addition, Erie and Niagara Counties have seen an increase in contamination of drug supply with animal tranquilizers such as Xylazine and synthetic opioids such as carfentanil. For prevention and intervention programs working with youth, this means that education about "safer" recreational drug use is increasingly difficult to frame coherently when the drug supply is so unpredictable.

ii. Current Conditions

Policy priorities continue to focus on prevention and early intervention efforts aimed at strengthening family-centered interventions, increasing screening for SUD and mental health risk factors in school-based, pediatric and primary care settings, and programming in schools. Timely access to SUD treatment remains a significant concern, with goals to reduce wait times, increase availability of youth-specific outpatient and residential treatment programs, and address workforce shortages. Other current efforts include expanding access to naloxone and implementing overdose education programs tailored to youth.

Over the past five to ten years, advocates have increasingly emphasized the integration of mental health and SUD services, given the high crossover prevalence shown in HHS Substance Abuse and Mental Health Services Administration (SAMHSA) and OMH/OASAS data. The state's response is reflected in a proposed FY26-27 budget initiative to co-designate through the OMH/OASAS joint Co-Occurring Capable (CoC) designation, as well as the expansion of Certified Community Behavioral Health Clinics (CCBHCs) designed to deliver coordinated care for individuals with co-occurring conditions. Integrated service models typically include co-located care, cross-training of providers, and shared data systems.

Erie County has made significant investments in harm reduction infrastructure through its opioid settlement funds, including the launch of Bridge Erie to Harm Reduction in 2025 and the deployment of naloxone (Narcan) vending machines, wall mounts, and community-based distribution points across the County. Community-based agencies across Niagara County, supported by NCDMH, have expanded Narcan access through community distribution infrastructure including wall mounts, Narcan stands, and vending machines as well. To date, two Narcan vending machines have been installed, one at Community Missions in Niagara Falls and one at Lockport City Hall, providing free, 24/7 access to naloxone and fentanyl test strips. These harm reduction resources are distributed across community locations including barbershops, gas stations, and apartments. The Erie County Department of Health (ECDH) facilitates a text for Narcan program in which residents can text to receive free Narcan or fentanyl test strips. ECDH also offers harm reduction resources to K-12 school administrators and educators, along with family-centered harm reduction initiatives and overdose death review processes to guide prevention and intervention strategies.

In addition, the NCDMH's 2024–2027 plan includes expanding integrated co-occurring mental health and SUD treatment and expanding early intervention services to prevent long-term negative health outcomes. The plan also identifies system navigation as a central challenge to identifying and accessing appropriate services. Erie County's plan shares similar insights regarding navigation challenges, highlighting that service gaps and workforce shortages prevent timely access to services.

iii. Advocacy Opportunities

There are numerous opportunities for meaningful advocacy engagement focused on youth substance use disorders in Erie and Niagara Counties.

Related Advocacy Opportunities:

- **Invest in the Workforce Pipeline:** The local services plans in both Counties identify workforce shortages as a primary barrier to timely SUD treatment access for youth. Stakeholders could advocate for training pipeline investments, including supporting BOCES programs, community college partnerships, or loan forgiveness for SUD counselors who commit to serving youth in WNY. This strategy could help address the root cause underlying pervasive service access gaps. Existing loan forgiveness and scholarship programs could serve as models, such as the Nurses Across NY Program. Advocacy could include discussions with NYS Executive Chamber and OASAS or the introduction of legislation creating a program specifically focused on the youth SUD workforce.
- **Encourage the Expansion of Integrated SUD and Mental Health Programming for Youth**: Make the case for increased funding for program integration. The most effective interventions for youth with SUD address co-occurring mental health conditions simultaneously rather than sequentially. Ripe opportunities for Foundation stakeholders' engagement include advocating for expanded funding for integrated co-occurring treatment programs that combine evidence-based SUD treatment with trauma-informed mental health supports; supporting state Medicaid policy that reimburses integrated co-occurring treatment for youth; and advocating for local provider agencies to develop or expand co-occurring youth tracks. This could also include advocating for a youth specific OASAS provider

designation or funding tier. Currently, there is no dedicated youth SUD treatment provider in Niagara County and very limited capacity in Erie County. Advocacy efforts could include urging OASAS to designate or fund at least one youth-certified SUD provider in WNY — through a competitive RFP or targeted funding. Erie County's existing OASAS-funded provider network is a foundation to build upon, while Niagara County has a limited provider landscape, reflecting an equity gap in need of correction.

- **Support Specific Usage of Opioid Settlement Funds:** Advocate for youth carve-outs. Erie County has received over $32.7 million in opioid settlement funds to date, and Niagara County has received $4.27 million since 2023. A significant portion of these funds has been directed toward adult harm reduction and treatment infrastructure. Stakeholders could advocate for a youth-designated carve-out in both Counties' settlement spending plans to ensure that a predetermined percentage of funds is directed toward prevention, early intervention, and treatment programs specifically serving youth under 26. Additionally, stakeholders could advocate for more transparency in how much funding is received and spent, specifically in Niagara where reporting is less up to date than in Erie. Making the case for youth investment, before state spending plans are fully locked in, is a viable near-term strategy working outside of the state budget schedule. This could also include advocating for carve-outs in remaining uncommitted funds and in future settlement payments.
- **Advocate for S9272 and Expanded Naloxone Access Legislation:** Support New York Senate bill S9272 introduced in February 2026 (and its companion bill S5779), which would require school districts, Boards of Cooperative Educational Services (BOCES), charter schools, libraries, and non-public schools to provide and maintain on-site opioid antagonists. (NYS state law already permits schools to stock naloxone, and they can receive it free through the state; this bill would make on-site access mandatory. This is important because the gap is based on compliance and resources, not legal authority.) This legislation directly addresses the reality that overdoses can occur in or near school settings, and bystander reversal is most effective when naloxone is immediately available. Advocacy efforts include urging Erie and Niagara County legislators to co-sponsor and advance the bill, educating school administrators about the legislation and its implementation implications, and pairing legislative advocacy with public awareness efforts that address concerns about stigma and liability that often slow school-based naloxone adoption.
- **Focus on School Settings:** Advocate for additional support of school-based SUD programs. Schools remain an underutilized entry point for identifying and responding to youth substance use, particularly in Erie and Niagara Counties where access to SUD treatment can be limited. Accordingly, advocacy opportunities include: supporting partnerships between school districts and community-based SUD providers to help embed prevention and early intervention services directly in schools; investing in prevention programming; and including peer support models and trauma-informed approaches that address underlying risk factors. As discussed above, many opioid settlement dollars are used for adult services without specific carve-outs for youth. Advocacy is needed to encourage appropriate direction of funds to youth-focused programming.

- **Support a Western New York Recovery High School:** Advocate for the establishment of a recovery high school in Erie or Niagara County, serving students in recovery from substance use disorder and co-occurring mental health conditions. Recovery high schools provide a specialized, substance-free academic environment that integrates clinical support directly into the school day, yet this model remains underrepresented across New York State, with only three programs currently operating statewide, in Long Island, Binghamton, and Rochester. Advocacy efforts include urging Governor Hochul and OASAS to direct dedicated funding toward establishing an alternative high school program for youth navigating SUD and co-occurring disorder recovery in Western New York, while building awareness among Erie and Niagara County local officials and statewide elected representatives about the meaningful impact such a school could have in their communities.
- **Encourage Peer Support Expansion for Youth:** Encourage OASAS to recognize and fund youth peer specialists, young people with lived experience with SUD, as a reimbursable service. Peer support for youth with SUD is underutilized and underfunded across both Counties. Advocacy efforts could both strengthen the SUD system and address stigma simultaneously. OASAS has hired peer specialists to work across the state, but specific advocacy is needed to encourage more youth specific specialists and placement in Western New York.
- **Address Adulthood Transition:** Urge OASAS to establish and fund a statewide transition standard of care for youth SUD treatment. Young people who age out of C-SPOA eligibility or HCBS waivers often face abrupt service cliffs. Advocacy could draw upon effective existing models for transition-age youth.
- **Support Crisis Stabilization Centers & Youth Specific Wings:** Encourage NYS to expand the crisis continuum to include a dedicated Crisis Stabilization Center in Erie and Niagara Counties, and ensure existing crisis infrastructure, including 988 and Mobile Crisis Teams, is explicitly connected to stabilization options that can serve youth without defaulting to emergency hospitalization. The Dutchess County Stabilization Center is an effective model to draw from. Advocacy efforts could also support a specific wing in Crisis Stabilization Centers with properly trained staff and peer-specialists focused on youth.
- **Advocate for Reform of the OASAS Funding Model:** Urge the state to modernize its OASAS reimbursement framework to allow providers to retain modest surpluses for reinvestment. Under the current funding model, providers are reimbursed for costs that they are unable to cover through other revenue streams, but they are prohibited from retaining any year-end surplus. This model makes it difficult for providers to grow, build capacity, innovate, or establish operating reserves to sustain them in challenging times. Advocacy opportunities also include encouraging OASAS and the Division of the Budget to establish an operating reserve policy for nonprofit providers and joining coalition efforts pushing for Medicaid payment reform that rewards quality outcomes.[5]

A. Youth Mental Health

i. Policy Context

Youth in Erie and Niagara Counties face mental health challenges consistent with national and statewide trends, including elevated rates of depression, anxiety, suicidal ideation, and behavioral health concerns. According to the 2023 CDC Youth Risk Behavior Survey, approximately 40% of high school students nationally reported feeling persistently sad or hopeless for two or more weeks in the past year — up from 30% a decade earlier and reflecting a sustained worsening of adolescent mental health that predates but was accelerated by the COVID-19 pandemic. In Erie County specifically, deaths by suicide among residents rose from 72 in 2023 to 94 in 2024, with males accounting for approximately 79% of those deaths. In Niagara County, the suicide death rate exceeded statewide averages in 2020-2022, with the NYS Health Connector reporting that the suicide death rate is 14.2 per 100,000, compared to the NYS average of 8.8 per 100,000. According to the Kids' Well-Being Indicators Clearinghouse, Niagara County hospitalizations of youth from 10-14 years, and 15-19 years old, are significantly above the NYS overall rate. These trends have prompted increased focus across both counties on coordinated prevention, early intervention, crisis response, and school-based mental health services, against a backdrop of persistent provider shortages that continue to limit timely access to care.

Erie County has responded to the heightened youth mental health crisis with a range of resources, including mobile crisis teams, walk-in urgent care support, peer support services, crisis hotlines, and the County's own Erie Path app to help families access services for youth. Programs through the Erie County Department of Mental Health (ECDMH) and partner agencies provide outpatient support, family counseling, and community-based care, but chronic workforce shortages and service gaps continue to challenge timely access for all youth in need. Local planning emphasizes expanding crisis services, early intervention in schools, and community education while addressing system fragmentation and workforce capacity. Additionally, the County's suicide prevention coalition is actively raising awareness of suicide risk among youth in Erie County.

Niagara County, similar to Erie, has responded to youth mental health needs through NCDMH and their Youth Bureau, providing outpatient services, crisis intervention, and community based care. The County has a crisis services call center operating 24/7, and launched the Well Niagara app and webpage in late 2023, to connect residents to local mental health and wellness resources. The Niagara County Suicide Prevention Coalition leads public education and awareness efforts across the county. Both Counties utilize the Western NY Children's Psychiatric Center, which offers inpatient, outpatient, and mobile consultation services.

ii. Current Conditions

Erie and Niagara Counties have increasingly prioritized youth mental health initiatives over the past 5 years. One emerging priority focuses on expanding access to crisis response and stabilization. The state and Counties have invested in mobile crisis teams,[5] crisis stabilization services, school-based crisis supports, and youth-specific 988 implementation. These strategies not only reduce reliance on emergency services and law enforcement, but divert youth from inpatient hospitalization when appropriate, and expand step-down and community-based stabilization options. For example, Spectrum Health's C.A.R.E.S. (Community, Assessment, Response, Emergency Services) program provides 24-hour mobile crisis intervention for youth and families throughout Erie and Niagara Counties. The C.A.R.E.S. team specializes in telephone-based support and

two-person face-to-face risk assessment, and is funded through Erie County Department of Mental Health contracts. Additionally, Crisis Services operates a Mobile Outreach Program, which provides community-based mental health intervention to individuals in Erie County experiencing a mental health crisis, with the goal of diverting individuals from unnecessary emergency room visits. The mobile crisis and law enforcement coordination programs are funded by the Erie County Department of Mental Health and a federal SAMHSA grant.

In Niagara County, Catholic Charities operates Monsignor Carr Children's Clinic, a series of behavioral health children's clinics offering youth counseling and evaluation, along with family, group, and individual therapy and medication management for individuals ages 3 to 21. These clinics are funded through a combination of Medicaid, private insurance, sliding-scale fees, and Catholic Charities' broader organizational support. New Directions Youth & Family Services delivers children's mental health programs including community crisis intervention, non-Medicaid care management, and children's mobile crisis outreach. These services are primarily accessed through the Coordinated System of Care's Single Point of Access (C-SPOA) and are funded through a mix of county contracts, state grants, and Medicaid reimbursements. The Mental Health Association of Niagara County (MHANC) provides community-facing support including educational presentations, self-help materials, advocacy resources, referrals, and peer support for individuals living with a mental health diagnosis. MHANC is largely funded through county allocations, state grants, and charitable contributions. Community Missions of Niagara Frontier, Inc. offers a broad range of programs spanning crisis and community services, mental health housing, mental health recovery, and youth services. Community Missions is funded through a combination of government contracts, Medicaid, private grants, and donations.

Erie County has also developed a school-focused initiative to address rising anxiety and behavioral health concerns. Known as the SMART collaborative (Supporting Mental Health by Advocating for Resources Together), it is a professional learning community that brings together educators, community agencies, and Erie County representatives to collaborate on available mental health and social-emotional learning tools, with the goal of meeting the needs of the whole child through integrated community supports.

In addition, in response to the increases in youth mental health needs, the state has increased funding for Youth Assertive Community Treatment (ACT) teams, a model adapted from adult ACT services, which provide intensive, community-based support to youth ages 10 to 21 with serious emotional disturbance who are at risk of entering, or transitioning home from, inpatient or residential settings. As of 2025, the state supports 20 Youth ACT teams across 27 counties, including Erie and Niagara.

There are significant opportunities for meaningful advocacy engagement that focus on youth mental health in Erie and Niagara Counties, from school-based programs and partnerships to workforce training and retention efforts.

iii. Advocacy Opportunities

There are significant opportunities for meaningful advocacy engagement that focus on youth mental health in Erie and Niagara Counties, from school-based programs and partnerships to workforce training and retention efforts.

Related Advocacy Opportunities

- **Support Workforce Retention:** Advocate for state investment in supervised training pipelines for youth-serving clinicians. This could include expanded practicum and internship placements in school and community settings; supporting credentialing pathway reforms that make it faster and more financially viable for paraprofessionals and peer specialists to enter and advance in the youth mental health workforce; and urging the state legislature and the Governor to prioritize workforce retention through COLAs, loan repayment programs, and competitive compensation for mental health workers serving youth in high-need communities. Additional advocacy opportunities could include advocating for the expansion of workforce extender models focused on community health workers and certified recovery peer-advocates to help address lower-acuity needs and enable credentialed clinicians to practice closer to the top of their licensure, further reducing burnout and increasing capacity.
- **Expand Youth In-School Mental Health Training:** Encourage the expansion of evidence-based youth mental health training programs in Erie and Niagara County schools, with a focus on local Mental Health Association in New York State (MHANYS) programming/capacity building (or similar efforts). This could include Youth Mental Health First Aid, which equips teachers, coaches, and other trusted adults to recognize and respond to signs of mental health distress in young people. Advocacy efforts could also urge sustained district-level funding to train staff annually (rather than as a one-time initiative), and prioritize districts in Niagara Falls, Lockport, Lackawanna, and Buffalo, where need is high and trained capacity is low.
- **Expand Group Counseling at Afterschool Programs and Summer Camps:** Support the expansion of group counseling models, including in school-based clinic satellites and non-clinical settings such as afterschool programs and summer camps, where youth are already present and engaged. Erie County has piloted models through partnerships with Say Yes Buffalo and local outpatient clinics. Advocates can support replicating and scaling similar approaches in Niagara County, where few equivalent structured models currently exist, and support state Medicaid billing policy changes that make group counseling in non-traditional settings more financially viable for providers.
- **Support LGBTQ+ Youth Mental Health Infrastructure:** Support dedicated LGBTQ+-affirming programming in schools and community settings, building on the work of local organizations like GLYS (Gay and Lesbian Youth Services) in Erie County, which provides drop-in services and school training. The 2023 Youth Risk Behavior Survey data shows LGBTQ+ youth experience dramatically higher rates of depression, suicidal ideation, and suicide attempts than their peers. Advocates can also encourage the expansion of similar programs in Niagara County.
- **Advocate for Medicaid Parity Enforcement and Rate Reform:** Advocate for the state to increase Medicaid reimbursement rates for children's outpatient mental health services and enforce mental health parity requirements for commercial insurers. Youth mental health providers in Erie and Niagara Counties consistently cite low Medicaid reimbursement rates as a primary driver of workforce shortages and service gaps. While existing advocacy efforts on these issues are robust,dditional advocacy directed toward these structural levers is important and could benefit the entire provider

in state awards to expand health clinics and improve access to healthcare for people with disabilities. While the largest award of $5M was given to NYU Dentistry Oral Health Center for People with ecosystem, not just individual programs. Given that many groups focus on this issue area already, advocacy efforts could include joining coalitions, signing-on to support letters and campaigns, and elevating the issue with local stakeholders in Erie and Niagara Counties.

- **Create a Mental Health Training Collaborative:** Encourage the replication in Niagara County of the Erie County Mental Health Training Collaborative, which offers school-based professional development on topics including neurodiversity-affirming care and digital wellness for youth, to help address the thinner school-based mental health training infrastructure in Niagara County.
- **Include Niagara County in the SMART Collaborative:** Advocate for formal Niagara County participation in the SMART Collaborative, a professional learning community established to prioritize P-12 student mental health. Composed of Erie County School Districts, educators, community agencies and representatives from Erie County, SMART serves as a vital link between available mental health resources and students. Advocacy efforts could focus on expansion of this collaborative to both counties.
- **Support Implementation of the FY26-27 Budget Proposal on Joint OMH/OASAS Co-Occurring Capable Designation, if Enacted**: Advocate to ensure WNY providers have the technical assistance and transition support needed to achieve this designation, and that Niagara County providers are included. The Governor's state budget proposal includes a joint OMH/OASAS Co-Occurring Capable designation for providers. Advocacy efforts could help address the integrated care gap.

C. Intellectual Disabilities

i. Policy Context

Recent state-wide data released from the Office for People With Developmental Disabilities (OPWDD) reveals that approximately 52% of individuals served have an intellectual disability as their primary diagnosis. In 2024, OPWDD supported approximately 130,000 people across New York State, 35% of whom were children aged 20 or younger[8]. County-level data for Erie and Niagara Counties are not publicly reported in disaggregated form by OPWDD, and both Counties fall under the Western New York Developmental Disabilities Regional Office, which serves Erie, Niagara, and several surrounding counties.

State and local systems coordinate early intervention, special education supports, community habilitation, and adult service planning to support quality of life and community participation for young people with intellectual and developmental disabilities. Within this complex system, public schools play a pivotal role in supporting youth with intellectual disabilities, as they are required to locate, evaluate, and serve students with disabilities aged 3-21 under IDEA. For many families, the school district is their first point of contact with the broader disability system. The division of responsibility between these systems is largely age-driven: school districts hold the primary service role during the school years (from 3-21), while OPWDD assumes a more central coordinating function as youth transition to adulthood between ages 18-21 (sometimes extending to 26). Both systems can be simultaneously involved during the 18-21 age overlap, which can cause friction points in oversight and coordination of care. Many individuals who had fully functioning wrap-around

services up until transition age face significant challenges when looking for new programs designed for the young adult population. These challenges include long waiting lists due to lack of workforce and available spots, piecemeal services that fill in gaps but do not service the whole individual and family, and a lack of viable options for the youth population.

ii. Current Conditions

Erie and Niagara Counties rely on a combination of state-administered OPWDD systems and a network of local nonprofit providers, family support programs, and independent living centers to deliver a continuum of supports for young people with intellectual and developmental disabilities. These services include early intervention, education, residential living, community participation, employment, advocacy, and life-skills development. The Niagara County Department of Mental Health's (NCDMH) 2024-2027 strategic plan includes a goal of integrating individuals with intellectual and developmental disabilities into the workforce, with additional community education efforts across employment-based training. NCDOH also participates in the Hidden Disability Sunflower Campaign, offering free sunflower lanyards, IDs and wristbands to individuals with hidden disabilities at county offices and community events.

Local providers (some of whom were interviewed as part of this Landscape Analysis) include, but are not limited to, The Arc Erie County, Aspire of WNY, Beyond Support Network, Cantalician Center for Learning, the Parent Network of WNY & Family Support Programs, People Inc. (Western NY), and Developmental Disabilities Alliance of Western NY (DDAWNY). Western NY Independent Living (WNYIL) provides independent living services through its regional centers for ages 14-28, and provides specific youth transition services. In 2025, The Arc Erie County broke ground on its Black Water Acres project in Alden, NY, a 12,000 square-foot facility that plans to include adaptive workforce training, an accessible farm, commercial teaching kitchen, programming areas, and shared community space with a neighboring senior development to promote inclusion opportunities.

Additional programs similar to what is being planned at the new Black Water Acres facility, are emerging with concentrated focus on employment support and transition services, where specialists assist with job skills placement and training and competitive integrated employment planning for youth with disabilities. Self-advocacy and peer training is also on the rise, with regional SANYS groups providing training, seminars, and other programs to help individuals build advocacy skills and know their rights.

The Neurodiversity Network of WNY, based in Buffalo and serving the WNY region, focuses on empowering neurodivergent individuals and their communities by hosting events, sharing resources, and providing neurodiversity-affirming training that helps cultivate a sense of belonging and inclusive spaces where all can thrive.

Finally, both Erie and Niagara Counties are experiencing an intellectual disabilities direct service professional (DSP) workforce crisis. OPWDD's strategic plan reports a 35.6% DSP turnover rate and a 17% vacancy rate statewide. This workforce shortage, and associated service waitlists, affects youth in both counties and poses a dramatic systemic challenge in the intellectual disabilities landscape.

iii. Advocacy Opportunities

There are numerous opportunities for meaningful advocacy engagement focused on youth intellectual disabilities in Erie and Niagara Counties.

Related Advocacy Opportunities

- **Expand Workforce Support:** Call attention to workforce shortages that continue to heavily impact the intellectual disabilities workforce, impacting programs' ability to serve youth. Advocates could encourage the expansion of state investment in the intellectual disabilities workforce pipeline, including scholarship programs, loan repayment initiatives, credential ladders, and fellowships for direct support professionals and intellectual disabilities-focused clinicians. In addition, advocates could urge the state legislature and Governor to provide meaningful COLAs and rate increases for direct support professionals during each budget cycle to help address workforce shortages.
- **Expand Access to Employment Training and Supports:** Advocate for expanded, early access to job training and pre-employment transition services for transition-age youth (ages 14–22) with intellectual disabilities. There is powerful evidence that the Individual Placement and Support (IPS) model can help people with intellectual disabilities overcome barriers and achieve successful employment. IPS involves rapid job search, competitive employment, and client job preferences; small caseloads; benefits counseling; and coordination between employment services staff members and mental health care providers. New York State has already made initial investments in the IPS model that should be expanded to meet the full extent of need.
- **Advocate for Supported Decision-Making (SDM):** Provide education to providers and families in Erie and Niagara counties on New York's Supported Decision-Making Agreement Act, and push for implementation in Western New York. Youth with intellectual disabilities who are turning 18, and their families, face an immediate legal crossroads in determining guardianship and decision- making. SDM, a newly enacted law, with a statewide facilitator, provides a less restrictive alternative to guardianship. Supporting the implementation of regulations and expanding public awareness of this Act is an opportunity that could have a significant positive impact on young adults with intellectual disabilities and their caregiver
- **Expand Dental Access:** Advocate for expanded dental access for youth with intellectual disabilities, including support for legislation and state budget initiatives to fund a network of intellectual and developmental disabilities-competent dental providers across New York. This could include supporting the passage of S4711, a bill that would direct the commissioner of health to authorize additional Medicaid reimbursement to providers of health and dental care primarily serving people with intellectual disabilities for uncompensated time, staffing and services. A NYS 2024 Oral Health Needs Assessment found that disability status was the strongest predictor of high oral health need, above geography, income and insurance status. Locally, advocates could educate Erie and Niagara County providers, families, and legislators on the critical oral health equity gap facing this population, the underutilized Medicaid enhanced reimbursement tools already available, and the urgent need to

address the access cliff that youth with intellectual and developmental disabilities face when transitioning from pediatric to adult dental care. On April 13, 2026, Governor Hochul announced $25M Disabilities, almost $4M was given to University at Buffalo School of Dental Medicine. Advocates can push for continued funding to protect ongoing services, and expand centers to underserved areas in Niagara County.

- **Increase Family Support Services (FSS) Program Funding:** Support expansion of the Family Support Services (FSS) program, which helps families who are caring at home for a relative with a disability and provides support, including respite, and financial reimbursement for goods and services. The FSS Family Reimbursement cap is currently $3,000 annually. Potential advocacy opportunities include pushing for an increased cap and including additional items that are of importance to families to the allowable reimbursement list.
- **Advocate for passage of S28c/A1006b, Eliminating the Sub-Minimum Wage for People with Disabilities:** Advocate for passage of legislation that would eliminate the sub-minimum wage for people with disabilities. New York State does not have any remaining sheltered workshops, but the state does still allow for subminimum wage certificates (which are slowly being phased out) Advocates can support passage of the legislation and, if signed into law, educate stakeholders on implementation in Erie and Niagara Counties.
- **Address Housing Issues:** Call for increased funding to the housing voucher program. Through the OPWDD Self-Direction program, a housing voucher can be provided to individuals with intellectual disabilities living in the community (i.e., not in institutional settings). Advocating for increased funding to the housing voucher program can specifically assist individuals living in cities like Buffalo, which have higher rents than surrounding areas. Additionally, support OPWDD's efforts to open more Comprehensive Adult Transitional Homes (CATH) that specialize in short-term residential stays for young adults with intellectual disabilities transitioning from a residential school setting to community living. These CATH homes act as a stepping stone to more independent living and entry into adult residential group homes.

D. Learning Disabilities

i. Policy Context

According to the WNY Reading Report Card (an analysis of 2022-23 NYSED ELA assessment data), data on students in grades 3–5 in school districts across Erie and Niagara Counties show an overlap between high rates of poverty and low English language Arts (ELA) proficiency. For example (as noted in the Report Card Appendix A) the Niagara Falls City School District in Niagara County serves a student population that is nearly 80% economically disadvantaged, and only about 20% of students demonstrate ELA proficiency. Outcomes are similar in the Lackawanna City School District in Erie County, where nearly 90% of students are economically disadvantaged, and ELA proficiency is approximately 15%. Moreover, analysis by the WNY Education Alliance estimates that one in every two students is not reading at grade level, with substantially lower proficiency rates among economically disadvantaged students, children with dyslexia, and English learners.

These numbers signal that a meaningful number of students could have unidentified or underserved learning disabilities. Left unaddressed, reading struggles in early elementary school predicts long-term academic disengagement, higher dropout rates, and reduced economic opportunity. The data also make clear that early identification, evidence-based instruction, and targeted support are needed to meet the needs of youth.

ii. Current Conditions

Youth in Niagara County access services primarily through local school-based support. State-run services include the Center for Dyslexia and Dysgraphia within the State Education Department, which was established through legislation signed into law by Governor Hochul in December 2025, and designed to "improve how schools identify and support students with reading and writing difficulties." The Center's goals are to "create a statewide approach for collecting and sharing best practices, set standards for universal screening in K-5th grade and for new entrants, and establish evidence-based interventions and teacher training." Additionally, the Dyslexia and Dysgraphia Task Force, established in 2024, examines appropriate and effective evidence-based dyslexia and dysgraphia screening methods, reading interventions, and other educational supports for students in K-5th grade.

Additionally, Erie County is home to The Gow School in South Wales, which is a college-prep boarding and day school for students in grade 5-12 with dyslexia and similar language-based learning disabilities.

Existing non-government efforts in Western NY and statewide include the WNY Education Alliance, a nonprofit organization committed to improving educational outcomes for students in Western New York through research and advocacy, community engagement, and strategic partnerships. The Kids Can't Wait Coalition advocates for infants and toddlers diagnosed with developmental delays or disabilities to have access to Early Intervention (EI) services and Preschool Special Education (PSE) (for children ages 3-5) to continue their development and get ready for kindergarten. Kids Can't Wait is a statewide coalition anchored by The Children's Agenda, operating since 2018. Both EI and PSE are proven to reduce or prevent the need for more intensive services later in life. Additionally, Decoding Dyslexia New York State is a "grassroots movement that aims to raise dyslexia awareness, empower families to support their children, and implement science-based instruction for students with dyslexia in New York State public schools."

In Erie and Niagara Counties, gaps in early identification, classroom practice, community infrastructure, and post-school transition compound disadvantages that fall hardest on students in high-need urban and rural districts. Advocacy efforts can help strengthen the full continuum of support, from earlier years of schooling through transitioning into adulthood.

iii. Advocacy Opportunities

There are numerous opportunities for meaningful advocacy engagement focused on learning disabilities in Erie and Niagara Counties.

Related Advocacy Opportunities:

- **Support Expansions of In-School Programming:** Support expansion of structured literacy and science-of-reading aligned programming within school districts across both counties, particularly in high-need urban and rural districts. This includes advocating for teacher training aligned with NYSED's new

standards, funding for literacy coaches, and accountability mechanisms to ensure that evidence-based instruction is actually reaching classrooms.

- **Strengthen Post-School Transition Support:** Support Vocational Rehabilitation (ACCES-VR) job training and pre-employment transition services for youth and young adults with learning differences who are approaching or past the school exit age. Advocate for stronger coordination between school districts and ACCES-VR so that students with IEPs do not fall through the gap at age 21 without a clear next step.
- **Support Universal Screening Implementation:** Advocate for passage and implementation of dyslexia and dysgraphia early identification screening (K-5) mandate (including the A37/S6844 bills in the 2025-26 legislative session) in every Erie and Niagara County school district, with particular attention to ensuring that economically disadvantaged districts like Niagara Falls and Lackawanna receive the training and resources needed to comply.
- **Support the Kids Can't Wait Coalition's Early Intervention Rate Reform:** Engage in rate reform advocacy. New York ranks 50th in the nation for timely delivery of Early Intervention services, and the rate reform fight is active in every budget cycle. For children with learning disabilities specifically, delays in EI and PSE services are a direct upstream cause of later unidentified and underserved learning disabilities.

Landscape Analysis Section IX Addendum

Erie and Niagara counties are represented at the State and Federal levels by the following elected officials:

Erie County Assemblymembers and Senators

Senator Patrick Gallivan (R, SD- 60). *Senate Minority Whip and Ranking Member of the Senate Committee on Health. Though he is in the minority, Sen. Gallivan is well-respected across the aisle and well-positioned to move bills and negotiate.*

Senator Jeremy Zellner (D, SD-61). Recently won a special election in February 2026.

Senator April Baskin (D, SD- 63)

Assemblymember William Conrad III (D, AD-140)

Assemblymember Crystal D. Peoples-Stokes (D, AD-141). *Majority Leader of the State Assembly. Assemblymember Peoples-Stokes announced that she is retiring in early April, and Buffalo Common Council Majority Leader Leah Halton-Pope announced her campaign for the open seat.*

Assemblymember Patrick Burke (D, AD-142)

Assemblymember Patrick Chludzinski (R, AD-143)

Assemblymember Karen McMahon (D, AD-146)

Assemblymember David DiPietro (R, AD-147)

Assemblymember Jonathan Rivera (D, AD-149)

Niagara County Assemblymembers and Senators

Senator Robert Ortt (R, SD-62). Senate Minority Leader.

Assemblymember Paul Bologna (R, AD-144)

Assemblymember Angelo Morinello (R, AD-145)

Assemblymember Karen McMahon (D, AD-146)

U.S. Congress & Senate

Rep. Tim Kennedy (D-NY-26). *Represents most of Erie and Niagara counties, including the cities of Buffalo, Niagara Falls, Lackawanna, Tonawanda, and North Tonawanda.*

Rep. Nick Langworthy (R-NY-23). *Represents the southern and rural parts of Erie County, along with Chautauqua, Allegany, Cattaraugus, and several Southern Tier counties.*

Senator Charles Schumer (D-NY). Senate Minority Leader.

Kirsten Gillibrand (D-NY). Committee assignments include the Committees on Appropriations.

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Landscape Analysis: Advocacy for Impact

SECTION X

APPENDIX

Landscape Analysis

SECTION X
APPENDIX

Federal Funding Streams

- A summary chart of federal funding streams, prepared by America Forward (and referenced in Section VII: Federal: Federal Landscape, Policy Context, Advocacy Opportunities), includes state-specific tabs for Massachusetts and New York that map to key federal funding streams supporting children and youth through 2024. This document was developed using data from the Children's Funding Project's database titled Federal Funding Streams for Children and Youth Services (their database has not yet added 2025 funding numbers).

Relevant Policy Letters, Updates, and Statements

- America Forward FY27 Appropriations Letter sent on March 31, 2026 to the House and Senate appropriations leaders.
- "America Forward Policy Pulse," a biweekly policy update produced by America Forward, recent editions:
  - January 13, 2026
  - January 28, 2026
  - February 10, 2026
  - February 24, 2026
  - March 10, 2026
  - March 24, 2026
  - April 7, 2026
  - April 23, 2026
- America Forward Policy Platforms
  - Early Learning
  - K-12 Education
  - Higher Education
  - Economic Mobility
  - Social Innovation and Evidence-Based Policy
- Capitol Hill Partners FY26 Appropriations Update, by America Forward's government affairs partner, Capitol Hill Partners. These updates are published weekly.
- Select organizations' statements responding to proposed SAMHSA cuts
  - National Council for Mental Wellbeing Statement
  - NAMI Statement
  - Alliance for Rights and Recovery Statement

Resource Pages from Organizations Interviewed as Part of this Landscape Analysis

- Alliance for Justice Bolder Advocacy Initiative Resource Hubs and Fact Sheets
  - **Publications**
    - Worry-Free Lobbying for Nonprofits: How to Use the 501(h) Election to Maximize Effectiveness
    - Philanthropy Advocacy Playbook
    - Being A Player: A Guide to the IRS Lobbying Regulations for Advocacy Charities
    - Keeping Track: A Guide to Recordkeeping for Advocacy Charities
    - The Rules of the Game: A Guide to Election-Related Activities for 501(c)(3)s
    - The Connection: Strategies for Creating and Operating 501(c)(3)s, 501(c)(4)s, and Political Organizations
  - **Fact Sheets & Resources**
    - Lobbying Flowchart
    - Lobbying Defined for Private Foundations
    - Private Foundations May Advocate
    - Understanding the Lobbying Disclosure Act
    - Nonpartisan Candidate Education: How 501(c)(3)s Can Talk to Candidates During an Election Year
    - Praising and Criticizing Incumbents
    - 501(c)(3) Organizations and National Party Conventions
    - Project Grant Rule Hub
    - State Lobbying Practical Guidance Series (all 50 states and DC)
  - Additional publications and fact sheets are available at bolderadvocacy.org.

- Center for Law and Education's "Tracking Federal Government Action in Education" website, which provides weekly updates on important legislation, analysis of salient issues, and a calendar of deadlines for submission of comments to various documents on the Federal Register.

- The Arc's resources page, which includes a variety of press releases, blog posts, comments submitted to the federal government, and perspectives from people with disabilities. Examples include a statement condemning Reductions in Force (RIFs) at the Department of Education, a letter to the leadership of the House Committee on Appropriations, and an explanation of how the One Big Beautiful Bill Act will affect people with intellectual and developmental disabilities. Additionally, The Arc New York has a similar resources page, with resources including a list of NYS budget priorities, an analysis of relevant highlights of the FY27 budget, an archive of past Advocacy Updates, and a list of their position statements. *Note: Northeast Arc (an affiliated chapter of The Arc) was interviewed as part of this Landscape Analysis.*

- The Children's Agenda's reports page, which includes a variety of fact sheets, reports, and responses to NYS legislative and executive actions. Examples include a review of the NYS budget, an explainer of New York's proposed Solutions, Not Suspensions legislation (S134/A118), and a response to the NYS Senate and Assembly budget proposals.

- New York Alliance for Innovation and Inclusion's Guide to Advocacy in New York State, which provides information on NYS government structure, legislative and state budget processes, key terminology, and tips on how to communicate with NYS legislators.

- Legal Action Center's resources page, which includes reports, memos, toolkits, and sample letters. Examples include a list of recommendations regarding spending Opioid Settlement Funds in NYS, a guide on developing an effective advocacy strategy to overcome local opposition to SUD programs in NYS, and a fact sheet on NY's Transitional Reentry Health Act (S614/A1008).

- DDAWNY's documents and resources page, which includes a variety of reports, guidance, and one-pagers. Examples include a one-pager on the NYS budget, a report on the lived experiences of direct service providers in NYS, and district profiles for WNY legislators.

- Community Catalyst's newsroom, which includes articles, statements, memos. Examples include a statement on Homeland Security's proposed changes to "public charge," a statement on the effects of cuts to ACA subsidies, and a memo elevating the voices of people with lived experience.

Policy Platforms from Interviewed Organizations

- Boston Children's Hospital 2025-2026 State Legislative Agenda
- Self-Advocacy Association of New York State (SANYS) 2025 Policy Statement
- Massachusetts Health and Hospital Association Priority Legislation
- Massachusetts Association of Mental Health (MAMH) Budget Priorities
- Schuyler Center 2026 Policy Priorities
- The Children's Agenda 2026 Policy Platform

Additional Policy Platforms

- Inseparable Mental Health Policy Platform
- Learning Disabilities Association of America Public Policy Priorities
- Massachusetts Organization for Addiction Recovery (MOAR) Policy Priorities
- Mental Health America 2025 Priorities
- National Association of Councils on Development Disabilities Policy Platform
- National Alliance on Mental Illness (NAMI) Massachusetts Legislative Priorities
- The Arc Massachusetts 2025-2026 Legislative Priorities

Informative Newsletters and Email Lists

- Association of University Centers on Disabilities
  - AUCD's Disability Policy News (DPN) is a weekly newsletter highlighting federal policy issues affecting people with disabilities and their families. DPN features updates in plain language and action steps that people can take to educate policymakers.

- Council for Exceptional Children
  - CEC is a professional association of educators dedicated to improving educational outcomes for infants, toddlers, children, and youth with disabilities and/or gifts and talents. CEC's advocacy work centers on promoting evidence-based best practices in special education, supporting educators at all levels- from early intervention through higher education, and securing the fiscal resources necessary to enable each individual to attain their highest level of education, employment, and life success. Their Policy Insider newsletter is posted weekly on their website.

- EducationCounsel
  - EducationCounsel is a mission-driven education consulting firm that works with leading nonprofit organizations, foundations, and policymakers at all levels to help significantly improve education opportunity and outcomes. EducationCounsel's E-Updates provide biweekly updates on federal policy affecting education systems, from early learning to K–12 to higher education.

- HHS- Administration on Community Living
  - The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. ACL's email list shares important announcements, events, and resources.

- Manatt
  - Manatt is a multidisciplinary, integrated national professional services firm known for quality and an extraordinary commitment to clients. Mannat's Health Updates newsletter features insights on health care litigation, health technology, artificial intelligence, and health systems.

- National Association of Addiction Treatment Providers
  - NAATP champions excellence in addiction treatment through high-quality care and strong public policy advocacy. Their work combines compassionate, day-to-day treatment with active efforts to drive systemic change. NAATP's email list features updates and insights related to federal addiction and mental health policy.

- National Alliance on Mental Illness
  - NAMI takes a nonpartisan approach to advocate on a wide range of policy issues, including expanding access to health care coverage, advancing research, diverting people from justice system involvement, promoting early intervention and more. The NAMI E-News delivers the latest news about federal action alerts, legislation and policy updates.

- National Association of State Alcohol and Drug Agency Directors
  - NASADAD works to foster and support the development of effective alcohol and other drug use prevention and treatment programs throughout every State. The Public Policy Department at NASADAD creates a weekly update that includes newly released resources on substance use disorder prevention, treatment, and recovery; other timely news or information that members might be interested in; and information on meetings in which NASADAD staff have participated.

- National Council For Learning Disabilities
  - NCLD works to improve the lives of people and young adults nationwide with learning disabilities—by empowering parents and young adults, transforming schools, and advocating for equal rights and opportunities. This pamphlet outlines five policy priorities with supporting data for young advocates and LD Champions to use when advocating for disability rights. Their newsletter features learning disability resources and actionable insights.

- The Arc
  - For nearly 75 years, The Arc has been at the forefront of the fight for the civil rights and inclusion of people with intellectual and developmental disabilities (IDD) and their families. The Arc partnered with AAIDD, ANCOR, ASA, ASAN, AUCD, TASH, and UCP to create this public policy agenda. They work together to shape, expand, and protect a strong federal role that provides vital benefits, services, and supports and assures civil rights for our constituency.

- The National Council for Mental Wellbeing
  - The National Council for Mental Wellbeing is a membership organization that drives policy and social change on behalf of more than 3,200 mental health and substance use treatment organizations and the more than 15 million children, adults and families they serve. Their weekly Friday newsletter covers updates in federal mental health and substance use policy.

List of Coalitions Mentioned in Stakeholder and Expert Interviews

- **Federal Coalitions**
  - America Forward
  - American Network of Community Options and Resources (ANCOR)
  - Center for Public Representation (CPR)
  - Community Catalyst
  - Consortium for Constituents with Disabilities (CCD) Rights Task Force
  - Council of Autism Providers
  - Democracy Forward
  - Education Civil Rights Alliance
  - Families USA
  - Faces and Voices in Recovery
  - Legal Action Center (LAC)
  - National Alliance on Mental Illness (NAMI)

- National Council on Disability
- Public Citizen
- The Arc

- **Massachusetts Coalitions**
  - Children's Mental Health Campaign (CMHC)
  - Dignity Alliance
  - Health Care for All
  - Massachusetts Association for Mental Health (MAMH)
  - No Small Feat Massachusetts
  - Parent/Professional Advocacy League (PPAL)
  - Protect Education Equity Coalition
  - The Arc of Massachusetts

- **New York Coalitions**
  - Beyond Support WNY
  - Care Management Coalition of WNY
  - Coalition for Economic Justice
  - Council for Developmental Disabilities (CDD)
  - Crisis to Care Collaborative
  - Developmental Disabilities Association of WNY (DDAWNY)
  - Drug Policy Alliance (NY Chapter)
  - Erie County Anti-Stigma Coalition
  - Friends of Recovery -New York (FOR-NY)
  - Liftoff WNY
  - Medicaid Matters
  - Mental Health Association of NYS (MHANYS)
  - Motion Project
  - NY Alliance for Inclusion and Innovation
  - NY Disability Advocates
  - NYS Alternatives to Incarceration
  - NYS Master Plan for Aging Coalition
  - Parent Network of WNY
  - PX21
  - Self-Advocacy Association of NYS (SANYS)
  - The Arc of Erie County
  - Vocal NY
  - VOICE Buffalo
  - WNY Digital Equity Coalition
  - WNY Independent Living Family of Agencies

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Landscape Analysis: Advocacy for Impact